



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Surgery for endometrial cancer

Information for patients, relatives and carers

Cancer Services

① For more information, please contact:

Clinical Nurse Specialists Office

Telephone: 01094 726478

York Hospital, Wigginton Road, York, YO31 8HE

Open Monday to Friday, 8am to 3.30pm

Out of hours, please contact ward G1 on 01904 726001

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Introduction

This booklet has been written to help answer some of the questions you may have about endometrial cancer. If you have recently been diagnosed with cancer of the lining of the womb (endometrial cancer), it is normal to experience a wide range of emotions. This can be a very frightening and unsettling time. Whatever you may be feeling at present, try talking about it with someone who can help - such as your GP, Consultant or Clinical Nurse Specialist (CNS). They will listen, answer any questions you have and put you in touch with other professionals or support agencies if you wish. Some useful contact numbers are listed at the back of the booklet.

What causes cancer of the womb?

The exact cause of cancer of the womb is not yet known. Women who are still having periods and who take the contraceptive pill are believed to have a lower risk of developing cancer of the womb. Women who have gone through the menopause and who take oestrogen-only hormone replacement therapy (HRT) for a long time may have a slightly increased risk of developing the disease. Women who have not had their womb removed and are taking HRT should make sure that they are taking a combination of the hormone's oestrogen & progesterone, rather than oestrogen on its own. Taking combined oestrogen and progesterone HRT does not increase the risk of developing cancer of the womb. Cancer of the womb most commonly occurs in women over the age of 50 years, although this can sometimes develop in women under 50.

What operation is needed?

Most women with endometrial cancer will need an operation to remove their womb (uterus and cervix), fallopian tubes and ovaries. This is known as a Total Hysterectomy and Bilateral Salpingo Oophorectomy. Most commonly, the operation is done by keyhole surgery (laparoscopy) but sometimes an open procedure (through a larger cut in the tummy) is required. The aim of the operation is to remove all of the cancer. If there is any evidence that the cancer has spread, you may be offered further treatment which would be radiotherapy and, in some cases, chemotherapy. This will be discussed with you when all your results are available.

Are there any alternatives to surgery?

Yes. An operation and/or a general anaesthetic may not be the most appropriate treatment plan. Radiotherapy alone can be used as an alternative to surgery, although this option is not always suitable for everyone.

What are the risks and benefits?

The aim of the operation is to remove the cancer. As with any surgical procedure, there are risks associated with having a general anaesthetic. Also, there is the risk of infection and bruising both internally and in the wound. Very occasionally, there may be excessive bleeding after the operation and a blood transfusion may be necessary.

Women occasionally suffer from blood clots in the leg or pelvis – these are known as deep vein thrombosis (DVT). In some cases, this can then lead to a blood clot in the lungs. Moving around as soon as possible after your operation can help to prevent this. You will be given special surgical stockings (known as TEDS) to wear whilst in hospital and injections to thin your blood. A physiotherapist will visit and show you some leg exercises to reduce the risk of blood clots developing.

After the operation, your bladder and bowel may take some time to begin working properly. Some women have a loss of feeling in the bladder that may take some time to return to normal. During this time, you need to take special care to empty the bladder regularly. Rarely, during the surgery there may be damage to the bowel / bladder / ureter - the tube between the kidneys and the bladder, which may require repair.

During your pre-assessment appointment, we will give you a leaflet on preparing for surgery.

Will I have a scar?

Yes, although it will fade. The surgeon will close the wound with sutures (stitches) or clips. The area around the scar will feel numb for a while after the operation but sensation will usually return to it.

What about my fertility?

At any age, having your womb and ovaries removed can affect the way you feel about yourself. A hysterectomy will prevent you from getting pregnant. The loss of fertility can have a huge impact if you have not started or completed your family, and you have an operation that takes your choice away. You may want to make sure that you have explored all your options. It is important that you have the opportunity to discuss this and your feelings with your Clinical Nurse Specialist before you have the operation. They will continue to offer you support when you are recovering from the operation too and advice is also available from our fertility team.

Will I need Hormone Replacement Therapy (HRT)?

You may need HRT if you have both your ovaries removed and have not already been through the menopause. HRT is available in many forms, such as implants, patches, tablets, gels, sprays and vaginal creams. There are also alternative ways of managing any potential symptoms. Please discuss the options available to you either with the Gynaecological Oncology Team before you are discharged from the hospital, or with your GP. You can also contact your Clinical Specialist Nurse for further information or advice.

