



Radical Hysterectomy
A guide for patients and their carers



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Introduction

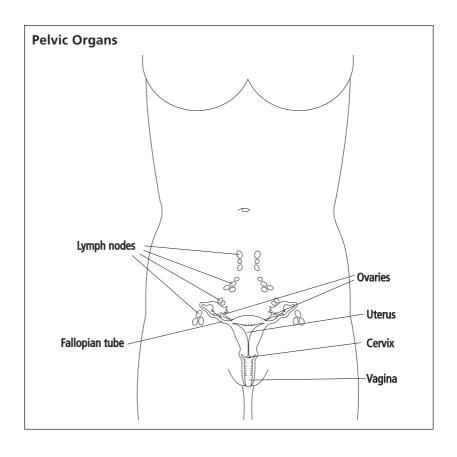
This booklet has been written to help answer some of the questions you may have about radical hysterectomy.

If you have recently been diagnosed with cancer of the cervix or uterus, 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 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 radical hysterectomy and why is it necessary?

Women with cancer of the cervix (neck of the womb) or uterus (womb) may be offered a radical hysterectomy. This is different from a 'simple' hysterectomy because not only are the cervix, uterus and fallopian tubes removed, but also the top 2-3 cm of the vagina and the tissues around the cervix. The pelvic lymph nodes will also be removed at this time because the cancer can spread to these nodes first (please see diagram). The doctor will discuss with you whether it is necessary to remove your ovaries as well.

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 or chemotherapy. This will be discussed with you when all of your results are available.



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 and 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 cancer team will discuss the options available to you. The options will depend on the stage of your disease. For some women the options are:

- Radiotherapy: this is as effective as surgery in women with cervical cancer. This tends to be offered to women with a larger tumour or women who are not medically fit enough to have major surgery. Chemotherapy is often given in combination with the radiotherapy.
- Radical trachelectomy: this is surgery which can be carried out if the tumour is very small and is definitely

confined to the cervix. It should be considered only if you have a strong desire to maintain your fertility.

What happens if I have no treatment?

Your wishes about treatment 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 or 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. Very 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. 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. Some women have loss of feeling in the bladder that may take some months to get better. During this time, you may need to take special care to empty your bladder regularly.

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.

There is a small risk of swelling, called lymphoedema, of the legs or lower abdomen. If this occurs please tell your GP or cancer team. Normally, lymphatic fluid circulates throughout the body draining through the lymph nodes. The pelvic lymph nodes are removed during the operation to prevent the spread of cancer cells. The lymphatic system may then become blocked, resulting in a build up of fluid in one or both legs or in the genital area. Preventative measures can be taken to reduce the risk of it developing and you will be given information about this. However, if you do develop lymphoedema the problem can be managed and you will be referred to a specialist to manage the swelling.

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

Some women have problems emptying their bladder after surgery. This usually settles with time but a small number will have long term problems. Occasionally it is necessary to show you how to put a catheter tube into the bladder to make sure it is emptying completely. This does not mean wearing a catheter permanently and is known as intermittent self catheterisation (ISC). It affects only about 1 in 50 of women having radical hysterectomy.

Will this operation affect my fertility?

At any age, having your womb and/or ovaries removed can affect the way you feel about yourself. A hysterectomy will prevent you carrying a pregnancy in the future, and removing your ovaries will bring on an early menopause. 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 my ovaries continue to produce eggs?

Yes, if you still have your ovaries after the operation. As you will have had a hysterectomy, you will not menstruate (have periods) each month and so the eggs will be absorbed harmlessly by your body.

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 – as an implant, patches (similar to a nicotine replacement patch), tablets, gels, sprays and vaginal creams. There are also alternative ways of managing the potential symptoms. 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

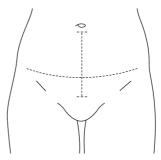
What is removed during my operation?

- Cervix (neck of the womb)
- Uterus (womb)
- Fallopian tubes
- Top 2-3 cm of the vagina
- Pelvic lymph nodes
- In some cases, the ovaries

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. The wound will be closed together using either sutures (stitches) or clips.

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



Possible incision sites (dotted lines)

(the surgeon will use one of these)

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 Smokefree NHS on 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 gynaecology CNS 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. To allow your abdomen to recover from surgery you may only have something light to eat until the next day. 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 the bladder. As the bladder is positioned close to the cervix, uterus and vagina, where the surgery has taken place, the catheter will allow the area to recover

and heal. The catheter will need to stay in for approximately 5-10 days. Once it has been removed we need to make sure that you have emptied your bladder completely. We can do this by inserting another small catheter or by scanning your bladder to see if it is completely empty.

Occasionally, the catheter will need to remain in place for a little longer or you may need to insert the catheter at regular intervals (known as 'intermittent self catheterisation') to enable your bladder to return to working normally. This varies from woman to woman and will not necessarily prevent you from going home. If needed, a district nurse can visit you at home to help you care for your catheter.

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. Depending on the type of incision used, the sutures or clips will be removed 5-10 days later.

We will encourage you to do gentle leg and breathing exercises 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 help. 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 usually be in hospital between 5 and 7 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 3 weeks 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 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 CNS 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 muscles 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 radical hysterectomy for 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 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 radical 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 if no further treatment is necessary.

Will I need further treatment?

You may need further treatment if cancer is found in the lymph nodes or close to the edge of the tissue removed. If the histology show that you need further treatment, an appointment will be made with the clinical oncology team 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, cervical cancer may return and 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, a diagnosis of cancer can affect any aspect of your life. You can discuss these issues with 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

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 cervical cancer explained

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

- **Stage 1.** The cancer cells are found only in the cervix.
- **Stage 2.** The cancer has spread into nearby organs and tissue, such as the upper vagina or tissue next to the cervix.
- Stage 3. The cancer has spread further to the lower part of

the vagina, nearby lymph nodes, and / or tissue at the sides of the pelvis.

Stage 4. The cancer has spread to the bladder or bowel and / or outside the pelvic area. This stage includes cancer that has spread to the lungs, liver or bone although these are less common.

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 have experienced a premature menopause.

Jo's Cervical Cancer Trust

Helpline: 0808 802 8000

Website: www.jostrust.co.uk Email: info@jostrust.co.uk

A charity dedicated to women, their families and friends affected by pre-cancer and cancer of the cervix. Web-based

support group.

The Lymphoedema Support Network

St. Luke's Crypt, Sydney Street, London, SW3 6NH.

Telephone: 020 7351 4480

Website: www.lymphoedema.org

Email: adminlsn@lymphoedema.freeserve.co.uk

A charity that aims to ensure that every patient with lymphoedema receives a correct diagnosis and suitable level of care.

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

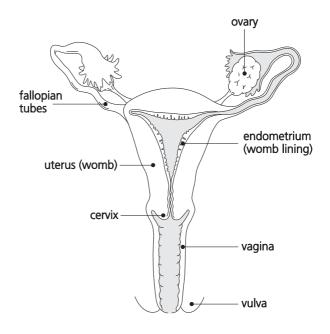
research into gynaecological cancers.

NHS Choices

Website: www.nhs.uk

Information from the National Health Service on conditions,

treatments, local services and healthy living.



| My 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

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