Extended Laparoscopic Surgery for Endometriosis (RLEE)

Patient Information
The purpose of this document is to provide information about your forthcoming operation. Even if your doctor has explained to you what your operation entails, many of us do not take in all of what is said in clinic.

This document is intended to help you understand your condition and the purpose of the intended treatment.

It is not, however, a personalised document and there may be differences between your individual case and the information given here.

If you have any queries regarding the information given please discuss them with the consultant or a member of his / her team (doctors or nursing staff).

What is endometriosis?

Endometriosis is a condition usually affecting women between the ages of twenty and fifty. However, it can affect young women in their teens and can occur at any time between the onset of menstruation (periods) and the end of the menopause.

The inside of the uterus (womb) is lined with tissue called endometrium which thickens every month under the influence of hormones, to prepare for pregnancy.

If no pregnancy occurs, the endometrium is shed, passes through the cervix (neck of the womb) and out through the vagina. This is recognised as a woman’s period.

Endometriosis occurs when endometrium is found outside its normal place in the uterus and grows on other places in the body.

The most common place for endometriosis to occur is in the surrounding pelvic tissue where deposits can attach themselves to various organs and structures such as the ovaries, fallopian tubes, bladder and bowel.

These deposits respond to hormones in the same way as normal endometrium, and bleed each month at period time. However, the blood is released directly into the surrounding area and has no way to escape.

Pain is caused because the bleeding irritates other tissues in the pelvic area and occasionally because some of the blood and tissue develop into cysts.

The continual releases of blood into the pelvic cavity each month also contributes to the formation of adhesions (scar tissue).
What causes endometriosis?
Despite extensive research worldwide, no-one really knows why some women develop endometriosis while others do not, but there are various theories.

The most widely accepted theory is that some tissue and blood may pass backwards, up the fallopian tubes and into the pelvis during menstruation (periods).

Another theory is that some women may have an abnormality of the immune system, or genetic factors which make them more susceptible to the disease.

How would I know if I had endometriosis?
Because the pain associated with this condition is caused by the endometrial tissue bleeding internally at the time of menstruation, the symptoms are usually at their worst during a period.

However, individual experiences vary considerably and symptoms may include:
- Painful periods
- Pain at ovulation (mid-cycle)
- Painful bowel motions (particularly at period time)
- Changes in normal bowel function at period time (eg constipation or diarrhoea)
- Painful urination (particularly at period time)
- Painful sexual intercourse
- Infertility
- Many women also complain of general tiredness and pre-menstrual type symptoms

What is extended laparoscopic surgery for endometriosis?
It is ‘conservative’ surgery used to try to restore the function of any organs damaged by endometriosis, to reduce symptoms and to improve fertility. It involves removing as much endometriosis and scar tissue (adhesions) as is possible through the laparoscope using minimal access techniques commonly known as ‘keyhole surgery’.

Are there any alternatives?
The treatment of endometriosis can be complex and will depend on many factors. These include age, severity of symptoms, the extent of the disease (including how various organs might be affected), whether you might want to have children in the future, and of course, the treatment approach preferred by you and your doctor.

Many women require a combination of approaches or treatments.

Drugs such as a group of hormones called ‘GnRH Analogues’ (e.g. Zoladex) have the effect of ‘turning off’ the natural hormones so that the woman becomes temporarily menopausal and menstruation is stopped, or at least reduced to only three or four periods a year.

During such drug treatment, clusters of endometriosis may shrink and disappear and the pelvis will be given time to rest and heal, often giving symptomatic relief.

Other drug treatments currently favoured include the use of progestogens, e.g. Provera, Duphaston; and synthetic steroids, e.g. Danazol. They also disrupt normal hormonal release, affecting ovulation and menstruation.
Drug treatments, however, are usually short-term measures and cannot be continued indefinitely because of potential risks to the heart, the circulation and bones.

