NHS
The Christie
NHS Foundation Trust

Hysterectomy for Endometrial Cancer

A guide for patients and their carers

Contents

Introduction

This booklet has been written to help answer some of the questions you may have about surgery for endometrial cancer.

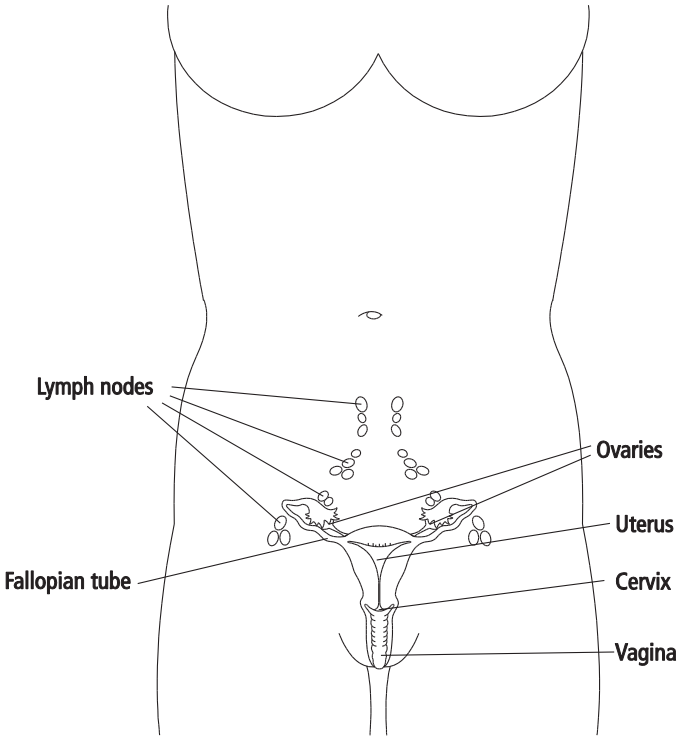
If you have recently been diagnosed with endometrial cancer (cancer of the lining of the womb), it is normal to experience a wide range of emotions. For some women, it can be a frightening and unsettling time. Whatever you may be feeling at present, try talking about it with someone who specialises in dealing with this condition such as your consultant or the gynaecology cancer nurse specialist (CNS). They will listen, answer any questions you may have about your surgery for endometrial cancer and can put you in touch with other professionals or support agencies if you wish. Some useful contact numbers are also listed at the back of this booklet.

What is a hysterectomy and why is it necessary?

Women with cancer of the lining of the womb (uterus) need an operation to remove their womb, fallopian tubes and ovaries. This is known as a hysterectomy and bilateral salpingo-oophorectomy. The pelvic lymph glands may also be removed, this will depend on the type and stage of cancer. This will be discussed with you before your operation.

The aim of the operation is to remove all of the cancer. If there is any evidence that the cancer has spread, or if the results of the operation suggest that you may be at increased risk of recurrence of the cancer (your cancer returning), you may be offered further treatment such as radiotherapy and/or chemotherapy. This will be discussed with you when all of your results are available.

Pelvic Organs



Agreeing to treatment

Consent to treatment

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had a written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

What are the benefits of this operation?

The aim of the operation is to remove all the cancer so that we can assess the extent of the disease. This is known as staging. This will enable the team to know whether further treatment is recommended.

Are there any alternatives to this operation?

Yes, but these vary from patient to patient. The treatment options will depend on the stage of your disease. The medical team will discuss this with you. For some women the options are:

- Radiotherapy: this may be recommended for some women. This tends to be offered to women who are at higher risk of recurrence or women who are not felt to be medically fit enough to have major surgery.
- Chemotherapy: this can be given in combination with the radiotherapy.

What happens if I have no treatment?

Your wish to have or not to have treatment for your cancer will be respected at all times by your medical team. If you choose not to have treatment, your cancer will progress and your health is likely to deteriorate.

At this time you may wish for us to transfer your care to the supportive care team, who will discuss with you what will happen next and help you to manage your symptoms and support you either in hospital, at home or in the local hospice.

Are there any risks?

As with any operation there are risks but it is important to realise that the majority of women do not have complications.

