This information 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 is an introduction to the diagnosis, treatment and effects of vaginal cancer.

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 might want to ask your doctors.

What is cancer?

Cancer is a disease that can occur in any type of cell in the body. Our bodies are continually making new cells: to replace dead cells, to heal damaged cells after an injury, and to enable us to grow in size. All cells are controlled by genes.

If something goes wrong with the genes that control a cell, that cell may start behaving strangely. Instead of growing normally, it may grow and divide in an uncontrolled way, forming a mass of cells. The mass of cells looks and feels like a lump, and is called a tumour.

A tumour can be benign (not cancer) or it can be malignant (cancer). The difference is that benign tumours do not spread to other parts of the body, while malignant tumours can.

A malignant tumour is made up of cancer cells. When it first develops, the tumour stays in one place. This is called the primary tumour.

If the cancer cells that make up the primary tumour are not treated, they may start to spread to other areas of the body and form new tumours. These new tumours are called secondary cancers or metastases.

How cancer spreads

Some benign tumours are precancerous and may progress to cancer if left untreated. Other benign tumours do not develop into cancer.
The vagina

The vagina (birth canal) is a muscular tube. It 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.

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 spread from the cervix, the lining of the womb (the endometrium), the vulva or from nearby organs such as the bladder or bowel.

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. However, research is ongoing to try to find the cause.

• **DES:** A hormone drug called diethy stilboestrol or DES has been identified as a cause of a particular type of cancer of the vagina. Between 1938 and 1971, and occasionally beyond, DES was prescribed to pregnant women to try to prevent miscarriages. The female children of women who were prescribed DES during pregnancy have an increased risk of developing a type of cancer of the vagina called clear cell adenocarcinoma. Approximately one in 1,000 DES daughters develop this type of cancer. The risk appears to be highest for those in their teenage years and early 20s. However, some cases have been reported for DES daughters in their 30s, 40s and 50s. For this reason, DES daughters would benefit from regular medical examinations to check for clear cell adenocarcinoma throughout their lifetime.

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).

Primary 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, which means the cancer originated from the skin cells. 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 begins in the glandular cells in the lining of the vagina. It usually affects women under 20 years of age, but occasionally occurs in other age groups.
Although DES and some other female hormones (oestrogens) can be safely used to treat some medical conditions, DES is no longer prescribed during pregnancy in Australia.

For more information or a fact sheet on DES, contact the Cancer Council Helpline on 13 11 20.

- **HPV**: The human papilloma virus (HPV) is also a risk factor for vaginal cancer. HPV 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 of vaginal cancer. However, this complication of radiotherapy is very rare.

### What are the symptoms?

The most common symptoms of vaginal cancer are:
- blood-stained vaginal discharge
- bleeding after sexual intercourse
- pain in the pelvic area.

Problems with 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 rectum (back passage) may sometimes occur.

### 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 help diagnose vaginal cancer.

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### Internal 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 rectum.

### Cervical smear

You will have a Pap smear to check for 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 small low-powered microscope called a colposcope 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.

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### 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 nodes (also known as lymph glands) that are linked by fine ducts containing lymph fluid.

The results of these tests will help the specialist to recommend 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, to see if the cancer has spread to this region. The cystoscope is a slender tube with a lens and a light that is inserted into the urethra and moved 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 build 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 can be noisy and claustrophobic. If you feel uncomfortable, you can communicate with the technologist who is carrying out the scan through a microphone and speaker inside the scanner. You will also be able to see the technologist through a window.

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 decide on the most appropriate treatment.

Stage 1: The cancer is only in the vagina and has not 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 your 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 oncologist any questions you have about the treatments being considered. You should also feel free to ask the doctor to explain something more than once if necessary. It is important that you understand the options clearly so that you can make an informed decision about your treatment.

Radiotherapy
Radiotherapy is a commonly used treatment for 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 with cancer of the vagina 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.

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This next part might get a bit bumpy for a while, ladies.
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.

The internal radiotherapy wasn’t painful but it was uncomfortable not being able to move. The time passed quickly with meal times and I did a lot of reading.

Side effects

Radiotherapy for vaginal cancer can cause both short-term and long-term side effects. The most common effects occur during or soon after treatment. Side effects happen because radiotherapy can cause damage to healthy cells as well as cancer cells.

Short-term side effects

Diarrhoea
Radiotherapy may irritate the bowel and cause some diarrhoea. If this is a problem, let your doctor know as drugs can be prescribed to reduce it.

Drinking plenty of water will help to replace the fluid lost through diarrhoea.

Hair loss
Radiotherapy can cause hair loss in the area being treated. 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 or medical examinations to the vagina uncomfortable or difficult, but there are methods to ease the discomfort and prevent the vagina from closing over completely.