**How is extended laparoscopic surgery for endometriosis performed?**

A laparoscopy is a surgical procedure performed under general anaesthetic. The laparoscope is a long, pencil-slim telescope which is connected to a camera and a television system so that the inside of the abdomen can be seen magnified on a screen.

Once you are asleep, a small incision is made, usually at the bottom of the umbilicus (navel).

At the start of the operation, carbon dioxide gas is pumped through the incision in order to distend the abdomen. This ensures that the surgeon has a clear vision of the pelvic and abdominal organs throughout the procedure.

The laparoscope itself and other surgical instruments are then inserted through further small incisions.

During the laparoscopy, the deposits of endometriosis may be excised (that is, cut out and removed). The alternatives to excision are either to use a laser or to use heat from electrosurgical instruments (diathermy). Excision is our preferred practice as we feel that we can be more sure that all the endometriosis is fully removed.

If there are cysts containing endometriosis, they are usually drained first then each cyst lining is destroyed so that it cannot reform. If there are any cysts actually on the ovaries, the same method is used and fertility may be retained in most cases.

When the instruments are removed at the end of the operation, the gas used to inflate the abdomen is released, then a stitch or a small amount of special glue may be put in each of the small incisions. Quite often the wound requires nothing to seal it.

**Are there any complications or risks associated with extended laparoscopic surgery for endometriosis?**

We know there may be complications following various gynaecological operations or procedures, that are not particularly serious but do happen more often.
These frequently occurring risks include:
Pain, bruising, delayed wound healing, scarring of the skin or scar tissue inside (adhesions).
Numbness, tingling or burning sensation around the laparoscopy scars. Anaemia, fatigue / tiredness. Urinary frequency or loss of control.
Wound infection, urinary tract infection or chest infection which is usually easily treated with antibiotics. Patients are encouraged to follow the recommended post-operative breathing exercises and to reduce or stop smoking if possible.

Are there any more serious risks?
It is also known more serious risks are present in certain circumstances in these operations. These risks are rare but some risks are increased if you already have underlying medical problems or if there is lots of endometriosis and/or scar tissue (from previous operations or disease) which makes the laparoscopy more difficult. The risks are also increased if you are obese or if you smoke. The more serious risks are as follows:

1) Infection. This may occur in the pelvis, bladder, incision site or in the chest. Infections are usually easily treated with antibiotics but occasionally an abscess may form which may require surgical drainage under anaesthetic. All ladies having extended laparoscopy are given antibiotics pre-operatively to help prevent occurrence of infection.

2) Bleeding. This may occur during the operation or, rarely, afterwards and may be sufficient to require a transfusion. If you are found to have a collection of blood in the pelvis (a haematoma) it can usually be treated with antibiotics but occasionally it may need to be drained surgically under anaesthetic.

3) Visceral injury. This is essentially injury to the bowel, bladder or ureters (the two tubes coming from the kidneys into the bladder). The risk of this type of injury is directly related to the severity and extent of the endometriosis. If the endometriosis is mild, then the risk is small. However, if the endometriosis is severe and is known to involve the bowel, bladder or ureters, then the risk is significantly higher. If, for instance, endometriosis is growing into the wall of the bowel, it may be necessary to purposefully remove part of the bowel wall in order to completely excise the endometriosis. This would result in a laparotomy which involves a larger incision and a longer stay in hospital. Very occasionally, it may be necessary to perform a temporary colostomy. These complications would usually be detected during the operation and be dealt with immediately. In rare cases the problems may not become apparent until a few days later and a second operation may be required.

4) Deep Vein Thrombosis (DVT). Following extended laparoscopy it is possible for clots of blood to form in the deep veins of the legs and pelvis. If this does occur, a deep vein thrombosis would cause pain and swelling in a leg and can be treated relatively simply with drugs. The risk of developing a DVT is minimal, as many precautions are taken to help prevent and minimise the risks. These include reduction of smoking in the weeks before your operation, use of support stockings and/or the use of medication to ‘thin the blood’, the use of special equipment in the operating theatre and also recommended post-operative leg exercises.

