Vulval Surgery

Information for patients
This booklet has been written to answer some of the questions you may have about vulval surgery.

If you have recently been diagnosed with cancer of the vulval area, you may find that you are experiencing a wide range of emotions. These can include fear, anger, denial, low mood and anxiety. Reactions differ from one person to another and there is no right or wrong way to feel. Whatever you may be feeling at present, try talking about it with someone who can help; such as your GP, consultant or gynaecology specialist nurse. They will listen to you and answer any questions that you may have. They can also put you in touch with other professionals or support organisations if you wish. Some useful contact numbers are 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 below).
The type of surgery will depend upon the size and site of your cancer, your general health and any symptoms you may have such as discomfort, pain, burning or itching. The aim of the operation is to remove all of the cancer, at the same time 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.

**Types of surgery**

**Removing the skin covering the vulva (for VIN)**
This operation is called a *skinning vulvectomy* and is used to treat vulval intraepithelial neoplasia (VIN). This is sometimes called ‘pre-cancer’. Although there are cancer cells in the skin, they are trapped there and cannot move anywhere else. Because the affected cells are only on the vulval surface, it is possible to take away only the skin and leave the healthy tissue underneath. You will usually be able to go home on either the same day or the day after your operation.

**Wide local excision**
This operation is usually recommended if the cancer is quite small. The area containing the cancer is removed, along with a border of healthy tissue around it. With this operation, you may also have lymph nodes removed from the groin, on the same side as the cancer (lymph node dissection). You will be able to go home one to three days after your operation depending on the extent of your surgery.
Removing part of the vulva

This operation is called a **partial vulvectomy**. This may involve having just the inner or outer labia removed or the labia may be removed from one side only. How the operation is done and whether the lymph nodes are removed (lymph node dissection) from one or both sides of the groin will depend on where the cancer is. If lymph nodes are removed from both sides of the groin then this is called a triple incision vulvectomy, as there is one incision to remove part of the vulva and two more - one on each side- to remove the lymph nodes. You will have either one or two wound drains placed into your groin, so that any blood or fluid that collects in the area can drain away safely. You will go home with these drains in and return to the out-patient clinic two weeks later where they will usually be removed. You should be able to go home five to fourteen days after your operation.
Hemi-vulvectomy

Lymph nodes on one side removed

Anterior vulvectomy

Lymph nodes on both sides removed

Posterior vulvectomy

Lymph nodes on both sides removed
Removing the whole vulva

This operation is called a **radical vulvectomy**. It involves having the entire vulva removed, including the inner and outer labia and the clitoris. The lymph nodes are usually removed from both sides of the groin (lymph node dissection). The operation is often known as a **triple incision vulvectomy** as there is one incision to remove the vulva and two more - one on each side - to remove your lymph nodes. You will usually have two wound drains placed into your groin, so that any blood or fluid that collects in the area can drain away safely. You will go home with these drains in and return to the out-patient clinic two weeks later where they will usually be removed. You should be able to go home five to fourteen days after your operation although some women may need to stay on the ward a little longer.

**Radical vulvectomy**
Some women may need to have surgery to reconstruct their vulva using a skin flap. A skin flap is made from a piece of skin close to the vulva that is moved (rotated) onto the vulval area to cover the wound. This would usually be done at the same time as the operation to remove the cancer.

**Sentinel node biopsy**

The lymph nodes in the groin are usually the first place that vulval cancer can spread to, so a large number of women have some or all of these nodes removed during surgery. Afterwards, the lymph nodes that have been removed are checked for cancer. Having lymph nodes removed can lead to a condition called *lymphoedema* (mentioned later as a risk of vulval surgery). To reduce your risk of lymphoedema you may be offered a sentinel node biopsy which is a way of checking lymph nodes for cancer without removing all of them.

The sentinel node is the first lymph node that fluid drains to from the vulva, so it is the first node the cancer could spread to. If the sentinel nodes are free from cancer, it’s likely that no further lymph nodes have cancer cells in them and no more need to be removed. To find the sentinel node(s), the surgeon injects a tiny amount of radioactive liquid, close to the cancer, the morning of the operation. Then, during the operation, a blue dye is injected into the same area. The nodes that stain blue and take up the radioactive liquid are the sentinel nodes.
These nodes are removed and tested for cancer cells. If the sentinel nodes don’t contain any cancer cells, then no further lymph nodes are removed. However, if there are cancer cells in one or more sentinel nodes more treatment will be required.

**Other treatments along with surgery**

Some women need to have treatment alongside their surgery. This is called adjuvant treatment. Your specialist may suggest you have radiotherapy after your surgery. This may be to the remaining vulval tissue, to lymph nodes in your groin, or both. The aim of this treatment is to try and kill off any remaining cancer cells to lower the risk of cancer coming back in the future.