To reduce narrowing and the build-up of scar tissue in the vagina, you will be advised to use a device called a dilator, which is shaped like a tampon and is made from plastic or rubber. Used with a lubricating jelly, the dilator is usually inserted into the vagina for up to 10 minutes every day for at least six weeks. Later, you may only need to use the dilator once a week for 6 to 12 months. Ask your doctor or nurse to show you how to use a dilator and discuss how long you need to use it for.

Regular intercourse can also help to keep the vagina from narrowing. To reduce discomfort, using a vaginal moisturiser throughout the week and using a lubricant during sex can be helpful. Initially, you may not feel emotionally or physically ready to have penetrative sex with your partner. This is normal, but during this time it is important to continue to use the dilator.

Applying a hormone cream to your vagina may also help keep the vaginal tissue supple and lubricated. These creams are available on prescription from your doctor.

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.

Other effects

You may have slight bleeding or discharge from the vagina once the radiotherapy treatment has ended. If this 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.
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
Radiotherapy for cancer of the vagina affects the uterus and the ovaries. This means that if you have not already been through menopause, you will experience an early menopause. During menopause, your periods will stop and you may have symptoms such as hot flushes, dry or itchy skin, mood swings, or loss of libido (interest in sex). An early menopause also means that you will no longer be able to become pregnant. If this is a concern for you, talk to your doctor about your fertility and any options available to you before you start treatment.

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, 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.

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

Surgery
Sometimes the cancer needs to be removed with an operation. The type of surgery 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 of tissue 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.

Side effects
Sometimes the scar tissue from the surgery may cause pain during intercourse. If this occurs, using a lubricant and trying different positions can help. If vaginal dryness is an ongoing problem, water-based and non-perfumed lubricants are best. Using a vaginal moisturiser several times a week will also help to keep tissue more flexible. Using a dilator may also be beneficial (see page 6).

If you have a hysterectomy, you will no longer be able to become pregnant. If fertility is an important issue for you, talk to your doctor before your surgery to discuss any options available to you.

Chemotherapy
Chemotherapy is the name given to the treatment of cancer using strong anti-cancer drugs. In women with vaginal cancer, chemotherapy is mainly used if the cancer is advanced, or if the cancer returns after treatment.
Effect on emotions

Most women feel shocked and upset by the idea of having treatment to one of the most intimate and private parts 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 effects of chemotherapy and/or surgery, as well as all the emotions that go with having a cancer diagnosis, you may find the closeness of your relationship with your partner is affected. Sharing your feelings may help bring you and your partner closer together.

Everyone has their own ways of coping with new or difficult situations. Some people find it helpful to talk to friends or family, while others prefer to seek professional help from 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, your partner, family and friends time to deal with the emotions that cancer can cause. Refer to the Emotions and Cancer booklet for more information.

Effect on your sex life

People’s sex lives often change during and after cancer treatment. As well as the emotional impact of cancer diagnosis and treatment, the physical changes to your body can also affect the ways in which you experience intimacy. Physical changes depend on the type of treatment you undergo.

If you have radiotherapy, the vagina becomes irritated and tender, resulting in dryness, scarring, shortening and narrowing of tissue. This will initially make intercourse uncomfortable but it will not affect your ability to have an orgasm. See page 6 for information on the use of a dilator to keep the vagina more flexible.

If you have a vaginal reconstruction, you may still be able to have intercourse, but it may not be possible to have an orgasm through penile penetration of the vagina. However, as surgery to the vagina does not affect the clitoris, it is still possible to have an orgasm through oral sex and masturbation.

If you do not feel like having sex, or you find penetration uncomfortable, let your partner know how you’re feeling. It is natural to take some time to become comfortable again, so it is important for you both to be patient. Even if penetration feels pleasurable, because of the physical and emotional effects of both radiotherapy and surgery, it often takes time to experience an orgasm. However, there are different ways to reach a climax, which you might like to explore. For example, the breasts, inner thighs, neck, feet and buttocks are all very sensitive areas of the body, which, if caressed, can increase sexual excitement and lead to orgasm.

You and your partner can still be intimate without trying to have intercourse or reaching an orgasm. Sharing your feelings for each other in intimate ways such as cuddling, kissing, stroking and massage can often be as satisfying and enjoyable as full penetration and climax.

The booklet Sexuality for Women with Cancer has many tips for dealing with issues on sexuality. Your doctor or nurse will also be able to discuss changes to your sex life with you. You may also wish to speak to a sex therapist or counsellor who is experienced in this area.
Regaining confidence

For most women, sex is more than arousal, intercourse and orgasms. It involves feelings of intimacy and acceptance, as well as being able to give and receive love. If we are not comfortable with the way we feel about our bodies, this may affect our confidence and desire for sex.

Some women worry about being rejected by their partner, or any new partner, because of changes to their body, even if these changes are not visible.

