

Treating Vulval Cancer - A Quick Guide



Contents

This is a brief summary of the information on 'Treating vulval cancer' from CancerHelp UK. You will find more detailed information on the website.

In this information there are sections on

- Stages of vulval cancer
- Statistics and outlook
- Types of treatment for vulval cancer
- Surgery
- Radiotherapy
- Chemotherapy
- Follow up for vulval cancer
- Vulval cancer research

Stages of vulval cancer

The stage of cancer tells doctors how large it is and how far it has spread. It is important because treatment is often decided according to the stage of a cancer.

Vulval cancer can be staged using the TNM and number system. TNM looks at the tumour size, whether cancer is in the lymph nodes, and whether it has spread to other organs (metastasised). There are 5 main stages. Stage 0 (VIN3) is the earliest and stage 4 the most advanced. In the UK, vulval cancers are often staged using the FIGO (International Federation of Gynaecological

Oncology) system, which has stages from 1 to 4.

Recurrent disease means that the cancer has come back after treatment. It may come back in the vulva or in another part of the body.

Stages 0 to 4

Stage 0 is a very early stage, when abnormal cells are present only in the uppermost layer of skin of the vulva. It is sometimes called carcinoma in situ (CIS). This stage is not an invasive cancer.

In stages 1 and 2 the cancer is in the vulva or vulva and perineum only. In stages 3 and 4 the cancer has spread further away.

Grade

Cancer cells are graded according to how they look under a microscope. The more normal they look, the lower the grade. The lower the grade, the more slowly the cancer is likely to grow, and the less likely it is to spread or come back after treatment. Doctors usually look at stage and grade together to decide on the best treatment. Vulval cancer is usually graded from 1 (low grade) to 3 (high grade).



Statistics and outlook for vulval cancer

Outlook means your chances of getting better. Your doctor may call this your prognosis. With vulval cancer, the likely outcome depends on how advanced the cancer is when it is diagnosed (the stage). The grade of the cancer and your general health can also affect your prognosis.

On our website, we have quite detailed information about the likely outcome of different stages of vulval cancer. The statistics we use are taken from a variety of sources, including the opinions and experience of the experts who check every section of the website. They are intended as a general guide only. For the more complete picture in your case, you'd have to speak to your own specialist.

How reliable are cancer statistics?

No statistics can tell you what will happen to you. Your cancer is unique. The same type of cancer can grow at different rates in different people. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

Types of treatment for vulval cancer

The main treatments used for vulval cancer are surgery, radiotherapy and sometimes chemotherapy. Your specialist may suggest a combination of treatments. The treatment you need depends on the stage of the cancer when it is diagnosed.

VIN

With VIN, you are most likely to have surgery to remove the affected skin. Or

the surgeon may use a laser to kill off the abnormal skin cells.

Stage 1 and 2

For stages 1 and 2 you are most likely to have surgery. For most tumours stage 1b or more, you will need to have a radical vulvectomy. This means removing the whole of the vulva. If you are unable to have surgery, you are likely to have an intensive course of radiotherapy. Your specialist may want you to have chemotherapy at the same time.

Stage 3 and 4

You may need to have quite a big operation. This could mean removing the vagina, urethra or rectum as well as the vulva and the lymph nodes in the groin. If your urethra and bladder have to be removed, you would need to have a bag to collect your urine. If your rectum is removed, you will need to have a colostomy. Doctors will try to do the smallest operation possible while trying to keep the risk of the cancer coming back as low as possible too. You may have radiotherapy before surgery or you may have a smaller operation with radiotherapy afterwards.

If you have stage 3 or 4 vulval cancer, but are unable to have surgery, you may have radiotherapy with or without chemotherapy.

Which surgery for vulval cancer?

Different types of surgery can be used to treat vulval cancer. Which operation you have will depend on the stage of your cancer. Your surgeon will try to leave as much normal skin as possible, while making sure the cancer is completely taken away.



Many women are cured of vulval cancer with surgery.

