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# Living with Vulval Cancer - A Quick Guide

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## Contents

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

In this information there are sections on

- Coping with vulval cancer
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- Caring for your vulva
- What to ask your doctor
- Vulval cancer organisations

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## Coping with vulval cancer

It can be very difficult coping with a diagnosis of cancer, both practically and emotionally. You are likely to be feeling very upset and confused at first. As well as coping with the fear and anxiety that a diagnosis of cancer brings, you have to work out how to manage practically. There may be money matters to sort out. Who do you tell that you have cancer? There may be children to consider.

The coping with cancer section of our website contains lots of information you may find helpful. There are sections on coping with your feelings, on telling people about your cancer, sex and sexuality,

helping yourself, who else can help, and getting help with financial matters.

As well as possibly qualifying for some state benefits, such as sick pay, you may be able to get a grant for any major expense associated with your illness. If you have lymphoedema, for example, and need to buy new clothes to accommodate a swollen leg, you may be able to get help from Macmillan Cancer Support. They offer grants for one-off expenses for people with cancer.

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## Life after vulval cancer surgery

It is not unusual to feel very angry and upset for some time after surgery to your genital area. These are very private parts of your body and you may find it very difficult to talk to others about how you are feeling. Many women need time to come to terms with the changes surgery may bring. In time, your initial feelings of fear, shock, or anger will almost certainly improve, particularly if you have support from family or friends. If these negative feelings don't go, you may be becoming depressed. Talk to your doctor or specialist nurse if you are worried about this.



### Getting help and support

Not everyone feels comfortable asking for outside help and support, but many people find it very useful. There are organisations and support groups that help people who have been through vulval surgery.

### Sex and sexuality

Vulval surgery will affect your physical ability to have sex. And your emotions may change your sexual feelings for a while. One recovered patient said to us that it was certainly possible to have a very satisfying sex life after radical vulvectomy, but not until you've accepted the new you.

### Swelling in your groin or legs

The swelling from your operation should go down within a few weeks. If you have had surgery or radiotherapy on your lymph nodes, there is a risk of developing swelling later. This is called lymphoedema. If you think you are developing swelling, it is very important to tell your specialist right away.

### Caring for your vulva

The skin of the vulva is very sensitive. After vulval surgery, the area will be even more sensitive. Try and avoid contact with soap, perfumes, moisturisers, personal wipes, shampoo (from washing your hair in the shower), feminine hygiene sprays or deodorants, or biological washing powder.

### How to clean the vulva

To keep the area clean, use either aqueous cream or emulsifying ointment. Both are available cheaply in large tubs from any chemist's shop. You apply a small amount of the cream with warm water to your vulva. Then rinse off with clean water. You can use tissue, a clean hand or soft gauze swabs to put the cream on and wipe off.

If you've had treatment for VIN in the skin near the anus, you can use either of these creams on a bit of toilet paper to clean after you've been to the loo. It cleans well and stops the toilet paper being scratchy.

Towels can be scratchy too. You can dab very gently to dry, using the softest towel or other material you can find. Some women prefer to use a hairdryer set on 'cool'.

### Underwear and clothes

It is best to wear only loose fitting cotton underwear. If the seam on your knicker gusset rubs, wear them inside out. Some women prefer not to wear any pants at all. Stockings are healthier than tights because they allow air to circulate. Or you can buy tights without a gusset, or cut it out yourself. You'll probably be more comfortable in skirts rather than trousers.

### What to ask your doctor about living with vulval cancer

- What should I do if I am worried between appointments?
- Will I ever get back to normal, or will I have some long-term effects?
- Will I be able to resume my sex life after treatment and if so, when?
- What difficulties should I expect?
- Where can I get help with claiming benefits and grants?
- What can I get grants for?
- What practical help is available?
- Why did this happen to me?
- Where can I get help dealing with my feelings?
- Can you refer me for counselling?
- Do I have to pay for counselling?
- Could you refer me to a Macmillan nurse?



- Can you put me in touch with any support groups?

## Vulval Cancer Organisations

Cancer Research UK

Main website: [www.cancerresearchuk.org](http://www.cancerresearchuk.org)

Patient information website:

<http://cancerhelp.cancerresearchuk.org>

Cancer Information Nurses phone: 020 7061 8355

The RV Club

Jane Bramley

Tel: 01977 640243

Jane is an ex-patient who has had a radical vulvectomy. She is happy to talk to women who are going to have (or have had) a vulvectomy, as well as to their friends and families.

Vulval Awareness Campaign Organisation

Website: [www.vaco.co.uk](http://www.vaco.co.uk)

Support network:

<http://health.groups.yahoo.com/group/vaco-vulvacare>

Phone: 0161 747 5911

Email: [vacouk@yahoo.com](mailto:vacouk@yahoo.com)

Vulval Pain Society

PO Box 7804

Nottingham

NG3 5ZQ

Website: [www.vulvalpainsociety.org](http://www.vulvalpainsociety.org)

Lymphoedema Support Network

Tel: 020 7351 0990 (10am-4pm)

Email:

[adminlsn@lymphoedema.freeserve.co.uk](mailto:adminlsn@lymphoedema.freeserve.co.uk)

Website: <http://www.lymphoedema.org/lsn>

## 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 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.

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