Is there anything I can do to prepare for the operation?

Make sure that your questions have been answered to your satisfaction and that you fully understand what is going to happen. You are welcome to visit the ward and meet the staff before you are admitted to hospital. Ask your Clinical Nurse Specialist or pre-assessment nurse to arrange this for you. If you are a smoker, it would benefit you greatly to stop smoking or cut down before your operation. This will reduce the risk of chest problems as smoking makes your lungs more sensitive to chest infections after the anaesthetic. Please note the trust operates a no smoking policy.

You should also eat a balanced diet, and if you feel well enough take some gentle exercise before the operation as this will also help your recovery afterwards. Your GP, practise nurse or the doctors or nurses at the hospital will be able to give you further advice about this. Before you come into hospital for your operation, try to organise things ready for when you come home. If you have a freezer, stock it with easy-to-prepare food. Arrange for relatives and friends to do your heavy work (such as changing bedding, vacuuming and gardening) and to look after your children, or dependants if necessary. If you think you may have problems after your discharge home, you may wish to discuss this with the nurses on the ward.

If you have any concerns about your finances whilst you are in hospital and recovering, you may wish to discuss this with your Clinical Nurse Specialist or with ward staff. You can do this either before your admission or whilst recovering in the ward.

If you would like to be assessed for home or personal care for when you are recovering at home, the social work department or discharge team can arrange this whilst you are in hospital. Please discuss your cultural and religious needs with a member of the ward nursing team who will endeavour to meet your needs.

What tests will I need before my operation?

Before your operation you will be invited to attend the hospital so that the details of the operation can be checked, and tests can be done to ensure you are physically fit for surgery. You may have one or more of the following:

- ECG - recording of your heart
- Chest X-Ray
- Respiratory function tests
- Blood samples, to check that you are not anaemic and that the function of your kidneys and liver is normal
- MRI, CT or Ultrasound scan

The investigations you need may be done at a pre-assessment clinic or on the ward during your admission. You will also have the opportunity at this time to ask the doctor or specialist nurse any questions you may have. It may help to write them down before you come to hospital.

When will I come for my operation?

When you arrive, the ward clerk or one of the nurses will greet you on the pre-operative ward. You will meet the doctors involved in your care. They will discuss the management of pain after the operation. Any further questions you may have can be answered at this time. You will be asked to sign a consent form to confirm that you understand and agree to the operation and recognise any possible complications if you have not already done so in the pre-assessment clinic.

The tissues removed at the time of your operation can be used in research into gynaecological cancer. One of the doctors or nurses may discuss with you whether you are happy for us to use your tissue in this way. You may need to have a bowel preparation which may be in the form of an enema, suppositories or it may be oral medication, this is usually given the day before and the morning of your surgery. This will vary depending upon the type of operation planned but it will be discussed with you when you attend for your pre-operative visit.

What happens on the day of my operation?

You will not be allowed to eat or drink anything (including sweets and gum) for a number of hours before your operation. The ward nurses will advise you when to stop eating and drinking. Before going to the operating theatre, you may be asked to take a bath or shower. You will need to remove make-up, nail varnish, jewellery (can tape over a sentimental ring or band) however, all body jewellery will have to be removed. Dentures, contact lenses, wigs and scarves will also need to be removed. You will be given a theatre gown and TED stockings to wear, paper pants will be provided if you wish to wear them. Nursing staff will try to ensure you feel as comfortable about this as possible so dentures are often removed just before you are put to sleep.

What happens after my operation?

Laparoscopic Hysterectomy

Once you are back on the ward you will be given pain relief (analgesia) as you need them but often pain is minimal. When you feel ready to you will be helped to get out of bed and move about. You will be able to eat and drink normally. You will be able to go to the toilet normally, it is uncommon to have a catheter (fine tube in the bladder) after a laparoscopic hysterectomy.

Open (abdominal) Hysterectomy

Immediately after the operation you will be monitored in the recovery room within the theatre department for a period of time. The ward nurse will come and collect you and take you back to the ward. In some cases, there is a need for patients to go to High Dependency Unit (HDU) or Intensive Care Unit (ICU) but this is usually arranged before you go to theatre. This will depend upon how long the surgery takes and the level of nursing and medical support needed after the operation.

