

Care After Cancer of the Vulva

Introduction

You have now completed treatment for cancer of the vulva and this leaflet has been written to support you moving forward; with guidance on recovery, getting back to “normal”, your follow up and to help you decide if, or when, you should contact your Gynaecology Oncology Clinical Nurse Specialist (CNS). Your CNS and cancer support worker will be happy to provide further information & advice on all the aspects mentioned in this leaflet.

Recovering from Cancer Treatment

After treatment, you'll probably be keen to get back to a sense of ordinary life. But you may still be coping with the side effects of treatment and with some difficult emotions. Recovery takes time, so try not to be hard on yourself. you may find you have 'up' and 'down' days for a while afterwards.

Recovering from surgery for cancer of the vulva

The aim of surgery for your vulval cancer is to remove all the cancer. There are different operations to treat vulval cancer and which one you have is dependent on what stage of vulval cancer you have been diagnosed with.

How quickly you recover from surgery will depend on the type of surgery you have had and there is very good evidence that by encouraging patients to return to normal as quickly as possible following surgery, reduces problems and complications. This is called an enhanced recovery and you will have received information about this during your hospital admission. Your recovery will depend on many things which makes it difficult to give an exact timeline. We encourage you to try to do a little more each day and use self-awareness to determine what is right for you. Usually, this type of surgery can take several months for you to feel fully recovered. Information regarding your recovery will have been provided to you prior to your discharge from hospital. However, if you do have any questions, you can contact your CNS and cancer support worker.

Depending on your diagnosis, further treatment may be required, this being adjuvant (additional) treatment such as radiotherapy, chemotherapy. This decision is made on an individual basis dependent on results. Not everyone needs adjuvant (additional) treatment after surgery. If required, we would aim to start adjuvant treatment approximately six

weeks after your surgery. This allows time for wound healing and for you to recover after your surgery.

Caring for your vulva

Your vulval skin will be more sensitive after your surgery and it can take a few weeks to completely heal. It is important to keep this area clean and dry. We encourage gentle rinsing using a jug of lukewarm water, slowly pour the contents over the wound area. You may need to repeat this a few times. Alternatively, you may use a shower head gently while standing in the bath or the shower, or even while sitting on the toilet.

Keeping the wound area clean and dry after using the toilet is important in order to prevent infection. If you are not at home, you can use a water-filled squeeze bottle and some clean gauze in your handbag for when you need to use public toilets.

Dry the area carefully using a hairdryer on a cool setting. If you prefer not to use a hairdryer, you may dab gently with clean, soft gauze (this can be bought from a chemist.) or clean soft towel. Avoid rubbing the area as this may cause discomfort and irritation. The area should be dry before you get dressed.

When you are at home, try to expose the area to air as much as possible. This can be done by not wearing underwear for short periods of time or overnight. We recommend wearing loose-fitting cotton clothing, avoiding close fitting clothing like tights, cycling shorts, leggings and tight jeans.

We suggest avoiding traditional soaps, talc, wipes, creams and perfumed products which may cause irritation and alternatively use a soap substitute such as dermol or hydramol.

Getting back to “normal”

Reaching the end of treatment can be a difficult time, whilst for others, it is a sign that things can start to get back to “normal”. Many women can return to “normal”, or find and be comfortable with a new normal, but for others this may be more difficult. There is no right or wrong way to feel. Your CNS will be happy to provide more information on all the areas mentioned below.

Emotional impact

Coping with a vulval cancer diagnosis and treatment can be hard. You may have many different emotions, from numbness, shock, or fear, to anger, guilt, or sadness. It may leave you feeling out of control of your life and future. It is often more difficult to deal with the unknown, so having the right amount of information and support may help you feel more in control. Your CNS is happy for you to talk through any concerns or questions when you have them. Remember, if you need more help, don't be afraid to ask for it. Your healthcare team want to support you with any concerns or questions, no matter how big or small. After treatment, you may feel relieved that it's over but also nervous about the future. It is common to feel anxious that the cancer may come back. Knowing the risks and what options are available if this happens can help you to cope with any fears.

Physical impact

Fatigue: Though fatigue is a common symptom, there are steps you can take to reduce or cope with this. Top tips include – take it easy, conserve your energy, maintain your energy & get moving.

