Saint Mary's Managed Clinical Service
Division of Gynaecology

PATIENT INFORMATION LEAFLET

SURGERY FOR SEVERE/COMPLEX ENDOMETRIOSIS

You have been given this leaflet as you may have a severe form of endometriosis and are listed for complex keyhole surgery (Laparoscopy). The aim of this leaflet is to give you some understanding of endometriosis and what to expect from surgery during your stay in hospital and after surgery during the recovery period. The leaflet explains the potential risks associated with surgery for complex endometriosis.

You may have had keyhole surgery to treat or diagnose endometriosis in the past. Keyhole surgery for severe endometriosis is more complex and carries a greater risk of accidental injury to organs in your tummy. This will be discussed with you as part of the surgical planning and when you give your consent to undergo surgery.

WHAT IS ENDOMETRIOSIS

Endometriosis is a condition which effects 1 in 10 women during their reproductive years. It is a condition where tissue similar to the lining of the womb (endometrium), starts to grow in other places in the body, such as the ovaries, surrounding pelvic tissue (side walls of the pelvis, ligaments supporting the womb etc.). Endometriosis can cause pain by inflammation, formation of scar tissue and entrapment of nerves. It may have a significant effect on your quality of life by impacting on your: physical health, emotional and mental wellbeing. Medical and surgical treatment can help alleviate symptoms of endometriosis.

Endometriosis is a non-cancerous condition and can affect the quality of life. Endometriosis can get worse over time. It is difficult to predict progression of the disease.

WHAT ARE THE COMMON SYMPTOMS OF ENDOMETRIOSIS?

Symptoms of endometriosis can include:

- Lower abdominal / pelvic pain and low backache
- Heavy, painful periods – often since the start of your periods
- Pain during or after sex
- Infertility - Difficulty in getting pregnant

- Bowel symptoms especially around periods (pain when going to the toilet, constipation, loose stools or rectal bleeding)
- Bladder symptoms especially around periods (pain when peeing or blood in pee, symptoms suggestive of a urinary tract infection, increased frequency etc.)

The severity of endometriosis does not directly correlate with symptoms. Some with severe endometriosis may have no symptoms. Endometriosis may not be a contributory factor to all of your pain related symptoms. There may be other medical conditions that can mimic endometriosis pain.

WHAT IS SEVERE /COMPLEX ENDOMETRIOSIS

Endometriosis is severe / complex when it involves a larger area within the pelvis (Figure: 1) and tummy and / or the disease is deeper (not just on the surface of organs). Often the ovaries, womb, bladder and bowel (intestines) are involved in the disease. Severe endometriosis is often associated with deeper involvement of the organs, extensive scar tissue formation with organs stuck to each other.

Women with severe endometriosis are more likely to experience painful symptoms which can be debilitating. For some women, surgery may be the only option available to alleviate their symptoms and improve their quality of life.

Up to 10% of women with severe pelvic endometriosis can have endometriosis outside the confines of the pelvis. This can be present outside the pelvis as on the appendix, small bowel, large bowel, peritoneal surfaces, Diaphragm, chest cavity etc.

Endometriosis is staged depending on the severity of the disease from stage 1 to stage 4 (most severe form of the disease). There are different staging systems for endometriosis as no staging system is perfect. The most commonly used staging system is the revised American Fertility Society (AFS) staging system.