You may still be very sleepy and need the support of oxygen through a clear facemask to help you breath comfortably immediately after your operation. Your blood pressure, heart rate and breathing rate will be monitored regularly. Your eating and drinking may be restricted for a period of time or until bowel sounds are heard and you are able to pass wind. A drip will be attached to you to provide fluids and prevent dehydration during this time.

Occasionally, you may have a small tube (drain) from your wound. This is used so that any blood or fluid that collects in the area can drain away safely, it will help to prevent swelling. The tube will be removed when it is no longer draining fluid, this can take several days. A fine tube (catheter) will be placed inside your bladder to drain urine away and allow your bladder to rest. The catheter will stay in until you are able to move around, this is usually one to two days. You may have trouble opening your bowels or have some pain due to wind for the first few days after the operation. This is temporary and we can give you laxatives and medication if you need it.

How will I feel after the operation?

Laparoscopic Hysterectomy

You can expect to feel tired and sleepy due to the anaesthetic and surgery for the first day or two. You will have some aches and pains in the tummy but these are often minimal and controlled with simple medications like paracetamol. You may have some vaginal bleeding or blood stained discharge but this does usually does not last more than a few days. The small wounds (less than a centimetre) from the keyhole surgery will have dressings which are usually removed a few days after the surgery. Dissolvable stitches will usually be used, and these do not need to be removed.

Open (abdominal) Hysterectomy

You can expect to feel extremely tired and sleepy due to the anaesthetic and surgery for the first day or two. Please tell us if you are in pain or feel sick when you return to the ward. We have tablets, suppositories and injections that we can give you as required so that you can remain comfortable. You may have a device that you use to control your pain yourself. This is known as Patient Controlled Analgesia – or PCA device; don't worry, you will be shown how to use it. Alternatively, an epidural may be inserted in your back for pain relief. The choice between a PCA and epidural will be discussed with you by the anaesthetist before surgery.

You may have some vaginal bleeding or a blood stained discharge but this does not usually last for more than a few days. The wound will have a dressing on and it will be removed the day after the operation. Depending on the type of incision used, the sutures or clips will be removed according to your surgeon's instructions. This is usually five to twelve days after the operation. Nurses in the community may do this, and it will be arranged before you are discharged home.

You will be encouraged to do gentle leg and breathing exercises to help circulation and reduce the risk of a chest infection. You will be expected to become mobile as soon as possible after your operation.

A physiotherapist may see you before or after your surgery.

Is it normal to feel weepy or depressed afterwards?

At times you may feel a little weepy or depressed, this is a common reaction to the operation. If these feelings persist when you leave the hospital you may wish to discuss this with your GP or Clinical Nurse Specialist. There are also a number of local and national support groups. Details are given at the end of this booklet.

When can I go home?

Laparoscopic Hysterectomy

If your operation was in the morning, you would usually go home later on in the afternoon or evening on the same day. Most people do not need more than a night in hospital after a laparoscopic hysterectomy.

Open (abdominal) Hysterectomy

You will be in hospital for between two and five days, depending on the type of operation you have had, your individual recovery, how you feel physically and emotionally and the support you have at home. This will be discussed with you before you have your operation and again whilst you are recovering. If you require hospital transport for your discharge home, please let a member of the nursing team know well in advance.

When can I get back to normal?

Laparoscopic Hysterectomy

In the first one to two weeks after the operation you will feel tired, but your energy levels will gradually increase, and the pain will lessen. You can wash and shower as normal. Build up your activity slowly and steadily, starting with short walks. Avoid any heavy lifting in this time. After two to four weeks, you can begin to resume daily activities such as shopping, vacuuming, ironing, and light gardening. After four to six weeks, you will feel almost back to normal, and it is ok to resume exercise and you would normally be ready to return to work.

Open (abdominal) Hysterectomy

It is usual to continue to feel tired when you go home. It can take up to three months to fully recover from this operation, sometimes longer, especially if you require any further treatment after surgery. However, your energy levels and what you feel able to do will usually increase with time. This is very individual so listen to your body's reaction and rest when you need to. This way you will not cause yourself any harm or damage.

Rest as much as possible, gradually increasing your level of activity. Continue with gentle activities such as making cups of tea, light dusting and washing up. Avoid lifting or carrying anything heavy (including small children and shopping). Spring cleaning and vacuuming should be avoided for six weeks after your operation. Generally, within three months you should be able to return to your normal activities but you can discuss this further on your return to the follow-up clinic.