Scaring: Depending on the type of surgery you have; you may have some scars. These should fade over time. Some scars may cause localised numbness which should improve after a few months. If you have any problems with scaring speak to your surgical team and CNS.

Lymphoedema: Lymphoedema is more likely to develop after surgery that has involved the removal of lymph nodes from the groin and in women who have radiotherapy following vulval cancer surgery which included the removal of lymph nodes in your groin. Lymphoedema is when your leg, legs, pelvic area or both swell with fluid that struggles to drain on its own. The job of your lymph nodes is to drain lymphatic fluid (waste fluid from cells) so it can be removed by your body. When lymph nodes are removed this can affect the natural circulation and drainage of tissue fluid from the legs. It is common that fluid can accumulate in the groin and genital area following surgery and should improve over time, yet for some women this may be more uncomfortable or painful. If you think you are developing swelling it is very important to let your specialist know and your doctor may want to examine you. There are ways to reduce the risk of lymphoedema and to manage it through exercise, massage and light compression hosiery and you may be referred to a lymphoedema specialist if lymphoedema becomes a persistent problem. If you are concerned about lymphoedema, speak to your CNS who can offer you more advice.

Changes to your bowel or bladder: After surgery, some people experience changes in how their bowels, bladder or both. This usually settles after a few weeks. If part of the vulva near to your urethra was removed, this may cause the stream of your urine to flow to one side or spray when you pass urine. This may feel odd the first few times you pass urine. If you experience bowel or bladder changes, it is important to speak to your CNS who can help you get the right support.

Changes to your vulva: Immediately after surgery, your genital area will be swollen and bruised. This will heal but there will be changes in how your genital area looks. The inner and outer labia of your vagina may have been removed which will make the area look very different and this may come as a shock when you first see this. Sometimes surgery affects the nerves and can cause numbness, tingling or pins and needles around the vulva. You may also experience sensation changes in your groin and down your legs. This usually improves over the months after surgery. Sometimes it is permanent. It can be very hard to accept sudden changes in your body and it is not unusual to feel angry and upset. You may feel more body conscious and worry you somehow look different. It is important to remember that those around you will want to support you as much as they can, and it is encouraged you talk about these feeling. Your CNS will be happy to discuss your worries with you and you may find speaking to other women who have had similar experiences useful.

Changes to your sex life: Following your surgery, it is strongly advised that you abstain from penetrative intercourse for 6 weeks. It is important that your vulval area has time to fully heal. Your sex life may also change following your treatment for cancer of the vulva because of physical and emotional factors and, it is not uncommon to lose interest in sex and intimacy following your treatment for cancer. You may feel differently about yourself or your sexuality and have other physical changes such as scars that affect your body image which may impact on your relationships. Treatment may have caused physical issues such as tightening and scaring of the vulval skin and reduced elasticity to the skin. You may have reduced sensation to the vulval and clitoral area or may have had your clitoris removed. Your surgery may have included the opening to the vagina making penetrative

sex more uncomfortable and you may also have vaginal dryness which can cause sex to be uncomfortable or even painful. We encourage you to share your feelings if your feelings towards sex and intimacy have altered and take time to introduce intimacy if you wish to do so. You may need time to adjust to the changes to your vulval area and explore what feels good now. You can discuss this privately with your CNS for advice. If you feel you have ongoing problems with sex and intimacy that are not getting better with time, you may wish to consider speaking to a psychosexual counsellor

Other concerns

Support: Some people prefer not to talk things through, while others get support from speaking about their experience. Details of support groups can be provided by your CNS.

Exercise: Try to gradually increase your daily activity, with the aim of trying to build up to four or more thirty-minute sessions each week of activities that increase your heart rate. If you require further information to access any local programmes, please speak to your CNS team.

Diet: Evidence shows that maintaining a healthy weight, avoiding excessive weight gain, and maintaining levels of physical activity is associated with an improved quality of life and enhanced recovery. Top tips: keep to your meal routines, choose reduced fat, walk off the weight, pack a healthy snack, look at labels, caution with your portions, think about your drinks & focus on your food.

Work: You can return to work whenever you feel ready to do so. All jobs are different so it's hard to be specific. Whenever you return, remember it may be a shock to the system to begin with and it can be very useful to return in a phased manner, increasing your work hours over a few weeks.