There can be risks associated with having a general anaesthetic and major abdominal surgery. The risks include:

- Bruising in the wound. Internal bruising (inside your tummy) may occur. A blood transfusion is sometimes needed to replace blood lost during the operation. Occasionally, there may be internal bleeding after the operation, making a second operation necessary.
- Infection in the wound or internal infection may occur needing treatment with antibiotics. Occasionally, a second operation may be necessary.
- Blood clots in the leg or pelvis (deep vein thrombosis or DVT). This can lead to a clot in the lungs (pulmonary embolism or PE). Moving around as soon as possible after your operation can help to prevent this. We will give you special surgical stockings (known as 'TEDS') to wear whilst you are in hospital and injections to thin the blood. You may continue to have blood thinning

injections for four weeks following discharge. The physiotherapist may visit you and show you some leg exercises to help prevent blood clots.

- Your bladder and bowels may take some time to begin working properly after your operation. Occasionally, a hole may develop in the bladder or in the tube bringing urine to the bladder (ureter). If this happens it is generally identified at the time of surgery. If not, it results in leakage of urine into the vagina. The hole may close without surgery, but another operation may be necessary to repair this.

Are there any long-term complications?

The skin around the wound is usually numb for several months until the small nerves damaged by the incision grow back. Sometimes the numbness may affect the tops of the legs or the inside of the thighs. This should get better in 6-12 months.

If you have lymph glands removed the flow of the lymphatic fluid around the body may be disrupted. If this happens the fluid may collect in one or both legs and/or the genital area. The body usually adapts to the removal of these glands, but sometimes swelling results called lymphoedema. You will be given information and advice to reduce the risk of lymphoedema developing if you have your lymph glands removed. Most patients can experience swelling after surgery. However, if your lymph glands have been removed and the swelling has not resolved after 6 weeks, or you have any new swelling or pain, please inform your gynaecology CNS. The condition can be managed, and if necessary we can refer you to a specialist lymphoedema clinic.

Occasionally you may develop a lump or cyst in your abdomen (called a lymphocyst) which contain lymphatic fluid. Often it can be left to settle on its own.

Will this operation affect my fertility?

At any age, having to have your womb and ovaries removed can affect the way you feel about yourself. A hysterectomy will prevent you carrying a pregnancy in the future. 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 that 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 how you feel about it with the gynaecology CNS before your operation. She or he will continue to offer you support when you are recovering from the operation. Advice is also available from the specialist fertility team.

Will I need Hormone Replacement Therapy (HRT)?

No, as it is usually best to avoid HRT in women who have had endometrial cancer. Your cancer team will discuss this with you further. If you have not already experienced the menopause you will have a premature menopause by having both of your ovaries removed. You may have menopausal symptoms such as hot flushes or night sweats. If you have already experienced the menopause then by having your ovaries removed you should not have any menopausal symptoms.

There are other ways of managing any symptoms you may have. Please discuss the options available to you either with the gynaecological oncology team before you are discharged from hospital, or with your GP. You can also contact the gynaecology CNS for further information or advice.

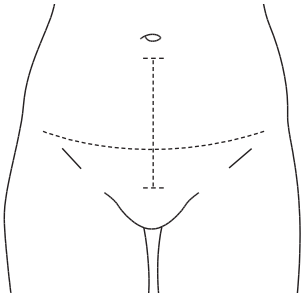
The operation

What is removed during my operation?

- Cervix (neck of the womb)
- Uterus (womb)
- Fallopian tubes
- Both ovaries
- Pelvic lymph glands (in some cases)

Will I have a scar?

Yes, although it will fade. The surgeon will either make an incision (cut) across your tummy just above your pubic hair, or a vertical incision down your tummy (see diagram below). The wound will be closed together using either sutures (stitches) or clips.



Possible incision sites (dotted lines)

(the surgeon will use one of these)

There will be an internal scar at the top of your vagina where your cervix has been removed. This will heal over time.

Is there anything I should do to prepare for my operation?

Yes. Make sure that all of your questions have been answered to your satisfaction and that you fully understand what is going to happen to you. You are more than welcome to visit the ward and meet the staff before you are admitted to hospital. Just ask the gynaecology CNS to arrange this for you.

You may take part in the Enhanced Recovery Programme (ERP). The aim of this programme is to improve the quality

of your care and get you back to full health as quickly as possible after your surgery.

If you are a smoker, it would benefit you greatly to **stop smoking** or cut down before you have your operation. This will reduce the risk of chest problems as smoking makes your lungs sensitive to the anaesthetic. If you need further information about stopping smoking please contact your GP or the Smokefree NHS **0300 123 1044**. A specialist adviser is available Monday to Friday from 9am–8pm and on Saturday and Sunday from 11am–4pm.

