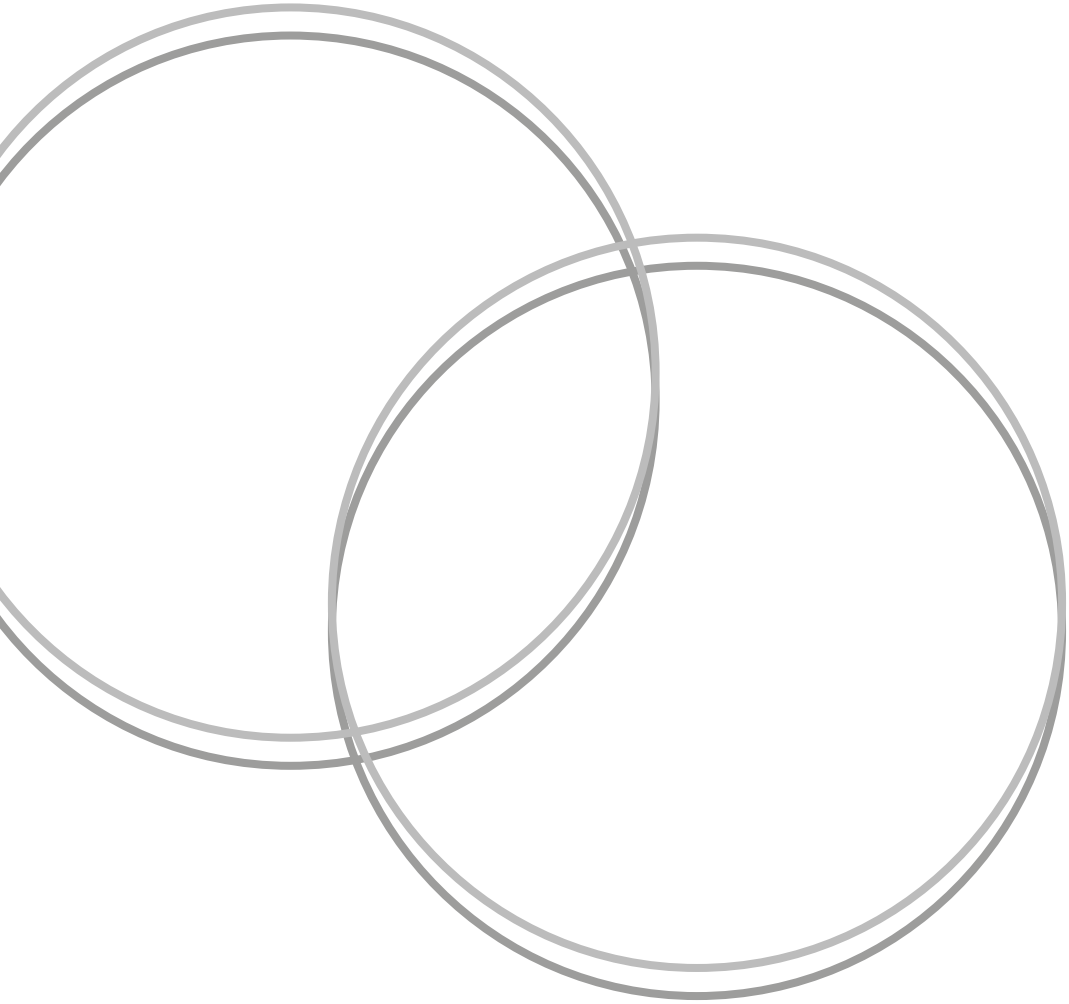
Oxford University Hospitals
NHS Foundation Trust

Gynaecological Oncology

Vulval cancer

Information for patients



Contents

How is vulval cancer diagnosed?

Symptoms

Women diagnosed with vulval cancer may have experienced the following symptoms in the vulval area which have not gone away:

- discomfort or pain
- swelling, a lump or wart like growth
- burning pain when passing urine
- itching
- a sore or ulcerated area
- thickened, raised, red, white, or dark patches on the skin
- a mole on the vulva that changes shape or colour
- bleeding or blood-stained discharge

It is important to note that there are conditions other than cancer which can result in the above symptoms.

