Pan-Birmingham Gynaecological Cancer Centre

Radical Hysterectomy and Pelvic Lymphadenectomy

Information and advice for patients, relatives and carers

Gynae-oncology

Introduction

This leaflet provides information about having a radical hysterectomy and pelvic lymphadenectomy and the care you will receive before, during, and after your operation. We hope it will answer the questions that you may have at this time. It is not meant to replace the discussion between you and your surgeon, but to help you understand what is discussed.

If you have been recently diagnosed with cervical or womb cancer 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 Macmillan Gynaecological Oncology Clinical Nurse Specialist (CNS). They will listen, and be able to answer any questions you may have and can put you in touch with other professionals or support agencies if you wish.

What is a Radical Hysterectomy with Pelvic Lymphadenectomy?

Women with cancer of the cervix, (neck of the womb) or rarely, cancer of the uterus (womb) may be offered a radical hysterectomy. This is different from a 'simple' hysterectomy because not only are the cervix, womb and fallopian tubes removed, but also the upper third of the vagina and the tissues around the cervix (the parametrium). Pelvic lymphadenectomy is removal of the pelvic lymph nodes (glands) because the cancer can spread to these glands. The doctor will discuss with you whether it is advisable to remove your ovaries as well.

The surgeon will either make a bikini line (horizontal) incision or an up and down (vertical) incision starting at the pubic hair line and going up to and sometimes beyond the belly button (umbilicus). The wound will be closed with metal staples or sutures, and these are removed 14 days after surgery by the practice nurse or district nurse.

The operation can be performed through keyholes (laparoscopy) but recent studies proved that this approach comes with a higher risk of the cancer returning, (recurrence), therefore we stopped performing this type of surgery.

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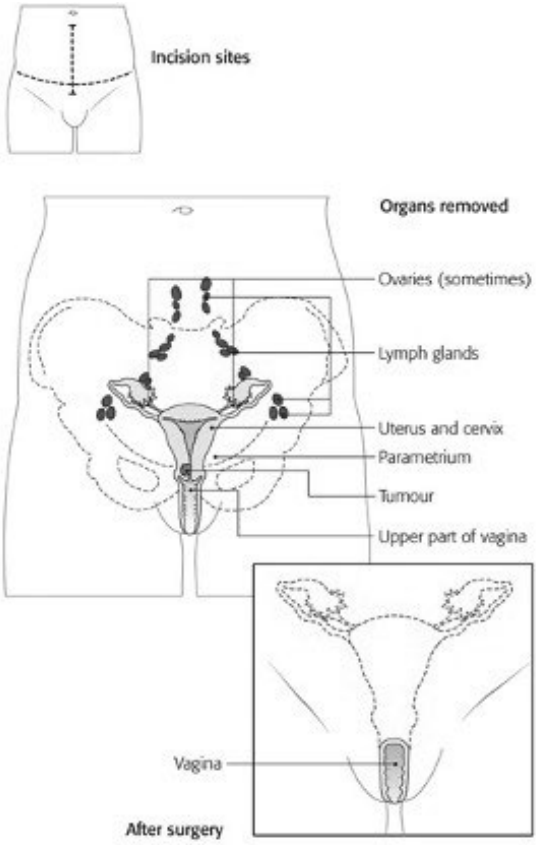

Images showing the incision sites and the organs to be removed, (McLean, D. and Nordin, A., 2014).

Are there any alternatives to this operation?

Yes, but they vary from patient to patient. Sometimes less extensive surgery can be considered for smaller cancers. The team will discuss your options with you.

Fertility-sparing surgery called **radical trachelectomy** (to remove the cervix and the cancer but to leave the womb behind) is sometimes an option for patients wishing to preserve their fertility.

Radiotherapy is also a valid treatment option but it is not the standard treatment for smaller cancers due to its long-term side effects.

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Choosing not to have any treatment - Waiting and not treating the cancer is an option, but it comes with a likelihood that the cancer will continue to grow and may become incurable.

An alternative to removing all the pelvic lymph nodes is a technique called sentinel node biopsy. A sentinel node is the first lymph node close to a cancer and if that node is negative, the rest of the lymph nodes beyond are negative. An injection of a special dye to the cervix under general anaesthesia is carried out before the removal of the sentinel lymph nodes. The removal can be performed either via keyhole or via a cut on the tummy (laparotomy). The benefit of this procedure is to reduce the risks and complications associated with the removal of all lymph glands.

