

This leaflet has been written to help you understand about cancer of the vulva, its diagnosis, treatment and support available. You may wish to discuss some aspects with your doctor or support nurse.

What is Cancer?

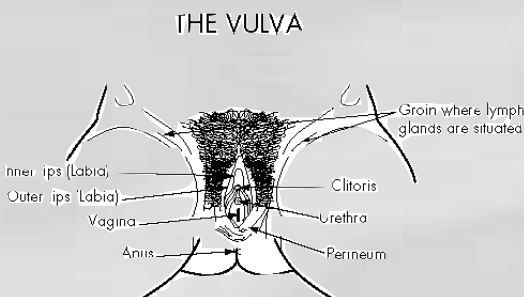
The organs of the body are made up of cells. Cancer is a disease of these cells. The cells normally divide in an orderly manner. Sometimes the cells divide out of control - developing into a lump/tumour. A tumour which is malignant consists of cancer cells which have the ability to spread beyond the original site, destroying surrounding tissue. Sometimes they can break away and spread to other parts of the body.

The Vulva

The vulva is the area of skin between a woman's legs and it is made up of all the visible sex organs. The vulva consists of two outer lips (labia majora) and two inner lips (labia minora). The clitoris (a very small structure which can be an area of sexual climax) lies at the top of the vulva. Below this is the urethra (a tube through which urine passes) and just next to this is the vagina (birth canal). The anus (back passage) is separate from the vulva but is in the same area.

Lymph glands are situated in the groin area at the top of each leg. Lymph glands are part of the lymphatic

system which act as the body's natural defence against infection and disease.



How does Cancer of the Vulva develop?

We may not know the exact cause of your cancer, but some wart virus infections (Human Papilloma Virus) have been linked to vulva cancer. This is an uncommon cancer, approx 950 cases per year in the UK (ONS 2005). It usually affects women between the ages of 55 and 75 but it can occur in younger women and the more elderly.

What are the signs and symptoms?

The most common symptoms include soreness or an itchy area on the vulva. Some women have a burning sensation, bleeding or may find a lump on the vulva. A change in colour or the appearance of an ulcer on any part of the vulva should also be investigated by a doctor. All these symptoms can be a sign of many conditions other than cancer of the vulva.

Diagnosing Cancer of the vulva

A full medical history will be undertaken and a number of other tests may be carried out before a definite diagnosis can be made. This may include:

- Examination of the vulva, vagina and rectum.
- Biopsy will be needed - a minor operation done under local or general anaesthetic. The doctor will take a small sample of tissue from the vulva (for further examination under a microscope).

If the biopsy shows you do have cancer, the doctor may wish you to have:

- Further biopsies from the vulva and perineum (known as mapping).
- Blood tests
- Chest X-Ray
- ECG Electrocardiograph (tracing of your heart)
- An MRI scan, see Clatterbridge Centre for Oncology (CCO) may be needed to determine if the cancer has spread to other areas.

Stages of Cancer

Staging is a process of investigations which may be used to determine type/size of the tumour and if there is any spread. Staging is important to help decide treatment options. If the cancer is diagnosed at early stage, the treatment may be more successful.

Stages of cancer of the Vulva

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| Stage 1 | Cancer is found only in the vulva and is less than 2cm in size. |
| Stage 2 | Cancer is found only in the vulva but it is greater than 2cm in size. |
| Stage 3 | Cancer cells have spread outside the vulva and/or the lymph nodes in the groin. |
| Stage 4 | Cancer cells have spread beyond the vulva to the bladder (sac that holds urine) or the bowel or other distant parts of the body. |
| Recurrent Disease. | Means the cancer has come back (recurred) after it has been treated. |

Treatment Options

There are three main treatment options for cancer of the vulva:

- Surgery
- Radiotherapy
- Chemotherapy

The type of treatment best for you will be decided by your consultant in discussion with yourself.

