

Women, children and clinical support

Surgery for vulval cancer

Information for patients and carers

Introduction

This leaflet provides information to help answer some of the questions you may have about surgery for vulval cancer.

What is vulval surgery?

The vulva is a woman's external genitals. Women with cancer of the vulva may need to undergo surgery to remove either some or all of the tissue in this area. How much is removed during the operation will depend on the type of cancer cells, the size, the position and whether it has spread beyond the original area. You may also need to have some lymph nodes removed from one or both groins.

Your general health and symptoms, such as discomfort or 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. 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.

What is removed during the operation?

The type of surgery is decided on an individual basis and can include:

- a 'radical local excision' – removal of the tumour (cancer) and some normal tissue around it
- a 'hemivulvectomy' – removing one side of the vulva (known as the labium minus, and labium majus or inner and outer lips) if the tumour is on a single side only
- a 'radical vulvectomy' – removing the whole vulva (inner and outer lips) on both sides, possibly the clitoris and some lymph nodes. The clitoris is a small sensitive area above the openings of the urethra and the vagina (the urethra is the tube that carries urine from the bladder to outside the body).
- removal of the perineal body – the tissue positioned towards the back passage or anus
- removal of the regional lymph nodes – glands situated on either side of the groin area
- sentinel node surgery – may be offered and this is where a dye is injected into the affected area during surgery to highlight the lymph nodes allowing the surgeon to selectively remove lymph nodes to be tested. This increases accuracy of diagnosis and reduces the long-term side effect of lymph node surgery called lymphoedema.

We aim to preserve as much of your vulva's physical appearance as possible while removing the cancer. Reconstructive surgery to restore the shape and form of your vulva using tissue grafted from other areas of the body is sometimes an option if a large area is removed due to cancer. The hospital doctor and gynaecological cancer Clinical Nurse Specialist (CNS -who may also be your keyworker) will discuss all the options available to you as well as the exact treatment recommended for your condition.

Are there any risks associated with vulval surgery?

As with any operation, there are risks. Specific to this operation, there is a risk of:

- wound reopening also known as wound breakdown
- wound infection
- lymphoedema (swelling) of the vulva and/or legs
- lymphocyst (a collection of fluid which can build up where lymph nodes have been removed)
- haematoma (a collection of blood at the operation site)
- blood clots in your legs also known as deep vein thrombosis (DVT) or pulmonary embolism (PE -blood clot in the lung)

We take many steps to keep the risks to a minimum. For example:

- we give you antibiotics to prevent infection and the procedure is carried out in sterile conditions
- we ask you to wear special support stockings and you will receive medication to reduce blood clotting
- your anaesthetist (a specialist doctor) will see you before the operation to check that you are fit for the general anaesthetic

Are there any alternatives to surgery?

Yes, but this varies from person to person. Radiotherapy can be used as an alternative to surgery in special circumstances. This will depend on the type, size and spread of the cancer. Please discuss the options available to you with your hospital doctor or your gynaecological cancer CNS.

Will I have a scar?

Yes, although it will fade with time. The size of the scar will depend on how much tissue (skin) has been removed. If only a small amount of tissue is removed, the scar may be almost invisible. If the tumour is larger, then the appearance of the vulva will be different than before, but the wound itself normally heals well. If the lymph nodes in the groin have also been removed, you can expect scars in this area as well. If you wish, the specialist hospital

doctor or gynaecological cancer CNS can draw a diagram to show you the position and extent of the scar.

Emotions

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. It may be a frightening and unsettling time.

You may find it helpful to talk about your feelings with someone who specializes in dealing with this condition and who will listen and answer your questions, such as your gynaecological cancer CNS or a counsellor. Some useful contact numbers for other support agencies are listed at the end of this leaflet.

It can also be a worrying time for your partner. He or she may like to be involved in discussions about the operation and how it is likely to affect you both.

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 gynaecological cancer CNS if you have any queries or concerns about your diagnosis, the surgery, or to discuss the support you may need, including intimate issues or concerns about your sexuality, change in body image or your sexual relationship.

