Understanding Cervical Cancer
A guide for women with cancer, their families and friends

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Understanding Cervical Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy of the booklet is up to date. To obtain a more recent copy, phone Cancer Council Helpline 13 11 20.

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Note to reader
Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor’s or other health professionals’ advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Cancer Council Australia
Cancer Council Australia is the nation’s peak non-government cancer control organisation. Together with the eight state and territory Cancer Councils, it coordinates a network of cancer support groups, services and programs to help improve the quality of life of people living with cancer, their families and carers. This booklet is funded through the generosity of the people of Australia. To make a donation and help us beat cancer, visit Cancer Council's website at www.cancer.org.au or call your local Cancer Council.
Introduction

This booklet has been prepared to help you understand more about cervical cancer.

Many women feel understandably shocked and upset when told they have cervical cancer. We hope this booklet will help you understand how cervical cancer is diagnosed and treated. We also include information about support services.

We cannot advise you 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 other questions you want to ask your doctors or other health carers.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. You may also like to pass this booklet to your family and friends for their information. Some medical terms that may be unfamiliar to you are explained in the glossary.

How this booklet was developed
The information in this booklet was developed with help from medical experts and women who have been affected by cervical cancer. The booklet is based on clinical practice guidelines for cervical cancer.

Cancer Council Helpline 13 11 20 can arrange telephone support in different languages for non-English speakers. You can also call the Telephone Information Service (TIS) direct on 13 14 50.
Cancer is a disease of the cells, which are the body’s basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury.

Normally cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in a lump called a tumour or may develop into abnormal blood cells.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread to other parts of the body. A malignant tumour is made up of cancer cells, which grow out of control and are able to spread. The cancer that first develops
in a tissue or organ is called the primary cancer. When it first develops, a malignant tumour may not have invaded nearby tissue. This is known as a cancer in-situ (carcinoma in-situ) or localised cancer. As the tumour grows it may spread, becoming invasive cancer.

Cancer cells can spread to other parts of the body by travelling through the bloodstream or lymphatic system. They may continue to grow into another tumour at this new site. This is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, cervical cancer that has spread to the lungs is still called cervical cancer, even though the person may be experiencing symptoms caused by problems in the lungs.
The cervix is part of the female reproductive system. The female reproductive system also includes the uterus (womb), ovaries, Fallopian tubes, vagina and vulva.

The cervix is the lower, cylinder-shaped part of the uterus that connects to the vagina. It is also called the neck of the uterus. It has an outer surface that opens into the vagina and an inner surface that faces into the uterus. The inner part is called the cervical canal.

The functions of the cervix include:
• producing moistness to lubricate the vagina
• producing mucus to help sperm travel up to the Fallopian tube to fertilise an egg from the ovary
• holding a developing baby in the uterus during pregnancy
• widening so the baby can be born via the birth canal (vagina).

The cervix is covered by two types of epithelial cells, which line the surfaces of many organs and body systems:
• **squamous cells** – flat, thin cells found in the outer layer of the cervix that opens into the vagina (ectocervix)
• **glandular or columnar cells** – column-shaped cells that produce cervical mucus and are found in the cervical canal (endocervix).

The area where squamous and glandular cells meet is called the transformation zone. It is also called the squamocolumnar junction. Among the squamous cells and glandular cells is strong, supportive connective tissue called the stroma.
The cervix

- Fallopian tube
- Uterus (womb)
- Ovary
- Cervix (neck of uterus)
- Vagina
- Vulva (external genitals)

Glandular cells
Transformation zone
Squamous cells
Cervical cell changes

Sometimes the cells in the cervix start to change and no longer appear normal. This may mean you have a pre-cancerous lesion, which is not cancer but may lead to cancer. Cervical cell changes may be found during a routine Pap smear. This test is explained in detail on page 13.

There are different types of early cell changes, which are also called epithelial abnormalities.

Atypia – The cervical cells have changed slightly. The cells may return to normal by themselves or the changes may worsen. If a cell shows signs of atypia, it does not necessarily mean you have cancer or will get cancer. Atypia can also be caused by infection or irritation.

Squamous abnormalities – The squamous cells of the cervix are abnormal. This may be classified as a low grade or a high grade abnormality on a Pap smear. High grade abnormalities are pre-cancerous, and although they do not usually cause symptoms they can sometimes progress to early cervical cancer if they are not detected and treated.

These squamous changes are also called cervical intraepithelial neoplasia (CIN) and are graded according to how severe they appear on a biopsy of the tissue (see page 16). Early changes are categorised as CIN 1 and these will usually disappear without treatment. Further abnormal changes are categorised as CIN 2 or CIN 3.
Glandular abnormalities – The glandular cells of the cervix are abnormal. These abnormalities on a Pap smear always require further assessment as they may be either pre-cancerous or cancerous.

If the results from a Pap smear show that your cervix has some abnormal changes, your doctor will recommend that you have one of the following based on the grade of the changes:

• another Pap smear in 12 months time to monitor the cells
• treatment right away
• a biopsy to look at the cervical cells in more detail under a microscope (see page 16).

“ My doctor said that because I had regular Pap smears, the cancer was picked up while it was small. The treatment was straightforward and my body is intact. ”

Patient
Q: What is cervical cancer?
A: Cervical cancer is a malignant tumour found in the tissues of the cervix. It occurs when abnormal cells in the cervix turn into cancer cells. The cancer cells break through the surface cells (epithelium) to the underlying tissue (stroma) of the cervix.

Cervical cancer most commonly begins in the cells of the transformation zone. At diagnosis, the cancer is often just within the cervix, but it may have spread to tissues around the cervix (e.g. the vagina) or to other parts of the body.

Q: What types are there?
A: The two main types of cervical cancer are named after the cells they start in.

• **Squamous cell carcinoma** – The most common type, accounting for about eight out of every 10 cases.

• **Adenocarcinoma** – A less common type starting in the glandular cells. It is difficult to diagnose, as it is high in the cervix and hard to reach with the tools used for testing.

Q: What are the causes?
A: The main cause of cervical cancer is now known to be infection with human papillomavirus (HPV). There are also other known risk factors.
**Human papillomavirus (HPV)** – Most cases of cervical cancer occur many years after infection with a strain of human papillomavirus, which is the name for a group of wart viruses. It is a common infection affecting the surface of different body areas, such as the skin, vagina and cervix.

About eight out of 10 women will become infected with genital HPV at some time in their lives. Genital HPV is usually spread via the skin during sexual contact. In most women, the virus is cleared quickly by the immune system and no treatment is needed. Because there are rarely symptoms, most women are unaware they have the virus.

The pre-cancerous cell changes caused by HPV can be found by a Pap smear. There is now also a vaccination against HPV. See page 14 for more information.

**Smoking** – Chemicals in tobacco can damage the cells of the cervix and make cancer more likely to develop.

**Family history** – If you have a first-degree relative (mother or sister) who has had cervical cancer, you have an increased chance of developing it.