Your doctor may want you to have treatment before your operation. This is called neo-adjuvant treatment. The treatment may shrink the cancer and make it easier to remove. It may mean that you can have a smaller operation. Radiotherapy is the most commonly used adjuvant treatment but your doctor may suggest chemotherapy at the same time. Some chemotherapy drugs are known to help radiotherapy work.
What are the risks of vulval surgery?

- **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.

- **Bleeding** during or after the operation.

- **Bruising** around the wound site.

- **Infection** - this would be treated with antibiotics.

- **Wound breakdown** - this may be due to tightness in the surgical area where the tissue has been removed and the skin has been rejoined. If the wound is going to breakdown it normally happens within the first ten days after your operation. 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 need a district nurse to visit you to continue caring for your wound until it has healed.

- **A blood clot in the leg** (*deep vein thrombosis*) which can sometimes lead to a blood clot in the lungs (*pulmonary embolus*) - moving around as soon as possible after your operation can help to prevent this. You will be given surgical stockings (known as TEDS) to wear and injections to thin the blood which both help to reduce the risk of blood clots. You may continue to have these injections for up to four weeks.
• **Lymphoedema** fluid circulates around your body draining through the lymph nodes. If your lymph nodes are removed from the groin area, either to stop the cancer spreading or because it already has, there is a greater risk of the lymphatic fluid not being able to drain away. The fluid may gather in one or both legs and/or the genital area which will make them swell. This may happen months or years after your operation and is called lymphoedema. Lymphoedema can be managed and treated but there are things you can do to reduce the risk of it happening in the first place. There is a small section about lymphoedema on page 15. There is also a separate booklet specifically about lymphoedema that can give you more information. You can also discuss this further with your

• **Lymphocyst**; this is a fluid collection at the site where lymph nodes have been removed. The fluid is often naturally reabsorbed by your body but may require draining if large or causing you discomfort.
• If groin lymph nodes are removed you may also feel numbness in your outer thigh area after surgery. This usually improves over time but may leave you with some permanent numbness at the tops of your legs.

• **Scarring** - scar tissue may narrow the entrance to your vagina and make it painful to have penetrative sex. You may be able to stretch your vaginal opening using dilators. You would be shown how to use these by your doctor or nurse.

• **Difficulty reaching climax** - some women who have had a vulvectomy have a reduction in sexual desire or pleasure and may also have problems reaching orgasm. This is most likely if you’ve had to have your clitoris removed.

• **Numbness, tingling and pins and needles** - these are caused by nerve damage during surgery. They will slowly get better in time, but may not disappear completely.

**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 than before. If the lymph nodes in your groin have been removed, you can expect scars in this area but they are usually hardly visible when healed.
Is there anything I should do to prepare for the operation?

Make sure that all of your questions have been answered and that you fully understand what is going to happen. You are welcome to visit the ward and meet the staff before you are admitted to hospital - ask your specialist nurse or pre-assessment nurse to arrange this.

You should eat a balanced diet and if you feel well enough, take some gentle exercise before your operation, as this will 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 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 changing your bedding, vacuuming and gardening) and to look after your children, or other dependants if necessary. Arrange for somebody to take you home from hospital when you are discharged. If you think you may have problems coping at home, you can discuss this with the nurses on the ward.

If you would like to be assessed for home/personal care for when you are recovering at home, the social work department or the ward nursing staff can arrange this whilst you are in hospital.
Vulval hygiene

Before your operation
It is important that the vulval area is scrupulously clean before you have your operation so we ask that you have a bath or shower on the morning of your surgery.

Advice after a wide local excision or skinning vulvectomy
It is very important to keep your wound clean. Have a shower every day. If you have a hand held shower head use it on a cool and low setting and let the water run over the vulval area. Gently pat dry with a soft clean towel or use a hairdryer on a cool setting.

We will provide you with a tube of antiseptic cream to apply to your wound twice a day. The cream has anti-bacterial properties which can reduce your risk of infection whilst also supporting your wound to heal. Apply a pea size amount of cream to your wound twice a day until you have finished the tube.

Advice after vulvectomy or radical vulvectomy
It is very important to keep your wound clean. We will provide you with a bottle of a brown antiseptic liquid. Have a bath every day putting 1-2 capfuls of the antiseptic in the water as you run your bath. After bathing pat your wound dry with a soft clean towel or use a hairdryer on a cool setting.