It is sometimes difficult to communicate sexual needs, fears or worries with your partner in an intimate relationship. After treatment to the vagina, you may find it even more difficult, but you may be surprised and encouraged by the amount of tolerance, trust, tenderness and love that exists between you.

However, problems can arise because of misunderstandings, differing expectations, and different ways of adapting to changes to your sex life. If this happens, you may find counselling helpful, either with your partner or on your own. You may be able to work through these challenges towards a new closeness and understanding.

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 someone who is new 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.

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.

Seeking support

When you are first diagnosed with cancer, it is normal to experience a range of emotions. If anxiety or depression is ongoing or severe, tell your doctor about it, as counselling or medication can help.

It will help to talk about your feelings with others. Your partner, family members and friends are a good source of support. You might also want to talk to:
• members of your treatment team
• a hospital counsellor, social worker or psychologist
• your religious or spiritual adviser
• a support group – see the Cancer support groups section on page 10.

If you have children, the prospect of telling them that you have cancer can be frightening and unsettling. The Cancer Council’s When a parent has cancer: how to talk to your kids book can help you prepare for this difficult conversation.

You may find that your friends and family don’t know what to say to you because they are having difficulty with their feelings as well. You may feel able to approach your friends directly and tell them what you need. Alternatively, you may prefer to ask a close family member or a friend to talk with other people for you, and to coordinate practical support and offers of help.

Some people may feel so uncomfortable that they avoid you. They may expect you to ‘lead the way’ and tell them what you need. This can be difficult to handle and can make you feel lonely. The Cancer Council’s booklet Emotions and Cancer may help at this stressful time. Read it online at www.cancercouncil.com.au or call 13 11 20 for a copy.
Practical and financial help

A serious illness often causes practical and financial difficulties. You don’t need to face these alone.

Many services are available to help:

- Financial assistance, through benefits and pensions, can help pay for the cost of prescription medicines and for travel to medical appointments.
- Home nursing care is available through community nursing services, or through local palliative care services.
- Meals on Wheels, home care services and aids and appliances can make life easier.

To find out more, contact the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline.

Cancer support groups

Cancer support groups offer mutual support and information to people with cancer and their families. It can help to talk with others who have gone through the same experience. Support groups can also offer many practical suggestions and ways to cope. Your hospital may run a support group; check with your doctor, nurse or social worker. Joining a consumer advocacy group can also be a rewarding experience for some people.

Call the Cancer Council Helpline on 13 11 20 for information on advocacy or support groups and telegroup counselling.

Telephone support groups

Most support groups meet face to face, however telephone support groups are also available through the Cancer Council’s Telephone Support Groups program. This is a good option for people who live in remote areas or prefer not to meet face to face. Groups are supported by two specially trained facilitators.
Talking to someone who’s been there

Cancer Council Connect 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.

Being able to talk to someone who has experienced cancer is the most marvellous feeling. With that person, I can be completely honest with my feelings and fears.

Understanding Cancer program

If you want to find out more about cancer and how to cope with it, you may find the Cancer Council’s Understanding Cancer program helpful. The program offers practical information about many of the issues people experience after a diagnosis of cancer, including: what is cancer, cancer symptoms and side effects, palliative care and diet, exercise and complementary therapies. Groups are small, with plenty of time for discussion. Courses are held frequently at hospitals and community organisations throughout NSW. Call the Cancer Council Helpline on 13 11 20 to find out more.

Caring for someone with cancer

You may be reading this information because you are caring for someone with cancer. Being a carer can be very stressful, especially when the person you are looking after is someone you care about very much. Look after yourself during this time. Give yourself some time out, and share your worries and concerns with someone outside.

Many cancer support groups are open to carers as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping.

There are several support services such as Home Help, Meals on Wheels and visiting nurses that can help you with treatment at home. There are also many organisations and groups that can provide you with information and support. Some of these, such as the Cancer Council Helpline, can let you know about other services that may be of help to you.

Information on the Internet

The Internet can be a useful source of information, although not all websites are reliable. The websites listed below are good sources of reliable information.

Australian

The Cancer Council New South Wales
www.cancercouncil.com.au

The Cancer Council Australia
www.cancer.org.au

Gynaecological Cancer Support
www.gynaecancersupport.org.au

International

American Cancer Society
www.cancer.org

Cancerbackup
www.cancerbackup.org.uk

National Cancer Institute
www.cancer.gov

Call the Cancer Council Helpline on 13 11 20 to talk to a health professional, or to ask for free information booklets, including:

- Understanding Chemotherapy
- Understanding Radiotherapy
- Emotions and Cancer
- Food and Cancer
- Sexuality for Women with Cancer
- Caring for Someone with Cancer, and
- When a parent has cancer: how to talk to your kids.
Understanding Cancer of the Vagina
An information sheet for women with cancer, their families and friends.

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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.

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