**Diethylstilboestrol (DES) exposure** – DES is an oestrogen-based medication prescribed to women from the 1950s to the early 1970s to prevent miscarriage. Studies have shown that the daughters of women who took DES have an increased risk of developing a rare type of adenocarcinoma.
Q: How common is it?
A: In Australia, about 750 women are diagnosed with the disease every year. Only 1.6% of all cancers in women in Australia are cervical cancer.

Between 1999 and 2008, the rate of cervical cancer fell by 25%. This is probably because more regular Pap tests are conducted as part of the National Cervical Screening Program. With the introduction of the National Immunisation Program against HPV, there should be a further fall in cervical cancer cases in the coming years.

Q: What are the symptoms?
A: If early cell changes develop into cervical cancer, the most common symptoms include:
• vaginal bleeding between periods or after menopause
• bleeding after intercourse
• pain during intercourse
• unusual vaginal discharge
• excessive tiredness
• leg pain or swelling
• lower back pain.

These symptoms can also be caused by other more common conditions. However, see your general practitioner (GP) if you are worried or the symptoms are ongoing. If necessary, your GP will refer you for tests to see if you have cancer. See page 15 for more information.
**Q: What is a Pap smear?**

**A:** The main role of the Pap smear (also called a Pap test) is to help prevent cancer. It shows whether women have abnormal pre-cancerous cells in their cervix.

All women under 70 years of age who are or who have ever been sexually active should have a Pap smear every two years. Women who have had abnormal cell changes should be tested more often.

During a Pap smear, a doctor uses an instrument such as a brush or spatula to take some cells from the surface of the cervix. This may feel slightly uncomfortable but usually only takes a minute or two. The cells are smeared onto a glass slide or put into a fluid. The cells will then be examined under a microscope for any changes.

Occasionally cancer cells are detected in a Pap smear, but this is uncommon. A Pap smear is not used to diagnose cancer – if cancer is suspected, you will need other tests.

If you have an abnormal result, your GP or gynaecologist will discuss whether you need treatment, further tests or another Pap smear at an earlier interval than two years.

To learn more about Pap smears, talk to your doctor. You can also call Cancer Council Helpline to request a free copy of the National Cervical Screening Program booklet *An Abnormal Pap Smear Result: What this means for you.*
Q: What is the HPV vaccine?

A: The National HPV Vaccination Program was introduced to Australia in 2007. The HPV vaccine provides protection against the two main strains of HPV that are known to cause cervical cancer.

The vaccine, however, can’t be given to treat cancer once a woman has already been diagnosed with pre-cancerous cells or cancer. It also doesn’t provide protection against all types of HPV, so it is important to continue to have Pap smears even if you’ve been vaccinated.

For more information, talk to your doctor or see the website www.immunise.health.gov.au.

The HPV vaccine is free for schoolgirls aged 12 or 13 in Australia. Women under 27 were able to receive free vaccinations between 2007 and 2009. Young women who missed out are still able to obtain the vaccine through their GP for a fee.
If your Pap smear results show a high-grade abnormality or you have had symptoms of cervical cancer, you will need to have further tests to confirm the diagnosis. You may be referred to a specialist called a gynaecological oncologist. Some tests allow your doctor to see the tissue in your cervix and surrounding areas more clearly. Other tests show your general health and whether the cancer has spread. You will have some of the tests that are outlined on pages 15–21.

**Colposcopy**

A colposcopy can help identify where abnormal or changed cells are located and what they look like.

In this procedure, the doctor puts an instrument called a speculum into your vagina to hold the walls slightly apart. Using an instrument called a colposcope, which looks like a pair of binoculars sitting on a large stand, the doctor can see a magnified picture of your cervix, vagina and vulva. The colposcope is not put into your body. The doctor will probably take a tissue sample (biopsy) during the colposcopy.

Before the test, the doctor may coat your vagina and cervix with a fluid that will help to highlight any abnormal areas. Some colposcopes are fitted with a camera connected to a TV screen, so you can watch what the doctor is doing if you’d like to.

You may experience some mild discomfort for 10–15 minutes while the colposcopy is performed.
Biopsy
A biopsy is when your doctor removes some tissue and sends it to the laboratory for examination under a microscope. Biopsies are typically done in a clinic and the results are usually available in about a week.

Side effects
You may feel uncomfortable for a short time when the tissue is removed. Afterwards, you may experience some pain, similar to menstrual cramping. You can ask for medication to relieve the pain. You may also have some bleeding or other vaginal discharge for a few hours, but these side effects will soon disappear.

To allow the cervix to heal and to reduce the chance of infection, you will probably be advised not to have sexual intercourse or use tampons for 2–3 days. Check with your doctor.

Large loop excision of the transformation zone (LLETZ)
LLETZ is another type of procedure to remove some cervical tissue for examination. A loop of wire carrying an electric current is used to cut out the abnormal tissue from the cervix. Sometimes the doctor can remove all visible abnormal cells.

The procedure takes about 10 minutes. It may be done under a local anaesthetic in the doctor’s clinic or under a general anaesthetic at hospital. In some cases, the doctor may do it at the same time as a colposcopy.
Side effects
After a LLETZ, you may have some vaginal bleeding and cramping. This will usually ease in about two weeks. To give your cervix time to heal and to prevent infection, you shouldn’t have sex or use tampons for 4–6 weeks. LLETZ does not usually affect your ability to become pregnant in the future, but you may have a slightly increased risk of an early birth.

Cone biopsy
A cone biopsy is used to determine how deeply cancer cells have spread into tissue beneath the surface of the cervix. A cone biopsy is also used to treat very early and very small tumours. Further treatment is needed for cancers that are larger.

This procedure removes a cone-shaped piece of tissue containing the abnormal cells from the cervix. It is performed under a general anaesthetic and involves a day or overnight stay in hospital. Cone biopsy results are usually available within a week.
Side effects
After the cone biopsy, some light bleeding or cramping for a few days is common. You may have a small gauze pack put into your vagina to help stop the bleeding. After the gauze is removed, you should avoid doing anything physically strenuous for a few weeks, as this could restart your bleeding or make you bleed more heavily. If the bleeding lasts longer than two weeks, becomes heavy or has a bad odour, see your doctor.

To allow your cervix to heal and to prevent infection, you should not have sexual intercourse or use tampons for 4–6 weeks.

A cone biopsy may weaken the cervix. You can still become pregnant but you may be at a higher risk of miscarriage or a having a premature baby. If you would like to become pregnant, talk to your doctor before having the cone biopsy. Supportive stitches may be inserted into the cervix to strengthen it, and are usually removed before you give birth.

I had period-like pain for a few days after the cone biopsy but a hot water bottle and mild pain-killers helped a lot. Julie

Further tests
If a biopsy shows you have cervical cancer, other tests may be needed. These will help determine if the cancer has spread to other parts of the body. This is called staging – see page 22 for more information. You may have one or more of the tests on pages 19–20.
Blood tests
Blood samples may be taken to check your general health.

Chest x-ray
The doctor may take a painless x-ray scan of your chest to check your lungs for any signs of cancer.