This is shown below -

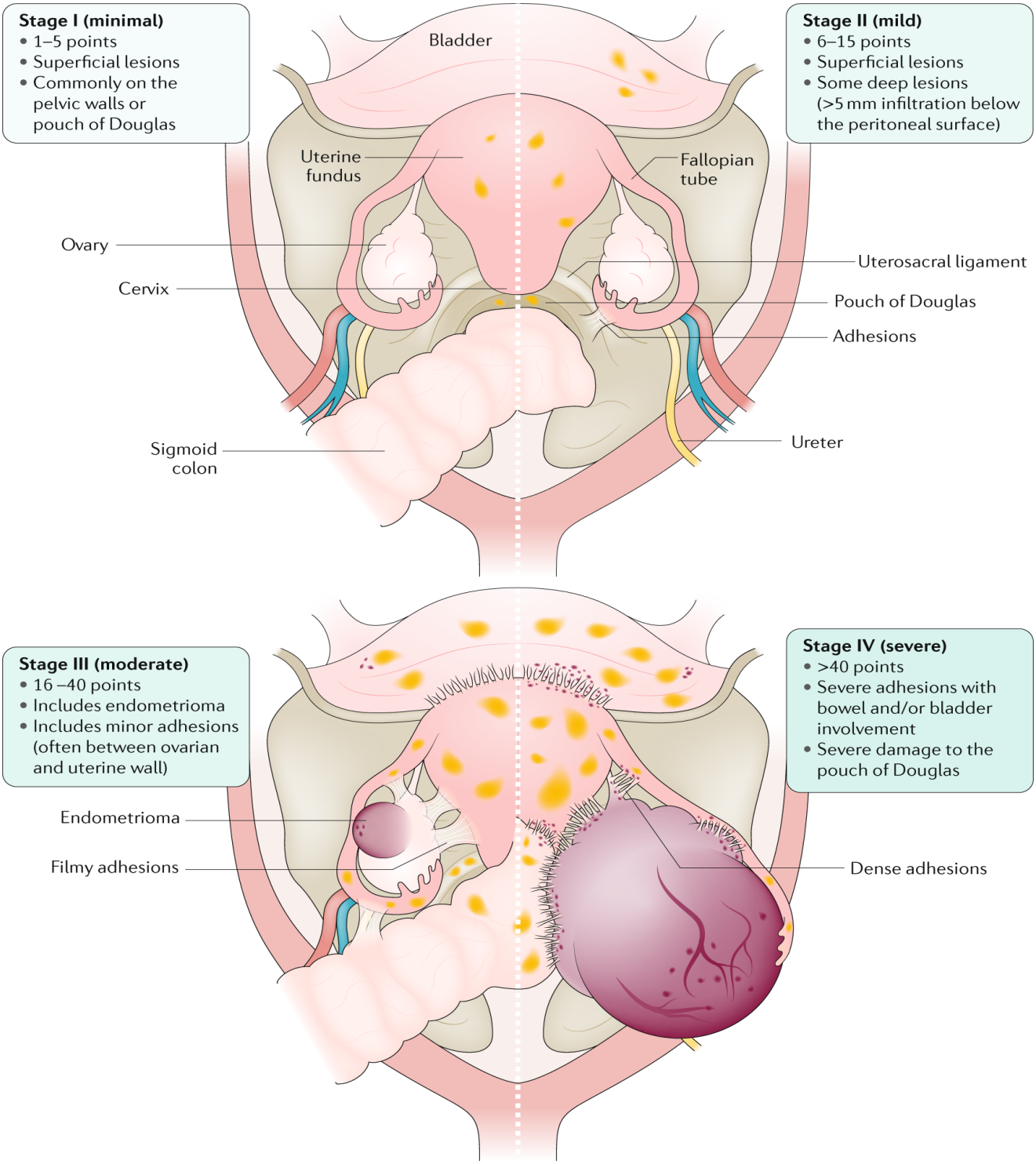

Image: Nature.com: Endometriosis. *Nature Reviews Disease Primers* volume 4, Article number: 9 (2018)

WHAT DOES SURGERY FOR SEVERE ENDOMETRIOSIS INVOLVE?

Endometriosis causes significant distortion within the pelvis due to scar tissue and inflammation. The aim of surgery is to remove endometriosis by excision (cutting it away) and restore the anatomy of the pelvis as much as possible. This may involve:

- Vaginal examination under anaesthesia, cystoscopy (camera in the bladder) and inserting stents (fine tubes) into the water pipe connecting your kidneys to your bladder.
- Releasing the intestines (bowel), ovaries and fallopian tubes from scar tissue and removing any cysts (endometriomas / chocolate cysts)
- Identifying and releasing the ureters (tubes that carry pee from the kidneys to the bladder) from surrounding scar tissue and endometriosis
- Cutting away tissue affected by endometriosis around the back and the side of the womb, the space between the vagina and rectum (back passage), the bowel wall, the ureter and the bladder
- If endometriosis affects your vagina, a small part of the top of your vagina may need to be removed.
- Removing endometriosis from outside of the pelvis if feasible.

HOW CAN YOU PREPARE FOR SURGERY?