When can I start driving again?

This will depend on the extent of the surgery you have had, how you are feeling and your individual recovery. You will be able to discuss this further with the doctor at your follow-up appointment. We suggest that you contact your car insurers following discharge to check your policy following surgery.

When can I return to work?

This will depend on the type of work you do, how well you are recovering and how you feel physically and emotionally. It also depends on whether you need any further treatment (such as radiotherapy) after your operation. Most women need two to three months to recover fully before returning to work or their usual routine. However, this will depend upon your individual recovery, which you should discuss further with your doctor, Clinical Nurse Specialist or GP. Remember - returning to normal life takes time, it is a gradual process and involves a period of readjustment and will be completely individual to you.

What about exercise?

It is important to continue doing the exercises shown to you by the physiotherapist for at least six weeks after your operation. Ideally, you should carry on doing them for the rest of your life, particularly the pelvic floor exercises. Do not do any aerobic exercise, jogging or swimming until you are advised to. Your physiotherapist or Clinical Nurse Specialist will be happy to give you advice on your individual needs.

When can I have sex?

Following the diagnosis of and treatment for endometrial cancer, you may not feel physically or emotionally ready to have sex. It can take at least two months to recover from the operation and even longer for energy levels or sexual desire to return. During this time, it may feel important for you and your partner to maintain intimacy. However, some couples are both physically and emotionally ready to resume having sex much sooner and this can feel like a positive step.

If you have any individual worries or concerns, please do discuss them with your Clinical Nurse Specialist.

It can also be a worrying time for your partner. They should be encouraged to get involved in the discussions about your operation and how it is likely to affect your relationship afterwards. Their involvement can be a positive influence on your recovery. If you do not have a partner at the moment, you may have concerns either now or in the future about starting a relationship after having this operation. Please do not hesitate to contact your Clinical Nurse Specialist if you have any queries or concerns about your sexuality, change in body image or your sexual relationship before or after surgery.

Will I need to visit the hospital again after my operation?

Yes, it is important that you attend any further appointments arranged. If the tissues analysis (histology) results from your operation are not available before you are discharged home, an early appointment for the outpatient clinic will be made to discuss the results and any further treatments if necessary.

If you have a very early stage endometrial cancer you will be assigned to patient initiated follow up, please see the additional information sheet about this.

If you do not have a very early stage endometrial cancer you will need to attend regular, follow up appointments in the future.

If the cancer has not been fully removed or if it is found in the lymph nodes, you may be referred for further treatment such as radiotherapy or chemotherapy.

Should I continue to have cervical smears?

No, cervical smear tests are usually not necessary after this operation, as your cervix will have been removed. However, it is important to come for regular examinations in the outpatient clinic and a 'vault' smear (taken from the top of the vagina where the cervix was removed) may be taken as part of your routine examination.

How do I make a comment about my treatment?

We aim to provide the best possible service and staff will be happy to answer any questions you may have. If you have any suggestions or comments about your stay, please use the comments leaflets on the ward or in the outpatient department.

Who should I contact if I have any problems?

Your first point of contact is your local GP or District Nurse, however, you can contact the hospital 24 hours a day (call Ward G1 on 01904 726001) they will advise you too. Your CNS is a good point of contact and if you need it, they can re-arrange your clinic appointments or arrange an urgent review if this is considered appropriate.

Further Information and Support

We hope that this booklet answers most of your questions but, if you have any further queries or concerns, do not hesitate to contact the CNS or Ward G1.

Clinical Nurse Specialists Lynne Jackson & Claire Wise

Telephone 01904 726478

Working Hours are Monday – Friday 8am – 3.30pm

Ward G1- Gynaecology Ward at York Hospital

Telephone Number 01904 726001

Cancer Care Centre at York Hospital

Offers support and information for anyone affected by cancer. Telephone 01904 721166

Open Monday – Friday 9am – 4.30pm

Macmillan Cancer Support

Helpline 0808 808 00 00. Monday to Friday 9am-8pm
www.macmillan.org.uk. Macmillan provide information on all aspects of cancer via the helpline and the website.

The Hysterectomy Association

www.Hysterectomy-association.org.uk

Space for your questions and notes

Feel free to use this blank space to note down any questions you may have.

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact: The Gynaecological Nurse Specialists, The York Hospital, Wigginton Road, York, YO31 8HE or telephone 01904 726478.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:

www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

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