The team will discuss all the options available to you.

What is the benefit of the procedure?

The aim of the procedure is to cure/control your cancer by removing all the cancer and to see if the cancer has spread to the lymph nodes. If there is any evidence that the cancer has spread from the cervix you may be offered further treatment such as radiotherapy and chemotherapy. This will be discussed with you when all the results are available.

What are the risks of the procedure?

There are risks, but it's important to understand that most women do not have complications after this procedure. However, risks do increase with age and for those who already have heart, chest, or other medical conditions such as diabetes, if you are overweight or are a smoker.

The identified risks associated with this surgery include generic risks that can occur after any operation and those risks specific to radical hysterectomy:

Generic risks:

- Bleeding, rarely requiring a blood transfusion and very rarely requiring a second operation.
- Bruising or infection of the wound.
- Urine infection (8:100 patients).
- Chest infection.
- Blood clots in the legs (thrombosis) (2 in 100 patients) or lungs (embolism) (0.8 in 100 patients).

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- Paralytic Ileus – Paralysis of the bowel which is usually a minor event caused by handling of the bowel during surgery and settles in 1-2 days (2.9 in 100 patients).
- Hernia formation at the surgical incision.
- Risk from the general anaesthetic.
- Very rarely patients may die from major surgery (1 in 400).

Specific risks:

- Injury to neighbouring organs or structures like bowel, bladder, kidney pipes (ureters), blood vessels or nerves (1 in 100).
- Thigh numbness or weakness as a result of nerve injury (less than 1 in 100).
- Leg swelling (lymphoedema), as a result of removing the pelvic lymph nodes (1-2 in 10).
- Change in urinary function e.g. difficulty in emptying the bladder (3.6 in 100).
- Fistula: Leakage of urine through the vagina caused by injury to ureter(s) which are the urinary drainpipes from the kidneys emptying into the bladder. Leakage is rare (0.8 in 100). Secondly, sometimes urinary leakage through the vagina could be caused by injury to the bladder itself which is also uncommon (0.4 in 100).
- Lymphorrhea – some women may experience a yellow fluid loss of lymphatic fluid from the vagina.
- Changes to sex life and relationships may have more than one cause and women may experience change because of anxiety caused by their cancers or by the treatment itself. 2% will experience sexual dysfunction. Talk to the team, often advice and practical support can resolve problems and in most women this concern settles with time.

What else might happen as a result of surgery?

Fistula formation

Rarely, a hole, called a fistula, may develop in the bladder or in the ureter(s) (the two tubes that bring urine into the bladder from the kidneys) and urine can leak through the vagina. This can develop 7-10 days after the operation. Women are asked to report their symptoms to the CNS team or the ward staff to arrange for a doctor's review.

If a fistula is suspected then a special CT scan, with a dye injected via a cannula, is required to confirm the diagnosis. Tubes may be inserted into the kidney or ureter(s), and the bladder

for 4-6 weeks. These holes usually heal on their own in majority of women. If this is necessary, women are required to stay in hospital for about 2-3 days for these tests and insertion of these tubes. Rarely, women can require another operation to repair the hole which is usually done with support from the urology or the kidney specialist.

Lymphorrhea – Lymphatic fluid leakage
After pelvic lymph node removal, some women may experience a yellow fluid loss from the vagina. It can look like urine, but does not smell of urine, and usually occurs more when they have started mobilising. This is lymph fluid escaping from the tummy cavity through the vagina. The body usually adjusts, and the leakage settles in about 3-4 weeks, but women may need to wear pads until it stops. If one notices any leakage from the vagina, please call the CNS team or the ward for advice and clinical review.

Nerve damage
The skin around the wound is usually numb for several months and may remain so for many years. Sometimes very fine nerves in the pelvis are bruised or cut during surgery and one may experience numbness to the thighs. This usually gets better after a few months. Rarely, a large nerve in the pelvis can get injured during lymph node removal resulting in weakness of the inner thigh muscles.