You should also eat a **healthy diet**. If you feel well enough, take some gentle exercise before the operation as this will also help your recovery afterwards. Your GP, the practice nurse at his/her surgery or the doctors and nurses at the hospital will be able to give you further advice.

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 your bedding, vacuuming and gardening) and to look after your children if necessary. You may wish to discuss this further with the gynaecology CNS.

If you have any concerns about your finances whilst you are recovering from your operation, you may wish to discuss this with the gynaecology CNS.

What tests will I need before my operation?

Tests will be done to ensure that you are physically fit for surgery and help your doctor to choose the most appropriate treatment for the type and extent of your disease. Recordings of your heart (ECG) may be taken as well as a chest x-ray. An MRI or CT scan of your pelvis and abdomen will be needed.

We may take swabs from your nose, throat and groin to find out whether or not you carry the bacterium known as MRSA. This is so we can identify whether you will need any treatment for this infection during your stay in hospital. Do not worry, if you are carrying the bacterium this will not cause your operation to be cancelled.

You will also have the opportunity to ask the doctor and the specialist nurse any questions that you may have. It may help to write them down before you come.

Why do I need to attend the pre-operative clinic?

Before your admission to hospital, you will be asked to attend the pre-operative clinic to make sure that you are fit for the operation. During this visit the staff will discuss your operation with you and what to expect afterwards. You will have the opportunity to ask any questions.

Your temperature, pulse, blood pressure, respiration rate, height, weight and urine are measured to give the nurses and doctors a base line (normal reading) from which to work.

A blood sample will be taken to check you are not anaemic and to identify your blood group in case you need a blood transfusion.

When will I come in for my operation?

You will usually be admitted on the day of your operation or the day before if necessary. Any further questions you have can also be discussed at this time.

What happens on the day of my operation?

Each hospital has slightly different fasting times, and the ward staff will tell you more about this. You will be asked to change into a theatre gown. All make-up, nail varnish,

jewellery (except your wedding ring), dentures and contact lenses must be removed.

After the operation

What happens after my operation?

After your operation you will wake up in the recovery room before returning to the ward. You may still be very sleepy and be given oxygen through a clear face mask to help you breathe comfortably immediately after your operation. An intravenous infusion also known as a 'drip' will be attached to your hand or arm to give you fluids and prevent dehydration until you are drinking enough.

You may also have a drain (tube) in your wound which is inserted during your operation. This is so that any blood or fluid that collects in the area can drain away safely and will help to prevent swelling. The drain will be removed when the drainage has reduced which could take several days.

During your operation a catheter (tube to drain urine away) will be put into your bladder. The catheter will need to stay in for approximately 24 hours.

You may also have trouble opening your bowels or have some discomfort due to wind for the first few days after the operation. This is temporary and we can give you laxatives and painkillers if you need them.

How will I feel after my operation?

You can expect to be extremely sleepy, or sedated for the first few hours. This will allow you to rest and recover. Please tell us if you are in pain or feel sick. We have tablets/ injections that we can give you as and when needed, so that you remain comfortable and pain free. You may have a device that you use to control your pain yourself. This is

known as a PCA (Patient Controlled Analgesia) and the staff will show you how to use it. Alternatively, an epidural may be inserted in your back for pain relief. The anaesthetist will discuss these choices (PCA or an epidural) with you before surgery.

You may have some vaginal bleeding or a bloodstained discharge but this does not usually last for more than a few days. The wound will have a dressing on it to keep it clean and dry.

We will encourage you to get out of bed and walk around and carry out breathing excercises to help your circulation and prevent a chest infection.

Is it normal to feel weepy or depressed afterwards?

Yes, it is a very common reaction to your diagnosis and the operation. Also sometimes being away from your family and friends can make you feel weepy. If these feelings persist or develop when you leave hospital, the advice and support of your friends, family, GP, or gynaecology CNS may be able to help you. There are also a number of local and national support groups. (See page 20).

Leaving hospital and coping at home

When can I go home?

You will be in hospital between 3–5 days, depending on the type of operation you have had, your individual recovery, how you feel physically and emotionally and the support available at home. This will be discussed with you before you have your operation and again whilst you are recovering.

When can I get back to normal?