CT scan
A CT (computerised tomography) scan is a type of x-ray procedure that takes pictures of the inside of your body. It can help show if the cancer has spread to the lymph nodes or to other organs.

To make the scan pictures clearer, you may be asked to drink a liquid called contrast fluid or to insert a tampon into your vagina before the scan. Sometimes a liquid is also put into your rectum before the scan. This may make you feel hot all over for a few minutes.

You will lie flat on a table while the CT scanner, which is large and round like a doughnut, takes pictures. The test is painless and usually takes 30–40 minutes. After the scan, you can usually go home.

People who are allergic to iodine, fish or dye may also be allergic to the dye used in a CT or MRI scan. Make sure you tell your doctor or nurse before the scan about the allergy.
MRI scan
An MRI (magnetic resonance imaging) scan uses a powerful magnet linked to a computer to take detailed pictures of areas inside the body. The pictures are taken while you lie on a table that slides into a metal cylinder. The scan takes less than an hour, and most people are able to go home as soon as it is over.

An MRI scan is painless but some women find that lying in the cylinder is noisy and claustrophobic. Let your doctor or nurse know if you feel uncomfortable. They can give you medication to ease this feeling.

PET scan
Before a PET (positron emission tomography) scan, you will have an injection of a sugar (glucose) solution containing a small amount of radioactive material. You will need to sit quietly for 30–60 minutes while the solution spreads throughout your body.

Cancer cells absorb the radioactive glucose solution more than normal cells. When your body is scanned, the areas of active cancer show up clearly. The scan takes about one hour.

Examination under anaesthetic
You will be given a general anaesthetic so the doctor can examine your vagina, cervix, bladder and rectum. Your doctor will insert a narrow instrument called a cystoscope into your urethra to examine your bladder. During this examination, you may also have a biopsy.
You may also have some of the cells in your uterus removed for examination. This is called a dilation and curettage (D&C). After a D&C, bleeding is common for a few days. You may feel some cramping for a short time.

Sometimes if the cancer has spread into the tissues around the cervix, the tubes from the kidneys (ureters) can be blocked. The ureters may then need plastic or metal tubes (stents) inserted to keep the urine draining from the kidneys. These stents may be temporary or permanent.

**Julie’s story**

I was diagnosed with cervical cancer when I was pregnant with my first baby but I was lucky it was caught early. I had a Pap smear that came back with an abnormal result and a biopsy confirmed that I had early cervical cancer.

The doctor told me that I’d lose my baby which was absolutely devastating. I got a second opinion from a surgeon who recommended I have a cone biopsy to remove the cancer, putting my miscarriage risk at 30%. I went through with the operation when I was 14 weeks pregnant and I recovered from it pretty quickly. Although I worried the whole pregnancy that the baby would fall out, I gave birth to a beautiful boy.

I needed to have thorough checks twice a year for a while (a colposcopy) but then I just moved on to having a Pap smear once a year.

All my tests have come back clear and I haven’t had to undergo any further treatment. My baby is now aged 16!
Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of your disease. However, the sooner cervical cancer is diagnosed, the better the prognosis. Most women with early cervical cancer will be cured.

Test results, the type of cancer you have, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as age, fitness and medical history are all important factors in assessing your prognosis.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tbody>
<tr>
<td>Stage 1</td>
<td>The cancer is found only in the tissue of the cervix.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>The tumour has spread beyond the cervix and uterus to the vagina and other tissue next to the cervix.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>The cancer has spread to the bone and ligaments on the side of the pelvis (pelvic sidewall).</td>
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<tr>
<td>Stage 4</td>
<td>The cancer has spread to the bladder or rectum, or beyond the pelvis to the lungs, liver or bones.</td>
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Which health professionals will I see?
Your GP will arrange the first tests to assess your symptoms. If these tests don’t rule out cancer, you will usually be referred to a gynaecological oncologist for more tests and treatment.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This multidisciplinary team will probably include:

<table>
<thead>
<tr>
<th>Health professional</th>
<th>Role</th>
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<tbody>
<tr>
<td>gynaecological oncologist</td>
<td>a doctor who has completed specialist training in cancers of the female reproductive system and their treatment</td>
</tr>
<tr>
<td>medical oncologist</td>
<td>a doctor who prescribes and coordinates the course of chemotherapy</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>a doctor who prescribes and coordinates the course of radiotherapy</td>
</tr>
<tr>
<td>nurses</td>
<td>give treatment and provide care and support when you’re in hospital</td>
</tr>
<tr>
<td>cancer nurse coordinator</td>
<td>supports patients and families throughout treatment and liaises with other staff</td>
</tr>
<tr>
<td>dietitian</td>
<td>recommends an eating plan for you to follow while you are in treatment and recovery</td>
</tr>
<tr>
<td>social worker, psychologist, physiotherapist and occupational therapist</td>
<td>link you to support services and help you and your family address emotional, physical or practical problems caused by the cancer</td>
</tr>
</tbody>
</table>
Key points

• A Pap smear is not used to diagnose cancer but shows whether there are early cell changes in the cervix that may lead to cancer.

• To diagnose cervical cancer, different tests are needed. These include tissue examination, scans and blood tests.

• A colposcopy lets the doctor see abnormal cells in the cervix through a viewing instrument called a colposcope.

• A biopsy is when tissue is removed from the cervix for examination under a microscope.

• A cone biopsy requires a general anaesthetic. A large cone-shaped piece of tissue is removed. This procedure is also used to treat early, small tumours.

• A large loop excision of the transformation zone (LLETZ) removes a large sample of tissue from the transformation zone of the cervix. This procedure is also used to treat early cancer.

• A chest x-ray, CT scan, MRI scan or PET scan may be done to check whether the cancer has spread to other parts of the body.

• An internal examination may be done to check your vagina, cervix, bladder and rectum.

• The diagnostic tests help the doctor to stage the cancer. The stages relate to whether the cancer has spread from the cervix and, if so, how far. Knowing the stage of the cancer allows the doctor to recommend the best treatment for you.
Your doctor will advise you on the best treatment for the cancer. This will depend on your test results, the location of the cancer and whether it has spread, your age and general health.

Surgery or a combination of chemotherapy and radiotherapy are the most common treatments for cervical cancer.

**Surgery**

Surgery is common for women who have small tumours found only within the cervix. The type of surgery will depend on the extent of the cancer.

**Hysterectomy**

A hysterectomy is the surgical removal of the uterus and cervix. There are two main types of hysterectomy. These are performed under a general anaesthetic.

**Total hysterectomy** – The uterus and cervix are removed. This may be done by keyhole surgery (laparoscopy) or by an open cut (laparotomy). Your surgeon will advise you on the best method for you, which will depend on the stage and size of the cancer, the availability of the surgeons and your own preference. You will probably spend 2–5 days in hospital.

