Patient information leaflet

Royal Surrey County Hospital NHS
NHS Foundation Trust

Surgery for Vulval Cancers

Including discharge information

Gynaecological Oncology Department

Patients 1st
The Patient's First Choice

This booklet has been written for women who have cancer of the vulva (also known as vulval cancer) and require surgery.

The vulva refers to women's outer sex organs and the skin around. The vulva is made up of:

- The external lips around the vagina (labia majora) and the inner lips (labia minora).
- The opening of the vagina.
- The opening of the urethra, the tube that runs from the bladder through which urine is passed out of the body.

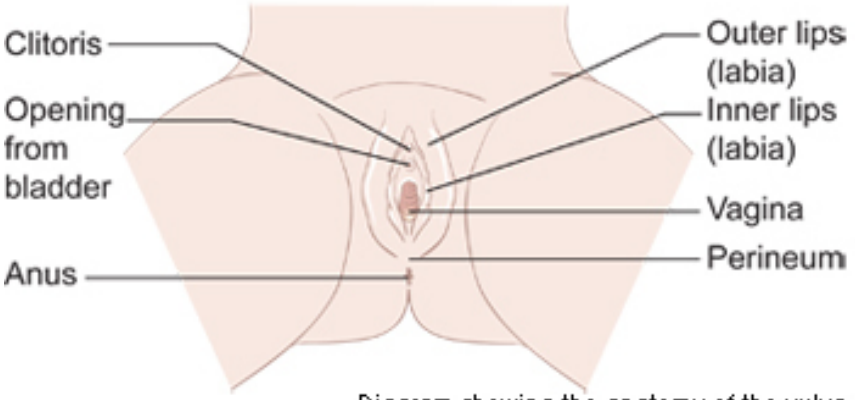

Diagram showing the anatomy of the vulva

Vulval cancer can occur on any part of the vulva but the most common sites are the outer lips (labia majora) and the inner lips (labia minora). Vulval cancer may also involve the clitoris, Bartholins glands (two small glands on each side of the vagina) and the perineum (the skin between the vulva and the anus).

What may the surgery involve?

How much of the tissue is removed during the surgery will depend on type and size of the cancer, the location of the tumour and whether there is evidence of lymphatic spread. Surgery is decided on an individual basis in discussion with you. Your general health and symptoms will play an important part in the decision.

Surgery can include

Wide local excision – removal of the tumour and a margin of normal tissue around it.

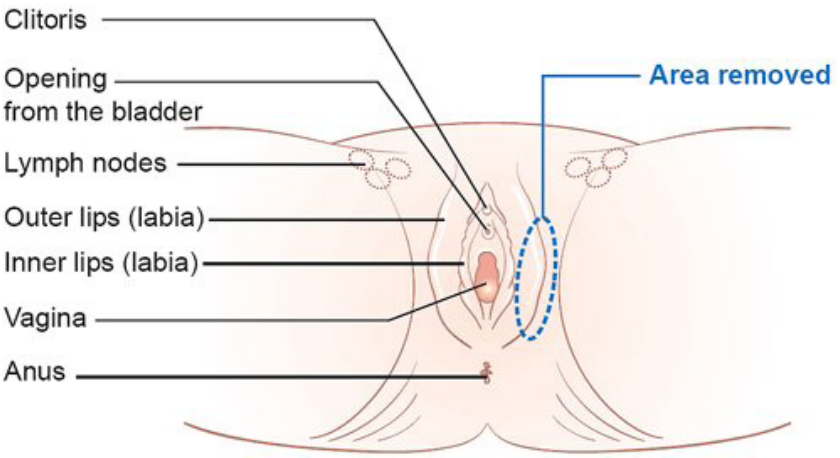

Diagram showing a wide local excision of the vulva

Partial Vulvectomy/Hemivulvectomy – removal of part of the vulva; or labia removed from one side only. Your surgeon will discuss this with you in more detail.