Lymphoedema:
After lymph node removal there is a risk of swelling of the legs, pubic area or lower abdomen when excess fluid in the tissues is unable to drain away and causes swelling. This fluid collection is called lymphoedema. Normally, lymphatic fluid circulates around the body draining through the lymph glands. As the pelvic lymph glands are removed during the operation to identify any spread of cancer cells, the lymphatic drainage system may not move the fluid around the body as it usually would. This may result in the build-up of fluid in one or both legs, or in the genital area. Lymphoedema can occur at any point after surgery.

Ways to reduce the risk of developing leg lymphoedema include the following permanent lifestyle changes:

- If you remove leg hair or bikini line hair we recommend an electric razor or cream rather than using a razor blade or waxing, this will reduce the risk of cuts or trauma to the skin.
- Keep the skin supple by moisturising regularly. This reduces the risk of the skin splitting and allowing infection in, which can result in lymphoedema.

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- Exfoliate to allow any dry skin to be removed and discourage hairs to grow inwards.
- Protect your skin from insect bites, wear long skirts or trousers, especially at dusk. If one gets bitten, treat quickly with antiseptic cream and cover with a light dressing.
- Take care when cutting toenails.
- Avoid injections into your legs wherever possible.
- Prevent sunburn.
- Keep active. Learn what sort of exercise works for you. Brisk walking, swimming, light aerobics, cycling, yoga and tai Chi are all recommended.
- Avoid standing or sitting in one position for long periods.

If one develops lymphoedema, please report this to the CNS team for assessment and onward referral to specialist lymphoedema teams. Women are encouraged to discuss this further with any of the nurses or doctors and we will give you information on the subject.

Will I have a scar?

Yes, although it may fade in time. The area around the scar will feel numb for a while after the operation but the sensation will usually return to it.

What about losing my fertility?

At any age having the womb and/or ovaries removed may affect the way one feels about oneself. A hysterectomy will prevent carrying a pregnancy in the future. Loss of fertility can have a huge impact if one has not started or completed their family. Women are given the opportunity to explore all fertility options. It is important to have the opportunity to discuss this and express feelings about it with the CNS before the operation. The CNS team will also continue to offer support during the recovery phase of the operation. Advice is also available from our specialist fertility teams and the CNS team can help arrange a consultation with fertility specialists where feasible.

Will my ovaries continue to produce eggs?

Yes, if the ovaries have not been removed at the operation. Women will continue to produce the hormones that ripen an egg and would previously have caused the monthly bleed. With a hysterectomy, menstruation (periods) stops and so the body will absorb the eggs harmlessly.

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Women can still experience pre-menstrual type symptoms caused by the hormone release from their ovaries. Sometimes, the operation can reduce the blood supply to the ovaries resulting in earlier menopause.

Will I need hormone replacement therapy?

Women who have not gone through the menopause before surgery, will become menopausal after having their ovaries removed. Symptoms of the menopause can include hot flushes, night sweats, loss of concentration, dry skin, mood changes, vaginal dryness and being less interested in sex.

Menopausal symptoms can be managed naturally or with the use of hormone replacement therapy (HRT). HRT is available in many forms – as implants, patches, tablets, gels, sprays and vaginal creams. Please discuss the available options with the CNS team for further information or advice.

Are there any risks if I do not have the operation?

This operation has been recommended after careful consideration within a multidisciplinary team of clinicians and is considered the best treatment for your type of cancer. If you decide not to have any treatment, the cancer may spread and may become incurable. Any symptoms relating to the cancer may get progressively worse.

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

Yes. Make sure that:

- All your questions have been answered and that you fully understand what is going to happen to you.
- If you smoke, please try to stop or cut down. This will reduce the risk of chest infection. Ask the gynae team about smoking cessation services that could support you to give up smoking.
- Eat a well-balanced diet, introducing more protein, vitamin C and some fats to help recovery.
- Increase your water intake, aim for two litres (about eight – ten glasses) per day, which will help with bowel movement and prevent dehydration.
- Some pre-operative nutrition drinks will be given to drink the day before, and the

morning of the procedure (if you are not diabetic) to support your recovery after the operation.

- Remain as active as you can in preparation for the operation. This allows for better energy levels, more positive mood and reduced tiredness. Moderate exercise to raise your heart rate is the recommended amount; however any amount of increased activity will help, gradually build up and do what you can. Brisk walking before surgery is helpful.
- Prepare for when you leave hospital. 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 bed sheets, vacuuming, and gardening) and to look after children if necessary. You may wish to discuss this further with your CNS.