Optimizing your health before surgery helps with safer surgery and a smoother post-operative recovery and minimizing complications. Things that you can do to help include:

- Maintaining a healthy weight (BMI).
  Surgery may only be offered if your Body Mass Index (BMI) is below 35. Further information can be found in our leaflet: *I want an operation and have a raised BMI. Why is this important?* You can access this online using the URL link at the end of this leaflet.
- Stop smoking
- Maintaining a well-balanced diet
- Exercising on a regular basis

In preparation for surgery, you may be prescribed GnRH agonist injections such as Prostap or Zoladex for 3-6 months prior to undergoing surgery. This is to alleviate your symptoms and suppress the endometriosis, to facilitate the operation. You will also see the pre-operative team for general health assessment and investigations prior to the operation.

You will need to have an enema (a procedure in which liquid medication is administered into the back passage) in the morning of your surgery to empty your bowel. This can be done at home or in the hospital depending on the time of your operation.

We will discuss with you the potential risk of needing a temporary stoma (where the bowel is diverted through an opening in the skin into a discrete bag). This will allow your bowel to heal. If we think you will require a stoma, we may offer you an appointment to see one of the specialist stoma nurses before your operation.

SURGERY FOR ENDOMETRIOSIS INVOLVING BOWEL (INTESTINES):

If endometriosis affects your bowel, a Gynaecologist with expertise in complex endometriosis surgery will perform the operation. A bowel surgeon may also be present for the procedure depending on the degree of bowel involvement with endometriosis. This may be determined based on pre-operative investigations and / or multi-disciplinary team discussion.

We will free up the bowel from scar tissue and surrounding organs. We may then need to remove the endometriosis tissue from the bowel by either:

- 'shaving' it from the outer surface of your bowel
- removing a small disc of bowel wall (discoid resection) and closing the hole in the bowel
- removing a section of bowel (segmental resection) and joining the ends together with metal staples

A bowel bag (stoma) may be required in some cases after removing a section of the bowel. This decision is often made during the operation depending on the location of the disease and the extent of bowel resection. A stoma is where the end of the healthy bowel is brought out through the tummy wall. A bag is attached to this opening to collect the faeces. This is usually temporary and is reversed after a few months after confirming the healing of the stapled part of the bowel. The closure of the stoma is usually a smaller operative procedure.

If a section of the bowel is removed at surgery, an additional cut is made along the bikini line to facilitate this part of the operation. This is usually 2 inches long.

SURGERY FOR ENDOMETRIOSIS INVOLVING THE BLADDER:

If deep endometriosis is present in the bladder or is blocking your ureter (water pipe which brings urine from the kidney to the bladder), a Urologist (surgeon who does operations on the urinary system) may help the specialist Gynaecologist perform the surgery.

The procedure involves looking inside your bladder with a telescope (cystoscopy). We may insert small plastic tubes (stents) into the ureters to help with the surgery. We will either remove these stents immediately after your surgery or we may need to leave these in for several weeks / months. If the ureter is affected by endometriosis, we may need to remove a small section of ureter. The cut ends of the ureter can be re-joined or diverted into the bladder.

If the bladder is affected by endometriosis; we may remove the diseased part of your bladder. This is called a partial cystectomy. The bladder is sown up with stitches. A urinary catheter in the bladder will help the bladder heal and may need to stay in for 10-14 days. You will be discharged home with the catheter and return for an X-ray test to check if the bladder has healed. Once this is confirmed, the catheter will be removed.

Depending upon the amount of the bladder all that is excised, you may not be able to hold as much pee due to the decreased capacity of the bladder. You may need to pee more often. However, this can improve over time.

WHAT ARE THE RISKS OF SURGERY FOR SEVERE ENDOMETRIOSIS?

Every surgical procedure has risks. Surgery for complex (severe) endometriosis has higher risks compared to most Gynaecology operations. The risks specific to surgery for severe endometriosis include:

- unexpected bowel injury (1-2 in 100)
- unexpected bladder injury (1 in 250)
- unexpected ureter injury (1-2 in 100)
- blood vessel injury (1 in 500)
- unexpected stoma formation (Bowel bag - an opening on the surface of the tummy): 1 in 100
- unexpected bowel fistula (abnormal connection between the bowel and another organ such as the vagina)
- 1 in 100 if segmental resection (removal of a segment of the bowel)
- bowel leak with risk of peritonitis (severe infection in the tummy)
- 1 in 50 if segmental resection
- fertility issues (decrease in the ovarian reserve of eggs if cysts removed from the ovary)

Complications can occur unexpectedly during the operation. However, sometimes complications may not be obvious during the operation and become obvious a few days or a few weeks after the operation. Symptoms to watch out for in the post operative period for complications are:

- Raised temperature
- Feeling unwell
- Increasing tummy pain
- Increasing back pain
- Vomiting
- Unusual discharge through the vagina

It is important to seek medical advice if you experience any of the above symptoms. You will be given a contact for the Gynaecology ward at discharge (24x7 phone contact). Details of Emergency Gynaecology will also be given to you at discharge (24x7 phone contact).

