

Understanding Cancer of the Vagina



An information sheet for women with cancer, their families and friends.

This information sheet has been prepared to help you understand more about cancer of the vagina. Women may feel understandably shocked and upset when told they have vaginal cancer, which is a very rare cancer.

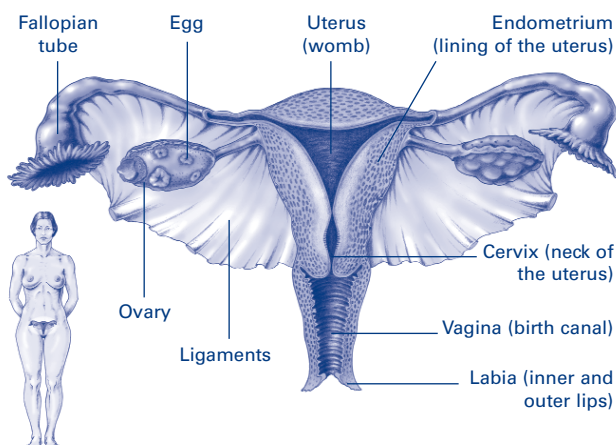
This information sheet is an introduction to the diagnosis, treatment and effects of vaginal cancer. For more detailed information, see the list of resources on page 8.

We cannot advise about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about the questions you want to ask your doctors.

The vagina

The vagina is a muscular tube that extends from the opening of the womb (cervix) to the external part of a woman's sex organs (vulva). It is the passageway through which menstrual blood flows, sexual intercourse occurs, and a baby is born.

The female reproductive system



How common is it?

Cancer of the vagina is very rare, with only around 25 cases diagnosed in NSW each year.

What are the causes?

As with many cancers, the exact cause of most vaginal cancers is unknown, but research is going on all the time to try to find the cause.

DES: A hormone drug called diethylstilboestrol (DES) has been identified as a cause of a particular type of cancer of the vagina. Between 1940 and 1970, DES was prescribed to pregnant women to try to prevent miscarriages. The female children of women who took DES during pregnancy have a slightly increased risk of developing a type of cancer of the vagina called clear cell adenocarcinoma. (Only one in 1000 DES daughters develop vaginal cancer. The incidence peaked in the 1970s and is now decreasing.)

Although DES and some other female hormones (oestrogens) can be safely used to treat some other medical conditions, DES is no longer used during pregnancy.

For more information, contact the Cancer Helpline on 13 11 20 for a factsheet on DES.

HPV: The human papilloma virus (HPV), which is the name for a group of wart viruses, is a risk factor for vaginal cancer. It is a common infection affecting the skin surface of any part of the body, including the vagina and the cervix.

Vaginal cancer is also more likely to occur in women who have had cervical cancer or pre-cervical cancer in the past.

Women who have had radiotherapy to the pelvic area also have a slightly higher risk, but this complication of radiotherapy is very rare, and women who have had this treatment still only have a tiny risk of developing vaginal cancer.

What are the symptoms?

The most common symptoms of vaginal cancer are:

- blood-stained vaginal discharge
- bleeding after sexual intercourse
- pain.

Problems with passing urine, such as blood in the urine, the need to pass urine frequently and the need to pass urine at night, can also occur. Pain in the back passage may sometimes occur.

Types of vaginal cancer

There are two main types of vaginal cancer: those that start in the vagina (primary vaginal cancer) and those that spread into the vagina from another part of the body (secondary vaginal cancer).

The two main types of primary vaginal cancers are named after the cells from which they develop.

- **Squamous cell:** The most common type of vaginal cancer is called squamous cell carcinoma. This is usually found in the upper part of the vagina and most commonly affects women who are 50-70 years old.
- **Adenocarcinoma:** This type of vaginal cancer usually affects women under 20 years of age but occasionally occurs in other age groups.

Other types of vaginal cancer that are very rare include melanoma, small cell carcinoma, sarcoma and lymphoma.

Secondary vaginal cancer

Secondary cancers in the vagina (those that have spread from other parts of the body) are more common than primary vaginal cancer. They usually come from the cervix, the lining of the womb (the endometrium), the vulva or from nearby organs such as the bladder or bowel.

