NHS
Lancashire Teaching Hospitals
NHS Foundation Trust

Information for patients and carers

Surgery for Cancer of the Vulva

Excellent care with compassion

Gynaecology, Women and Children's Health

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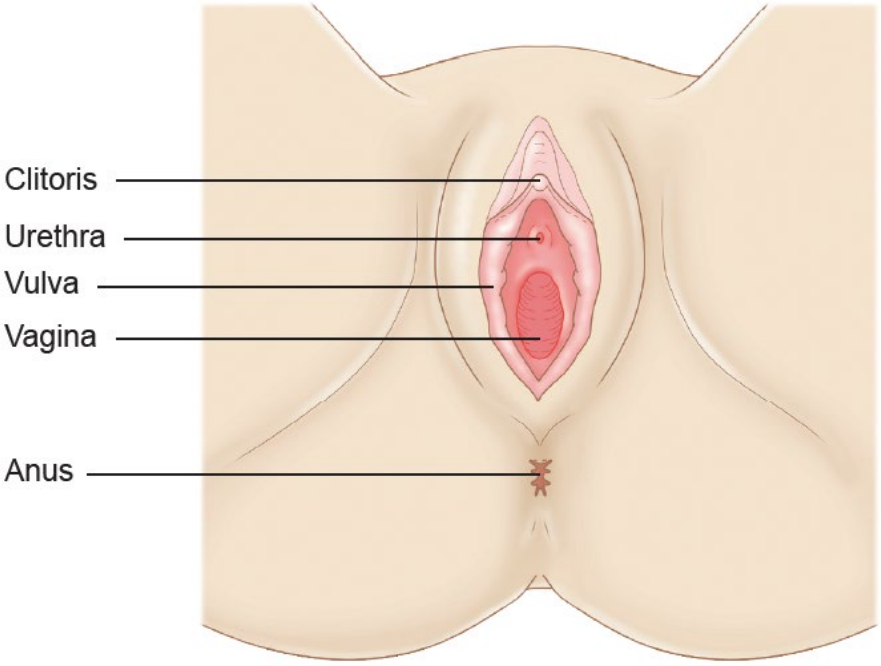
Introduction

If you have either 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 all women, this will 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 your Macmillan gynaecology oncology clinical nurse specialist (CNS).They will listen, be able to answer your questions and can put you in contact with other professionals or support agencies if you wish. Some useful contact numbers are also 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 undergo surgery to remove either some or all of the tissues in this area (see diagram). How much is removed during the operation will depend upon the type of cancer cells, the size, the position and whether it has spread beyond the original area. Your general health and symptoms (such as discomfort, pain, burning or itching) in the area are also considered when planning your surgery.



What is the aim of the vulval surgery?

The aim of the operation is to remove all of the cancer, trying to preserve as much vulval tissue as possible. Surgery for this disease in its early stages is usually very successful. However, if the cancer has spread, radiotherapy to the area may be recommended. Surgery and radiotherapy are also used to control 'local' (where the tumour is situated) symptoms of cancer.

The aim of your treatment as well as the specific treatment required will be discussed with you when all your results (eg MRI scan and histology reports) are available.

What is removed during the operation?

This will depend upon the location of cancer cells 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 ‘hemivulvectomy’ – one side of the vulva (inner and outer lips) may be removed if the tumour is only on one side.
- A ‘radical vulvectomy’ – removal of the whole of the vulva (inner and outer lips on both sides known as the labia minora and labia majora).
- Removal of the clitoris (the sensitive prominent erectile tissue positioned just above the urethra).
- Removal of the perineal body (the tissue positioned towards the anus).
- Removal of the regional lymph nodes (glands situated on either side of the groin area).
- Sentinel lymph node biopsy.

The aim of the operation will be to preserve as much of your appearance as possible, whilst removing the cancer. Reconstructive surgery (reshaping the area using tissue grafted from other areas of the body) is sometimes an option if a larger area is removed due to cancer. The doctor and your Macmillan gynaecology oncology clinical nurse specialist will discuss all the options available to you as well as the exact treatment recommended to treat your cancer.

What is a Sentinel lymph node?

A sentinel node (gland) is the first node in your groin that your cancer can spread to. Removing the sentinel node will tell us if the cancer has spread to this area. This information will help us to decide if we need to remove the groin lymph nodes.

How is the sentinel lymph node identified?

On the morning of your operation you will be taken to the nuclear medicine department. You will be awake for this procedure, a small amount of radioactive dye will be injected into the vulva (cream will be applied to the area to numb the skin). This fluid then travels to the sentinel lymph node. A scan of your lymph nodes will be taken. After the scan you will return to the ward.

How is the sentinel lymph node removed?

