



Surgery for Vulval Cancer

A guide for patients and their carers



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Introduction

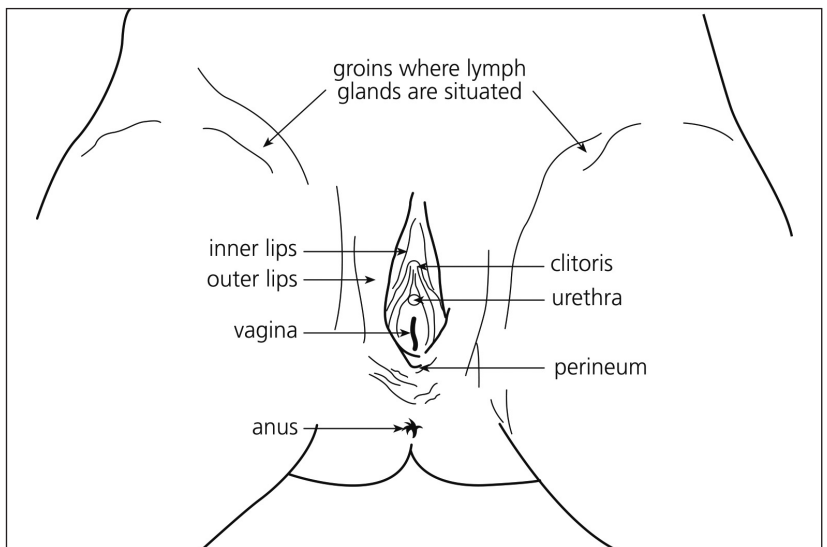
This booklet has been written to help answer some of the questions you may have about your surgery for vulval cancer.

If you have recently been diagnosed with cancer of the vulval area or it has been suggested as a possibility, it is normal to experience a wide range of emotions. For some women, it may be a frightening and unsettling time. Whatever you are feeling at present, try talking about it with someone who specialises in dealing with this condition, such as the gynaecology cancer nurse specialist (CNS) or consultant, who will listen and answer your questions. Some useful contact numbers are listed at the back of this booklet.

What is vulval surgery and why is it necessary?

Women with cancer of the vulva may need to have surgery to remove some or all of the skin in this area (see diagram). How much skin and tissue is removed during the operation depends upon the type of cells that the cancer is made of, the size and position of the cancer and whether it has spread. Your general health and other symptoms such as discomfort, pain, burning or itching in the area are also considered when planning your surgery.

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.



Agreeing to treatment

Consent to treatment

When we have all the results from the tests, such as biopsies and occasionally scans, we will be able to fully discuss with you the best way of treating your cancer.

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 vulval surgery?

The aim of the operation is to remove all of the cancer, whilst at the same time trying to keep as much vulval skin and tissue as possible. This is to assess the extent of the disease (known as staging). This will enable the surgical team to know whether further treatment is recommended. Surgery for vulval cancer in its early stages is usually very successful.

Are there any alternatives to surgery?

Yes, but this varies from person to person. Surgery is usually the most effective and straightforward treatment. Radiotherapy is sometimes used as an alternative to surgery.

Please discuss the options available to you with your consultant, the gynaecology CNS or your GP.

What happens if I have no treatment?

Your wishes about treatment for your cancer will be respected at all times by your surgical team. If you choose not to have treatment, your cancer will progress and your health will 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 surgery. The risks include:

- 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.

- Risk of wound breakdown due to tension or infection where the skin has been rejoined. This will depend upon how much skin/tissue has been removed. If this occurs, it is usually within the first 10 days of surgery and will need special care by the nurses to keep the area clean and dry. You may have a dressing to reduce the risk of infection until the wound has healed. If the wound does break down it may delay your discharge home from hospital. At first you may need a district nurse to visit at home and continue caring for your wound until it has healed completely.

Are there any long-term complications?

The lymph nodes in your groin(s) may be removed. This is to prevent the spread of cancer or to remove cancer that has already spread.

There is a 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 glands. The pelvic lymph glands 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 treated and you will be referred to a specialist to manage the swelling.

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

Some women may have problems emptying their bladder or have some urinary incontinence. 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.