Types of vulval cancer surgery

With VIN the affected cells are only on the surface. So it is possible for the surgeon to take away only the skin and leave the healthy tissue underneath. For vulval cancer, the surgeon will probably have to remove part or all of your vulva. They may also remove the lymph nodes on one or both sides of your groin. There is more information about the different operations on our website. There are also links to diagrams that show you what is removed in each type of surgery.

If the cancer has spread, you may have to have your womb, vagina, bladder, rectum or the lower part of your bowel removed. These operations are rare. But for some women it is worth doing, because it may cure even an advanced cancer.

Getting information and support

A few people prefer not to know about their operation in advance. But for most women, it may help you to cope better if you understand exactly what is going to happen. If your surgeon doesn't tell you, ask what he or she is intending to do. Most hospitals will have a specialist nurse who can give you information and support. Do ask for an appointment with her if you are not offered one.

Diagrams showing different types of surgery

For most women, knowing in advance what is going to happen can help you cope better with vulval cancer surgery.

On our website you can find diagrams that give you an idea of which areas are

removed with each type of VIN and vulval cancer surgery. If you are not sure which surgery you are going to have, ask your doctor or specialist nurse.

Having your operation for vulval cancer

When you go into hospital for your operation, the anaesthetist and either the surgeon or one of their team will see you. The doctor will ask you to sign a consent form for the operation. The doctors should give you a detailed explanation of what to expect. Do ask as many questions as you need to.

Before your operation, your nurse may shave your pubic hair. This reduces the risk of wound infection. Your nurse or physiotherapist will teach you breathing and leg exercises to do after your operation, to help prevent blood clots or chest infections.

After your operation

When you wake up you will have a drip in place, and perhaps a tube to drain your wound or a tube (catheter) to drain urine from your bladder. You may or may not have a dressing covering your wound.

Your wound is bound to be sore at first. There are many different types of painkilling drugs you can have. It is important to tell your doctor or nurse as soon as you feel any pain. They need your help to find the right type and dose of painkiller for you.

Getting over your surgery

You should get over a small operation quite quickly. After a bigger operation, you should allow at least 6 weeks. Do bear in mind, though, that it takes longer than that for some women to recover. You will find moving around difficult at first. Try not to



walk too much for the first few weeks, as this will put a strain on the healing wound.

Side effects of surgery for vulval cancer

You are very unlikely to get all the side effects we've covered here. Generally speaking, the smaller the operation, the fewer the side effects. Possible side effects after surgery for vulval cancer include

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. Your doctor or nurse will explain how to use them

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

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. We have more information about sexuality after vulval cancer on our website

Swelling - if lymph nodes in your groin are removed, you may develop swelling in the genital area or legs. This is called lymphoedema. It can be painful and tiring. If you do notice any redness, pain or swelling, it is important to tell your doctor straight away. Lymphoedema is easiest to control if it is caught early.

What to ask your doctor about surgery for vulval cancer

- Why do I need an operation?
- Will an operation cure my cancer?
- Which type of operation should I have and why?
- What will you remove?
- How long will the operation take?
- How long will I be in hospital?
- What are the risks and benefits of having this operation?
- Will I have pain after this operation?
- What other side effects will I have?
- Will any of the side effects be permanent?
- What are the possible complications of this surgery?
- How long will it take me to get better?
- How can I help myself get over the operation?
- Do you have any printed information I can take away with me?
- Who can I contact for support when I am at home?
- Who should I call if I feel unwell after leaving hospital?
- Do I need to come back to see the doctor again? How often?

About radiotherapy for vulval cancer

Radiotherapy uses high energy waves to treat cancer. For vulval cancer, your specialist may suggest radiotherapy

- Before surgery to shrink your cancer
- To try to stop the cancer from coming back after surgery
- To treat a cancer that wasn't completely removed with surgery
- To treat your cancer if you can't have surgery



- To control symptoms of advanced cancer

Having your treatment

You have radiotherapy treatment in the hospital radiotherapy department. You are most likely to have treatment once a day, Monday to Friday, with a rest at the weekends. Each treatment only takes a few minutes and does not hurt. It will not make you radioactive. At your first visit your doctor will plan your treatment using a machine called a simulator.