If there is a complication after your surgery, you may require additional investigations, in-patient admission and surgery. This might delay your recovery.

Additional risks associated with removing a part of the bowel include changes in the way your bowel works. These include:

- Increased frequency of bowel movements
- Urgency – unable to hold and needing to rush to the toilet
- Incontinence of flatus or stool – inability to control your bowels
- Incomplete bowel emptying – difficulty in emptying your bowel completely

Most of these symptoms resolve over time (usually a few months).

Extensive surgery in your pelvis may mean that your bladder does not work properly for a period of time. In the short term, you may need to self-catheterise (insert a small tube into your bladder to help it empty) until your bladder works normally again. It is very rare that this will be a long-term.

Other bladder symptoms include:

- Lack of sensation - Unable to feel the bladder when it is full

- Hesitancy and poor urinary stream
- Incomplete bladder emptying - Finding it difficult to empty the bladder completely
- Poor control of the bladder – Incontinence

General risks of surgery:

- Pain
- Bleeding requiring a blood transfusion, collection of blood in the tummy (Haematoma)
- Infection or abscess formation (collection of pus)
- Thrombosis - Blood clots in the leg or lung
- Scar tissue formation
- Bruising on the skin
- Hernia

WHAT TO EXPECT AFTER SURGERY?

PAIN RELIEF

We aim to keep you as comfortable as possible after a major operation with the help of a mixture of painkillers. You may feel pain in your tummy for several days after the operation. This is part of the normal healing process.

The Anaesthetist will discuss post-operative pain management with you on the day of the operation. If you have any concerns, please bring this to the attention of the Anaesthetist. Sometimes the Anaesthetist would offer you a spinal / epidural anaesthetic (needle in the back) along with a general anaesthetic to help with post operative pain. This may be particularly useful in patients who have chronic pelvic pain to achieve better pain relief in the first 24 hours after the operation.

The gas that we use to fill up your tummy to facilitate the keyhole operation can irritate the diaphragm (the muscle between the chest and the tummy). This can cause shoulder pain for 24 to 48 hours after the operation.

Taking regular pain relief will help you to feel more comfortable after your operation.

URINARY CATHETER:

A urinary catheter is inserted into your bladder during surgery. This is to keep your bladder empty during your operation as it increases safety. Sometimes a plastic tube (stent) is placed inside the ureter (water pipe connecting the kidney and the bladder) during the operation. This is usually removed at the end of the operation. The urinary catheter is removed the following morning.

If we have operated on the bladder, the catheter may stay in for longer. You may notice that the urine is pinkish (blood stained) after the operation if you have had stents inserted during the operation. This usually clears in 24-48 hours and the urinary catheter is removed once the urine is clear. The nursing staff will make sure you are emptying your bladder adequately.

VAGINAL BLEEDING:

You will experience some vaginal bleeding for a few days after your operation. During the operation we often place an instrument inside the womb to facilitate the operation. This instrument is removed at the end of the operation. Your first couple of periods after the operation may be different to what you have experienced prior to the operation. This will settle in a couple of months.

EATING AND DRINKING:

As part of the enhanced recovery plan, we will encourage you to drink water soon after your operation. We will offer you a light meal on your return to the ward if you feel hungry. It is not uncommon to feel nauseous or to be sick after an Anaesthetic. Please ask the nurse for anti-sickness medication if you feel so. Occasionally, we may ask you not to eat or drink anything or restrict dietary intake after the operation.

PREVENTION OF BLOOD CLOTS:

Undergoing surgery increases your risk of blood clots in the legs and / or lungs (venous thromboembolism). Poor mobility, diabetes, being overweight, smoking and previous clots in the legs or lungs (DVT / PE) increases the risk.