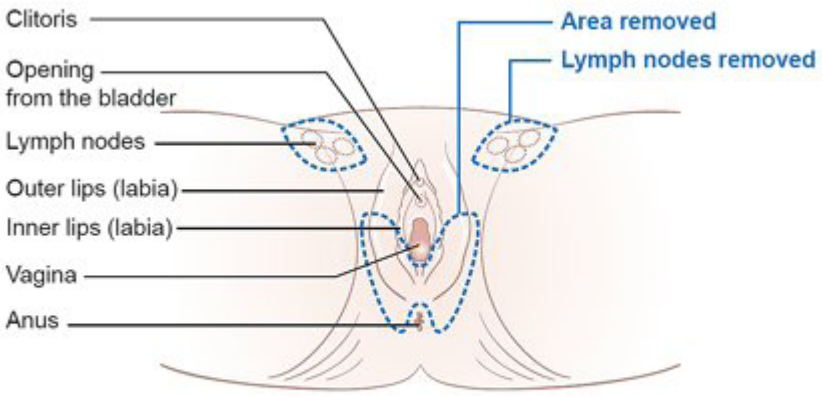

Diagram of a partial or simple vulvectomy for a cancer affecting the bottom part of the vulva and perineal area
© CancerHelp UK

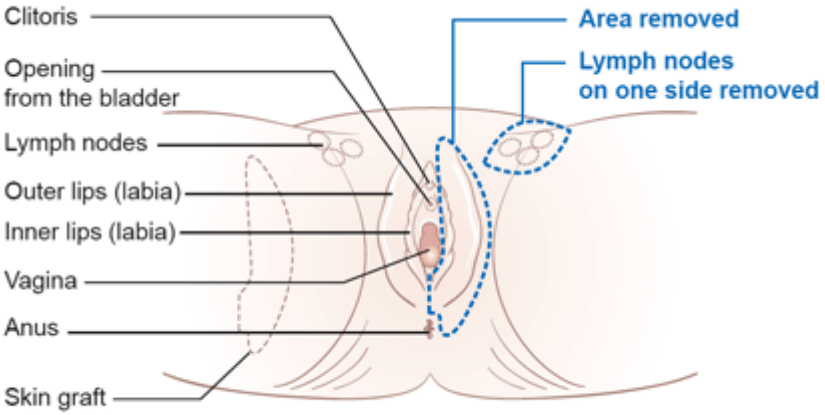

Diagram of a partial or simple vulvectomy on one side of the vulva
© CancerHelp UK

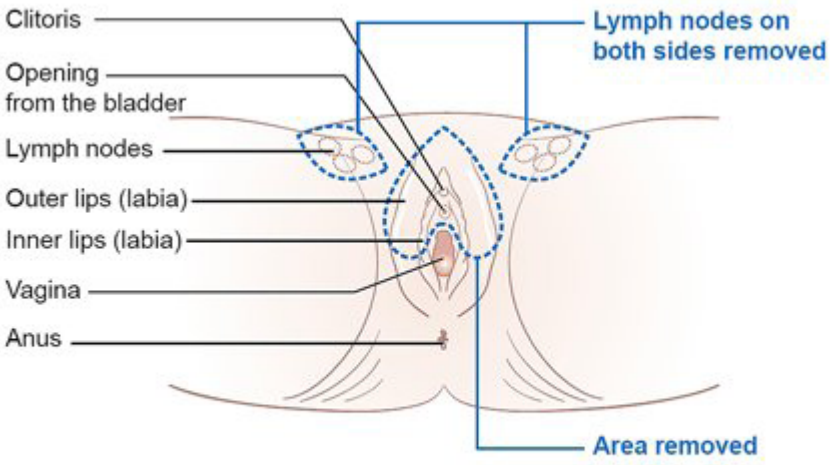

Diagram of a partial or simple vulvectomy affecting the top area of the vulva

Radical Vulvectomy – the vulva is removed, including the inner and outer labia and clitoris with a wide margin of healthy tissue.

Removal of lymph nodes

Lymph nodes might need to be removed from one or both groins at the time of your surgery. Lymph nodes are usually the first place the cancer can spread to.

You may be invited to take part in a trial called the GROINSS study; this will be discussed **in more detail at the time of your consultation**.

All your surgery will be fully discussed at your consultation, and before you sign a consent form.

Are there any alternatives to this operation?

Surgery is the main treatment for cancer of the vulva. If you decide not to have the operation, or can't have surgery based on the medical/ anaesthetic assessment (due to your general health) the possibility of chemotherapy and or radiotherapy will be discussed with you if appropriate.

What is the aim of the surgery?

- To remove the cancer.
- To assess the extent of spread (stage) of the disease.
- To assess if there is any need for further cancer treatment of either radiotherapy and/or chemotherapy.

What will happen before my admission for surgery?

It is important that you feel confident with your surgery and you fully understand the reasons why it is being performed. The surgical team will explain this. You will be given the opportunity to ask questions and voice your concerns before signing the consent form.