It is usual to continue to feel tired when you go home. It can take up to 3 months to fully recover from this operation, sometimes longer, especially if you need further treatment following surgery. However, your energy levels and what you feel able to do will usually increase with time. This is individual, so you should listen to your body's reaction and rest when you need to. This way, you will not cause yourself any harm or damage.

We suggest you shower and do not have a bath for the first three weeks after the procedure to minimise the risk of vaginal infection.

Avoid lifting or carrying anything heavy (including children and shopping). Vacuuming and spring-cleaning should also be avoided for at least 6 weeks after your operation.

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. Generally, within 3 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 to drive again?

We advise you not to drive for at least 4 to 6 weeks after your operation. However, this will depend on the extent of your surgery and your individual recovery. You will be able to discuss it further with your doctor at your follow-up appointment.

We advise you to contact your car insurers for advice on driving following major abdominal surgery.

When can I return to work?

This will depend upon 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 approximately 2-3 months to recover but remember that the return to normal life takes time. It is a gradual process and involves a period of readjustment and will be individual to you. You can discuss this further with your doctor, gynaecology cancer specialist nurse or GP.

What about exercise?

It is important to continue doing the exercises shown to you by the physiotherapist for at least 6 weeks after your operation. Ideally, you should carry on doing them for the rest of your life, particularly the pelvic floor exercises. Avoid all aerobic exercise, jogging and swimming until advised, to allow the tissues cut during your operation to heal. The physiotherapist or gynaecology CNS will be happy to give advice on your individual needs.

When can I have sex?

After a diagnosis and treatment of endometrial cancer, you may not feel physically or emotionally ready to start having sex again for a while. We normally advise women not to have sexual intercourse for 6 weeks following surgery.

During this time, it may feel important for you and your partner to maintain intimacy, despite refraining from sexual intercourse. 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 discuss them with the gynaecology CNS.

It can be a worrying time for your partner. He or she should be encouraged to be involved in discussions about the operation and how it is likely to affect your relationship afterwards.

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 a hysterectomy.

Please do not hesitate to contact the gynaecology CNS if you have any queries or concerns about your sexuality, change in body image or your sexual relationship either before or after surgery.

Follow up treatments and appointments

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

Yes. It is very important that you attend any further appointments arranged.

An early appointment in the outpatient clinic will be made to discuss the histology (tissue analysis) results and any further treatment options if necessary. This is usually within 3 weeks following discharge from hospital.

You will need to attend for regular follow-up appointments once your treatment is complete. These follow up appointments will be arranged for every 3-6 months for the first 2 years, then every 6 months up to 5 years. At these appointments you will be seen by a member of the cancer team. This may be a doctor or gynaecology CNS who works closely with your consultant.

After your first follow up appointment, your subsequent appointments will be at your local hospital.

Will I need further treatment?

If the histology (tissue analysis) indicates you need further treatment, an appointment will be made with the clinical oncology team (radiotherapy) or medical oncology team (chemotherapy) to discuss this with you.

Should I continue to have cervical smears?

No, cervical smear tests are not necessary after this operation, as your cervix will have been removed.

Why do I need to be followed up in the clinic for so long after my operation?

By having frequent appointments during the first 2 years any problems can be detected early. On occasion endometrial cancer may return even though you have had your womb removed. This is because endometrial cancer cells can regrow anywhere within the body and/or the top of the vagina. If this should happen it is usually within the first 2 years after your first treatment. These appointments are not only to look for medical problems, please remember that a diagnosis of cancer can have an affect on any aspect of your life. If you have any other issues related to your cancer then please contact your gynaecology CNS.

What symptoms should I report or be worried about?

If you have any of the following symptoms, please contact your gynaecology CNS, GP, or hospital for an earlier appointment:

- bleeding or discharge from the vagina
- lower tummy pain lasting for 2-3 weeks particularly if it keeps you awake at night
- swelling in one or both legs (if lymph glands removed).

After you have had treatment for cancer it can be a worrying time. Please remember that you will have the same aches and pains that you have always had. If you develop a new health problem, this may not be related to your cancer and its treatment.

Staging of womb cancer explained

The **STAGE** of a cancer describes its size and extent.

Stage 1 The cancer cells are contained within the lining of the womb or the muscle of the womb.

Stage 2 The cancer has spread to the cervix.

Stage 3 The cancer has spread to the vagina, through the womb to the outer edge of the womb and/or the lymph nodes.