What happens before my operation?

Make sure that all of your questions have been answered and that you fully understand what is going to happen to you.

The enhanced recovery programme (ERP) has been established at Imperial College Healthcare NHS Trust for patients undergoing surgery. It aims to reduce complications and the length of your hospital stay. An important part of this programme of care is your understanding of how you, and possibly your family and friends, can play an active part in your recovery.

An appointment at the pre-surgery assessment clinic will be arranged with you before your operation date. This appointment is to ensure that you are medically fit for the operation and anaesthetic. This will involve taking a full medical history and ordering any tests that you may need to prepare you for your operation, such as a blood test, chest x-ray or ECG (recording of your heart).

If you take anti-clotting medication (examples: warfarin, aspirin, clopidogrel, apixaban, rivoraxiban) and/or you are allergic to any medications, please tell your hospital doctor, gynaecological cancer CNS or pre-surgery assessment nurse when the date for surgery is discussed with you. You may be asked to start on anti-clotting injections the day before the operation, to prevent blood clots from forming following 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 troubles as smoking makes your lungs sensitive to the anaesthetic.

You should also eat a balanced diet and, remain as active as possible before the operation, as this will also help your recovery afterwards. Your GP and/or practice nurse at their surgery 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 things ready for when you come 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 housework, changing your bed sheets, vacuuming, gardening and shopping) and to look after your children if necessary.

You may wish to discuss this further with the gynaecological cancer CNS if this is a problem. A social services assessment may be suggested if you feel you need further support at home to recover from the operation.

Consent

You will be asked for your consent before your treatment begins. Your doctor and/or gynaecological cancer CNS/key worker will carefully explain the procedure. Details will vary according to each individual case. No medical treatment will be given without your written consent.

If you do not understand what you have been told, let the staff know straight away, so they can explain again. You may also find it useful to write a list of questions before your appointment and to have a relative or friend with you to help you remember the discussion when the treatment is explained.

All clinical communications copied to your GP will also be sent to you with your permission. Please discuss this with your hospital doctor or gynaecological cancer CNS if you do not wish to receive this information.

What happens on the day of the operation?

On the day of your admission, please bring all the medication that you take regularly. You will be admitted to hospital on the day of your surgery, unless your doctor recommends you should be admitted the day before due to a medical reason (such as diabetes, heart problems etc.).

Your temperature, pulse, blood pressure, breathing rate, height, weight and urine will be measured.

The anaesthetist who will be putting you to sleep for the operation and planning your pain relief after the operation will see you before surgery and make sure that you are medically fit to have a general anaesthetic. He/she may prescribe a 'pre-med' for you to take before surgery to help you relax and make you sleepy.

We will ask you to have nothing to eat for 6 hours. You may be provided with carbohydrate drinks before surgery – one to be taken the evening before surgery and another to be taken by 6am the morning of surgery. You may drink clear fluids up to 2 hours before the operation is scheduled to take place. This will be discussed further at the pre-admission assessment clinic.

We will give you special stockings to wear to prevent blood clots from forming in your legs following surgery. This will be discussed with you by your hospital doctor. This is necessary because when you are recovering from the operation, you may be less able to walk around and keep the blood circulating in your legs. The physiotherapists will also show you some useful exercises to do after surgery.

Please do let the ward nurses and hospital know of any bowel challenges [such as constipation]

We may ask you to have a shower or bath and put on a theatre gown before going to the operating theatre. All make-up, nail varnish, jewellery (except wedding rings, which can be covered with tape), body piercings, wigs, scarves, contact lenses and dentures must be removed. One of the nurses will then escort you to the operating theatre.

The operation will be carried out while you are asleep under a general anaesthetic.

What happens after the operation?

You will wake up in the recovery room before returning to the ward.