Clinical Trials

Clinical trials are research studies involving patients which compare a different type of medical care with the best treatment currently available. You may be approached regarding a

clinical trial which your consultant or specialist nurse will be able to discuss with you. Cancer Backup produce a booklet which may be helpful to you.

Surgery

Surgery is the main treatment. It may be used alone or with radiotherapy. Your doctor will discuss with you the type of surgery required to remove the cancer. This can vary from:

- Removing the cancer tumour and a small amount of surrounding tissue.
- Removing the cancer tumour and a larger area of surrounding tissue.
- Removing the above and the lymph glands in the groin. (At the same time or separately)
- Removing the whole of the vulva and the lymph glands. (At the same time or separately)
- In some situations the doctor may wish to assess the lymph nodes. This is carried out by ultrasound scan (USS) and fine needle aspiration (FNA) every 3 months

Your doctor will discuss with you whether remaining skin can be stitched back together or if a skin graft will be needed. For further information about surgery and your hospital stay, see the hospital information leaflets.

Radiotherapy

Radiotherapy is the use of high energy X Rays (like having an X-Ray) to destroy

cancer cells. Radiation comes from a machine outside the body (External Beam Radiotherapy). This may be offered pre-operatively or postoperatively. The type of radiotherapy and length of time will be planned and decided individually between the doctor and yourself. (see CCO radiotherapy booklet, for more information).

Chemotherapy

Depending on the type and stage of your cancer/tumour, your doctor may suggest chemotherapy treatment. (see CCO booklet & specific information sheets).

Life and Relationships

- Most people feel overwhelmed when they are told they have cancer.
- Many different emotions arise which can cause confusion.
- Reactions differ from one person to another.
- There is no right or wrong way to feel.
- You may experience the whole range of personal emotions and reactions both similar or different from family and friends.
- Support and guidance is available in coping with these feelings.
- Many people find great comfort in their faith and or religious and spiritual beliefs.

Following the diagnosis of cancer and your subsequent treatment, you may experience physical changes. There may be some issues/concerns you wish to raise /explore, i.e..

- Body Image
- Sexual Health
- Menopause Symptoms
- Others

Your support nurse will be able to support you by explaining about the issue /concern and provide advice and information if required. This may help you adjust/cope with these changes. This may include involvement of other members of the Health Care Team (HCT) i.e.

- Dietician
- Macmillan Social Worker
- Lymphoedema Practitioner
- Physiotherapist
- Occupational Therapist and your Primary Health Care Team (PHCT), General Practitioner (GP), District Nurse (DN), Community Macmillan Nurse (CM)

You may not be aware of who can help with changes in social and financial matters, but your support nurse can put you in touch with the relevant people who can provide guidance and advice in these and other aspects, including childcare, how to tell the children and practical day to day issues i.e. Macmillan Social Worker

You may wish to explore information and coping methods to help yourself. Therefore the following booklets may be helpful, (there are many others).

- Adjusting to life after cancer - Cancer Backup
- Close relationships & cancer - Cancerlink
- Life with cancer - Cancerlink
- Sexuality & Cancer - Cancer Backup
- Body image and sexuality - Cancerlink
- Lymphoedema - hospital information leaflet

Complementary Therapies

Complementary therapies may be helpful to you and your family. There are many different types i.e.

- Reflexology
- Massage
- Relaxation

and many others. Your support nurse can advise you by providing information regarding the appropriateness for you and how to access them.

Your Follow up Care

This will be tailored to your specific needs. The doctors will see you on a regular basis in the outpatient department (OPD). If you develop any further symptoms the doctor will see you promptly and may start further investigations.

Your Gynae Support Nurse/Clinical Nurse Specialist will also be able to offer you and your family advice, information and support, regarding your cancer, subsequent treatment and associated health issues. of the Cancer Guide, which can guide, support and inform you through your cancer experience.