Most people have this treatment as an outpatient. You will have to travel to the hospital every day. It is a good idea to bring someone with you. You may not feel like driving yourself, or getting yourself home on public transport alone. If travel costs are a worry ask your nurse specialist to put you in touch with a social worker. They might be able to arrange financial help.

Side effects of vulval cancer radiotherapy

Most side effects go away within a few weeks of your treatment course finishing. But there are some side effects that can come on after your treatment has finished or continue to be a problem long after your treatment is completed.

Skin reactions in the treatment area are common. Your skin may look and feel sunburned. Sometimes the skin can break down. It will heal when treatment is over. Your nurses will advise you on how to care for your skin during treatment.

Bladder and bowel problems - diarrhoea is common. Your doctor can give you anti-diarrhoea medicine to help control it. You may get symptoms of cystitis (sore bladder).

Fertility and menopause - if you are still having periods, you may have a premature menopause. Menopause can cause symptoms such as feeling emotional, hot flushes, sweats, dry vagina and thinning bones. You may want to take hormone replacement therapy (HRT) to control your menopause symptoms.

Your sex life - your vagina may shrink and lose its ability to stretch. You may also have vaginal dryness. Both of these are likely to be long term problems after radiotherapy to this part of the body. There are different moisturisers and creams available to help with dryness. Using dilators may help stretch the vagina.

What to ask your doctor about radiotherapy for vulval cancer

- Why do I need radiotherapy?
- Will I need any other treatment as well?
- Is there any choice of treatment?
- Would concurrent chemoradiation help me?
- How long will my treatment course be?
- What are the likely short term side effects?
- Who can I contact if I have any problems during and after my radiotherapy treatment?
- Am I likely to have any long term side effects and if so, what will they be?
- Can you give me any written information on radiotherapy?
- Is it possible to get any financial help with travelling costs to the hospital, or is hospital transport available to me?
- Should I bring someone with me when I come for treatment?



Chemotherapy for vulval cancer

Chemotherapy uses anti-cancer drugs to destroy cancer cells. Your specialist may suggest chemotherapy to try to control vulval cancer that has spread. Or, you may have chemotherapy alongside radiotherapy.

Having chemotherapy

Chemotherapy is most often given into the bloodstream through a drip or by injection. But some drugs are available as tablets or creams you put on your skin.

Chemotherapy is generally given in cycles of treatment, with breaks in between. It is difficult to generalise because there are different timetables for different chemotherapy drugs. But you are most likely to have treatment for one to 5 days, with a break of 2 or 3 weeks between each treatment.

Side effects

Chemotherapy side effects vary. Each drug has a different set of side effects and each person will react differently. You are very unlikely to get all the side effects listed for any particular drug.

The commonest side effects with chemotherapy are tiredness, feeling or being sick, a drop in blood cells that causes increased risk of infection, diarrhoea, sore mouth, and hair thinning or hair loss. Chemotherapy can cause an early menopause. You may not be able to become pregnant after this type of treatment.

Follow up for vulval cancer

After your treatment has finished, your doctor will want you to have regular check ups. These will usually include a general check up on your health, and a vaginal

examination by your doctor. You may have scans or blood tests at some visits.

At first your follow up appointments will be every few months. But if all is well, they will gradually become less and less frequent, until they are every 6 months or every year. Vulval cancer can sometimes come back after a long time, so it is likely you will be followed up for life. If you have any problems between visits, you can contact your doctor straight away - you don't have to wait for your next appointment.

Many people find their check ups can bring back all the worry about their cancer. You may find it helpful to tell someone close to you how you are feeling. It is quite common nowadays for people to have counselling after cancer treatment.

Vulval cancer research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know that they are safe.

First of all, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe to test are they tested in people, in clinical trials.

Researchers are looking into treatment using light (photodynamic therapy), mapping lymph nodes, HPV tests and vaccines, anti-viral creams for pre-cancerous cells and support for women with vulval cancer.



Notes

More information

For more information about vulval cancer, visit our website
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in March 2012. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2012. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666)