You may feel light-headed or sleepy after the operation. This is due to the anaesthetic and may continue until the next morning. You may have a bag of fluid going into your vein (drip) to provide you with fluids. This is to prevent dehydration until you are able to drink. It is important that you start to drink and eat after your operation as soon as it's recommended by your doctor. There is no restriction on the type of food you can have. You will also have protein or milk drinks every day until you are ready to go home to help you recover and your wound heal better.

You may have a sore throat for 2 or 3 days after having a general anaesthetic. This sometimes happens because the anaesthetist has to pass a tube down your windpipe to give you the anaesthetic gases that keep you asleep during the operation.

A catheter (tube) will be inside your bladder to drain urine away. As the urethra (bladder opening) is 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 about 2 to 5 days, depending on the type of incision (cut) you have had and how your wound is healing.

You may also have trouble opening your bowels for several days. This is temporary and we can give you medication to help you open your bowels (laxatives) if you need them.

We will encourage you to do leg and breathing exercises to help with circulation and prevent chest infections. The physiotherapist and ward nursing team will help and advise you on this. They will also help and encourage you to get out of bed and start moving around as soon as possible, as this will help with your recovery.

Pain

Pain management is an important part of your wellbeing and recovery. The anaesthetist may suggest for you to have a device which you use to control the pain relief going into your veins yourself. This is known as a 'PCA' (patient- controlled analgesia) pump and you will be shown how to use it. The anaesthetist may also discuss the use of an epidural as an option.

An epidural is a method of pain relief commonly used during childbirth and also for people with back pain, and is an injection in the back.

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.

Wound(s)

Your wound on the vulva will have been closed using dissolvable stitches. The wound in the groin will either have a stitch that will need to be removed about 7 to 10 days after the operation or dissolvable stitches, depending on the type of surgery you have.

There may be no dressings on your vulva after the operation. To keep the area clean, you will need to wash (rinse) area with water 2 to 3 times per day and carefully dry it each time. While you are an inpatient on the ward, the ward nurses will help and guide you on how to care for your wound and keep it clean. This is in order for you to be able to self-care when you are at home.

After surgery, you may have some bruising and swelling. This will gradually disappear with time.

Please note that the area around the scar may feel numb for a while after the operation, but sensation should return to it eventually.

If there are any wound(s) on your groin(s), these may be initially be covered and will be removed after two days.

You may have one or more drains (tubes) attached to vacuum bottle(s) [redivac] if you have wounds in your groin. This is so that any blood or fluid that collects in the area can drain away safely and it will help to prevent swelling. The tube(s) will need to stay in for about 10 days after the operation. Some patients may have the vacuum - assisted (VAC®) therapy. This VAC therapy is a machine that pump/suctions/draws fluid out of the wound and it is attached to the dressing on your wound. This therapy can be managed at home by community/district nurse.

If surgery involves skin grafting, dressings will normally stay in place on the donor site until new skin has grown.

Sometimes surgery affects the nerves and causes numbness, tingling or pins and needles in the area around the vulva. It can also cause a change in sensation in your groin or down your legs. This is because of the effects of surgery on the nerves close by.

These effects usually improve over a period of months, but sometimes it can be permanent. Depending on the type of vulval surgery, the surgery can change the appearance of area. You may not want to look at the area at all, or you may want someone with you when you look for the first time. The ward nurse or gynaecology cancer nurse can explain what has happened to the area and give you support and advice.

You may prefer to look at the area alone or with a nurse, partner, relative or close friend. Should you decide to look at the area where you had surgery, you may feel shocked, even if you were well prepared. This is understandable. Everyone copes with changes in appearance differently. Some women would not be very upset by change in appearance, where some others may find these changes harder to cope with. Please, do not force yourself to do things before you feel ready.

Constipation

It can be normal not to have bowel movements for a few days after your operation. This may be due to the combined effects of the operation, painkillers, changes to your diet and activity levels. The hospital doctors will prescribe laxatives to alleviate constipation. If opening your bowels is painful or difficult, please do let your doctors know so they can prescribe some extra laxatives to help.

When can I go home?

Length of stay in hospital is between 2 and 10 days, occasionally longer, depending on the extent of the surgery and your recovery.