The exact cause of vulval cancer is unknown. However, some risk factors can increase the chances of developing it, include skin conditions such as: Lichen sclerosis, lichen planus and Paget's disease. Lichen planus and Lichen sclerosis are common, non-cancerous skin conditions. Paget's disease causes abnormal changes to the skin cells that cover the vulva. The human papilloma virus (HPV) is a very common group of viruses which can increase the risk of developing vulval cancer, along with smoking, or having a weakened immune system.

Vulval cancer is diagnosed by performing a biopsy. A biopsy involves taking a small sample of tissue from the affected area.

You may also have the following investigations:

Chest x-ray – This involves using a small amount of radiation to take a picture of your chest.

Computerised tomography (CT) scan – Takes a three-dimensional (3D) picture of inside the body using x-rays taken by the CT scanner.

Magnetic resonance imaging (MRI) scan – Uses a powerful magnet to build up detailed pictures of an area of your body.

Grading and staging

Your surgeon and specialist nurse will discuss the grade (how quickly the cancer is growing and what it looks like under the microscope) and stage (the size and spread) of the vulval cancer. Your specialist nurse will provide you with further written information from Macmillan cancer support to help you understand the grade and stage of your cancer.

Treatment for vulval cancer – What are the options?

Surgery is most commonly used to treat vulval cancer.

Radiotherapy or chemotherapy is rarely offered as the main treatment for vulval cancer. However, it may be offered as an adjuvant treatment (additional treatment) after surgery.

You also have the choice to not have any treatment. The implications of this will be discussed with you by your team and you will be supported in making your decision.

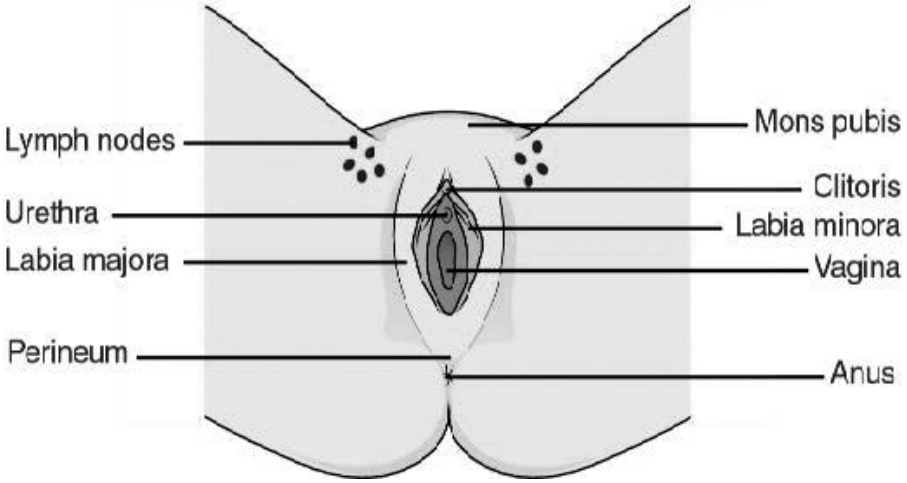
Treatment is planned on an individual basis, taking into consideration your concerns.

What is vulval surgery and why is it necessary?

Women diagnosed with cancer of the vulva may need to have surgery to remove the skin and tissue in the vulval area. The amount of skin and tissue removed is dependent on the following:

- Type of cancer cell
- The size of the cancer
- The position of the cancer
- The spread of cancer to other areas such as the lymph nodes or proximity to the anus, clitoris or urethra

Vulval anatomy



This image was produced by Macmillan Cancer Support and is reused with permission.

The extent and length of surgery will depend on these factors. This will be discussed with you on an individual basis by your surgeon and specialist nurse.

The aim of the surgery

The aim of vulval surgery is to remove the cancer with a clear margin of skin which does not contain cancer cells. The surgeon will try to keep as much unaffected vulval tissue as possible.

