Having an operation for vulval cancer

The aim of this leaflet is to help you prepare for surgery to help treat cancer of the vulva. It will give you general information about your surgery, as well as a list of useful contacts. If you have any questions or concerns, please speak to the doctors and nurses caring for you.

Women with cancer of the vulva will need surgery to remove some or all of the tissue in this area. How much tissue is removed will be based on the type of cancer, its size and position and whether or not the cancer cells have spread further. It is not unusual for people to feel anxious about having an operation.

The vulva
The vulva is the area of skin between a woman’s legs. It is made up of all of a woman’s sex organs that can be seen. It has two outer lips which are called the labia majora. These are usually covered in pubic hair and they surround two inner, thinner, looking lips which are called the labia minora. The clitoris is situated just above the opening of the water passage. The groin area is where the skin creases at the top of each leg. The groin contains glands called lymph nodes. These are part of the lymphatic system and can become swollen if they are affected by infection or cancer.
What types of surgery are there for vulval cancer?

Surgery is the main treatment for cancer of the vulva. It may be used alone or in combination with radiotherapy and chemotherapy.

The aim of surgery is to completely take away the cancer. Making sure that all the cancer is removed is the most important factor in trying to cure the cancer. At the same time your surgeon will try, as far as possible, to preserve the appearance and function of the vulva and nearby tissues.

Different operations can be used to treat vulval cancer. The type of operation you have will depend on the size and position of the cancer. The operation aims to remove both the cancer and a border (margin) of normal tissue all around it. The lymph nodes in one or both groins are usually also removed during the operation.

Surgery is decided on an individual basis. The type of treatment you need, and the reason why the treatment is being offered to you, will be carefully discussed with you when all your results are available.

Types of vulval surgery include:

- **A wide local excision.** This operation involves taking away the cancer and some normal tissue, (a margin, that surrounds the cancer cells)
- **A partial vulvectomy.** This operation removes part of the vulva.

- **A total radical vulvectomy.** This operation involves removing the whole of the vulva on both sides. This means that the inner and outer labia and the clitoris are removed. The surrounding lymph nodes are also removed.

**Reconstructing the vulva**

If surgery is needed to reconstruct the vulva, it is usually done at the same time as the operation to remove the cancer.

If only a small amount of skin is removed from your vulva, it may be possible to stitch the remaining skin neatly together. However, if a larger area of skin is taken away, you may need to have skin flaps or a skin graft. A skin flap is made from a piece of skin close to the vulva. The flap of skin is moved (rotated) onto the vulval area to cover the wound. A skin graft involves the surgeon taking a piece of skin from another part of the body (usually the thigh or abdomen) and attaching it over the area from where the cancer has been removed. If you need surgery that involves a skin flap or skin graft, a plastic surgeon will also be involved in the surgery.
Pain
You will have some pain and discomfort after your operation which will be controlled with painkilling drugs.

Depending on the extent of your surgery, you may need a strong painkiller, such as morphine, for the first few days after your operation. Morphine may be given through a patient controlled analgesia (PCA) pump. If you have a PCA pump it will be attached to a cannula (fine tube) which is placed in a vein in your arm. You can control the pump yourself using a handset which you press when you need more of the painkiller. You can press the handset as often as you want, as the pump will not let you have too much painkiller. You will be shown how to use this type of pump.

Some women may have a different method of pain relief called an epidural infusion. A fine tube is inserted through your back into the area just outside the membranes around your spinal cord, called the epidural space. This is carried out while you are awake and just before surgery. A local anaesthetic and other painkilling drugs are given by infusion (drip) into this space using an electronic pump. The anaesthetic drugs work by numbing the nerves in the operation area.

Changes to your vulva
There may be numbness or altered sensation around the operation site after surgery. This is due to the effects of surgery on the nerves close by. It often improves over a period of months.

Some types of vulval surgery can change the appearance of your genital area. How you approach looking at the vulval area after your operation will be very personal to you. If you’ve never looked at your vulva before, the idea of doing so may seem strange. You may not want to look at the area at all, or you may want a nurse with you when you look for the first time. A nurse can explain what has happened to the area and can offer support and advice. You may prefer to look alone or with a friend, partner or relative. Whoever you choose, make sure it’s someone that you trust and can talk to about your feelings.

Don’t force yourself to do things before you feel ready. If you decide to look at the area where your surgery was, you may feel shocked, even if you were well prepared. This is completely normal.

Your surgeon and nurse can offer you expert advice if you have been told that you require vulval surgery. They can also refer you to the Dimbleby Cancer Centre for counselling and other supportive therapies to help you make your decision about what treatment you wish to give your consent to. Contact details are at the end of this leaflet.