Diagnosis

Usually you begin by seeing your GP, who will do a vaginal examination. If there is a chance you have vaginal cancer, you should be referred to a gynaecological oncologist, who diagnoses and treats women with cancer of the reproductive organs.

Your doctor may also arrange for you to have a blood test and chest x-ray to check your general health. The following tests are commonly used to diagnose vaginal cancer.

Internal vaginal examination

At the hospital, the gynaecological oncologist will do a full pelvic examination. This will include examining the inside of your vagina to check for any lumps or swellings. The doctor will also feel your groin and pelvic area to check for any swollen glands and may also check your back passage.

Cervical smear

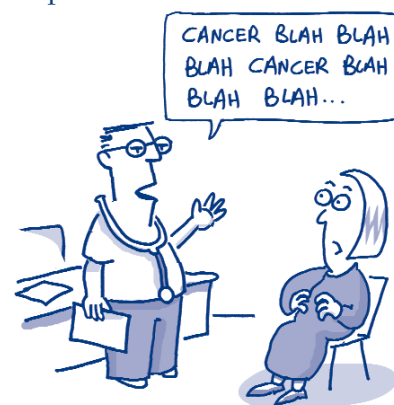
You will have a Pap smear to check for early cell changes in the vagina or cervix.

Colposcopy

If the cells taken in the smear test are abnormal, your doctor may ask you to have a colposcopy. This is a closer examination of the vagina using a colposcope, which is a small low-powered microscope that allows the doctor or specialist nurse to see the vagina in more detail.

Biopsy

A small sample of tissue will be taken from any abnormal areas, and examined under a microscope.



Early cell changes

The tests may show early cell changes in the vagina known as vaginal intraepithelial neoplasia or VAIN. This is sometimes referred to as carcinoma in-situ. VAIN is not cancer so the treatment for this condition is not the same as for cancer.

Further tests

If the above tests show that you have a vaginal cancer, further tests may be necessary to find out whether any cancer cells have spread.

Cancer can spread in the body, either in the bloodstream or through the lymphatic system. The lymphatic system is part of the body's defence against infection and disease. The system is made up of a network of lymph glands (also known as lymph nodes) that are linked by fine ducts containing lymph fluid.

The results of these tests will help the specialist to decide on the best type of treatment for you.

Cystoscopy

Cystoscopy is a test that allows the doctor to look at the interior lining of the bladder and the urethra. The cystoscope is a thin, lighted-viewing instrument that is inserted into the urethra and advanced into the bladder.

Chest x-ray and blood tests

These are necessary to assess your general health and to check whether there is a possibility of the cancer having spread to the lungs.

CT scan

A CT (computerised tomography) scan is a series of x-rays that builds up a three-dimensional picture of the inside of the body. The scan is painless and takes between 10 and 30 minutes. Before the scan you will be asked to drink a special liquid that shows up on x-ray. You may also need to have an injection of a contrast medium into a vein in your arm.

MRI

MRI (magnetic resonance imaging) is similar to a CT scan, but uses a magnetic field instead of x-rays to build up cross-sectional pictures of your body. Some people are given an injection of dye into a vein in the arm to improve the image.

During the test you will be asked to lie very still on a couch inside a long chamber for up to an hour. An MRI is painless but some people find that lying in the cylinder is noisy and claustrophobic. If you feel uncomfortable, let your doctor or nurse know.

Stages of vaginal cancer

The stage of a cancer is a term used to describe its size and whether it has spread beyond its original site. Knowing the particular type and the stage of the cancer helps doctors to decide on the most appropriate treatment.

Stage 1: The cancer is only in the vagina and has not begun to spread.

Stage 2: The cancer has begun to spread through the wall of the vagina, but has not spread further into the walls of the pelvis.

Stage 3: The cancer has spread to the pelvis and may also be in the lymph nodes close to the vagina.

Stage 4: The cancer has spread to the bladder or the bowel, or to other parts of the body such as the lungs.

If the cancer comes back after initial treatment, this is known as recurrent cancer.

Grading

Grading refers to the appearance of the cancer cells under the microscope and gives an idea of how quickly the cancer may develop.

Low grade means the cancer cells look like the normal cells. They are usually slow growing and are less likely to spread.

High grade means the cells look very abnormal. They are likely to grow more quickly and to spread.