**Radical hysterectomy** – The uterus, about 2 cm of the upper vagina, and the soft tissue around the cervix are removed. The surgery may affect your bowel or bladder function due to damage to the nerves in the area. You may be in hospital for about a week.
Depending on the extent of the cancer, you may also need to have a bilateral salpingo oophorectomy. This is when the ovaries and the Fallopian tubes are removed. They will be taken out at the same time as the hysterectomy. Women who have a bilateral salpingo oophorectomy and/or a hysterectomy will be unable to have children naturally (infertile). For information about infertility, see page 43.

If the tumour is very small, a cone biopsy may be the only treatment you need (see page 17).

**Removing lymph nodes**
Your doctor may decide to surgically remove some lymph nodes in your pelvic and/or abdominal area to see if the cancer has spread beyond the cervix. This is called a lymph node dissection or a lymphadenectomy. If you have cancer in your lymph nodes, your doctor may advise you to have additional treatment.

A lymph node dissection may cause one or both of your legs to swell (lymphoedema). For ways to manage this condition, see page 29.

**Trachelectomy**
A radical trachelectomy is the removal of only the cervix. This is not a common procedure, but it may be done in young women who have a small cancer. A trachelectomy preserves a woman’s ability to become pregnant (fertility).
The side effects and recovery of a radical trachelectomy are similar to those of a hysterectomy, but you will still have periods (menstruate) after the surgery.

**After the operation**

When you wake up from a hysterectomy, you will have several tubes in place. An intravenous (IV) drip will give you fluid and medication. There may also be one or two tubes in your abdomen to drain fluid from the operation site and a small plastic tube (catheter) in your bladder to drain urine. These tubes will be removed 3–5 days after the operation.

As with all major operations, you will have some pain or discomfort. You will be given pain relief medication through a drip or with an injection of drugs into the spine (epidural). Let your doctor or nurse know when you feel uncomfortable – don’t wait until the pain becomes severe.

While you are in bed, your doctors, nurses and physiotherapist will show you how to move your legs to prevent blood clots and help drain any lymph fluid. As soon as you are able, you should get out of bed and walk around.

After the catheter is removed from your bladder, the nurses will test that your bladder is emptying properly before you go home. This is called a trial of void. It is done by measuring the amount of urine you pass each time you go to the toilet, and then checking how empty your bladder is with an ultrasound scan. This painless test is quick and easy, and is done in the ward.
When the nurses are satisfied with the test results and your post-surgical recovery, you can generally go home.

Most women feel better within six weeks but recovery may take longer for women who have had a radical hysterectomy. The following tips may help.

**Tips**

- Rest as much as you need to. Take things easy and only do what is comfortable.
- Avoid heavy lifting for at least three months. Ask others for help around the house. Services are also available to help. See *Seeking support* on page 55.
- Check with your doctor when you can drive again. You may have to wait 2–4 weeks after the operation.
- Don’t have penetrative sexual intercourse for about six weeks after the operation to give the wound time to heal.
- Try not to become constipated. Drink plenty of water and eat lots of fresh fruit and vegetables. Your doctor may ask you to take some bowel softeners (laxatives) for a few weeks.
- Walk regularly, if you are comfortable, and wear compression stockings for two weeks, if possible, to avoid getting blood clots.

“After a hysterectomy and radiotherapy I was off work for five months. I wasn’t in pain, but I was uncomfortable and couldn’t do things I was used to doing.” *Angelica*
**Side effects**

After a hysterectomy and a bilateral salpingo oophorectomy, some women experience the following side effects:

**Problems with bladder or bowel function** – You may feel the sensation of not being able to empty your bladder completely, or emptying your bladder or bowel too slowly. These problems will improve with time. Some women need to use a small tube inserted into the urethra to help empty their bladder, but this is rare.

**Menopause** – If you have a bilateral salpingo oophorectomy and have not been through menopause before the surgery, the removal of your ovaries will cause menopause. See page 39.

**Lymphoedema** – If some of your lymph nodes are taken out, your legs may swell because your lymphatic system is not working properly. This is called lymphoedema. Symptoms may appear straightaway or some years after surgery.

Swelling in your legs can be helped by a special form of massage called manual lymphatic drainage, wearing compression garments and doing gentle exercise. A physiotherapist trained in lymphoedema management will be able to give you further advice.

You can also call the Helpline on 13 11 20 for a copy of Cancer Australia’s booklet *Lymphoedema: What you need to know*.

**Sexuality issues** – The physical and emotional changes you experience may affect how you feel about sex. See page 42.
Radiotherapy

Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply. The radiation is targeted at cancer sites and treatment is carefully planned to do as little harm as possible to your healthy body tissues.

Radiotherapy is usually given if you are not well enough for a major operation or if the cancer has spread into the tissues or lymph nodes surrounding the cervix. It may also be used after surgery or in combination with chemotherapy (see pages 33–35).

Many women have both external and internal radiotherapy.

External radiotherapy

In external radiotherapy, x-rays from a machine are directed at the cervix and other parts of your body that need treatment.

The planning session takes about 45 minutes. During this time, a simulator is used to work out where to direct the x-ray beams.

Preparation before and during each treatment session only takes a few minutes. You will lie on a metal table under the radiotherapy machine. Once the machine is turned on, you will be alone in the room, but you will still be able to talk to the radiation therapist through an intercom. The treatment is painless.

You will probably have radiotherapy from Monday to Friday for 4–6 weeks as an outpatient. You will have regular blood tests to make sure your red blood cell levels are not getting low (anaemia).
**Internal radiotherapy**

Internal radiotherapy is also called brachytherapy. The radiation source is placed inside the body close to the cancer. This means the radiation will be less likely to affect the surrounding organs.

You will be given high-dose rate (HDR) brachytherapy, which means the dose is highly concentrated. You usually need several sessions every few days or every week. Each treatment takes a few hours and you can go home the same day.

You will have a CT scan, x-ray, ultrasound or MRI scan to check the location of the tumour and to determine the best dose. You will be given a general anaesthetic, and then the radiotherapy device (implant) will be inserted into the vagina and cervix. You may have gauze packing and a stitch put into the lips of your vagina (labia) to keep the implant in place. You will also have small tubes inserted into your bladder and rectum to drain waste. You will then have another scan to check that the implant has been placed correctly.

The implant may feel uncomfortable but you will be offered pain-relievers for this. You also won’t be able to sit up in bed while the implant is in place.

*I had radiotherapy for six weeks, which I found quite difficult. I felt a burning inside my abdomen that is hard to describe.*

*Angelica*
While the brachytherapy is delivered, you will be alone in the treatment room. You may feel anxious, but talking on the phone or listening to music can help you pass the time. During treatment, nurses or other visitors may come into the room. When the door opens, the delivery of the brachytherapy cuts off automatically. Once people leave the room, the treatment will start again.

When the brachytherapy is over, the implant will be removed. If you still feel discomfort, you can take pain-relievers. You will not be radioactive and you will be able to be with other people. Your doctors will monitor you for bleeding following treatment.

**Side effects**
The side effects of radiotherapy vary depending on the strength of the radiotherapy dose and the length of your treatment. Most side effects occur during or soon after treatment, however some women experience long-term side effects. Talk to your health care team about ways you can manage any side effects.