The operation

What is removed during my operation?

This depends upon where the cancer cells are found on the vulva. Surgery is decided on an individual basis and can include:

- A 'wide local excision' – removal of the tumour (cancer) and some normal tissue around it
- A 'hemi-vulvectomy' – removal of one side of the vulva (inner and outer lips known as the labia minora and labia majora) if the cancer is just found on one side
- A 'radical vulvectomy' – removal of the whole of the vulva (inner and outer lips on both sides)
- Removal of the clitoris (the sensitive prominent erectile tissue positioned just above the urethra, or opening to the water passage)
- Removal of the perineal body (the tissue in the perineum situated towards the back passage, or anus)
- Removal of the lymph nodes (glands) in the groin

The aim of the operation is to preserve as much of your normal anatomy as possible, whilst removing all the cancer. If the surgeon has to remove a large area of skin and tissue during the operation it is sometimes possible to have reconstructive surgery. This is refashioning of the area using skin and tissue grafted from other areas of the body.

The surgeon and nurses will discuss all the options available to you as well as the exact treatment recommended to treat your cancer.

Will I have a scar?

Yes, although it will fade. The size of the scar will depend upon how much skin and tissue is removed. If only a small amount of skin is removed, the scar may be almost invisible. If the tumour is larger, then the appearance of the vulva will be different from before, but the scar itself normally heals well. If the lymph nodes in the groin are removed, you can also expect to have groin scars. If you wish, a specialist doctor or nurse can draw a diagram to show you where the scar(s) will be.

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 (for example, is all of the labia going to be removed? Will the clitoris be removed?) 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 more sensitive to chest infections after 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 or the practice nurse will be able to give you further advice about this.

Before you come into hospital for your operation, try to organise the following ready for your return 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 or dependants if necessary. You may have concerns about your finances whilst you are recovering from surgery. You can discuss these things with the gynaecology CNS.

If you would like to be assessed for home or personal care for when you are recovering at home, ask the ward staff to arrange this whilst you are in hospital.

It is important that you have access to a bathroom and/ or bidet to continue your wound care once at home. If you think that this may be a problem, please discuss it with the nursing staff.

Will I need to have tests before my operation?

Yes. These tests will ensure that you are physically fit for surgery and help your doctor to choose the most appropriate treatment for your type of disease and stage (extent of the cancer). Recordings of your heart (ECG) may be taken as well as a chest X-ray, scans and imaging of your pelvis (MRI and CT scans).

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 to hospital.

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 the 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 baseline (normal reading) from which to work.

A blood sample will be taken to check that 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 to the ward 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. Before going to the operating theatre, 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.

If your lymph nodes have been removed, you are likely to have drains or tubes in the wounds in your groins. This is so that any blood or fluid that collects in the area can drain away safely and will help to prevent swelling. The tube(s) will need to stay in for up to 10 days after the operation.

During your operation a catheter (tube to drain urine away) will be put into the bladder. This will allow the area to remain dry and help recovery and healing. The catheter will need to stay in for approximately 5 days, following which it will be removed quite simply and painlessly on the ward by your nurse.

You may have trouble opening your bowels or have some discomfort due to wind for the first few days after the operation – this is because you are immobile, not eating your usual diet and having strong painkillers. This is temporary and we can give you laxatives or painkillers if you need them.

Please note that the area around the scar/s may feel numb for a while after the operation, but sensation should return to most areas eventually. The nurse will help you care for your wound(s) and keep the area clean.

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.

Is it normal to feel weepy or depressed afterwards?

Yes. It is a very common reaction to the diagnosis, to the operation and also sometimes to being away from your family and friends. If these feelings persist or develop when you leave hospital, the advice and support of your friends, family, GP, the gynaecology CNS or other support agencies may help you. There are also a number of local and national support groups (see page 19).

Leaving hospital and coping at home

When can I go home?

You will be in hospital between 5 and 14 days, occasionally longer, 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 recover from this operation, but this depends upon the type and the extent of the surgery. However, your energy levels and what you feel able to do will usually increase with time. This will vary from individual to 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 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 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. The speed of your recovery will depend upon the type and extent of the surgery you have had. Generally, within 6–8 weeks you should be able to return to your normal activities but you can discuss this further at your follow-up clinic appointment.