Later the same day you will be taken to the operating theatre and once you are asleep the surgeon will inject a small amount of blue dye into the vulva. The surgeon is then able to identify the position of the sentinel node containing the radioactive fluid and the blue dye. The node can then be removed through a small cut in your groin.

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 rarely used as an alternative to surgery, but in special circumstances it may be offered. This will depend on the type, size and spread of the cancer. Please discuss the options available to you with your consultant or your Macmillan gynaecology oncology clinical nurse specialist.

Are there any risks?

As with any operation, there is a risk associated with having a general anaesthetic. Specific to this operation, women occasionally suffer from deep vein thrombosis (DVT), a blood clot in the leg. Moving around as soon as possible after your operation can help to prevent this. The ward nurse will show you some gentle leg exercises, safe ways to move in and out of bed and breathing exercises to reduce the risk of blood clots or a chest infection. You will also be given special surgical stockings (anti-embolism stockings) to wear whilst in hospital and injections to reduce the risk of blood clots.

There is a risk of wound breakdown due to tension in the surgical area where the skin has been rejoined, although this will depend upon how much tissue has been removed. If this occurs, it is usually within the first 10 days of surgery and will require special care by the nurses to keep the area clean and dry. A wound dressing may need to be applied to reduce the risk of infection until it has healed. This may delay your discharge home from hospital. When you go home you may initially require a district nurse to visit and continue caring for your wound until it has healed completely.

Common to all major surgery, there is also a risk of wound haematoma (bruising under the skin) or infection. These are easily recognised and should be treated before you are discharged home.

What are the risks associated with a general anaesthetic?

Please refer to the separate Trust leaflet “you and your anaesthetic”.

Are there any long-term complications associated with this operation?

If the lymph glands in the groin area on one or both sides are removed as part of the operation, then there is a significant risk of developing lymphoedema, which causes swelling in one or both legs.

Normally, lymphatic fluid circulates throughout the body, draining through the lymph glands. If the lymph glands are removed either to prevent the spread of cancer in the area, or because this has already happened, this may cause the lymphatic drainage system to become blocked. Consequently, this fluid may collect in one or both legs and/or the genital area. Lymphoedema can be managed and treated but we will try to reduce the risk of it happening in the first place by providing specific advice. You will be able to discuss any concerns both before and after your operation and at anytime during your follow-up treatment.

If you would like further information about lymphoedema, please ask for a leaflet. There are also specialist lymphoedema clinics in the community, which you may be referred to if this becomes a problem.

Will I have a scar?

Yes. Although it will fade. The size of the scar will depend upon how much tissue has been 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 have also been removed, you can expect scars in this area as well but groin scars are usually hardly visible when healed. If you wish your doctor or nurse can draw a diagram to show you where the scar will be.

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

Yes. Make sure that all of your questions have been answered to your satisfaction (including whether or not the clitoris will 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 your clinical nurse specialist to arrange this for you.

If you are a smoker, it would benefit you greatly to stop smoking or cut down before you have your operation. This will reduce the risk of chest problems as smoking makes your lungs sensitive to the anaesthetic.

You should eat a balanced diet and, if you feel well enough, take some gentle exercise before the operation as this will also help your recovery afterwards. Your GP, practice nurse, or the doctors and nurses at the hospital 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 bed sheets, vacuuming and gardening) and to look after your children or dependents if necessary. You may wish to discuss this further with your Macmillan gynaecology oncology clinical nurse specialist.

If you have any concerns about your finances whilst you are recovering from surgery, you may wish to discuss this with your Macmillan gynaecology oncology clinical nurse specialist. You can do this either before admission to hospital or whilst you are recovering on the ward. If you would like to be assessed for home/personal care when you are recovering at home, this can also be arranged 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 any 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 (position of the cancer).

Recordings of your heart (ECG) may be taken as well as a chest x-rays, scans and imaging of your pelvis (MRI and CT scans) and a blood sample to check that you are not anaemic.

You will also have the opportunity to ask the doctor and your Macmillan gynaecology oncology clinical nurse specialist any questions that you have, it may help to write them down before you come to hospital.

The tests are normally arranged at a pre-operative clinic appointment 1 - 2 weeks before you are due to be admitted for surgery.

When will I come in for my operation?

You will be admitted to the ward on the day of your surgery.

You will meet the ward nurses and doctors involved in your care. The anaesthetist will also visit you to discuss the anaesthetic and to decide whether you will have pre-medication (tablets or an injection) to relax you before you go to the operating theatre. Any further questions you have can be also discussed at this time.

Your temperature, pulse, blood pressure, respiration rate, height, weight and urine are measured to give the nurses and doctors a base line (normal reading) from which to work. You will be asked to sign a consent form to confirm that you understand and agree to the operation.