5) Pulmonary Embolism. In rare cases, it is possible for a clot to break away and be deposited in the lungs or heart and if this occurs it is a serious situation and will need immediate treatment with drugs. The precautions against pulmonary embolism are the same as for DVT.
If you do have any concerns about the risk of complications, please discuss them with the consultant or a member of his/her team (doctors or nursing staff) and your questions will be answered as clearly and as honestly as possible.

What happens before I am admitted into hospital?

You will probably have had some MRSA swabs taken at the end of your appointment with the consultant, then filled in some medical forms and had your weight, height, pulse, and blood pressure recorded. You will then be invited back to the hospital for your preadmission appointment. Some blood samples will probably be taken and, depending on your general health and age, you may also need a heart tracing (ECG - electocardiogram), a chest x-ray or a lung function test. We may want to listen to your chest or take a more detailed history of your medical problems for the anaesthetist. You will already have had your operation explained to you by your consultant so he/she is not usually involved in preadmission and there is not usually any need for an internal examination. You will have the opportunity to ask the nurse any questions you might have.

Shortly before your operation, we usually phone you to make sure your general health has not changed since you were seen by the preadmission team and you have understood the information you have been given. An appointment will be made for the telephone call. The nurse or healthcare assistant calling you will complete your hospital paperwork and also make sure the arrangement we have made for your discharge day is still right for you.

Your anaesthetist would prefer you to stop, or at least reduce, cigarette (and cannabis) smoking in the weeks before your operation, as this is known to increase the risk of anaesthetic complications, e.g. breathing difficulties, coughing, nausea and sickness and chest infection. Please avoid drinking alcohol on the evening before your operation as this may lead to dehydration.

To reduce the possibility of skin infection, we request you do not shave your bikini-line or your legs during the week before your operation but some ‘trimming back’ of excess pubic hair may be required, you can do this yourself at home or the nursing staff will help you after you are admitted.

If you have severe endometriosis ‘bowel prep’ may be required, particularly if it is known or suspected that there is a possibility of endometriosis on or close to the bowel.

Bowel prep involves taking a low fibre diet for three days prior to the operation. During the day before the operation two doses of a laxative preparation are taken and you are allowed ‘fluids-only’ in the afternoon, evening and overnight.

If you need bowel prep it will have been discussed with you in clinic when your operation was being organised and you will receive detailed, written information to help you with this.

The supply of the laxative preparation for your use at home will be organised and if you are to be admitted into hospital the day before your operation, the nursing staff on the ward will have your laxative. **You do not need to get your own laxatives from the chemist.**
Admission into hospital

Please wear comfortable clothes that are not tight around the waist.

You will need to bring a packet of sanitary towels into hospital with you, toiletries, dressing gown, nightgown and slippers, plus any medications that you are currently taking. You may also choose to bring in a book or magazine.

You will need to take off as much of your jewellery as possible although we are able to cover wedding rings/bangles if you are unable to remove them. To reduce the possibility of any damage to your eyes, it is very important you remove all mascara and wear glasses instead of any type of contact lenses.

Please be aware that South Tees Hospitals NHS Trust cannot be held responsible for any personal belongings, valuables or money you bring in with you.

Do not have anything to eat as instructed in your admission letter. If you are having bowel prep, please refer to your booklet for instructions on drinking. Do not suck sweets or chew gum.

If you are already in hospital, the nurses will advise you when to have your bath/shower and you will be given a surgical gown to wear. If you are being admitted into hospital on the day of your operation, you will need to take a bath or shower before you arrive. You will be provided with a gown on arrival, then the nurses will advise you to put it on at the appropriate time.

Please read your admission letter carefully to see where you are being admitted to. If you are unsure, you may phone the nursing staff:

- Surgical Admissions Unit (Female) at The James Cook University Hospital: 01642 854603
- Women’s Health Unit / Ward 27 at The James Cook University Hospital: 01642 854527

Partners or friends may drop you off at the unit but unfortunately we do not have the facilities to let them stay with you. For patient confidentiality, you be asked if you will be expecting any telephone enquiries. If an unexpected enquiry is received, the person calling will be told that you are not on the unit.