The clinical nurse specialist (CNS) will be available for your support before, during and following your operation.

You will be asked to attend a pre-operative assessment clinic to ensure that all the required investigations are undertaken to check your fitness for anaesthesia and surgery. It will also give you a further opportunity for questions about the surgery. On request, you might be able to visit the surgical ward.

Your husband, partner or significant other is welcome to attend any of these appointments with you and ask questions about your surgery.

Please inform the Doctor or Nurse if you take any medications (for example heart, blood pressure, diabetic, warfarin or asprin). Please bring your medicine list with you and ask your doctor if you can take them before surgery.

You will be admitted to either a surgical ward the day before surgery, or the 'Elective Surgical Unit' (ESU) on the day of surgery. Following your operation you will be moved to a surgical ward.

If you're taking part in a trial, you will be given further information by the research team and your surgeon about your admission and any further tests or procedure you need to have before surgery.

What are the risks and side effects of the surgery?

As with any surgery there are risks of bleeding, bruising and infection. You may need a blood transfusion during your admission.

The main side effects following surgery that might occur:

- Breakdown of wound(s).
- Deep vein thrombosis and pulmonary emboli: anti-emboli (T.E.D) stockings, fragmin (sub-cutaneous blood thinning injection) and early movement following surgery are recommended to help to prevent these.
- There may be numbness or altered sensation around the operation site and the top of your legs (thighs) after surgery. This should get better over a period of months.
- Lymphocyst/Lymphoedema (collection of fluid in pubic, groin and/or leg area).
- Changes in bowel function.
- Discomfort/or burning on passing urine.
- Infection.
- Changes in sensation during intercourse.

What will happen following the operation?

Following your surgery you will be transferred to a recovery room and then to one of the surgical wards.

When you are waking up you may have a mask over your nose and mouth providing you with oxygen, and have intravenous fluids. You

should be able to eat and drink as soon as you have woken up from your anaesthetic.

You will have a tube (urinary catheter) inserted into your bladder while you are in surgery. The catheter will drain urine to prevent the wound from coming into contact with acidy urine, to allow the wound to heal. It will be removed approximately 3-5 days after your surgery.

If you have had lymph nodes removed, you may have a tube (redivac drain) in one or both groins. This is to drain lymphatic fluid that collects in the area and helps to prevent any swelling and infection that can occur. Your team will review the drain(s) daily and based upon how much fluid is draining will decide when the drain(s) can be removed. In some cases you may go home with a drain(s), but that will be discussed with you by your team before going home.

On your groin(s) will be dressing(s) covering your wound(s). Wound(s) will be regularly checked for any signs of infection or changes in colour (ischaemia) by your surgical team and nursing staff. After a few days the dressing(s) will be removed and the wound(s) will be exposed to the air. If there are any concerns about the healing of your wound, you may need to stay in hospital for longer than planned or be referred to District Nurses.

Surgical staples are usually used to close groin(s) wound(s). The time of their removal will be discussed with you by your surgical team (usually 10-14 days after surgery).

The vulval wound will have dissolvable stiches in and will require regular douching (the nurses will show you how to do this) and monitoring for any signs infection.

Analgesia used during and after surgery will be discussed with you by an anaesthetist on the morning of your surgery. The vulva is a sensitive area and your wound is likely to be sore/uncomfortable at first. It is important to tell your nurses when you are in pain as they will able to review this and offer an appropriate pain relief medication. Taking this regularly from the start should also help you to get moving sooner.

Day one and onwards

After your operation you will feel tired. The nurse looking after you may help you to have a wash and change your night clothes. If you feel well enough the nurses will encourage you to sit out in a chair, this will reduce any stiffness in your muscles.

The physiotherapist will visit you and teach you deep breathing and gentle leg exercises, these will help to prevent chest infections and deep vein thrombosis after your surgery.

You might find moving around difficult at first. However, you will be encouraged to start moving short distances as soon as you can, to prevent blood clots. Walking with drains might be difficult so please ask for assistance.

On the first day after your surgery, you will be wearing anti-embolism stockings (TED stockings) given to you on the day of your surgery. You will also start Fragmin injections to prevent blood clots. This is an injection, given around same time every day for four weeks after your surgery. The nurses on the ward will show you or your family member how to give this before going home.

Nurses on the ward will check your blood pressure, heart rate, oxygen saturation and temperature every day. They will also check your wound(s), drains and urinary catheter regularly for first few days after your surgery.