Types of vulval surgery

- **Wide local excision (WLE)** – removal of cancer and a margin of normal tissue around it.
- **Hemi-vulvectomy** – removal of one side the of the vulva (inner and outer lips known as labia majora and labia minora).
- **Radical vulvectomy** – removal of the whole vulva (inner and outer lips on both sides)
- **Removal of the clitoris** – (the sensitive prominent tissue positioned just above the urethra/ the opening that allows you to pass urine).
- **Removal of the perineal body** – (tissue in the perineum – area between the vagina and back passage.
- **Removal of groin lymph nodes** – either on one or both sides depending on the grade and stage of cancer.
- **Sentinel lymph node Biopsy (SLNB)** – Sentinel lymph node is the first lymph node that the cancer may have spread to. It involves injection of a radioactive fluid into the tumour area, and then the sentinel node [if present] lights up on the CT scan. This is carried out in the Nuclear Medicine Department. It is not 100% successful and the normal removal of the lymph nodes may be required. Blue dye is sometimes used along with the radioactive fluid. The removal of the sentinel lymph node significantly reduces the side effects of surgery.
- **Pelvic exenteration** – This is **rare** and only offered when cancer has spread to organs close to the vulva such as the womb, bladder or lower bowel. This involves possible removal of the vulva, vagina, womb, bladder, bowel, lymph nodes and reconstructive surgery in conjunction with plastic surgery. If the bladder and bowel are removed, you will have one or two stomas

(an opening on the tummy which allows urine and/ or faeces to be collected in a stoma bag). If this is the case, you will be referred to the stoma nurse who will go through this in detail. Further information relating to this extensive surgery will be provided by your specialist nurse.

- **Reconstruction of the vulva** – Plastic surgeons will work with the gynae oncology surgeon if reconstruction of the vulva or vagina is required.

Consenting for surgery

Prior to surgery you will have met the surgeon and the specialist nurse in the Outpatient department where the plan for surgery will be discussed in detail. The surgeon will discuss the risks and benefits of the surgery specific to you. You will have time to ask any questions you may have. You will then sign your consent and be given a copy of your consent form prior to your surgery.

Risks of vulval surgery

There are risks with any surgery and anaesthetic. These will be dependent on your diagnosis, medical history and risk factors specific to you.

Frequently occurring risks/side effects:

- Infection, bleeding, wound breakdown and pain

Less common risks/side effects:

- Blood clots in legs – Deep Vein Thrombosis (DVT) or lungs – Pulmonary Embolus (PE). Return to theatre to stop bleeding, anaesthetic risks (which are low – but other health conditions can make this a higher risk)
- If you have surgery to remove lymph nodes you may have additional risks:
- Lymphocyst formation (fluid filled cyst), lymphoedema (swelling of legs/vulva). The management of these are detailed in the wound care section of this leaflet. Some numbness in the upper thighs – which may settle with time.

- Your surgery may be carried out under sedation and spinal block (injection of local anaesthetic or opioid into your back) or under a general anaesthetic. The surgeon and anaesthetist will discuss this with you prior to your procedure.

The specialist nurse will give you further information leaflets and contact details for the team and will be able to go over any questions you may have prior to your surgery.

Pre-operative assessment

Prior to surgery you will need to attend the hospital for a pre-operative assessment appointment. This is to ensure that you are fit for the operation. You will have general health checks carried out such as bloods taken, blood pressure, weight, height and any other tests which may be relevant to assess your current fitness for surgery. Occasionally, further tests may be requested at this stage, or you may need to be seen by an anaesthetist for an additional assessment.

Please bring a list of your current medicines and past medical history with you to your appointment. Often your GP can provide you with a printout of this information.

You will be given information regarding your admission including what to bring with you, when to stop eating and drinking and what medications you may need to stop at this appointment. (See Preparation for your operation and Theatre Direct Admission Information for patients' leaflet – this will be given to you at your preoperative assessment appointment).

Preparation for your surgery

If you have questions about your surgery, please call your specialist nurse/key worker for advice.

Smoking – If you are a smoker, it would benefit you to cut down or stop smoking prior to your surgery. This can help with your recovery after surgery and will help with wound healing.

Diet and Exercise – Have a healthy diet and take gentle exercise as this will help with your recovery after surgery.

Alcohol – If you can reduce your alcohol intake this will help with your recovery.