Depending on your individual recovery and to make it possible for you to go home sooner, occasionally drain(s) can be managed at home. You will be taught how to deal with the drain(s) and will be encouraged to keep in regular contact with the ward nurses. If necessary, a district nurse can visit you at home to help you care for your drain(s).

You may be supplied with anti-clotting injections to take home and be shown how to inject yourself before you leave. Please discuss this with the nurse.

Please arrange for someone to come and collect you by car or accompany you in a taxi on the day of your discharge home, as you will not be able to drive yourself or travel on public transport.

If you have been prescribed medication during your stay in hospital, the nursing staff will give you a supply of this to take home with you.

Is there anything I need to watch out for at home?

Please contact the ward, your GP, gynaecological cancer specialist nurse or go to your nearest accident & emergency (A&E) department if you have:

- excessive redness or discharge around the wound site
- a high temperature or fever (38°C or above)
- heavy bleeding from the wound area
- a smelly discharge from the wound
- pain or swelling in your calves or the veins in your legs
- difficulty in breathing
- difficulty opening your bowels or passing urine

What happens when I leave the hospital?

It is normal to feel tired when you go home. However, your energy levels and what you feel able to do will usually increase with time. This is individual, so you should listen to your body's reaction.

Avoid lifting or carrying anything heavy (including children and shopping). Vacuuming and cleaning should also be avoided for 4 to 6 weeks after your operation, or until you have had your check-up at the hospital and discussed this with your doctor.

Gradually increase your level of activity. The speed of your recovery will depend on the type and extent of the surgery you have had.

If lymph nodes were removed from your groin, you may find initially that some movements are uncomfortable, such as walking or getting into a bath. This is normal and it will get easier as the wounds heal.

Some helpful tips:

- avoid wearing synthetic materials or tight clothing - cotton is better. You may find loose-fitting skirts comfortable
- avoid using any moisturiser/lotions or perfumes in the area where you had your surgery
- avoid talcum powder completely as this can increase your risk of developing internal scarring
- avoid doing a lot of walking or long walks until the skin has healed. Short walks would be more comfortable
- keeping the wound(s) clean and dry is important. Rinse the area with a hand-held shower
- if passing urine makes your wound sting, try pouring a small jug of warm or tepid water over the wound while you are still sitting on the toilet
- a hairdryer on a cool setting or using a fan can be a comfortable way of drying the vulval skin. You can try gently patting your skin dry with a clean towel
- if you can avoid wearing underwear, this may help to keep you more comfortable
- if you become constipated, ask your doctor to prescribe you some laxatives.

Before you leave hospital, the staff can arrange for a district nurse to visit you at home if you need them. They can also organise other appropriate social support services if required. If you need help with a wound or a wound drain, the district nurses can visit you at home to help with this.

Generally, within 6 to 8 weeks you should be able to return to your normal activities, but this will depend on your individual recovery and the type of work and activities you do. You can discuss this further at your follow-up clinic appointment.

It is important to continue doing the exercises shown to you by the physiotherapist. You may need to avoid high impact exercise for 6 weeks or until advised otherwise, but exercise is an important part of the recovery process. The doctors, nurses or physiotherapist will be happy to give advice on your individual needs.

When can I start driving again?

Each insurance company will have its own conditions for when you are insured to start driving again. Check your policy. However, before you drive you should be:

- free from the sedative effects of any painkillers
- able to sit in the car comfortably and work the controls
- able to wear the seatbelt comfortably
- able to make an emergency stop
- able to comfortably look over your shoulder to manoeuvres.

In general, it can take 3 to 6 weeks before you are able to do all of the above. It is a good idea to practice without the keys in the ignition. See if you can do the movements you would need for an emergency stop and a three-point turn without causing yourself any discomfort or pain. When you are ready to start driving again, build up gradually, starting with a short journey.

When can I return to work?

This will depend on the type of vulval surgery you have had. You may experience some tiredness after the operation, so your return to work should be like your return to physical activity, with a gradual increase in the hours and activities at work.