If you have any concerns about your finances whilst you are recovering from your operation, you may wish to discuss this with your CNS. You can do this either before you come into hospital or whilst you are recovering on the ward.

What tests will I need before my operation?

You will be asked to attend the pre-admission clinic about one or two weeks before your operation. Tests will be arranged to ensure you are physically fit for surgery.

Recordings of your heart (ECG) may be taken as well as a chest X-ray. A blood sample will also be taken to check that you do not have anaemia and that your kidneys work well. We will also store a blood sample in the fridge in case you need blood transfusion. The nurses in pre-admission will then take some details and ask questions about your general health.

Your temperature, pulse, blood pressure, respiration, weight and urine are measured to give the nurses and doctor a base line (normal reading). The nurses will explain to you about the post-operative care following your operation. You will have the opportunity to ask any questions that you or your family may have. It may help to write them down before you come to the clinic.

The nurses will give you a bodywash to use when bathing or showering the night before, and on the morning of your operation. All make-up, nail varnish, jewellery (except wedding rings which can be taped over), must be removed.

You may be advised to take a laxative e.g., Senna for 3 nights before your operation to clear the bowel.

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When will I come in for my operation?

You will come to the admission ward on the day of surgery, usually around 7.30am. On your arrival, the ward clerk or one of the nurses will greet you and show you to your bed. You will meet the ward nurses and doctors involved in your care.

You will be asked to confirm that you understand and agree to have the operation and checks will be made that you have signed a consent form for the operation.

The anaesthetist will visit you to discuss the anaesthetic and pain relief during and after your operation. You can bring your own medicines with you and discuss with the anaesthetist if you should take them before the operation. After the operation, you will be taken to the gynaecology ward.

When do I need to stop eating and drinking?

You can eat up till midnight the day before your operation.
From midnight to 6am on the day of your operation you can drink water only.

From 6am nothing to drink or eat.

If you are on any medication, you may need to take your tablets in the morning with a little water, but you can do this at the hospital.

What will happen on the day of the operation?

Before going to the operating theatre, you will be asked to change into a theatre gown and helped to apply your surgical stockings. Rings (except for a wedding ring which can be taped), false teeth, contact lenses, wigs and scarves must be removed before going to theatre, and will be given back to you as soon as you are awake enough to ask.

What will happen after the operation?

One of the nurses will collect you from the recovery ward (where you wake up after your surgery) and escort you to the gynaecology ward.

When you return from theatre, please tell us if you are in pain or feel sick. We have pain medicines and anti sickness medicines that we can give to relieve these symptoms. Above all, we want you to be as comfortable as possible. You may have a device that you use to control your pain yourself. This is known as a PCA (Patient Controlled Analgesia), a simple button to release pain medicine via a drip in your arm into your bloodstream. We will explain to you how to use this device.

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Alternatively, an epidural tube may be inserted in your back for pain relief. The anaesthetist will discuss the choice between a PCA and epidural with you before surgery.

You may still be very sleepy and be given oxygen through a mask to help you breathe comfortably.

Once you are awake take several deep breaths, breathe deeply, feeling the lower ribs move out sideways. Repeat this 4-5 times, every hour and when you wake up. A rolled-up towel or pillow across your tummy will help support your abdomen if you need to cough. For circulation and mobility move your ankles up and down for 30 seconds, and once sitting bend and straighten your knees (one at a time) for 30 seconds.

While you are not able to drink, a drip will be attached to your arm or hand to give you fluids to prevent dehydration. This will remain in until you are drinking and eating well.

You may have a drain in your abdomen so that any blood or fluid that collects in the tummy area can drain away safely. The tube will be removed when it is no longer draining any fluid, which can take a few days.
Your wound will be covered with a dressing. This will be removed 1-2 days after your operation and the wound left exposed. You will be asked to take a shower to help keep your wound clean. Avoid highly scented soaps. When drying, pat the area dry and avoid rubbing the wound. You may shower daily. The stitches or clips can be removed around 10-14 days following surgery. Please book in to see your practice nurse for this and a letter with the equipment will be given to you. It is advisable to book your appointment before leaving the hospital, just in case you encounter any difficulties.