You will be required to wear anti-embolism stockings prior to the operation. A nurse will measure your calves and give you the appropriate size of stockings. If it is too tight, please inform the nurse looking after you as sometimes the calves may need to be remeasured especially after an operation. Please wear these stockings until you are fully mobile. You may wish to request an extra pair of stockings to take home, prior to discharge if you are not fully mobile.

We will also give you an injection (low molecular weight heparin) each day while you are in hospital to thin your blood slightly. The injections may continue for 7 days after surgery and your nurse will teach you how to do this at home after discharge.

The nursing staff on the ward will encourage you to move about and walk as soon as this is feasible. This will help reduce the risk of blood clots and also aid your general recovery. Drinking adequate amount of fluids and moving your feet regularly when sitting will further reduce the risk.

LENGTH OF STAY:

Most people will stay in hospital for between 1-3 nights. If your operation was complicated or required a large cut on the tummy, you may need to stay for longer.

SCARS:

Surgery for endometriosis is almost always done by keyhole. You will usually have four small scars (5mm to 10mm in size) on your tummy. One of these will be in your belly button. Sometimes one of these scars will be larger if the bowel is operated on. If you have an open surgery, you will have a longer scar on your tummy, which may be along your bikini line or up and down (sometimes extending above the belly button).

STITCHES AND DRESSINGS:

The keyhole surgery cuts on your tummy will be closed with a dissolvable stitch. We may also apply surgical glue over these cuts. Your surgeon will discuss this with you after the operation. If

your stiches need removal or if you have surgical staples on the skin, this will be removed in hospital or by the district nurse. We will make the arrangements for this before your discharge.

WASHING AND SHOWERING:

You should be able to have a shower 1 – 2 days after your operation. It is important to keep your wounds clean and dry to ensure they heal well.

RECOVERY AT HOME

It may take you 2 – 6 weeks to recover from the operation. You may feel very tired during this time, so it is important to take adequate rest. If you require a sick note for work, please inform the nurse looking after you on the ward.

CONCERNS AFTER DISCHARGE:

You will be given contact details of the Gynaecology ward and the Emergency Gynaecology unit (EGU) at discharge. We may need you to come back to the ward to be seen by one of our doctors after we have spoken to you by phone. If you are very concerned and cannot wait, please visit the emergency department. If you experience any of the following side effects in the days or weeks after the operation, you should contact your GP or call us for advice.

- Burning or stinging sensation when you wee. This may be due to a urinary tract infection, which we can treat with antibiotics.
- Worsening redness or pain around the scars. This may be due to a wound infection, which we can treat with antibiotics.
- Tummy pain that is getting worse. Please contact us immediately if you also have a fever, loss of appetite or vomiting.
- Swelling, redness or pain in your calf. This may be a sign of a blood clot.

EXERCISE AFTER SUGERY:

After undergoing complex surgery for endometriosis, your recovery will depend on the extent of surgery. Listen to what your body tells you. Start with walking in the first few days and then build up your distance.

Please avoid sexual intercourse and any heavy lifting for 6 weeks after your surgery.

DRIVING:

You should not drive for at least 2 – 6 weeks after your operation.

Please check with your insurance company their conditions for driving after an operation. You should be able to look over your shoulder and perform an emergency stop without causing any pain.

WORK:

You will require between 2-6 weeks off work. If you require a sick note, please ask us before you leave the ward. Your return to work will depend on the nature of your job. It is important that you contact occupational therapy at your workplace especially if your job is physically demanding.

If you require any further information or clarification of terminology, please do not hesitate to talk to one of the doctors or nurses, who will be happy to discuss your concerns.

CONTACT DETAILS

Endometriosis nurses: Endometriosis.nurses@mft.nhs.uk

Appointment queries: 0161 276-60000 (please select option 1).

https://mft.nhs.uk/saint-marys/services/gynaecology/endometriosis/

Please contact for any emergency advice within 4 weeks of your operation.

Emergency Gynaecology Unit (EGU)

(0161) 291 2561 (24 hours)

The EGU is located at Wythenshawe Hospital (enter via entrance 15)

There are no emergency gynae or early pregnancy services at Saint Mary's Hospital, Oxford Road

FURTHER INFORMATION

Royal College of Obstetricians and Gynaecologists (RCOG) patient information leaflet:

Recovering well: Information for you after a laparoscopy

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

RCOG patient information leaflet: Endometriosis

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