Support Networks

Available Locally

Further information, advice and support is available for you/partner family from: Knowsley
Lyndale Cancer Support Centre
Tel: 0151 489 3538

Sefton Cancer Support Group
Tel: 01704 876613
www.seftoncancersupport.org.uk

St Helens Cancer Support Group
Tel: 01965 632233/01744 884097

Warrington & District Cancer Self-Help Group
Tel: 01925 489540/01928 635925
07734 052576
www.cancerbackup.org.uk

Wirral Cancer Support Group
Tel: 0151 645 7824/0151 648 5604
www.cancerbackup.org.uk

The Wirral Holistic Therapeutic Cancer Centre
Tel: 0151 652 9213
www.wirralholistic.org.uk

Widnes & Runcorn Cancer Support Group
Tel: 0151 423 5730
www.widnesruncornsg.org.uk

Isle of Man
Manx Cancer Help Association
Tel: 01624 579554

Liverpool
Liverpool Cancer Support
Tel: 0151 726 8934

E.V.O.C.
Gynaecological Support Group
0151 702 4186

National Resource Organisations for Gynae Oncology Patients

Cancer Backup
3 Bath Place, Rivington Street, London EC2A 3JR
Tel: 0207 7392280
Freephone: 0808 800 1234 (Mon-Fri 9am-8pm)
www.cancerbackup.org.uk

National UK support organisation for all cancers, staffed by specialists providing information and counselling. They have recently compiled a fact sheet on Primary Peritoneal Cancer which can be requested by telephone and will be included in their website and in the Fact File next year. They also have a fact sheet on ascites.

The Daisy Chain Network

For additional information send an SAE to: The Daisy Chain Network, PO Box 183, Rossendale, Lancashire, BB4 6WZ
Email: membership&media@daisynetwork.org.uk
www.daisynetwork.org.uk

The Daisy network is a premature menopause support group which offers advice, information and support for women throughout the UK.

Menopause Matters

www.menopause.co.uk

For accurate up to date information about the menopause and its treatment options "An easy to use, independent, clinician-led website".

Gynae C

1 Bollingbroke Road, Swindon SN2 2LB
Tel: 01793 491116
Email: Gynae_C@yahoo.com
www.communicate.co.uk/wilts.gynaec

A support group/helpline run by Helen Jackson for women (and their family or friends) who have any gynaecological cancer.

Jo's Trust

Weedon Villa, Everdon, Northants NN11 3BQ
Tel: 01327 341965 - Pamela's direct line but she is happy to speak to patients.
Email: Pamela@jotrust.co.uk
www.jotrust.co.uk

Established in June 1999 Jo's Trust is a registered charity dedicated to women and their families and friends affected by pre-cancer and cancer of the cervix. The trust's principal activity is the provision of good information,

confidential medical advice and support about every aspect of this illness through its website.

Ovacome

Elizabeth Garret Anderson Hospital, Huntley Street, London WC1E 6DH
Tel: 0207 3809589
www.ovacome.org.uk

A national Support Group for all those concerned with ovarian cancer. Has recently adopted a new corporate logo.

VACO

Vulva Awareness Campaign Organisation
Tel: 0161 747 5911
Email: vacouk@yahoo.com or carolvaco2003@yahoo.com
www.vaco.co.uk

Help, support and friendly advice co-ordinated by a patient - Carol Jones.

Website information may be obtained from your hospital (www.lwh.nhs.uk), local and national support networks above.

Ask your support nurse for a free copy of The Cancer Guide which can guide, support and inform you through your cancer experience.