We will also provide you with a tube of antiseptic cream to apply to your wound twice a day (see section above).
General advice after surgery

If you have had lymph nodes removed from one or both groins, you will have a tube called a drain coming out of each groin wound. This is to drain fluid that collects in the area and to help prevent swelling and infection. These drains can stay in for up to two weeks and you can go home with them still in. They are removed either in the out-patient clinic or back on the ward. Initially the drainage tubes will be long and attached to a suction drain. Before you go home the tubes are cut down to just above your skin and a small bag is put over them which sticks to your skin. You will be shown how to measure the amount of fluid draining and empty the bags yourself. District nurses are usually arranged to support you with the drains at home.

Take your painkillers regularly throughout the day to keep on top of any soreness or pain. You may find it sore to sit down for a few weeks. Try putting your feet up on your sofa or on a foot stool to take the pressure off your wound. You could try sitting on two cushions leaving a gap between them and positioning your wound over the gap.

Take laxatives to make sure you don’t get constipated.

If passing urine makes your wound sting, try pouring a small jug of warm water over your wound whilst you are sitting on the toilet.

Avoid wearing tight clothing and do not use any lotions, perfumes and talcum powders in the area where you have had your operation.
If you can avoid wearing underwear then this may keep you more comfortable. However, if you have bleeding from your wound you may need to wear underwear to keep a sanitary pad in place. Please note that it is normal to experience a small amount of bleeding/loss until your wound has fully healed. This may take a number of weeks - sometimes months.

Avoid washing underwear in biological washing powders - use non-biological instead.

If you develop heavy bleeding, an offensive discharge or increasing pain then you should contact your GP as you may have an infection.

If you experience tenderness, swelling, redness, warmth or pain in your lower leg then you should see your GP or visit the Accident and Emergency (A + E) department as soon as possible as you may have a blood clot in your leg (deep vein thrombosis).

If you suddenly develop shortness of breath, chest pain or are coughing up blood then ring 999 as you could have a blood clot in your lung (pulmonary embolism) which is a medical emergency.

**Is it normal to feel weepy or depressed after my operation?**

Yes. It is a very common reaction to the operation. Most women feel shocked and upset by the idea of having surgery to the vulva. If these feelings persist when you leave the hospital, you may wish to discuss them with your GP or specialist nurse. There are also local and national support groups that you can contact. Details are given at the end of this booklet.
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 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. Please discuss any concerns you have with your nurse specialist or consultant.

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

Yes. It is very important that you attend any further appointments arranged either at St James’s Hospital, Bexley Wing, Leeds or at the hospital that referred you for your treatment.

The tissue results (histology) from your operation can take 2-3 weeks. An appointment for the outpatient clinic will be made to discuss these results with you and if any further treatment is necessary.
If the cancer has not been fully removed or if cancer is found in your lymph nodes, you may be referred to a clinical oncologist for consideration of further treatment.

Additional information

Lymphoedema
This is a condition that can occur if you have lymph nodes removed during your surgery and is referred to earlier in this booklet as a risk of vulval surgery. By taking certain precautions you can try to prevent it occurring. There is a separate booklet, specifically about lymphoedema, that you can read but here are a few points:

*It is very important to keep your skin in good condition, as any injury or break in skin can cause infection which increases the risk of lymphoedema.*

- Keep your skin well moisturised to keep it in good condition.
- Avoid extremes of heat and cold e.g. saunas, very hot baths/showers, ice packs.
- Avoid getting sunburnt. Wear high factor sunscreen and keep in the shade where possible.
- Use insect repellents to prevent insect bites.
- Avoid having injections to your legs.
- Take care to prevent scratches and cuts - if they do occur, wash them thoroughly and apply an antiseptic cream. If you notice any signs of redness or soreness of the skin, inform your GP.
• Use an electric razor or depilatory cream to remove unwanted hair on the legs. Do not use a razor blade.
• Take care when cutting your toenails - use nail clippers.

Physiotherapy Exercises

Pelvic Floor Muscles support the pelvic organs and pelvis itself. Strong muscles can maintain or improve bladder and bowel control, help to prevent prolapses and help to protect the back.

Pelvic Floor Exercises
Do in any position and start as soon as you feel comfortable. If you have a catheter, wait until it has been removed.

• Imagine trying to stop yourself from passing wind and at the same time trying to stop the flow of urine.
• You should feel a squeeze and lift - a drawing up feeling inside.
• Hold this squeeze and lift for a few seconds and then relax, repeat a few times.
• Don’t worry if you can’t feel it at first. As you improve, hold as long as you can (up to 10 seconds) and increase the repetitions (up to 10 times).

• **Do not** exercise by stopping your urine flow midstream - it could damage your bladder and lead to infections.

**Quick Pelvic Floor Contractions**
Squeeze strongly and relax immediately, allow a few seconds to relax, then repeat as many times as you can up to 10.

**How often should I do the exercises?**
Do both exercises 4-6 times daily for the first month, then 2-3 times daily for the rest of your life. Link to a regular activity or put a sticker somewhere as a reminder.