You can speak to your GP, practice nurse at the GP surgery or your specialist nurse if you require further advice and support to prepare for your surgery. You are also able to self-refer to the **Here for Health Service** at the hospital who can help with all aspects to improving health.

After surgery

If you have had a day surgery procedure under spinal anaesthetic and sedation you are likely to be discharged home on the same day. You will be given advice about caring for your wound and signs of infection to look out for, from the nurse discharging you in the day surgery unit.

If you are expecting to be admitted to the ward, you will go to a recovery area until you are ready to be cared for on the ward. You may have the following attachments after your surgery:

Fluids – A drip gives you fluid into your vein to prevent you getting dehydrated. Once you can drink this will be removed.

Oxygen – You will have an oxygen mask or nasal oxygen after your surgery. This helps you to breathe comfortably after surgery and will be removed when no longer required.

Removal of groin lymph nodes – If you have had groin lymph nodes removed you may have a drain into the groin which will drain blood and lymphatic fluid which collects in the groin. This helps to prevent swelling in the groin area. If you have had bilateral (both left and right) groin lymph node dissection you may have a drain in each groin. These drains will be kept in place until the surgeon decides they are no longer required. This can be up to 2-3 weeks after your surgery, and you may be discharged home with the drains. See Leaving Hospital Information leaflets – Drain care.

Urinary catheter – You may have a catheter tube to drain urine. This is placed in your urethra at the time of surgery. Dependant on the type of surgery this may be removed once you are able to mobilise to the toilet.

If you have had surgery involving/or close to the urethra the catheter may be left in for several weeks to allow the vulval area to heal. See Leaving Hospital – Catheter care.

Bowel function – After surgery women can become constipated. This can be due to the pain medication you are given or several

other factors such as being dehydrated. It is important to mobilise, eat and drink healthily and if constipated inform your nurse or doctor as you may require a laxative medication to ensure you are able to open your bowels without straining.

Caring for your vulval and groin wounds – The nurse on the ward will check your vulval/groin wound at least twice per day. Once you are mobile you will be encouraged to gently shower the vulval area and use a dry clean towel to gently dry the area. The nurse will show you how to clean the vulval area using a plastic syringe filled with water. This is called vulval toilet. You will be encouraged to do this once you are at home. This helps to keep the vulval area clean and dry. Your groin wound will usually be glued rather than sutured. See the wound care section in this booklet for information about risks of wound infection/breakdown.

Pain – When you attend your preoperative assessment, they will discuss the different options for pain relief following surgery. This may be a patient-controlled analgesia (PCA) an epidural or spinal block, or tablets. This is dependent on the type of surgery.

Mobility – You will be encouraged to mobilise as soon as possible after surgery. You will be measured for anti-embolism stockings (compression stockings) to reduce the risk of developing a blood clot known as a deep vein thrombosis (DVT) prior to your surgery and you will continue to wear these until your discharge. You may also have an inflatable cuff around your lower legs which automatically inflates and deflates. This is an additional device which is also used to prevent DVT. These are used on the first day after surgery.

If you have had extensive surgery involving plastic surgery, you will be given specific advice regarding post-operative mobility and positioning. If you have questions about this, please speak to your surgeon or specialist nurse.

Preventing blood clots – You will also be given Dalteparin injections to thin your blood and prevent blood clots.

How will I feel after my operation?

After your surgery it is likely that you may feel sleepy for the first few hours. If you experience pain or feel sick let your nurse know. Some patients will have a PCA (patient-controlled analgesia) pump. This enables the patient to administer a small dose of analgesia (pain reliefl) by pressing a button. There are other alternatives such as epidural or spinal block injection. The anaesthetist will discuss your preferences before your operation.

After surgery, some patients may feel emotional or low in mood. This is quite normal, and most patients will feel better once they are home in their own environment with the support of friends and family.

If these feelings persist you may wish to discuss this with your specialist nurse or contact the local support such as the Maggie's Centre or an alternative support group in your area.

Length of hospital stay

Depending on the type of operation you may be treated as a day case patient, or you may be admitted to a ward for several days. Your consultant will be able to give you an idea about the likely length of stay in hospital prior to your surgery.