You will be asked to have only water up until 2 hours before surgery. You will not be allowed to have anything to eat or drink after this time, including chewing gum or sweets. A ‘drip’ may be attached to provide you with fluids to prevent dehydration during this time.

What happens on the day of my operation?

Before going to the operating theatre, you will be asked to take a bath or shower and change into a theatre gown. You must remove all make-up, nail varnish, jewellery (except wedding rings, which can be taped into place), dentures, hearing aids, contact lenses, wigs and scarves. Glasses, wigs, scarves, hearing aids and dentures can be removed when you arrive in theatre.

What happens after the operation?

You will be admitted to the hospital ward. If you have any known heart or breathing problems you may be nursed in the high dependency unit (HDU) which is part of the critical care unit (CrCU) but this will be discussed if it is thought necessary.

You may still be very sleepy and be given oxygen through a clear facemask to help you breathe comfortably immediately after your operation. You may not be well enough to have anything to eat or drink and so a 'drip' will be attached to your hand/arm to provide you with fluids and prevent dehydration for the next 24 – 48 hours.

You are likely to have drains (tube in the wounds) in your groins if lymph nodes have been removed. 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 approximately 3-7 days after the operation.

A catheter (tube) will be inside your bladder to drain urine away. As the urethra (bladder opening) is placed close to where surgery has taken place, the catheter will allow the area to recover and heal. The catheter will need to stay in for approximately 3-7 days.

You may also have trouble opening your bowels or have some discomfort due to wind for the first few days after the operation. This will be temporary and we can give you laxatives or painkillers if you need them.

Your wound on the vulva will have been closed using dissolvable stitches. The wound in the groin will have stitches or staples that will need to be removed approximately 8-10 days after the operation.

The area around the scar may feel numb for a while after the operation, but sensation should return to most areas. The nurse will help you care for your wound and keep it clean.

How will I feel after my operation?

You should expect to be extremely sleepy for the first 24 hours after your operation. 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 required 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 patient controlled analgesia or a PCA and you will be shown how to use it. Alternatively you may have pain relief via an epidural pump. Both are usually very effective for pain relief. The choice between a PCA and an epidural will be discussed with you by the anaesthetist 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 to being away from your family and friends. If these feelings persist when you leave hospital, the advice and support of your friends or family will help but you may need additional support from your General Practitioner (GP), your Macmillan gynaecology oncology clinical nurse specialist or other support agencies. There are also a number of local and national support groups. Details are given at the end of this booklet.

When can I go home?

You will be in hospital between 3 to 14 days or occasionally a little longer, depending on the type of operation you have had. This will be

determined by how you feel physically and emotionally, the support available at home and the fact that everyone's recovery is a little different. Your return home will be discussed with you before you have your operation and again whilst you are recovering.

When can I get back to normal?

It is usual to continue to feel tired when you go home. It can take up to 3 months to fully recover from this operation, 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. Your recovery will vary from individual to individual, so you should listen to your body and rest when you need to. This way, you will not cause yourself any harm or damage.

Avoid lifting or carrying anything heavy (including children and shopping).Vacuuming and spring-cleaning should also be avoided for 6 weeks after your operation, or until you have had your check- up at the hospital.

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, but generally, you should be able to return to your normal activities within 6– 8 weeks. You can discuss this further at your follow-up clinic appointment.

When can I start driving again?

This will depend on the extent of the surgery you have had, how you are feeling and your individual recovery. You will be able to discuss this

further with the doctor at your appointment. It may be advisable to contact your car insurers following discharge to check your cover initially after surgery.

When can I return to work?

This will depend upon the type of work you do, how well you are recovering, and how you feel physically and emotionally. It also depends on whether you need any further treatment (such as radiotherapy) after your operation.

Remember the return to normal life takes time. It is a gradual process and involves a period of readjustment which will be individual to you.

What about exercise?

It is important to continue doing the exercises shown to you by the ward nurses. You may need to avoid all aerobic exercise, jogging and swimming until advised otherwise. The doctors, nurses or physiotherapist will be happy to give advice on your individual needs.

Sexual activity

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.

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. They should be encouraged to be involved in discussions about the operation and how it is likely to affect your relationship afterwards. Their 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. Your Macmillan gynaecology oncology clinical nurse specialist may be able to offer support or be able to refer you to someone who can help. Please do not hesitate to contact them if you have any queries or concerns about your sexuality, change in body image or your sexual relationship either before or after surgery.

Will I need to visit hospital again after my operation?

Yes. It is very important that you attend any further appointments arranged for you at the hospital.

If the histology (tissue analysis) results from your surgery are not available before you are discharged home, an appointment for the outpatient clinic will be made to discuss the results and any further treatment options, if necessary. You will also need to attend for regular follow-up appointments in future.