What can I expect before the operation?

You should normally have signed a consent form before your admission day but if you have not done this, you will be seen by your consultant or a member of his/her team who will explain your operation in detail and answer any questions you may have before you sign the consent form. You will also have the chance to speak to your anaesthetist before your operation. The nurses will give you ‘support socks’ and small injection of medication to thin the blood may be given during your operation but will be omitted if the endometriosis is extensive or widespread. You will then go to the theatre area with a nurse and/or porter.
What can I expect after the operation?

• When the operation is completed you will be woken by the anaesthetist and transferred to the recovery area in theatre, where a nurse will look after you and stay with you until he/she is satisfied with your condition. You will be transferred to the ward on your trolley and the ward staff, with the help of the theatre porter, will transfer you into your bed. You will probably feel drowsy for a few hours afterwards.

• You may have a ‘drip’ (also known as an I.V.) to provide intravenous fluids until you are able to start drinking.

• Post operative discomfort may occur in the shoulders, under the rib cage or in the lower part of the neck, caused by a small amount of gas remaining under the diaphragm after the operation. This gradually disappears over the next 24 – 48 hours as the gas is naturally absorbed by the body. You may also experience lower abdominal discomfort similar to period-type cramps.

The anaesthetist usually gives you pain relieving drugs while you are asleep in theatre and these should result in a comfortable postoperative recovery. If necessary, we can use other methods of pain relief such as a PCA (patient controlled device) allowing you to control the amount of pain relief you receive.

If you do have a PCA, it is usually removed the day after your operation, when it is no longer required, and painkillers are then given by mouth.

• You may have had a catheter inserted into the bladder. This is a very slim rubber tube which drains urine from the bladder so that:
  a) you do not have to get up to go to the toilet when you may still be feeling a bit drowsy and sore.
  b) we can make sure that the bladder is working well.

The catheter is usually removed the day after your operation and its removal is a simple and painless procedure.

• You may be visited by the physiotherapist the day after your operation, who will give you advice on gentle post-operative exercises and a physiotherapy leaflet, if you don’t already have one.

• It usually takes one or two days before your bowels start to work normally and you may experience discomfort associated with a build-up of wind. This usually resolves itself, but if it becomes a problem the nursing staff may provide some peppermint water to drink and encourage taking gentle exercise.

• You may have a small plastic tube drain coming out from one of the tiny incisions in your abdomen. This allows any blood or fluid that may collect in your pelvis, in the hours after your operation, to drain out. Again, this is usually removed the day after your operation and is a simple procedure.

• It is important to keep your genital area and any abdominal wounds clean. A daily bath or shower is advisable paying particular attention to these areas. Avoid the use of highly scented soaps, bubble bath and vaginal deodorants, etc. We will provide a separate sterile towel to dry the wound and a sterile dressing to cover the wound after bathing.
If dressings are still needed on discharge they will be provided by the nursing staff. You may have dissolving stitches in your wound, in which case you will be advised by the nursing staff how to care for them.

- You should expect to have some vaginal bleeding in the first few days after the operation. The bleeding normally turns into a red/brownish discharge before stopping completely and can last anything from a few days to a few weeks. If bleeding becomes heavier than a period or smells very offensive, let the doctor or nursing staff know as it may mean that you have an infection. We advise you to use sanitary towels in preference to tampons whilst the bleeding persists, as this will help you to keep a check on the amount you are losing and will help to reduce the risk of infection associated with tampon use.

How long can I expect to be in hospital after an extended laparoscopy?

Your length of stay depends on how quickly your bladder returns to normal function after the catheter is removed. Generally if things go to plan your stay is two days. The length of your stay may also depend on how quickly your bladder returns to normal function after the catheter is removed.