If you have an occupational health department at work they will advise on this. Depending on the type of vulva surgery some women are fit to work after two to three weeks and will not be harmed by this if there are no complications from surgery. It also depends on whether you need any further treatment (such as radiotherapy) after your operation.

Many women are able to go back to normal work after 2 to 3 weeks if they have been building up their levels of physical activity at home.

Returning to work can help your recovery by getting you back into your normal routine again. You do not have to be symptom free before you go back to work. It is normal to have some discomfort as you are adjusting to working life.

It might be possible for you to return to work by doing shorter hours or lighter duties and building up gradually over a period of time. Consider starting partway through your normal working week so you have a planned break quite soon.

You might also wish to see your GP or your occupational health department before you go back and do certain jobs – discuss this with them before your operation. You should not feel pressurised by family, friends or your employer to return to work before you feel ready.

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. It is important that the area has healed first before you try having sex again, as this will make it more comfortable for you and reduce the risk of a wound infection.

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 (such as kissing, stroking etc.), despite refraining from sexual intercourse.

However, some couples are both physically and emotionally ready to resume having sex much sooner and this can feel like a positive step.

If you have any individual worries or concerns, please do discuss them with the gynaecological cancer specialist nurse.

When can I travel?

If you are considering travelling during your recovery, it is helpful to think about:

The length of your journey: journeys over 4 hours where you are not able to move around (in a car, coach, train or plane) can increase your risk of thrombosis blood clot. This is especially so if you are travelling soon after your operation. How comfortable you will be during your journey.

Overseas travel:

- would you have access to appropriate medical advice at your destination if you were to have a problem after your operation?
- does your travel insurance policy cover any necessary medical treatment in the event of a problem after your operation?
- are your plans in line with the levels of activity recommended in this information?

If you have concerns about your travel plans, it is important to discuss these with your GP or the hospital.

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

Yes, for a check-up in the outpatient clinic about 2 to 3 weeks after your operation. We will either give you an appointment before you leave or post one to you.

You will receive an appointment to attend the gynaecological outpatient department to check your wound is healing well, give you your final results and discuss whether further treatment is recommended.

It is important that you make a list of all medicines you are taking and bring it with you to all your clinic appointments. If you have any questions at all, it may help to write them down as you think of them. It may also help to bring someone with you when you attend your outpatient appointments.

Other sources of information

Maggie's Cancer Caring Centre

Maggie's is a cancer charity that provides emotional, practical and social support that people with cancer may need. The centre combines striking buildings, calming spaces, professional experts offering professional support, and the ability to talk and share experiences with a community of people who have been through similar experiences. Maggie's West London is

located in the grounds of Charing Cross Hospital but please note it is independent of our hospital. The centre is open Monday to Friday, 09.00-17.00. For more information please call 020 7386 1750.

Macmillan Cancer Support Helpline

This is a free telephone line for people affected by cancer who have questions about cancer, need support or just someone to talk to. It is open from Monday to Friday, 09.00 – 20.00 (interpretation service available). Telephone: 0808 808 0000

Eve Appeal

The Eve Appeal is the leading UK national charity funding research and raising awareness into the five gynaecological cancers – womb, ovarian, cervical, vulval and vaginal.

Telephone: 020 7605 0100

Email: office@eveappeal.org.uk

Chaplaincy services

Hospital chaplains representing the major world faiths are appointed by the Trust. The chaplaincy service provides pastoral and spiritual support for patients, relatives, friends and staff.

Please tell your keyworker if you would like a chaplain of your faith to visit you. For details of chapel services, please contact the chaplaincy service on 020 3313 4574.

Contacting the hospital

- **Gynaecological cancer nurse specialists**

Monday to Friday, 8:30-16:30 via the Macmillan Navigator service on 020 3313 0303

- **Victor Bonney ward**

020 3313 5117 or 020 3313 4752

- **Gynaecology Outpatient clinic**

Monday to Friday, 09:00 -16:30 020 3313 5118

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or

020 3312 7777 (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:

imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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