**Using your muscles**
• For extra support, tighten up the pelvic floor before you do anything exerting like coughing or lifting.

• Very gently tighten the pelvic floor muscles for more control if you have difficulty holding on to reach the toilet in time.

• Listen to your body, don’t exercise if it hurts or you are too tired.

• Never do sit-ups or double leg lifts as both put too much pressure on your back and pelvic floor muscle.
Contacts
We hope that this booklet answers most of your questions but, if you have any further queries or concerns, please do not hesitate to contact your local gynaecology specialist nurse or Ward J98.

Ward J98, Gynaecological Cancer Ward
St James’s Hospital, Leeds.
Tel: 0113 206 8298, 206 8198 or 206 9198.

Local Information and Support Centres

Bradford

**Cancer Information Centre**
Main Entrance, Bradford Royal Infirmary
Tel: 01274 364307 Fax: 01274 366960
Email: cancer.informationcentre@bradfordhospitals.nhs.uk
Opening hours: 10am - 4pm Monday to Friday

**Bradford & Airedale Cancer Support Centre**
Daisy House Farm, 44 Smith Lane, Bradford BD9 6DA
Tel: 01274 776688
Website: www.bradfordcancersupport.org.uk
Opening hours: 9am - 5pm Monday to Friday
Calderdale & Huddersfield

*The Jayne Garforth Information & Support Centre*
Macmillan Unit, Calderdale Royal Hospital  
**Tel:** 01422 222709  
**Opening hours:** 10am to 4pm Monday to Friday  
(except on Tuesdays, when the centre closes at 1pm)

*Daylight Self Help/Support Group (for women from Huddersfield and Halifax)*
Meets on the 2nd Thursday of every month 10.30am-12.30pm  
Briar Court Hotel, Halifax Road, Birchencliffe,  
Near Huddersfield, HD3 3NT  
**Tel:** 01422 222720 for more information  
Support group for women with a gynaecological cancer.

Dewsbury, Pontefract & Wakefield

*WAGS (Women’s Association of Gynaecological Support)*
Meets on the last Wednesday of every month 6pm - 8pm  
The Cock and Crown pub, Doncaster Road, Crofton, WF4 1PP  
**Tel:** 01977 747421 for more information  
Support group for women with a gynaecological cancer

Harrogate

*Harrogate & District NHS Foundation Trust*
Harrogate Hospital Cancer Nurse Specialists, can signpost to other appropriate organisations as required.  
**Tel:** 01423 555719 (team secretary)
The Golden Girls Support Group
Meets on the 2nd Thursday of every month 7.30pm
Harrogate Fire Station, Skipton Road, Harrogate, HG1 4LE
Tel: 01423 555732 for more information
Support group for women with a gynaecological cancer

Leeds Cancer Support
Leeds Cancer Support complements care provided by your clinical team offering access to information and a wide range of support for you, your family and friends. We can be found in the information lounges in Bexley Wing and also in the purpose built Sir Robert Ogden Macmillan Centre.

The Sir Robert Ogden Macmillan Centre
The centre is on the St James’s Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. You can just drop in for a coffee and a chat anytime. Open from 10am - 4pm Monday to Friday.

Information Centre Level 1 Outpatients Department
Open from 10am - 4pm. Tel: (0113) 206 8816

Information Lounge Level -2 Radiotherapy Department
Open from 8.30am - 4.30pm Tel: (0113) 206 7603

Robert Ogden Macmillan Centre
Open from 10am - 4pm. Tel: (0113 206 6498)
All the above services can be emailed on: leedsth-tr.Cancersupport@nhs.net
York Cancer Care Centre

Junction 5 Entrance, York Teaching Hospital, NHS Foundation Trust

Tel: 01904 72 1166

Opening hours: 9am - 4.30pm Monday to Friday

Gynaecology Cancer Support Group

Meets on the 2nd Tuesday of each month (except in August) 9.30am - 11.30am

York Cancer Care Centre, Junction 5 Entrance, York Teaching Hospital NHS Foundation Trust

Tel: 01904 726478 for more information

Support group for women with a gynaecological cancer.

National Information and Support

Macmillan Cancer Support

89 Albert Embankment, London, SE1 7UQ

Tel: 0808 808 0000 (free)

This line also offers an interpretation service. When you call, just state in English, the language you wish to use.

Text phone service: (for hard of hearing) 10800 0808 808 0121

Opening hours: 9am - 8pm Monday to Friday

Website: www.macmillan.org.uk
The Eve Appeal

General Enquiries Tel: 0207 605 0100
Website: www.eveappeal.org.uk
Information about all gynaecological cancers.

Vulval Awareness Campaign Organisation

Website: www.vaco.co.uk
Email: vaco@yahoo.com
Support for ladies with vulval cancer.