**Lethargy and loss of appetite** – The radiotherapy will make you feel tired and you may lose your appetite. If you don’t feel like eating you can replace some meals with nutritious high-calorie drinks available from the chemist. It is often helpful to discuss this with a dietitian.

**Hair loss** – If radiotherapy is aimed at your cervix, you may lose your pubic hair. This hair may grow back after the treatment ends, but it will usually be thinner.
Diarrhoea and cystitis – Radiation passes through the bladder and bowel to reach the cervix. This may cause diarrhoea and a burning feeling when passing urine (cystitis). For suggestions on how to manage diarrhoea, see page 39. Avoiding acidic drinks but drinking water, cranberry juice and Ural® (available from chemists), can help relieve cystitis. Talk to your doctor if symptoms continue. You may need to do a urine test to rule out infection. You can also be given pain relief.

Menopause – Radiotherapy will permanently stop your ovaries from working if they weren’t removed during surgery. If you haven’t already been through menopause, you will experience menopausal symptoms. See page 39 for more information.

Shortening and narrowing of the vagina – Radiotherapy may cause internal scar tissue to form, which sometimes shortens and narrows the vagina. This is called vaginal stenosis. For more information see pages 42–43.

Chemotherapy
Chemotherapy uses drugs to kill or slow the growth of cancer cells. The aim is to destroy fast-growing cancer cells while causing the least possible damage to healthy cells. However, some healthy, fast-growing cells, such as hair and bone marrow cells, may be affected.

Chemotherapy is usually given through a vein (intravenously). You may need to stay overnight in hospital or you may be treated as an outpatient.
The number of chemotherapy sessions you have will depend on the cancer and what other treatment you are having. If you are only having chemotherapy, you will probably have it up to six times every 3–4 weeks over several months. If you have chemoradiation (see next page), you will usually have treatment every week.

**Side effects**

The side effects of chemotherapy vary according to the drugs used. You may experience nausea or vomiting, feel tired, or lose some hair from your body or head. Some women’s periods stop for a while and they may go through premature menopause.

While you’re having treatment, the chemotherapy may also reduce the number of blood cells in your body. Depending on the type of blood cells affected, you may feel very tired and will be more prone to infection such as colds and flu.

Most side effects are temporary and there are ways to prevent or reduce them. Tell your doctor or nurse about any side effects you experience.

To understand more about chemotherapy, radiotherapy and coping with side effects, call Cancer Council Helpline **13 11 20** for free copies of booklets on radiotherapy, chemotherapy and cancer and nutrition, or download them from your local Cancer Council website.
Palliative treatment

Palliative treatment helps to improve people’s quality of life by alleviating symptoms of cancer without trying to cure the disease. It is particularly important for people with advanced cancer. However, it is not just for end-of-life care and it can be used at different stages of cancer.

Often treatment is concerned with pain relief, but it also involves the management of other physical and emotional symptoms, such as depression. Treatment may include radiotherapy, chemotherapy or other medication.

For more information, call the Helpline for free copies of information on palliative care and advanced cancer, or view them online at your local Cancer Council website.
Key points

• If you have a cone biopsy or a large loop excision of the transformation zone for early cervical cancer, you may not need other treatment.

• When the cancer is more extensive, you will usually need surgery and/or a combination of chemotherapy and radiotherapy.

• You may have a hysterectomy, which is surgical removal of the uterus and cervix. Some women also need a bilateral salpingo oophorectomy, which removes the ovaries and Fallopian tubes.

• A trachelectomy removes only the cervix.

• Sometimes the doctor takes out the lymph nodes in the pelvic region too. This is a lymphadenectomy.

• It may take many weeks to recover from surgery. You should avoid heavy lifting, driving and sexual activity for a period of time.

• Radiotherapy uses x-rays to kill or damage the cancer cells. You may have external or internal radiotherapy (also called brachytherapy) or both treatments.

• Chemotherapy drugs kill or weaken cancer cells. It is usually given intravenously every 3–4 weeks.

• Chemoradiation combines chemotherapy and radiotherapy. It is usually given to women with advanced cervical cancer.

• All treatments can cause side effects. Most are temporary; others are permanent. Your health care team can help you manage different side effects.
Managing side effects

It will take some time to recover from treatment for cervical cancer. As well as physical changes, you may find that cancer has affected you emotionally too.

Side effects vary from person to person. Some women don’t experience any side effects; others may experience a few. Side effects last from a few weeks to many years. Fortunately, there are ways to reduce or manage the discomfort that side effects cause, and most go away in time.

This chapter provides information on side effects that are common to more than one type of treatment for cervical cancer. See also Cancer Council’s booklets on radiotherapy and chemotherapy for more details.

Tiredness

Many women treated for cervical cancer find that tiredness or fatigue is a major issue, particularly after radiotherapy and chemotherapy. The tiredness may continue for some time even after treatment has finished. Some women find it takes them several months or even up to a year or two to feel really well again.

Feeling tired is not only a side effect of treatment. Travelling to hospitals and clinics for treatment can be exhausting. If you work during treatment or if you have a family to care for, this will probably make you feel very tired too. It can be frustrating when other people don’t understand how tired you feel.
Bladder problems

Bladder sensations or control may change after surgery or radiotherapy. Some women find they need to pass urine more often, or feel that they need to go in a hurry. Others may lose a few drops when they cough, sneeze, strain or lift.

For ways to manage accidental or involuntary loss of urine (urinary incontinence), speak to the continence nurse or physiotherapist at your hospital. You can also contact the Continence Foundation of Australia on 1800 33 00 66 or www.continence.org.au.

The blood vessels in the bowel and bladder can become more fragile after radiotherapy. This can cause blood to appear in urine or stools, even months or years after treatment. Let your doctor know so the appropriate treatment can be given.
Bowel problems

After surgery and radiotherapy, some women find their bowel habits change. They may experience abdominal pain, constipation or diarrhoea.

- Drink peppermint or chamomile tea to reduce abdominal or wind pain.
- Drink plenty of liquids (but not alcohol) to replace fluids lost through diarrhoea or to help soften stools if you have constipation.
- Limit caffeine, spicy, greasy and processed foods as these can make diarrhoea and constipation worse.
- Talk to your doctor or a dietitian about making changes to your diet or taking medication.
- Call the Helpline for free information on nutrition and cancer, for more tips on managing digestive problems and eating well during and after cancer treatment.

Menopause

The ovaries produce the hormones oestrogen and progesterone, as well as eggs (ova). When oestrogen and progesterone are no longer made by the body, women go through menopause. This usually is a natural and gradual process, and for most women starts between the ages 45–55.

If you’ve had surgery to remove your ovaries or radiotherapy to your ovaries, they will also no longer produce these hormones.
If you are not already menopausal, this change will occur quite suddenly. The symptoms are usually more severe than a natural menopause because the body hasn’t had time to get used to a gradual decrease in hormone levels.