Financial concern: You will be eligible for free prescription, if you are not in receipt of this please speak to your CNS. You may also be entitled to certain grants and benefits; this can be individually assessed, or you can call the Macmillan helpline on 0808 808 00 00. If any other financial issues are causing you worry, speak to your CNS who can advise who can help.

Travelling abroad: Once you have completed your treatment, there is no reason not to travel abroad. Sometimes patients can have trouble in acquiring travel insurance, your local Macmillan Support and Information Centre and the Macmillan website will be able to offer advice.

Follow up after treatment

Clinical follow up. Once you have completed your treatment, you will begin a five-year surveillance period. The aim of this is to ensure everything is going well post treatment and to explore any of your concerns. You will have traditional follow up appointments. During your appointments you will be asked questions about your recovery and any side effects or symptoms you have been experiencing. You may also be offered a pelvic examination and internal examination. If you did not have groin node or sentinel node dissection as part of your original surgery, you may be offered ultrasound scans of your groins every 3-6 months to assess your lymph nodes for any changes. If you are experiencing problems or are worried about anything between your appointments, you are encouraged to contact

your CNS team who can assess you and if needed, can bring you back in for a clinic appointment sooner.

When to contact your CNS

It is important to remember you will still get coughs, colds, aches and pains and bowel upsets just like anyone else. Your GP will normally be happy to treat such problems. However, if they are concerned about your symptoms when they see you, they can contact your CNS who can arrange a clinic appointment.

For most patients their treatment is effective, and their cancer will not come back but sometimes people do have problems. We would like you to contact your CNS if you have any of the following symptoms and they persist for more than two weeks:

- Pain, itching or soreness on the vulva or around the back passage (anus).
- Bleeding from the vulva or vagina (front passage).
- Bleeding from the back passage (rectum).
- Discharge.
- New swelling of the legs.
- New swelling in the groin

It is important to remember that even if you have some or all these symptoms it does not necessarily mean the cancer has come back, but we will arrange to see you in clinic to check you over. Do remember, however, that some of these symptoms can also be caused by other conditions that are completely unrelated to vulval cancer.

You can contact your CNS team Monday – Friday 8am – 4pm using the details provided at the end of this leaflet. If you phone and they do not answer, please leave a message and contact number on the answerphone, and you will be contacted as soon as the CNS picks up your message.

Worries about cancer returning

It is entirely natural to feel anxious that your cancer may return, and we recognise that this can make you feel very uncertain about the future and lead to difficulties in “getting on with life”. Should there be any cause for concern, you will be reviewed by the clinical team and appointments, or appropriate investigations will be organised for you.

Ways to manage worry and uncertainty about cancer

- Learn to focus on the ways cancer has made you a stronger person.
- Talk to family and friends about your concerns
- Join a support group
- Write a diary about your fears and feelings.
- Get involved with an interesting hobby or other things you enjoy doing.
- Review your priorities towards interesting and meaningful activities.
- Remember that as time goes by, your worries can fade.
- If depression, anxiety or any part of the cancer journey becomes overwhelming seek advice from your CNS or GP

How to contact the Gynaecology Oncology Clinical Nurse Specialist team:

Monday to Friday 8am-4pm telephone 0151 702 4186.

If you get the answerphone please leave your name, date of birth, telephone number and a brief message. Your call will be answered within 24 hours, or on the next working day if it is a weekend or bank holiday.

Support Networks Available Locally

Further information, advice and support are available for yourself/partner and family from:

Lyndale Cancer Support Centre - Knowsley
Tel: 0151 489 3538

Sefton Cancer Support Group
Tel: 01704 879352
www.seftoncancersupport.org.uk

St Helens Cancer Support Group
Tel: 01744 21831

Warrington & District Cancer Self-Help Group
Tel: 01925 453139

Widnes & Runcorn Cancer Support Group
Tel: 0151 423 5730

Isle of Man
Manx Cancer Help Association
Tel: 01624 679554
www.manxcancerhelp.org

Liverpool Sunflowers
Liverpool Cancer Support
Tel: 0151 726 8934

The Wirral Holistic Care Services
Tel: 0151 652 9313
www.wirralholistic.org.uk

Maggie's Centre Clatterbridge
Tel: 0151 334 4301
www.maggies.org

Eve appeal
Tel: 020 7605 0100
www.eveappeal.org.uk

Macmillan
Tel: 0808 808 0000

This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at pals@lwh.nhs.uk

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