Prognosis

Prognosis means the expected outcome of a disease. Many factors affect prognosis, including the extent of the cancer – whether it is just in the vagina or has spread – and your general health. It is important to talk to your doctor about prognosis. Only someone who knows your medical history can tell you what to expect and the treatment options that are best for you.

Treatment

The treatment for vaginal cancer depends on a number of factors including your age, general health and the stage, grade and type of cancer. Radiotherapy, surgery and chemotherapy may be used, and you may have one, or a combination, of these treatments.

Before starting treatment, you should be given a chance to ask your gynaecological oncologist about the treatments being considered. It is important to ask the doctor to explain things more than once if there is anything you don't understand, however insignificant it may seem.

Radiotherapy

Radiotherapy is a commonly used treatment for many women with cancer of the vagina. In some younger women, radiotherapy may be combined with chemotherapy.

Radiotherapy treats cancer by using x-rays, which destroy the cancer cells, while doing as little harm as possible to normal cells. It is given in the radiotherapy department at the hospital.

The dose needed will depend on the exact type of cancer and whether it has spread into surrounding tissue, so you may find that you are having a different radiotherapy treatment from other women you meet at the hospital.

Radiotherapy can be given in two ways:

- From outside the body (external). A machine directs radiation at the cancer and surrounding tissue.
- From inside the body (internal). Radioactive material is put in thin tubes into your body on or near the cancer.

Most women have both external and internal radiotherapy.

External radiotherapy

This involves beams of radiation being directed at the cancer from outside the body. It is like having an x-ray. You will be asked to visit the radiotherapy department for treatment every weekday for 4-6 weeks. Each treatment takes several minutes and is painless.

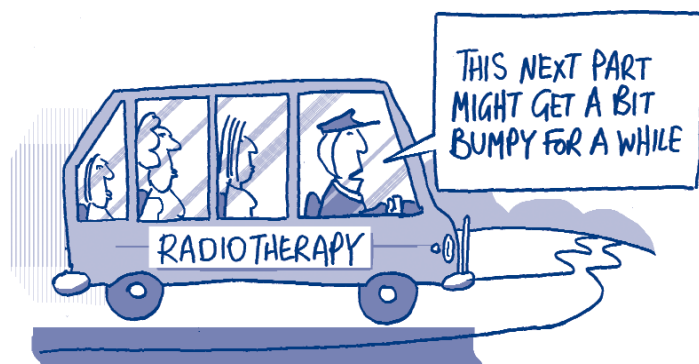
Internal radiotherapy

This involves an applicator (similar to a tampon) containing a radioactive substance being inserted into your vagina. The treatment may last several hours or a few days.

Sometimes, as well as the applicator, tiny radioactive needles may be placed into the area surrounding the vagina. If these are needed, they are put in under general anaesthetic and are removed once the treatment ends.

Side effects

Radiotherapy for vaginal cancer can cause short-term and long-term side effects. The most common effects happen during or soon after treatment. The side effects happen because, as well as destroying cancer cells, radiotherapy can also damage the healthy cells nearby.



Short-term side effects

Diarrhoea

Radiotherapy may also irritate the bowel and cause some diarrhoea. If this is a problem let your doctor know, as drugs can be prescribed to reduce it. It helps to drink plenty of water to replace the fluid lost through diarrhoea.

Hair loss

Radiotherapy can cause hair loss in the area being treated, and this may be permanent.

Shortening and narrowing of the vagina

Radiotherapy to the pelvic area can affect the vagina, which will become tender during the course of radiotherapy and for a few weeks after it ends.

In the long term this irritation can make the vagina drier and can leave scarring that makes the vagina shorter, narrower and less flexible. This may make having sex uncomfortable or difficult.

You will be advised to use a vaginal dilator with a lubricating jelly to keep the vaginal walls open and supple. Ask your doctor or nurse to show you how to use it. If they are not used, the vagina may close over completely.

Applying a hormone cream to your vagina may help. These are available on prescription from your doctor. Regular intercourse may also help to prevent the vagina from shrinking. However, you may not feel ready for intercourse for some time. Vaginal moisturisers can also help (see page 7 for more information).

Other effects

It is not unusual to have slight bleeding or discharge from the vagina once the radiotherapy treatment has ended. If it continues, or becomes heavy, it is important to let your doctor or nurse know.