Stage 4 The cancer has spread to the bladder or bowel and / or outside the pelvic area.

Grading of cancer explained

Tumour cells arise from normal cells within the body. If the tumour cells are very similar to normal cells then the tumour is described as being **well differentiated or grade 1**. If there is less similarity then the tumour is described as being **moderately differentiated or grade 2**. If the tumour bears little resemblance to the normal cell then the tumour is described as being **poorly differentiated or grade 3**.

Contacts and further information

We hope that this booklet answers most of your questions but, if you have any further queries or concerns, please do not hesitate to contact your key worker or gynaecology CNS. If your query is urgent and your CNS is not available

to take your call you should contact the ward you were admitted to for your operation, or your GP. Please note that the gynaecology cancer nurse specialists are not available evenings or weekends.

Support groups and useful organisations

Macmillan Cancer Support

89 Albert Embankment, London, SE1 7UQ.

Freephone: **0808 808 0000** (Monday–Friday 9am–8pm)
You can get:

- Answers to any questions about cancer
- Emotional and practical support
- Signposting to other organizations and services
- Access to specialist information, nurses and specialist welfare rights advisors
- If you are a non English speaker, there are interpreters available
- If you are hard of hearing, use the textphone on **0808 808 2121**

The website **www.macmillan.org.uk** has information about cancer treatment, living with cancer and Macmillan services, along with support through online communities.

The Daisy Network

PO Box 71432, London, SW6 9HJ.

Website: **www.daisynetwork.org.uk**

Email: **daisy@daisynetwork.org.uk**

They provide a support network for women who experienced a premature menopause.

Womb Cancer Support UK

Website: www.wombcancersupportuk.wix.com/home

Email: wcsuk@hotmail.co.uk

Provides online support and advice for women with womb cancer.

Eve Appeal

15B Bergham Mews, Blythe Road, London, W14 0HN.

Telephone: 020 7605 0100

Website: www.eveappeal.org.uk

The only UK national charity raising awareness and funding research into gynaecological cancers.

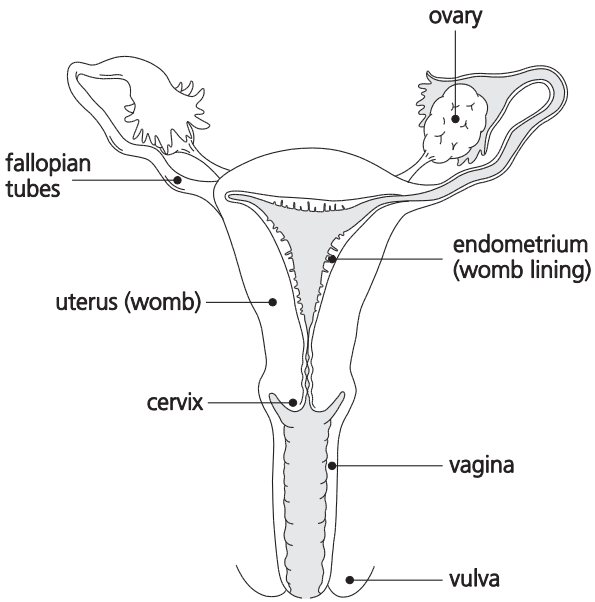
NHS Choices

Website: www.nhs.uk

Information from the National Health Service on conditions, treatments, local services and healthy living.

My cancer is _____

_____



My gynaecology oncology surgeon is _____

_____

My key worker is _____

_____

We hope that you have found this booklet helpful. Please feel free to ask us any questions you may have. We have suggested below some questions you may want to ask.

How quickly will I be seen by the team who will do my operation?

Will you let my GP know about my diagnosis?

How soon will I have my operation?

If I need chemotherapy or radiotherapy do I have to go to The Christie for this?

Who will I contact if I have questions or concerns, once my treatment has finished?

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence.

If you would like to have details about the sources used please contact patient.information@christie.nhs.uk

Written in collaboration by The Christie NHS Foundation Trust and Manchester University NHS Foundation Trust.

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**
The Christie at Oldham **0161 918 7745**
The Christie at Salford **0161 918 7804**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check before making a special journey.

The Christie NHS Foundation Trust
Wilmslow Road
Manchester M20 4BX

Switchboard 0161 446 3000
The Christie Hotline 0161 446 3658
www.christie.nhs.uk

The Christie Patient Information Service
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