If the cancer has not been fully removed or cancer is found in your lymph nodes, you will be referred to the medical oncologists for consideration for radiotherapy treatment.

How do I make a comment about my treatment?

We aim to provide the best possible service and staff will be happy to answer any questions you may have. If you have any suggestions or comments about your visit, please speak to the ward staff.

Clinical Trials

A clinical trial may be discussed with you as a potential option for treatment. This discussion does not commit you to taking part.

You may also want to ask your doctor or nurse if there are any clinical trials available for which you might be suitable.

Contact details

Should you require further advice or information please contact the team on 01772 524211 - Monday to Friday (8 am to 5 pm).

You may also contact the following departments for advice:

Gynaecology Out Patient Department: 01772 524386

Gynaecology Ward: 01772 524231

Sources of further information

www.lancsteachinghospitals.nhs.uk
www.nhs.uk
www.patient.co.uk
www.accessable.co.uk

All our patient information leaflets are available on our website for patients to access and download:

www.lancsteachinghospitals.nhs.uk/patient-information-leaflets

Lancashire Teaching Hospitals NHS Foundation Trust is not responsible for the content of external internet sites.

Further Support:

There are many organisations that provide information, support and advice. These include:

Macmillan Cancer Support
89 Albert Embankment London SE1 7UQ Tel: 0808 808 2020 www.macmillan.org.uk

Radical Vulvectomy Support Group
Tel: 01977 640 243 (Evenings only) Vulva Awareness Charity Organisation (VACO) Tel: 0161 747 5519 Carol_Jones@hotmail.com

Cancer Help Preston (Cancer Advice, Information and Day Centre)
Vine House 22 Cromwell Road, Ribbleton Preston Tel: 01772 793344 www.cancerhelppreston.co.uk

Cancer Help Preston (Cancer Advice, Information and Day Centre)
Croston House 113 Croston Road, Garstang PR3 1HB Tel: 01995 606469 www.cancerhelppreston.co.uk

Information on support groups

GYNAE-CAN Support Group

Held every third Wednesday 7pm – 9pm
at Cancer Help Preston, Vine House, Cromwell Road, Preston

If interested in attending the support group just turn up to the next meeting or get in touch through Vine House on 01772 793344

Lancashire Teaching Hospitals is a smoke-free site. Smoking is not permitted anywhere on any of our premises, either inside or outside the buildings. Our staff will ask you about your smoking status when you come to hospital and will offer you support and advice about stopping smoking including Nicotine Replacement Therapy to help manage your symptoms of withdrawal.

If you want to stop smoking you can also contact the Quit Squad Freephone 0800 328 6297.

Please ask if you would like help in understanding this information. This information can be made available in large print and in other languages.

Gujarati:
આ માહિતીને સમજવામાં સહાયતા જોઇતી હોય તો કૃપા|કરીને પૂછો. આ માહિતી મોટા છપાણ માં અને અન્ય ભાષામાં ઉપલબ્ય કરી શકાય છે.

Romanian:
Vă rugăm să întrebați dacă aveți nevoie de ajutor pentru înțelegerea acestor informații. Aceste informații pot fi puse la dispoziție în format mare și în alte limbi."

Polish:
Poinformuj nas, jeśli potrzebna jest ci pomoc w zrozumieniu tych informacji. Informacje te można również udostępnić dużym drukiem oraz w innych językach

Punjabi:
ਜੇ ਤੁਸੀ ਇਹ ਜਾਣਕਾਰੀ ਸਮਝਣ ਵੱਚਿ ਮਦਦ ਲੈਣੀ ਚਾਹੋਗੇ ਤਾਂ ਕਰਿਪਾ ਕਰਕੇ ਇਸ ਬਾਰੇ ਪੁੱਛੋ। ਇਹ ਜਾਣਕਾਰੀ ਵੱਡੇ ਪ੍ਰਰੰਟਿ ਅਤੇ ਹੋਰਨਾਂ ਭਾਸ਼ਾਵਾਂ ਵੱਚਿ ਮੁਹੱਈਆ ਕੀਤੀ ਜਾ ਸਕਦੀ ਹੈ।

Urdu:
دو سر ی زبـانوں او ر بـڑ ی اگـر آپ کـو ہی معلومـات سـمجھنے کـے یـئے ل مدد ی ک ضـرورت ہے تـو ی ئچھیا ی ہں ی ہـے ابـی دسـت ہو ی سـکت ہے بـرا ئے مہر ی بـان پـو ے ی چھ ہی۔ معلومـات

Arabic:
مطبـو عةً بـأ حر ف كبـــير ة و بلغـــات إذا كنتَ تـر يـد مسا عدةً فـي فهـم هذه لمعلـــو مات يُر جى أن .تطلـــب أخرى يمـكن تـو فـــير هذه المعلـــو مات

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