As can often happen during a natural menopause, you may experience hot flushes, mood swings, trouble sleeping (insomnia) and tiredness. The vagina can also lose elasticity and become dry because it needs oestrogen to stay moist.

**tips**

- Hormone replacement therapy (HRT) can help reduce symptoms of menopause. HRT has benefits and some risks, depending on your age, your general health, and sometimes the type of cancer you have had. Speak with your doctor about the benefits and risks to you as an individual.

- Locally applied oestrogen, contained in creams or pessaries, can be inserted into the vagina to relieve dryness. These creams have few side effects.

- You can also use vaginal moisturisers without oestrogen to relieve dryness.

- If you think about using complementary therapies to help ease your symptoms, check with your doctor to see whether they are safe. For example, some herbal medicines should not be taken before surgery or during chemotherapy.

- Talk to your doctor or health care team for more information.
Osteoporosis

Menopause may cause bones to become weak and brittle, and to break more easily. This is called osteoporosis.

- Eat three serves of calcium-rich food daily (e.g. yoghurt, milk, tofu, green vegetables).
- Limit alcohol to no more than two standard drinks a day and do not smoke.
- Get vitamin D from sun exposure before 10am and after 3pm – a few minutes per day in summer, and 2–3 hours per week in winter.
- Do weight-bearing exercise, such as walking or dancing. Ask your GP what is suitable.
- Call Osteoporosis Australia on (02) 9518 8140 for more tips.

Heart disease

After menopause, cholesterol levels can change and this can increase your risk of heart disease. Lifestyle changes can reduce your risk of heart attack and stroke.

- Ask your doctor to check your cholesterol levels. If high, seek advice about medications and/or diet.
- Eat lots of fruit, vegetables and fibre, and occasional lean meat and oily fish.
- Reduce your saturated fat intake (e.g. found in meat, palm oil and butter).
- Maintain a healthy weight.
- Increase your fitness.
- Don’t smoke.
Sexuality issues

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as your treatment and its side effects, the way you and your partner communicate, and your self-confidence. Knowing the potential challenges and addressing them will help you adjust to these changes. Sexual intercourse may not always be possible, but closeness and communication are vital to a healthy relationship.

A lack of interest or loss of desire for sex (low libido) is common because of the physical and emotional effects of treatment. If you do not feel like having sex, or if you find penetration uncomfortable, let your partner know. It is normal to take some time for sex to be comfortable again.

The main effect of treatment will be on your vagina. If the ovaries have been affected by surgery or radiotherapy, they will no longer produce oestrogen. This will cause dryness in your vagina and it may not expand as easily during sexual intercourse.

Radiotherapy can also cause the vagina to narrow or shorten (vaginal stenosis). This can make sex uncomfortable, but should not affect your ability to reach orgasm. See the tips on the next page for ways to keep your vagina open and more elastic.

Call 13 11 20 for a free copy of information on sexuality and body image after cancer treatment. For further information about relationships and body image, see page 51.
Infertility
Because treatment for cervical cancer affects the reproductive organs, after some procedures it will no longer be possible to become pregnant. For example, in a hysterectomy, the uterus is removed; after radiotherapy to the cervix, the ovaries stop working. These cause infertility. However, for some women there may be options for having children after treatment.

Many women experience a sense of loss when they learn that their reproductive organs will be removed or will no longer function. You may feel devastated if you are no longer able to have children and may worry about the impact of this on your relationship. Even if your family is complete, you may have mixed emotions. These reactions are not unusual.

You may be given vaginal dilators to help keep your vagina open and to prevent vaginal stenosis. A dilator is a tube-shaped device made of plastic or rubber designed to gently stretch the vagina. Ask your nurse or radiation therapist for information on how to use them.

Apply a vaginal lubricant to relieve dryness and tenderness. Some women find olive oil a good form of lubrication.

Have regular gentle sex to help widen the vagina, if you are ready and able to.

Ask your doctor about short-term hormone replacement therapy (HRT), which may help with side effects caused by a loss of oestrogen.
As well as talking to your partner about your feelings, speaking to a counsellor or a gynaecological oncology nurse may help.

If you have not been through menopause, talk to your doctor about ways to preserve your fertility before you have treatment. Your doctor may refer you to a fertility specialist. One option may be to store eggs or embryos before treatment for use in the future by a surrogate. If you require radiotherapy but your ovaries do not need to be treated, you may be able to have a surgical procedure to move the ovaries upwards into your abdomen to try to avoid the effects of radiation.

If you have a radical trachelectomy it may still be possible to become pregnant. However, mid-trimester miscarriage and premature delivery are more common. Discuss these risks with your doctor.
Managing side effects

Key points

• Many women experience side effects following treatment for cervical cancer. These may be caused by surgery, radiotherapy or chemotherapy. Side effects can last a few weeks, for many months or permanently.

• Tiredness is a common problem. Try to plan activities around your energy levels and talk to your family and friends about ways they can help you.

• Bladder and bowel problems may occur after treatment. Your doctor can give you suggestions on how to cope with these problems.

• Surgery or radiotherapy to the ovaries will cause menopause. You may have symptoms such as hot flushes, mood swings and insomnia. Your doctor may prescribe medication to help ease these.

• Menopause increases the risk of heart disease and osteoporosis. Talk to your doctor for advice on reducing your risk or managing these problems. Making some simple changes to your diet and activity levels can help.

• Sexuality issues following treatment are common. Both you and your partner will need to adjust to these changes. Communication is important, and a counsellor or sexual health physician can help you with other strategies.

• Some women are not able to have children after treatment for cervical cancer. This can be devastating and you may want to speak to your doctor or a counsellor about your feelings. Speak to your doctor about your options for preserving fertility.
Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast you don’t have time to think things through, but there is usually time to consider what sort of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, others want as much information as they can find. Making sure you understand enough about your disease, the treatment and its side effects will help you make your own decisions.

• If you are offered a choice of treatments, you will need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, particularly those that affect your lifestyle.
• If you have a partner, you may also want to talk about treatment options with them. You can also talk to friends and family.
• If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.

You have the right to accept or refuse any treatment.

Some people with more advanced cancer will choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects so they have the best possible quality of life. Some people may choose options that don’t try to cure the cancer but make them feel as well as possible.
Talking with doctors

When your doctor first tells you that you have cancer it is very stressful and you may not remember many details about what you are told. You may want to see the doctor a few times before deciding on treatment.

If your doctor uses medical terms you don’t understand, it’s okay to ask for a simpler explanation. You can also check a word’s meaning in the glossary (see page 63).

Before you see the doctor it may help to write down your questions – see the list of suggested questions on the page 62. Taking notes or recording the discussion can also help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you have several questions for your doctor, you may want to book a longer appointment.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor’s recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.
Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You may decide you would prefer to be treated by the doctor who provided the second opinion.

**Taking part in a clinical trial**

Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments to see if they are better than current treatments. Over the years, clinical trials have improved cancer treatment standards and led to better outcomes for patients.

If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

If you decide to join a randomised controlled trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being part of a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your treatment for cancer.