A catheter (tube) will be inserted into your bladder in theatre to drain urine away. As the bladder is positioned closely to the cervix, uterus, vagina and pelvic nerves, where the surgery has taken place, the catheter will allow the bladder to recover. The catheter will stay in for approximately five to seven days. You will go home with the catheter and equipment, after being taught how to empty the bag and keep it clean.

You will return to hospital for a trial without catheter, the catheter will be removed and the amount of urine you pass will be monitored to check you are emptying your bladder properly. This may take a few hours so plan to be at hospital for the day. Sometimes the bladder does not empty itself fully initially. A new catheter would be inserted and the bladder left to rest for another week before trying again.

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Some women have an initial loss of feeling in the bladder, which may take some months to get better. During this time, one may need to take special care to empty the bladder regularly.

Bowel movements can be slow initially before resuming your usual pattern. You may have discomfort due to the build-up of wind for the first few weeks following surgery. This is temporary and sometimes laxatives are needed. Hot peppermint water or peppermint tea is also helpful to relieve wind pain, as is walking, steadily build up your walking distance daily.

Risk Management of Blood clots

Patients having a hysterectomy are at risk of getting a blood clot in the legs or pelvis known as deep vein thrombosis (or DVT). This can lead to a clot in the lungs. To prevent this, we will ask you to:

- Move around as soon as possible after your operation.
- Wear special surgical stockings whilst in hospital and for 4 weeks after your operation, until you are moving around more.
- Give yourself a small daily injection of the medicine that thins the blood. These will continue for 28 days following your operation to prevent clots, it is a simple technique, and the ward nurses will teach you or a family member how to administer the injections prior to discharge. A physiotherapist will visit and show you some leg exercises to prevent blood clots, (and breathing exercises).

You may have some vaginal bleeding for the first few days following surgery and it may appear again at around 10 days after surgery. The initial bright red bleeding usually turns to a red/ brownish discharge before disappearing after a few days to a few weeks. If there is a lot of bleeding, like a heavy period and soaking pads, then please call us for advice. If there is an offensive smelling discharge please call for advice.

What about exercise?

There are specific gynaecological exercises to consider, a leaflet will be given to you.

You will meet the physiotherapist on the ward, who will help with mobility and breathing exercises. Please ask any individual questions to them, the nurses or the CNS team.

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When can I go home?

You will be in hospital for an average 5 days (between 3 and 7 days), depending on 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

6 to 8 weeks to fully recover from this operation. However, your energy levels and what you feel able to do will usually increase with time. For the first 6 weeks avoid lifting or carrying anything heavy.

When can I return to work?

This depends on the type of work you do, how well you are recovering and how you feel physically and emotionally. Any job requiring heavy lifting may take a bit longer to return to, but you are the best judge as to how you feel. A medical certificate (sick note) can be provided from hospital for the initial time after your surgery and your GP can provide further if necessary.

Most women need approximately 6-8 weeks away from work to recover fully before returning to work or their usual routine. You can discuss it further with your doctor, specialist nurse or GP. Remember, the return to normal life takes time, it is a gradual process and involves a period of readjustment and will be individual to you.

When can I start driving again?

We advise you not to drive for at least 6 weeks after your operation. However, this will depend on the extent of your surgery and how you are recovering. You can normally resume driving when you can stamp your foot hard on the ground without causing any pain or discomfort, as this movement is required in an emergency stop. It is advisable to check the details of your car insurance policy, as some contain clauses about driving following an operation.

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. It can take at least 8-12 weeks for the vagina to heal, and even longer for the energy and sexual desire to improve.

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During this time, it may feel important for you and your partner to maintain intimacy, despite refraining from penetrative sexual intercourse. Some couples are both physically and emotionally ready to resume having sex and this can feel like a positive step. If you have any individual worries or concerns, please discuss them with your Macmillan CNS.

With a radical hysterectomy, the upper part of the vagina is removed and you and/or your partner may be aware of this once you resume intercourse again. Take things slowly and explore first so that you are aware of the changes after your surgery. Trying different sexual positions helps identify what is most comfortable. Keep talking, explaining how you each feel can resolve issues quickly to get your intimacy back. Having a shortened vagina does not usually affect sexual enjoyment in the long term.

Your cancer journey can also be a worrying time for your partner. They 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, you may have concerns either now or in the future about starting a relationship after having a hysterectomy. Please do not hesitate to contact your CNS if you have any queries or concerns about your sexuality, change in body image or your sexual relationship either before or after surgery.