Vulval hygiene and appropriate wound care is very important. For the first few days ward nurses will be able to advise and assist you to douche the vulval area (clean) with sterile or tepid water. They will be also able to provide advice on how to use a shower or bidet when looking after wound post your discharge home. Keeping your vulval wound dry will be as important as keeping it clean, as increased moisture in the vulval area can lead to the wound break down.

Plenty of fluids are recommended while the catheter is in place. Following the removal, it is important for us to ensure your bladder is emptying properly. The nurse looking after you will check this.

Oral laxatives and/or suppositories can be taken to help your bowels to open.

It is common to feel low in mood following surgery, especially when you may have a diagnosis of cancer. You might find it helpful to talk to the ward nurses or clinical nurse specialist to ease your worries. Your CNS may refer you to a counsellor or local support group if appropriate.

You will be seen daily by your team to assess your progress, explain your operation and recovery. Your clinical nurse specialist and nurses on the ward are also available to answer questions or concerns.

If all has gone well after surgery and your bowel and bladder functions are returning to normal, discharge home is usually about day five following your surgery, this can vary.

Discharge advice/going home

Wound care

It is important to douche or shower daily. Avoid using scented products, lotions, perfumes and talcum powders in the area where you had your operation.

After washing, pat dry your wound with a clean (soft) towel. You might find a hairdryer on a cool setting a more comfortable way of drying the vulva skin than a towel (avoid use a dusty hairdryers).

If you have staples (surgical clips) to your groin(s), these will be removed on day ten after your surgery. This is usually done by your GP surgery or District Nurses. The ward nurse will be in charge of organising your discharge home and will discuss this with you.

It is normal to feel tingling, pulling and numbness in and around the area of your surgery, as your wound(s) goes through stages of healing. However, heavy discharge, offensive smell or feeling shivery and unwell is usually a sign of infection. If you experience any of these symptoms please get in touch with your CNS, surgical team or your GP.

Wearing loose-fitting clothing and exposure of the wounds to the air will aid healing.

If you are experiencing discomfort when passing urine due to the acidity of the urine coming in contact with the wound, pouring a warm

jug of water over the wound while passing urine to dilute it might ease your discomfort.

Lymphoedema / Lymphocyst formation

You are at risk of developing a lymphatic fluid collection called a **lymphocyst** in the area where the lymph glands were removed from the groin.

Some lymphocysts can resolve on their own with time. However, if you notice a swelling in your groin area that becomes increasingly uncomfortable or oozing, let your CNS or surgical team know, as the area will require an assessment and the collection of fluid might need to be drained.

As a result of the surgery you are also at risk of developing swelling in the legs, pelvic and groin area due to accumulation of lymph, called lymphoedema. The use of compression stockings and a specific massage therapy called manual lymphoedema drainage can help to control the accumulation of the fluid. Unfortunately, lymphoedema can't be cured but with appropriate management the symptoms can be reduced.

Your team will be able to refer you to our local Lymphoedema services for assessment and appropriate treatment to reduce the swelling and try to improve your quality of life.

Bowel function

After surgery bowel function is normally slow, due to the lack of food intake on the day of the surgery, anaesthetics and the pain relief medications.

Dietary management (daily prune juice, high fibre or high bulk diets) or stool softening medication or mild laxatives may help to prevent difficulties. Increasing intake of any type of fluids will also help to improve bowel function. Once your normal diet and activity are resumed, bowel function usually returns to normal.

Bladder function

Following removal of your catheter sometimes the sensation of bladder fullness is reduced and you may be less aware of a full bladder. If this happens, it is important to get into the habit of going to the toilet at regular intervals. Your Clinical Nurse Specialist will be able to give you advice.

Fatigue

It is common to feel tired and sometimes irritable and frustrated post-surgery. Even simple everyday tasks that we usually take for granted, such as having a shower, might make you feel exhausted. This is usually temporary and will improve with your recovery. In the meantime diet, exercises the physiotherapist will discuss with you, relaxation, help from your family, friends and others can ease the fatigue and its impact on your everyday life.

Sexuality and relationships

When can I resume sexual activity?

Following a vulvectomy, some ladies worry about intercourse being painful and are concerned about resuming sex. We would recommend no intercourse for the first six weeks whilst healing occurs.

After that, gentle penetration in a position which is comfortable for you, is recommended. Sometimes lubrication jelly can be used, such as **REPLENSE®** or **Liquid Sylk®** which can be prescribed by your G.P. You may find your feeling during penetration is a little numb and escalation of feeling (orgasm) may be different or difficult to achieve. This should improve with time.