Visitors – Please check the hospital website for the latest guidance (https://www.ouh.nhs.uk)

Leaving hospital

The ward will be able to provide you with a fit note (sick certificate) for the expected duration of recovery following your surgery. After this time, please contact your GP for an extension of this if required.

Care of drains

If you are discharged with 1 or 2 drains in your groin you may be shown how to monitor the output of serous fluid which collects in the drain/s. You may be asked to record the 24-hour output and write this down. If you are unable to do this the district nurse or practice nurse (DN or PN) may be asked to monitor this for you. You will be referred to the DN/PN who will look after your drain/s following your discharge from hospital. They will change the drain bottle if necessary and will watch out for signs of infection at the wound site. The drains used generally work on a vacuum. They do not need to be emptied but if they lose their vacuum/suction the bottle may need to be changed by the DN or PN.

Signs of infection – See wound care section below.

Wound care

Before you leave hospital, you will have been taught how to care for your surgical wound/s. This normally involves showering a couple of times a day or using a syringe to perform a vulval toilet and carefully drying the vulval area. It is not recommended to bathe until your wounds are fully healed.

Wear loose clothing as this will also help the wound to heal. Vulval and groin wounds are at risk of infection and breakdown due to the warm, moist environment.

Groin wounds may also develop leakage or a collection of serous lymphatic fluid which may require drainage (lymphocyst). Serous fluid is clear bodily fluid. Antibiotics may be required in this circumstance.

Signs of infection:

- redness of the wound and/or surrounding skin
- pain
- an offensive discharge
- fever

If you develop any of the above symptoms, you should contact your GP or local out of hour's service. You may need a course of antibiotics.

You may contact your specialist nurse for advice. You may need review /follow up in clinic earlier in this instance.

Long term complications of groin node removal

A small number of patients may experience lymphoedema, which is swelling of the legs or vulva due to fluid collection. This can occur at any time following surgery. If this occurs, please let your cancer team know as they will refer you to the lymphoedema team at the hospital who will be able to provide ongoing specialist support.

Sutures

Vulval sutures are usually dissolvable. If you have not been informed about the type of suture, please ask your nurse on the ward before leaving the hospital.

Catheter care

If you are discharged with a catheter, you will be discharged with either a flip flow valve or leg bags and night bags. You will be shown how to care for your catheter and informed about when the flip flow valve or catheter bag needs to be changed. You will be given supplies of equipment required and if necessary registered with a delivery company who will request a prescription from your GP so that further catheter supplies can be delivered to you directly.

You will be given a date to return to the hospital for a trial without catheter (TWOC) – The discharging doctor/nurse will let you know a date for this before you are discharged.

The nurse will give you information about signs and symptoms of urine infection that you will need to look out for such as:

- pain low down in your pelvis (tummy) or around your groin
- a high temperature (fever)
- feeling cold and shivery
- confusion
- offensive smelling/cloudy urine
- blood in the urine

Contact your GP or local out of hours service if you think you have a UTI (Urinary Tract Infection). You may need a course of antibiotics.

Pain

If required, you will be discharged with a supply of pain medications and any other new medications started in hospital.

Dalteparin

You will be discharged with a supply of Dalteparin injections to thin your blood for a total of 28 days inclusive of the days spent in hospital. The nurses will show you how to give this injection before your discharge or may show a friend or relative, at your request, how to give the injection if you feel you are unable to do this yourself. You will not need to wear compression stockings once you have gone home unless prescribed by the consultant at the time of discharge. Please see separate leaflet on how to administer Dalteparin at home.

Your results and follow up appointment after surgery

After surgery, the tissue removed is examined by the pathologist who will confirm if the cancer has been fully excised (removed) or if further treatment is required such as:

- further surgery to remove more vulval tissue (WLE, Wide local excision)
- groin lymph node removal from one or both sides
- radiotherapy or chemotherapy

You will be informed of your histology results at your follow up appointment which is around 2-3 weeks after your surgery. At this appointment you will be informed of the plan for follow up or if further treatment is required.

Further treatment

If further treatment such as radiotherapy or chemotherapy is required, you will be referred to the appropriate doctor who will discuss the plan for treatment with you and give you specific information regarding the treatment. Your specialist nurse/ keyworker will continue to care for you throughout your treatment.