Do I need to have cervical smears?

No, cervical smears are not necessary after this operation, as your cervix has been removed. However, it is important to come to your regular examinations in the outpatient clinic, these may sometimes be in a colposcopy clinic to visualise the area better. Before you are discharged the doctor or nurse specialist will let you know if this applies to you.

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

Yes, it is very important that you attend any further appointments arranged either at City Hospital or back at the hospital which referred you for treatment. An appointment is usually given for 2-3 weeks after your operation to discuss the results and your treatment plan. For some women, surgery alone, will be enough to treat the cancer and we will discuss with you how you will be monitored. For others, additional treatment may be recommended.

It is important that you make a list of all medicines you are taking and bring it with you to all your follow-up clinic appointments. If you have any questions at all, please ask your surgeon, oncologist or nurse. It may help to write down questions as you think of them so that you have them ready. It may also help to bring someone with you when you attend your outpatient appointments.

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Symptoms to report after your surgery:

Anything that worries you should be reported.

You can call the CNS team or the ward.

Look out for:

- New pelvic or back pain.
- Signs of infection, for example a high temperature, shivering when you are warm, a cough, burning sensation when you pass water, redness or leakage of the wound.
- Shortness of breath, redness or swelling to a calf, bruising (the injections for thinning your blood cause bruising which is normal).
- Leakage of either urine or stool (faeces).
- Heavy, persistent bleeding soaking pads.
- Vomiting, especially if your bowels aren't working.
- Oozing or breakdown of the wound.

Contact us

Macmillan Clinical Nurse Specialists
Tel: 0121 507 5511 (Monday - Friday Daytime)

Gynaecology ward (anytime via switchboard)
Tel: 0121 554 3801

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Glossary of medical terms used in this information:

Anaemia: a condition in which the blood is lacking in red blood cells.

Catheter: a flexible tube used to drain fluid from the bladder.

Cervix: the narrow outer end of the uterus or womb.

Chemotherapy: the treatment of cancer with drugs.

ECG: also known as an electrocardiogram, is a test which measures the electrical activity of the heart.

Epidural: a pain relieving injection into the spinal column.

Fallopian tubes: one of a pair of long, slender tubes that transport eggs released from the ovary to the womb.

Histology: the study of cells and tissues on a microscopic level.

Lymph nodes: hundreds of small oval bodies that contain lymph. These act as a first line of defence against infections.

Ovary: one of two small oval bodies in which eggs and hormones are developed.

Parametrium: tissue to the sides and in front of the cervix.

Physiotherapist: a therapist who treats injury or dysfunction with exercises and other physical treatments of the disorder.

Radiotherapy: X-ray treatment that uses high energy rays to damage or kill cancer cells.

Uterus: a hollow muscular organ in the female pelvis, in which a fertilised egg develops into an embryo.

Support Groups

Ask your CNS for the latest information on local support groups.

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Further information

Macmillan Cancer Support
www.macmillan.org.uk
Support line – 0808 808 00 00

Cancer Research UK
www.cancerresearchuk.org
Support line – 0808 800 4040

Jo's Cervical Cancer Trust
www.jostrust.org.uk
Support line – 0808 802 8000

The Eve Appeal
www.eveappeal.org.uk
Tel: 020 7605 0100

Various apps such as squeezy – the NHS Physiotherapy app for pelvic floor exercises. Can be downloaded from your usual app store.

Royal College of Obstetricians and Gynaecologists (RCOG)
Collection of patient information leaflets
https://www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/

(Websites checked 30 June 2022).

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Sources used for information

McLean, D. and Nordin, A., 2014. Patient Pictures: Gynaecological oncology: Clinical drawings for your patients. Patient Pictures, pp.1-34.

About this information

This guide is provided for general information only and is not a substitute for professional medical advice. Every effort is taken to ensure that this information is accurate and consistent with current knowledge and practice at the time of publication.

We are constantly striving to improve the quality of our information. If you have a suggestion about how this information can be improved, please contact the CNS team.

This information was produced by The Pan-Birmingham Gynaecological Cancer Centre Team at Sandwell and West Birmingham NHS Trust and was written by Macmillan Clinical Nurse Specialists, Consultant Surgeons, Allied Health Professionals, Patients and Carers.

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