Lymph nodes
The lymph nodes in the groin are usually the first place where vulval cancer can spread to. Your doctor may advise you to have the lymph nodes surgically removed from one or both of your groins. The lymph nodes are removed by the surgeon making a separate cut in the groin area. If the cancer is at an early stage then usually the lymph nodes do not need to be removed.
Giving my consent (permission)
We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

What are the risks?
There are risks associated with any surgical procedure. Your surgeon will explain these risks to you before you sign the consent form.

Possible risks and complications from this surgery are:
- bleeding during or after your operation – this may need to be treated with a blood transfusion
- infections – you will be given antibiotics during and after surgery to help prevent this
- deep vein thrombosis (DVT) (blood clots) – we will ask you to wear special stockings and to have anti-DVT injections for 28 days after your operation to prevent this
- a cut in your bowel or bladder – this would be repaired during the operation
- generally making a slow recovery
- problems caused by having a general anaesthetic – for example, you may feel sick afterwards. It is also possible to have an allergic reaction, although this is rare – please tell your doctor about any allergies you have.

Risks specific to this type of surgery include:
- Lymphoedema – may occur when the lymphatic drainage system becomes blocked and surrounding tissues may swell, causing swelling in the lower body and legs; this can lead to skin problems, pain and discomfort. This can become permanent and can happen months or years after surgery. If you notice any of these symptoms please speak to your nurse specialist or doctor who can refer you to a specialist lymphoedema service.
- Lymphocysts or lymphoceles – are swellings that develop after your operation. They are often naturally re-absorbed by your body, but if they are larger or are causing you discomfort, your surgeon may drain them.
• Bladder problems – for a small number of women they will have difficulty emptying their bladder after this surgery and may need to go home with catheter in their bladder. For a very small number of women they may have long-term difficulties with emptying their bladder, this is rare.
• Wound problems – after a radical vulvectomy, the vulval wound can often take time to heal. Some women will experience problems with their wound which may take a few weeks to heal. This can be improved by eating a healthy diet and not smoking. If you need advice on stopping smoking please speak to a doctor or nurse caring for you.

These complications are usually rare but you must be aware of them. Please talk to your doctor about any concerns you have before your operation.

After my operation
What happens after my operation?
The following information is a guide as to what may happen after your operation. Everyone recovers at a different pace and if you have any concerns please talk to your doctors or nurses.

A catheter will be put inside your bladder when you are asleep to drain urine from it. The length of time that the catheter will stay inside your bladder depends on the type of surgery you have had.

If you have had some groin lymph nodes removed then you will also have some drains (tubes) in place. These help to drain away the lymph fluid. These drains can remain in place for a number of days. You may not need to stay in hospital however as the district nurses can help to look after these when you are at home.

You will not have any dressings covering your vulval wound and any stitches you have are dissolvable. It is important to keep this area clean by gently rinsing it with water, this is called vulval douching. This can be done in the shower, if you do not have a shower at home then you can use a jug. Using a hair dryer on a cool setting can be a more comfortable way of drying the skin. The nurses on the ward will show you how to do this correctly.

Sexuality
Having treatment to a part of the body that’s normally associated only with the most intimate and private areas of our lives can bring up all kinds of feelings. We can offer psychological support.

It may take some months before you really begin to enjoy sex again after treatment. Don’t be surprised if you feel very unsure about it. Remember that you need to look after yourself and allow yourself time to heal. Talk to your partner if you have one, and be as honest as you can about what you want and don’t want. It’s fine to say no to any kind of sexual contact that doesn’t feel right.

Following some types of vulval surgery, some women find that, at first, intercourse isn’t physically possible because of the way their vulva has healed after treatment. For example, there may be some tightening or scar tissue from either surgery or radiotherapy. There are a number of things that can help with this, so it’s important to mention it to your specialist nurse or medical team if you’re concerned.

The treatment may have brought about changes in how your genital area looks or feels. For some, sex may feel different. Your nurse specialist can help you with this. You may also wish to speak to a sexual counsellor or psychologist who’s experienced in this area. Our cancer support specialists and counsellors from the Dimbleby service will be able to offer support.
When can I go home?
How long you stay in hospital after your operation will depend on what type of surgery you have had and how your wound heals. Ask your doctor or nurse for more information about this.

What happens after I go home?
Care at home
It is important that you follow all the advice you are given when you leave the ward. You will be referred to a district nurse if you have had a radical vulvectomy so that they can monitor your wound. If you are concerned once at home you can either call the ward or the clinical nurse specialists. The contact numbers are available at the back of this leaflet.