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 CNS or GP.

When can I start to drive again?

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 surgery.

What about exercise?

It is important to continue doing the exercises shown to you by the physiotherapist. 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 area to heal. The physiotherapist or gynaecology CNS will be happy to give advice on your individual needs.

When can I have sex?

You may not feel physically or emotionally ready to start having sex again for a while. It can take several months for the vulval area to heal and for sensation to improve. If your clitoris has been removed as part of the surgery, your sexual

response will feel different. You may wish to discuss this with your gynaecology CNS who may arrange for you to attend a sexual rehabilitation clinic.

It can also take time for energy levels and sexual desire to improve. During this time, it may feel important for you and your partner to maintain intimacy, despite refraining from sexual intercourse.

It can also 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. His or her involvement can have 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 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.

Will I need further treatment?

The results of your tissue analysis will tell the cancer team if you need further treatment. This will be discussed with you in clinic.

How will I be followed up?

Your first follow up appointment will be within a few weeks following your discharge from hospital. This appointment is to discuss the results (histology) of the surgery and to discuss any further treatment you may need. Your doctor will need to examine your wounds to ensure they are healing well.

Your follow up appointments will be arranged for every 3–6 months for the first 2 years, then every 6 months for up to 5 years after your operation. 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 may be at your local hospital if no further treatment is necessary.

Why do I need to be followed up in clinic for so long?

Cancer of the vulva can return some years after your operation. By having frequent appointments any problems can be detected early.

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:

- Persistent itching and/or soreness of the vulval skin
- A new change in colour of the vulval skin
- A noticeable lump or swelling on the vulva
- A noticeable lump in either groin
- 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 vulval cancer explained

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

Stage 1 Cancer is found only on the vulva and is less than 2cm in size.

Stage 2 Cancer is found on the vulva and is more than 2cm in size.

Stage 3 Cancer is found on the vulva and has spread to nearby tissues such as the lower part of the urethra (the tube through which urine passes), the vagina, the anus (the opening of the rectum) and/or nearby lymph nodes.

Stage 4 The cancer has spread beyond the urethra, vagina and anus into the lining of the bladder or the bowel; or, it may have spread to the lymph nodes in the pelvis or to other parts of the body.

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 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 has the condition correctly diagnosed and gets a suitable level of care.

NHS Choices

Website: www.nhs.uk

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

Eve Appeal

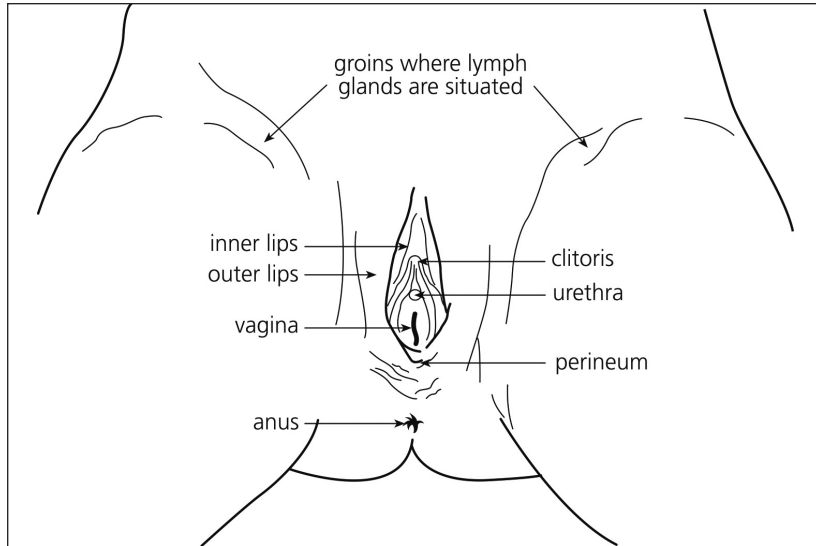
15B Bergham Mews, Blythe Road, London, W14 0HN.

Telephone: **020 7605 0100**

Website: www.eveappeal.org.uk

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

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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