For more information about clinical trials and other research, including questions to ask your doctor and how to find a suitable study, call 13 11 20 or go to www.australiancancertrials.gov.au.
Looking after yourself

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and improve well-being. Addressing changes in your emotions and relationships early on is also very important.

Healthy eating
Eating nutritious food will help you to keep as well as possible and cope with cancer and treatment side effects. Depending on your treatment, you may have special dietary needs. A dietitian can help you to plan the best foods for your situation. Cancer Council Helpline can send you free information about nutrition and cancer.

Being active
You will probably find it helpful to stay active and to exercise regularly if you can. Physical activity – even if gentle or for a short duration – helps to improve circulation, reduce tiredness and elevate mood. The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises.

If you aren’t used to exercise or haven’t exercised for a while, make small changes to your daily activities. You could walk to the shops or join a gentle exercise class. Incidental activity, such as walking up stairs, stretching or gardening, is helpful too. To do more vigorous exercise or weight-bearing exercise, ask your medical team what is best for you.
Complementary therapies

Complementary therapies are treatments that may help you cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, including acupuncture, massage, relaxation, meditation and herbal medicine. While some cancer treatment centres offer complementary therapies as part of their services, you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through some different techniques.

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your conventional treatment. For example, herbs and nutritional supplements may interact with your medication or surgery, resulting in harmful side effects. Massage, acupuncture and exercise therapies may also need to be modified if you have lowered immunity, low platelets or fragile bones. Call the Helpline for more information and resources about complementary therapies.

Alternative therapies are commonly defined as those used instead of conventional treatments. These therapies may be harmful if people with cancer delay or stop using conventional treatments in favour of them. Examples include high-dose vitamin supplements, coffee enemas and magnet therapy.
Relationships with others

For many people, the experience of having cancer and any ongoing challenges causes them to make some changes in their life. You may also have a new outlook on your values, priorities and life in general.

Sharing your those thoughts and feelings with family, friends and colleagues may help to strengthen your relationships with them. If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready.

Give yourself time to adjust to your cancer diagnosis, and do the same for your friends and family. People often react in different ways, for example being overly positive, playing down fears, or keeping a distance. They are also dealing with the diagnosis and the changes.

Look Good...Feel Better program

Cancer treatments, such as chemotherapy and radiotherapy, can sometimes cause side effects such as hair loss and skin irritation. These changes can make you feel self-conscious.

Look Good...Feel Better is a free two-hour program for both men and women to teach them techniques using skin care, hats and wigs to help restore appearance and self-esteem during and after treatment.

Call 1800 650 960 or visit www.lgfb.org.au for more information and to book into a workshop.
Changing body image
Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

For practical suggestions about hair loss, weight changes and other physical changes, call Cancer Council Helpline.

Life after treatment
You may be surprised to find out that life after cancer treatment can present its own challenges. You will need to take some time to adjust to physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than secure. You might worry about every ache and pain and wonder if the cancer is coming back.

Some people say that after cancer they have changed priorities and see life with a new clarity. For example, you may decide to travel, spend more time with family, change careers or do volunteer work.
Although you might feel pressure to return to normal life, it’s important to remember that you may not want your life to return to how it was before cancer.

You might find it helpful to:
• take time to adjust to physical and emotional changes
• re-establish a new daily routine at your own pace
• maintain a healthy diet and lifestyle
• schedule regular checkups with your doctor
• share your concerns with family and friends and tell them how to support you
• call the Helpline on 13 11 20 to connect with other people who have had cancer, or to request a free booklet about life after cancer.

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, talk to your doctor. You may be clinically depressed, and counselling or medication may help you.

**After treatment: follow-up**

After treatment, you will need regular checkups to make sure the cancer hasn’t come back. Blood tests, x-rays or other scans may be done. Most women will need to continue to have regular Pap tests too. Talk to your doctor about the checkups you need.

Checkups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any health problems.
What if cervical cancer returns?
For some people, cervical cancer does come back after treatment, which is known as a relapse. This is why it is important to have regular checkups. If it does return, you will usually be offered surgery or chemotherapy. You will only be able to have radiotherapy if you did not have it the first time you had treatment.

“I really felt alone when the treatments were finished and I worried about the cancer coming back. I found talking to other people who’d been through the same thing so important.” —Survivor
When you are first diagnosed with cancer, and throughout the different stages of your treatment and recovery, it is normal to experience a range of emotions, such as fear, sadness, anxiety, anger and frustration. If sadness or anxiety is ongoing or severe, talk to your doctor.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:

- members of your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 57
- Cancer Council Helpline.

If you need practical assistance, such as help around the house, it may be hard to tell people what would be useful. You might prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people you know are supportive, others struggle to know what to say to you. If you have children, the prospect of telling them you have cancer can be unsettling. Cancer Council has a range of resources to help people talk about cancer and deal with the emotions that cancer brings up.

Call 13 11 20 for resources and support. You can also download booklets from your local Cancer Council website.
Practical and financial help

A serious disease often causes practical and financial difficulties.

Many services are available so you don’t have to face these difficulties alone:

• Financial or legal assistance – through benefits, pensions and programs – may help pay for prescription medicines, transport costs to medical appointments, utility bills or basic legal advice.
• Meals on Wheels, home care services, aids and appliances can be arranged to make life easier at home.
• Subsidised travel and accommodation may be available if you need to travel long distances for treatment.
• Home nursing care may be available through community nursing services or local palliative care services.

Ask Cancer Council Helpline or your hospital social worker, occupational therapist or physiotherapist, which services are available in your area and if you are eligible to receive them.

Cancer Council library*

Following a cancer diagnosis many people look for information about new types of treatment, the latest research findings and stories about how other people have coped. Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you. Call the Helpline for more information.

*Not available in Victoria and Queensland
Talk to someone who’s been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. There are many ways for you and your family members to connect with others for mutual support and to share information.

In these support settings such as a gynaecological cancer support group, people often feel they can speak openly and share tips with others. You may find that you are comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Ask your nurse, social worker or Cancer Council Helpline about suitable support groups and peer support programs in your area.

Types of support services*

- **Face-to-face support groups** – often held in community centres or hospitals

- **Online discussion forums** – where people can connect with each other any time – see [www.cancerconnections.com.au](http://www.cancerconnections.com.au)

- **Telephone support groups** – for certain situations or types of cancer, which trained counsellors facilitate

- **Peer support programs** – match you with a trained volunteer who has had a similar cancer experience, e.g. Cancer Connect.

*Not available in all areas
You may be reading this booklet because you are caring for someone with cancer. Being a carer can be very stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and some types of programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many organisations and groups that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Association in each of the state and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information and resources.