If, upon reading this information, you have any queries regarding any aspect of your aftercare following your discharge home from hospital, you are welcome to contact Ward 27 on 01642 854527.

What happens when I go home?

The majority of women feel quite fit and well within four to six weeks after extended laparotomy but all patients are different. The actual rate of recovery depends to a large extent on your state of health before the operation and the extent of your endometriosis. It is important you resume your normal activities gradually and limit what you do by how tired or how uncomfortable you feel.

- If you were supplied with support socks you are strongly advised to wear them for a total of six weeks, day and night for the first two weeks then during the day for a further four weeks, until you are back to your full mobility.

- Continue with any exercises you were advised to do in hospital. You may find you get tired quite quickly at first, but this will improve with your general fitness level.

- Returning to work is up to the individual and depends on the type of job you do. For example, a job involving heavy lifting will take a bit longer to return to, usually about 10 to 12 weeks, but if you are in a job with no lifting involved, you may be able to return after six to eight weeks.

You are the best judge of how you feel, but please remember that although you only have tiny abdominal incisions, you have had a major operation and time is needed to allow the healing of the muscles and tissues on the inside.

- You can normally resume driving when you can stamp your feet hard on the ground without causing any pain or discomfort, and when you believe that your concentration will not be impaired. Your insurance company will probably assume you are not fit to drive after a major operation until your doctor says you can. If you have any concerns about this, check with your insurance company.
• You may resume sexual activity when you feel fit and able to do so, but it is advisable to give your internal tissues, and any stitches that you may have at the top of your vagina, time to heal (usually about three to four weeks).

General advice
If you have any of the following symptoms, you should contact your GP:
• Vaginal bleeding, which is heavy and fresh, bright red or the passing of clots.
• Pain which is severe and not controlled by your prescribed painkillers.
• A smelly vaginal discharge.
• Feeling unwell, hot and feverish.
• Pain in the calf muscles or chest.
• Redness or oozing from any of the incision sites.

You might find the following contacts useful:
The National Endometriosis Society,
50 Westminster Palace Gardens,
1-7, Artillery Row,
London, SW1P 1RL
www.endo.org.uk

Endometriosis UK
46, Manchester Street
London, W1U 7LS
http://endometriosis-uk.org/

Breathing exercises
The recommended breathing exercises mentioned should help maintain a clear chest, tone up muscles and ease wind pain following surgery. Start this exercise as soon as you wake up from the anaesthetic and do regularly until you increase your walking.

Bend your knees up with feet flat on the bed, breathe in through your nose until your lungs are as full as possible, then relax as you breathe out through your mouth. Repeat five times every half hour or so, and follow with two huffs.

Huff: Position as above with hands or pillows supporting any area of discomfort. Take a medium breath in, then force the air out quickly through an open mouth, as though you are trying to mist up a large mirror. Follow this with a cough – take a big breath in first, and do not worry about this doing any damage in the area of your surgery.

Foot and knee exercises: These should help the circulation and help prevent clots from forming in your legs. Repeat every time you do your breathing exercises and until you are walking about. Bend feet up and down at the ankle firmly and quickly. Draw circles with your feet. Press back of the knees into the bed and tighten up the thigh muscles.

We hope you have found this information helpful.

Please remember our staff will be happy to answer any questions you have about any aspect of your care and welcome any comments about this leaflet.
### Comments, compliments, concerns or complaints

South Tees Hospitals NHS Foundation Trust is concerned about the quality of care you receive and strives to maintain high standards of health care. However we do appreciate that there may be an occasion where you, or your family, feel dissatisfied with the standard of service you receive. Please do not hesitate to tell us about your concerns as this helps us to learn from your experience and to improve services for future patients.

### Patient Advice and Liaison Service (PALS)

This service aims to advise and support patients, families and carers and help sort out problems quickly on your behalf. This service is available, and based, at The James Cook University Hospital but also covers the Friarage Hospital in Northallerton, our community hospitals and community health services. Please ask a member of staff for further information.