Radiotherapy to the pelvic area can also cause tiredness and a burning sensation when passing urine (cystitis). These side effects can be mild or troublesome depending on the strength of the radiotherapy dose and the length of your treatment.

Most of these side effects can be treated and your doctor or nurse will be able to help you. Most side effects should gradually disappear once your treatment is over.

Long-term side effects

Radiotherapy to the pelvic area can sometimes lead to long-term side effects. However, improvements in treatment planning and the way in which the radiotherapy is given have made these long-term effects much less likely.

Menopause

If you are not already menopausal, radiotherapy for cancer of the vagina affects the ovaries and this brings on the menopause, usually about three months after the treatment starts. This means that your periods will stop and you may have menopausal side effects such as hot flushes, a dry skin and possibly loss of concentration. Some women become less interested in sex and notice that their vagina is dry.

Hormone replacement treatment (HRT) may help to control or minimise menopausal symptoms. Your gynaecologist can start HRT during the radiotherapy treatment or shortly after it has ended.

Bowel and bladder problems

In a small number of people, radiotherapy may permanently affect the bowel or bladder. If this happens, the increased bowel motions and diarrhoea may continue, or you may need to pass urine more often than before.

The blood vessels in the bowel and bladder can become more fragile after radiotherapy treatment and this can cause blood to appear in the urine or bowel movements. This can take many months or years to occur. If you notice any bleeding, it is important to let your doctor know so that tests can be done and appropriate treatment given.

Some people also find that the radiotherapy affects the lymph glands in the pelvic area and can cause swelling of the legs. This is known as lymphoedema and is more likely if you have had surgery as well as radiotherapy. Call the Cancer Helpline on 13 11 20 for information on how to cope with lymphoedema.

Surgery

Sometimes the cancer needs to be removed in an operation. The type of treatment you will have depends on the size and position of the cancer. It may be possible to have an operation to remove the cancer together with some of the surrounding normal tissue.

Depending on the amount removed, the remaining vagina may be stretched so that you may still be able to have sexual intercourse.

Some women may need to have a larger operation that removes all of the vagina (vaginectomy). Sometimes it is possible to make a new vagina (vaginal reconstruction) using tissue from other parts of the body.

It may also be necessary to remove the uterus (womb), cervix, ovaries and Fallopian tubes. This operation is called a radical hysterectomy. During this operation some of the lymph nodes in the pelvis may also be removed.

Effect on emotions

Most women feel shocked and upset by the idea of having treatment to the most intimate and private part of their body.

You may experience a wide variety of emotions including anger, fear and resentment, all of which are normal. When these strong feelings are combined with the trauma of surgery, as well as all the emotions that go with having a cancer diagnosis, you may find the normal closeness of your relationship is also affected. Sharing your feelings may help bring you and your partner closer together.

Everyone has their own ways of coping with difficult situations; some people find it helpful to talk to friends or family while others prefer to seek help from people outside their situation such as a specialist nurse or counsellor. Others prefer to keep their feelings to themselves.

There is no right or wrong way to cope but help is available if you need it. It is important to give yourself and your partner time to deal with the emotions that cancer can cause.

The Cancer Council can match you with a volunteer who has been through a similar cancer experience, and who understands how you're feeling. Call 13 11 20 to find out more about Cancer Council Connect for gynaecological cancer.

Effect on your sex life

How your sex life is affected physically will depend on the treatment you have. If you have a vaginal reconstruction and have to have your cervix and uterus removed, it may not be possible to have a vaginal orgasm. However, surgery to the vagina does not affect the clitoris so it will be possible to have an orgasm through oral sex and masturbation.

Because of the physical and emotional effects of surgery, orgasm may not happen for a while and sex may be uncomfortable. You may need to be patient while exploring different ways to reach a climax. There are many other parts of your body that when caressed, can increase your sexual excitement and lead to orgasm. The breast, inner thigh, neck, feet and buttocks are all very sensitive areas of the body.

Your doctor or nurse may be able to discuss this with you. You may also wish to speak to a sex therapist or counsellor experienced in this area.

Sometimes the scar tissue from the surgery may cause pain during intercourse. If this is a problem for you, use lubricant and try different positions. It is very important to continue to have intercourse and/or to use vaginal dilators after radiotherapy or the vagina walls will join together, making intercourse impossible.