Long term follow up

- The first follow up appointment is usually 2-3 weeks after the surgery
- If no further treatment is required, you will be followed up every 3 months for the first 2 years
- Then 6 monthly up to 5 years after your surgery

When can I get back to normal?

It is not unusual to feel tired and fatigued after surgery. It can take several months before you feel fully recovered. This is dependent on the extent of surgery and will vary from one individual to another. It is important to stay active, but you should listen to your body and rest when you need to. Gradually increase your daily activity levels.

Depending on the extent of your surgery you may be advised to avoid heavy lifting or carrying. Your surgeon or specialist nurse can give more specific advice in relation to your surgery.

Driving

This will depend on the extent of surgery. You may wish to discuss this with your surgeon at your follow up appointment. We would also suggest that you check with your car insurance provider.

Returning to work

This will depend on the extent of surgery. It will also depend on the type of work you do, your individual recovery, and whether you need any additional treatment such as radiotherapy.

Some employers will offer a phased return which will help you to readjust to normal life, but this is individual to you. You may wish to discuss this with your surgeon, specialist nurse or GP.

Exercise

It is important to continue to be active, but you should avoid all aerobic exercise, jogging, and swimming until the area is fully healed. If you have had extensive surgery, you may be given specific advice from the surgeon prior to your discharge. You may wish to discuss when to resume exercise with the surgeon at your follow up appointment.

Resuming sexual activity

It can take several months for the vulval area to heal and feel comfortable. You might not feel physically or emotionally ready to resume sexual activity for several months. You can look different following your surgery or you may have had surgery involving the clitoris. Sensation and sexual response can feel different after surgery. You may wish to discuss this with your specialist nurse. It may be possible to arrange for you to see a specialist psychosexual counsellor if required.

What symptoms should I report or be worried about?

- Any new changes in the colour of your vulval skin
- New lumps or swelling on the vulva
- Lumps in the groin/s
- Persistent itching/soreness of the vulval skin
- Swollen legs/groin/vulva
- Bleeding or blood-stained discharge

Checklist prior to discharge

Copy of discharge letter	
Tablets to take home	
Dalteparin injections	
Fit note (sick certificate)	
Post-operative wound care instructions and bladder syringe for vulval toileting	
Wound drain instructions/supplies of spare drains if required	
Catheter care instruction/supplies if required	
Aware of signs and symptoms of infection	
When will I have my follow up	
Follow up appointment for trial without catheter (TWOC) if required	
Details of my cancer specialist nurse/key worker	

If you have further questions, please contact the following:

Contacting your hospital team

In office hours, please contact:

Gynae oncology specialist nurse/key worker:

Tel: **01865 235 355**

Email: **GynaeoncologyCNS@ouh.nhs.uk**

Monday to Friday 9am to 4pm Please note phone messages and emails may not be answered on the same day

Gynae oncology administration team:

Tel: **01865 235 662**

Email: **Gynae.oncology@oxnet.nhs.uk**

Monday to Friday 9am to 4pm

In an emergency

Contact your local GP or out of hours service such as 111

How can you give feedback about your care?

We hope that you have found the information in this leaflet helpful in preparing you for your surgery. If you would like to give feedback to the team, please complete:

Friends and Family Feedback form

Patient Advice and Liaison Service (PALS)

Tel: **01865 235 855**

Monday to Friday 9.00am to 5 pm

Further support services

Macmillan Cancer Support

Tel: **0808 808 00 00**

Website: **www.macmillan.org.uk**

Maggie's Centre Oxford

Tel: **01865 751882**

Email: **oxford@maggiescentres.org**

Sobell House Services

Tel: **01865 225860**

Website: **www.sobellhouse.org**

The Hummingbird Cancer Support (Bicester)

Tel: **01869 244244**

Email: **mechelle@thehummingbirdcentre.org.uk**

Here for Health – tailored information for patients (Oxford Hospitals)

Tel: **01865 222958**

Website: **www.ouh.nhs.uk/patient-guide/here-for-health**

NHS Lymphoedema Support

Website: **www.nhs.uk/conditions/lymphoedema**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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www.ouh.nhs.uk/information

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