What can’t I do when I am at home?
These guidelines will give you an idea as to how much you can do at home.

- Avoid tight clothing and any lotions or perfumes in the area of your operation.
- Don’t do too much walking until the skin has healed comfortably.
- Don’t have sexual intercourse.
- Don’t put anything inside your vagina.
- Wear a loose fitting skirt and no underwear.
- Don’t drive.

Your nurse and doctor will advise you as you recover.

When to contact your doctor
It is fairly unusual to have problems once you are back at home. If you have any of the following symptoms, you should contact your GP immediately. If your surgery is closed, call the Gynaecology Ward (number at the end of this leaflet).

- A temperature of 38°C or above (100.4 Fahrenheit).
- Severe pain or increasing pain.
- Nausea (feeling sick) and vomiting (being sick).
- Increased bleeding from your vagina (bright red blood or clots).
- Offensive smelling, itchy, yellow/green discharge from your vagina.
- Burning pain or discomfort when passing urine.
- Unable to pass urine.
- Constipation which lasts longer than three or four days and does not get better after taking a laxative.
- Wound pain, or swelling/redness of your wound area.
- Discharge (pus) from your wound or your wound opening.
- Pain, swelling or redness in your calf.
- A sudden feeling of shortness of breath and/or chest pain.
- Any lumps or swelling in groin or abdomen

Will I have a follow-up appointment?
Yes. You will usually be seen in clinic two to three weeks after your operation. Please telephone the secretaries if you do not receive an appointment.
Checklist

Before your operation
- Stop taking your oral contraceptive pill six weeks before your operation. You must use another method of contraception instead, such as condoms.
- Stop smoking or at least cut down. Try using nicotine patches or gum – for more information contact your nurse or the NHS Smoking Helpline.
- Write down any unanswered questions you have, for example:
  - What type of radical trachelectomy am I having?
- Make arrangements for time off work, and support for when you come home.
- Try to take regular exercise and eat a varied and balanced diet.

Coming into hospital
You should have received the leaflet, Your inpatient stay. If you have not, please contact us or the Knowledge & Information Centre. Please look at the checklist in this leaflet to make sure you have packed everything you need. Please also bring:
- baby-wipes
- lip balm
- comfortable sanitary pads or panty liners
- larger fitting pants
- nicotine patches if you smoke and are trying to stop – please give them to your nurse when you arrive
- loose fitting nightdresses; the waist-line of pyjamas can be uncomfortable over your wound
- dressing gown
- supportive shoes or slippers.

Going home:
- Do you have a clinic appointment?
  Date ...................... Time ...................... Clinic ............................................
- Have you had advice about doing pelvic floor exercises?
- Have you got a sick certificate for work?
- Do you know when you can return to work?
- Have you been given your medicines to take home? Do you know what your tablets are for and how and when to take them?
- Are there any other questions you need to ask before going home?

Useful sources of information
Eve Appeal t: 020 7605 0100  w: www.eveappeal.org.uk
Cancer Research UK t: 020 7009 8820  w: www.cancerresearchuk.org
Macmillan Cancerline t: 0808 808 2020 (freephone)  w: www.macmillan.org.uk

Contact us
If you have any questions or concerns, please contact the clinical nurse specialists, t: 020 7188 2707, Monday to Friday, 9am to 5pm. Out of hours, please contact the on call Gynaecology Dr via the hospital switchboard on 0207 188 7188 or the Gynaecology Ward below.

Gynaecology Ward t: 020 7188 2697 or t: 020 7188 2694

Your consultant gynae-oncologist is ………………………………………………… t: 020 7188 2695.
Clinical nurse specialists t: 020 7188 2707. Admissions department t: 020 7188 3676

Dimbleby Cancer Centre t: 020 7188 5918 e: richarddimblebycentre@gstt.nhs.uk
Knowledge & Information Centre t: 020 7188 3416
NHS Smoking Helpline t: 0800 160 0 160 w: www.nhs.uk/livewell/smoking

Guy’s and St Thomas’ hospitals offer a range of cancer-related information leaflets for patients and carers, available at www.guysandstthomas.nhs.uk/cancer-leaflets. For information leaflets on other conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline
If you have any questions or concerns about your medicines, please speak to the clinical nurse specialist or other member of staff caring for you or call our helpline.
t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
t: 020 7188 8801 (PALS) e: pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

Language and accessible support services
If you need an interpreter or information about your care in a different language or format, please get in touch.
t: 020 7188 8815 e: languagesupport@gstt.nhs.uk

NHS Choices
Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health. w: www.nhs.uk