If you are having trouble with vaginal dryness, try lubricants that are non-perfumed and water-based. Using a vaginal moisturiser 2-3 times a week may also help.



YOU CAN STILL MAKE MUSIC ...
TO THE BEAT OF A DIFFERENT DRUM

Regaining confidence

For most women sex is more than just being able to feel aroused or to have orgasms. It involves fundamental feelings about intimacy and about being able to give and receive love. If we are not comfortable with the way our bodies look, this may affect our feelings about sex.

Some women worry about being rejected by their partner, or any potential new partner, because of the changes to their body.

Intimate sexual relationships always provide the challenge of sharing your fears, worries and needs with your partner. The time after surgery or treatment to the vagina is no different and you may be surprised by the amount of tolerance, trust, tenderness and love that exists between you.

However, sometimes difficulties may arise in your relationship with your partner. If this happens, you may find counselling helpful, either with your partner or on your own. If you can do this, you may find that it is possible to work through these feelings to a new closeness and understanding.

“My number one priority was to talk to another woman who had been through the same experience, because nobody else wanted to talk about it. The power of sharing my story with another woman was incredibly healing.”

What if I don't have a partner?

Finding a new partner after surgery to the vagina can be daunting. It can be difficult to tell a new person in your life about the surgery. It's natural to be worried about their reaction, and to be unsure about what to tell them and when.

It may be helpful to practise what you want to say, and to talk about the effect of the surgery before any sexual activity. You may also need to think about the right time in the relationship to raise the issue.

The Cancer Helpline can send you booklets that have more detail about cancer treatment and how to cope with it, as well as emotional issues. Call 13 11 20 for free booklets about chemotherapy, radiotherapy, emotions and cancer, food and cancer, and sexuality for women with cancer.

For more information

To find out more about cancer of the vagina, call the Cancer Helpline on 13 11 20.

The Cancer Helpline is a service of The Cancer Council NSW. It is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with specialist cancer nurses. The nurses can send you written information and put you in touch with appropriate services in your own area.

The Internet is also a useful source of information, although not all websites are reliable. The websites listed here are good sources of reliable information.

The Cancer Council NSW
www.cancercouncil.com.au

The Cancer Council Australia
www.cancer.org.au

GAIN (Gynaecological Awareness
Information Network)
www.gynsupport.com

CancerBACUP
www.cancerbacup.org.uk

National Cancer Institute
www.cancer.gov/cancer_information

American Cancer Society
www.cancer.org

Canadian Cancer Society
www.cancer.ca

Gynaecological Cancer Support
www.gynaecancersupport.org.au

Understanding Cancer of the Vagina

An information sheet for women with cancer, their families and friends.

First published January 2005
©The Cancer Council New South Wales 2005
ISBN 1 86507 086 6

Acknowledgements

We thank Cancer Bacup for allowing its booklet on cancer of the vagina to be used as a source of this information sheet. We also thank the reviewers of this information: Dr Greg Robertson, Gynaecological Oncologist, Royal Hospital for Women and St George Hospital; Tish Lancaster, Clinical Nurse Consultant, Gynaecological Oncology, Westmead Hospital; Kath Mazzella, Founder of the Gynaecological Awareness Information Network; Dr Kendra Sundquist, Manager, Supportive Care Development, The Cancer Council NSW; and Kim Kerin-Ayres, Cancer Information Consultant, The Cancer Council NSW.

Editor: Marge Overs
Cartoonist: Greg Smith
Illustration: Con Stamatis, The Cancer Council Victoria

The Cancer Council New South Wales

The Cancer Council is the leading cancer charity in New South Wales. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and patients, and raising funds for cancer programs.

This information sheet is funded through the generosity of the people of New South Wales. To make a donation to help defeat cancer, visit The Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.

Before commencing any health treatment, always consult your doctor. This information sheet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor's or health professional's advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

The Cancer Council New South Wales
153 Dowling Street
Woolloomooloo NSW 2011
Cancer Helpline: 13 11 20
Telephone: (02) 9334 1900
Facsimile: (02) 9334 1741
Email: feedback@nswcc.org.au
Website: www.cancercouncil.com.au

CC1140 Date: 01/05

cancerBACUP
helping people live with cancer



Building a
Cancer Smart
Community