Having a vulvectomy can have impact not only on your physical relationship with your partner but also affect you emotionally. If you feel that you or your partner struggle or have any psycho/sexual worries or issues related to the surgery, please contact your CNS who will be able to help or refer you to our psychosexual counselling service.

Going back to work

Full recovery times post vulvectomy vary and will depend on your physical as well as emotional recovery. Therefore, you will be the best person to judge when you feel ready to return to work.

We would also advise you talk to your employer, human resources and occupational health, with regard to the possibility of a phased return to work.

Your surgical team will be able to sign you off work for approximately six weeks after your surgery (depending on the extent of your surgery). If you require a sick note, please request that before you are discharged home from hospital. Your time off work can be reviewed again during your follow up appointment with your surgical team.

Results

All surgical specimen results will be discussed at the Multi-Disciplinary Team Meeting (MDT), by the histopathology team, between two-three weeks after your surgery. Rarely in complex cases: your histology (result of the operation) will be sent away for a 2nd opinion for further review. The MDT meets weekly to review results and decide treatment accordingly.

MDT members: Medical Oncologists, Clinical Oncologists, Gynae-Oncology Surgeons, Histopthologists, Cytologists, Radiologists and Clinical Nurse Specialists.

The Gynaecological Oncology follow up clinic

Your next appointment after surgery will usually be between two-three weeks. All results and further treatment options and follow up will be discussed with you at this appointment with the Consultant Gynaecologist. In some cases where there is no further treatment recommended and you have no concerns about your recovery, a six week follow up with your team will be organised. The Clinical Nurse Specialist is available to discuss any concerns you may have.

Future follow ups

This depends on your diagnosis:

If you have had previous cancer treatment, or will require further treatment following your surgery you will be followed up for five years post completion of all your treatment.

If the diagnosis is benign or borderline tumour your follow up will be discussed by your surgical team.

If you have entered into the GROINSS study the follow up appointments will be more frequent (two monthly for the first year) but this will be explained to you by our research team.

Who do I contact following discharge?

If you have any concerns when you are discharged, you can contact:

- **Clinical Nurse Specialist (CNS)**
  Telephone: 01483 571122 **ext** 2038 (Mon–Fri. 8am–4.30pm)
- **Elstead Ward**
  Telephone: 01483 571122 **ext** 4083, 4084 or 4085
- **Surgical team secretaries**
  Telephone: 01483 571122

  Miss Ellis's secretary **ext** 2720

  Mr Butler-Manuel & Mr Tailor's secretary **ext** 2176
- **Your GP surgery**
- **Your nearest Accident and Emergency (A&E) department**
  If you are being seen in an A&E department within six weeks of your surgery with issues related to your surgery, please request for your A&E team to contact your surgeon via Royal Surrey County hospital switch board for advice.

Elstead Ward visiting times

3pm–5pm and **6pm–8pm**

References

- www.patientspictures.com
- Blake, Lambert and Crawford (1998) 'Gynaecological Oncology' a guide to clinical management, pp62-63 Oxford University Press.
- Cancer Research UK
- NHS Choices (2013)

Local Support Group

Gynaecological Cancer Support Group

Location: Fountain Centre, St. Luke's Cancer Centre (held on alternate months.)
Contact: Gynaecological Oncology CNS to book or enquire.
Telephone: 01483 571122 **ext** 2038

The Fountain Centre

Supportive therapy and information in a friendly and relaxed environment. Based in the Royal Surrey County Hospital.
Telephone: 01483 406618
Website: www.fountaincentresupport.com

The Olive Centre

Crawley Cancer Support Sussex Annexe Crawley Hospital
Telephone: 01293 534465
Website: www.olivetreecancersupport.org.uk

National Support Information

Macmillan

Website: www.macmillan.org.uk
Freephone: 0808 808 0000

Cancer Research UK

Website: www.cancerresearchuk.org

The Lymphoedema Support Network (LSN)

Website: www.lymphoedema.org

PALS and Advocacy contact details

Contact details of independent advocacy services can be provided by our Patient Advice and Liaison Service (PALS) who are located on the right hand side as you enter the main reception area. PALS are also your first point of contact for health related issues, questions or concerns surrounding RSCH patient services.

Telephone: 01483 402757

Email: rsc-tr.pals@nhs.net

Opening hours: 9.00am–4.00pm, Monday to Friday

If you would like information documents in large print, on tape or in another language or form please contact PALS.

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