Equal Opportunities

The hospital is committed to promoting an environment which provides equal opportunities for all patients, visitors and staff. If you have special requirements such as dietary needs, interpreter

References

CancerBackup 2006
Understanding Cancer of the Vulva.
www.cancerbackup.org.uk

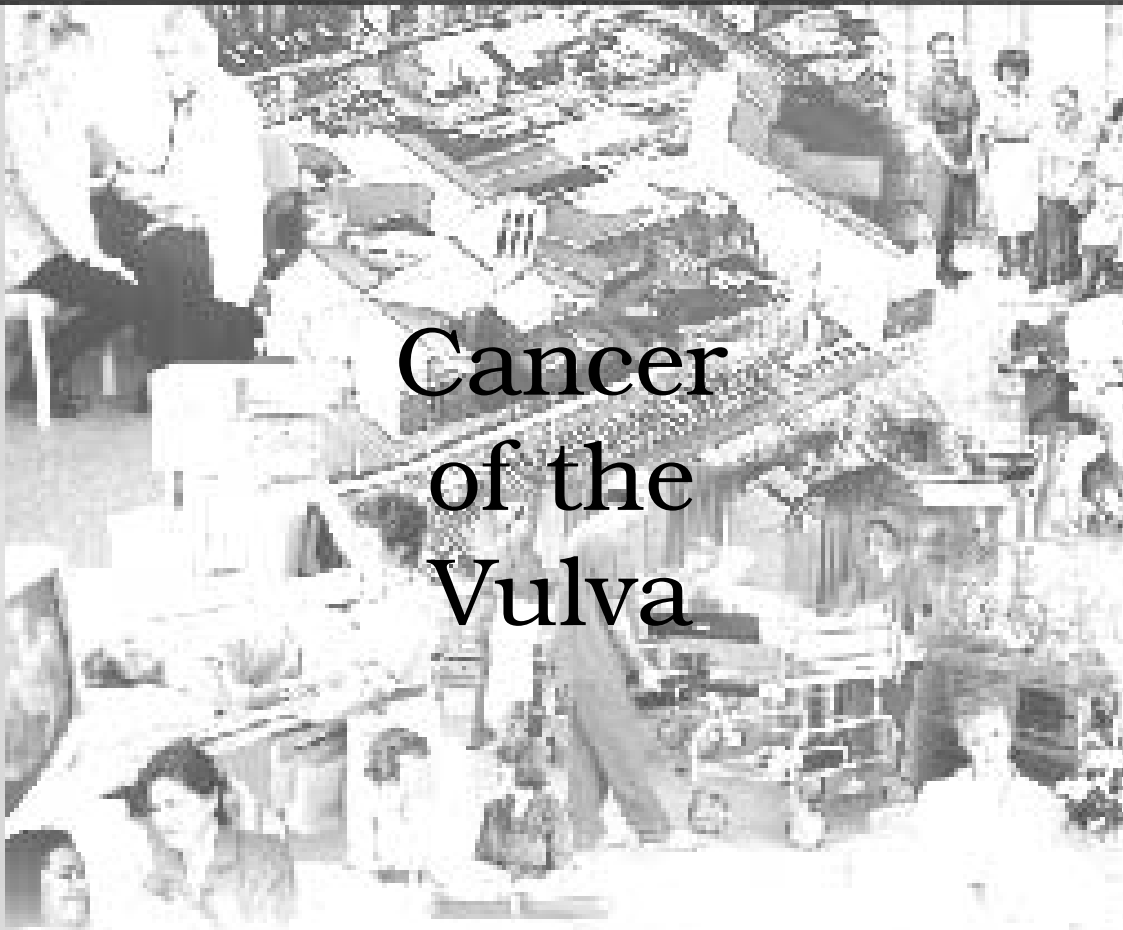
Office for National Statistics (2005)
Cancer Statistics Registration 2001.
www.statistics.gov.uk

services, disability needs or a preference for a female doctor, please do not hesitate to discuss this with a member of staff who will try to help you.

RCN Gynaecological Cancer 2005

BBC / Macmillan Cancer Relief
The Cancer Guide (2005).

CancerBackup (2002).
Understanding Clinical trials.



Cancer of the Vulva

Liverpool Women's NHS
NHS Foundation Trust

Liverpool Women's Hospital
Crown Street, Liverpool L8 7SS

Telephone: 0151 708 9988
Visit our Web site at www.lwh.nhs.uk

Liverpool Women's NHS
NHS Foundation Trust