You can also call Cancer Council Helpline 13 11 20 to find out more about different services and to request free information for carers and families looking after someone with cancer.
Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

**Australian**

Cancer Council Australia ..............................www.cancer.org.au
Cancer Australia ........................................www.canceraustralia.gov.au
Cancer Institute NSW ..............................www.cancerinstitute.org.au
Health Insite ........................................www.healthinsite.gov.au
Gynaecological Cancer Society ......................www.gcsau.org
Gynaecological Cancer Support .................www.gynaecancersupport.org.au
Gynaecological Awareness Information Network ........................................www.gain.org.au
Immunise Australia Program .................www.immunise.health.gov.au
Osteoporosis Australia ..............................www.osteoporosis.org.au
Heart Foundation ......................................www.heartfoundation.org.au

**International**

American Cancer Society .........................www.cancer.org
Macmillan Cancer Support .................www.macmillan.org.uk
HysterSisters Woman-to-Woman
Hysterectomy Support ..........................www.hystersisters.com
Be Cervix Savvy ......................................www.becervixsavvy.co.uk
You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don’t understand, it is okay to ask for clarification.

- What type of cervical cancer do I have?
- How extensive is the cancer?
- What treatment do you recommend and why?
- Will it cost me anything?
- What are the risks and possible side effects of each treatment?
- Are there other treatment choices for me? If not, why not?
- How long will treatment take? Will I have to stay in hospital?
- Will I have a lot of pain with the treatment? What will be done about this?
- Will the treatment affect my sex life?
- Will the cancer or treatment affect my fertility?
- Are there any clinical trials of new treatments?
- How frequently will I have checkups?
- Are there any complementary therapies that might help me?
You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words at www.cancercouncil.com.au/words or www.cancervic.org.au/glossary.

**adenocarcinoma**
A cancer that starts in the glandular cells of the cervix.

**advanced cancer**
Cancer that has spread deeply into surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

**anaesthetic**
A drug that stops a person feeling pain during a medical procedure. Local anaesthetic numbs part of the body; general anaesthetic makes a person lose consciousness for some time.

**atypia**
Slight changes in the cells of the cervix that could be precancerous abnormalities.

**bilateral salpingo oophorectomy**
Surgical removal of the ovaries and Fallopian tubes.

**biopsy**
The removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease.

**brachytherapy**
A type of internal radiotherapy in which an implant of radioactive material is placed into or near cancerous cells.

**catheter**
A hollow, flexible tube through which fluids can be passed into the body or drained from it.

**cells**
The building blocks of the body. A human is made of billions of cells that are adapted for different functions.

**cervical intraepithelial neoplasia (CIN)**
Abnormal changes in the surface
of the cervix. These changes are not cancer but are precancerous cells. Also called dysplasia.

cervix
The end of the uterus that forms a canal and extends into the vagina.

chemoradiation
Treatment that combines chemotherapy and radiotherapy.

chemotherapy
The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

colposcope
An instrument that enables the doctor to see an enlarged view of the cervix, vagina and vulva from outside the body.

colposcopy
Examination of the cervix with a magnifying instrument called a colposcope.

cone biopsy
Removal of a cone-shaped piece of the cervix for examination under a microscope.

CT scan
A computerised tomography scan. It uses x-rays to create a picture of the body.

cystoscope
A lighted viewing instrument that is inserted into the urethra and advanced into the bladder.

cystoscopy
A test using a cystoscope to examine the vagina, cervix, bladder and rectum. It is performed under a general anaesthetic.

diethylstilboestrol (DES)
A medication given to women to prevent miscarriage from the 1950s–1970s. It is now linked to some rare forms of cancer.

dilation and curettage (D&C)
When the cervix is dilated and the lining of the uterus (endometrium) is scraped out.

dysplasia
See cervical intraepithelial neoplasia (CIN).

ectocervix
The outer layer of the cervix.

endocervix
The cells lining the cervical canal.
**endometrium**
The inner lining of the uterus.

**epithelial abnormality**
Changes in the cells of the cervix.

**epithelium**
Layers of cells covering internal and external surfaces of the body, including the cervix.

**glandular cell**
A type of cell found in the endocervix.

**grade**
A score showing how deeply into tissue abnormal cells have grown.

**gynaecology oncologist**
A doctor who specialises in treating cancers of the female reproductive system.

**hormone replacement therapy (HRT)**
Drug therapy that supplies the body with hormones that it is no longer able to produce.

**hormones**
Chemicals in the body that send information between cells.

**human papillomavirus (HPV)**
A group of viruses that can cause infection on different surfaces of the body, including the genitals. Some strains increase the risk of cervical cancer. Also called a wart virus.

**hysterectomy**
Surgical removal of the uterus and cervix.

**invasive cervical cancer**
Cancer that has spread deep into tissues at the primary site, and/or to other parts of the body.

**laparoscopy**
Surgery done through small cuts in the abdomen using a laparoscope for viewing. Also called keyhole surgery.

**large loop excision of the transformation zone**
A procedure used to remove cervical tissue for examination.

**lesion**
An area of abnormal tissue.
lymph nodes
Small, bean-shaped glands in the lymphatic system. Also called lymph glands.

lymphadenectomy
Removal of the lymph nodes from a part of the body. Also called a lymph node dissection.

lymphatic system
A network of capillaries, ducts and nodes that removes fluid from tissues, absorbs fat, and produces immune cells.

lymphoedema
Swelling caused by a build-up of lymph.

malignant
Cancer. Malignant cells can spread (metastasise) and may eventually cause death if they cannot be treated.

menopause
When a woman stops having periods (menstruating).

metastasis
A cancer deposit that has spread from a primary cancer in another part of the body.

MRI scan
A magnetic resonance imaging scan. It uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

oestrogen
A female sex hormone mainly produced by the ovaries that helps mature and regulate the female reproductive system.

Pap smear
A test that can detect changes in cervical cells. Some cells are scraped off the cervix and sent to a laboratory for examination. Also called a Pap test.

pelvic sidewall
A structure of bone and ligament on the side of the pelvis.

pessary
A solid medicinal substance that is inserted into the vagina where it will dissolve.

PET scan
A positron emission tomography scan. This uses radioactive glucose to identify cancer cells.
prognosis
The expected outcome of a person’s disease.

radiotherapy
The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

class effect
The unintended effects of a drug or a treatment.

speculum
An instrument used to hold open the walls of the vagina so the cervix can be examined.

transformation zone
The area in the cervix where the squamous cells and the glandular cells meet. Also called the squamocolumnar junction.

trial of void
A test to see how much urine you produce (void) when you go to the toilet.

tumour
An abnormal growth of tissue on or in the body.

uterus
The hollow muscular organ where a fertilised egg grows into a baby. Also called the womb.

vagina
The passage leading from the vulva to the uterus in females.

vaginal stenosis
Shortening and narrowing of the vagina.
How you can help

At Cancer Council we’re dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia’s Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.
Cancer Council Helpline is a telephone information service provided throughout Australia for people affected by cancer.

For the cost of a local call (except from mobiles), you, your family, carers or friends can talk confidentially with oncology health professionals about any concerns you may have. Helpline consultants can send you information and put you in touch with services in your area. They can also assist with practical and emotional support.

You can call Cancer Council Helpline 13 11 20 from anywhere in Australia, Monday to Friday. If calling outside business hours, you can leave a message and your call will be returned the next business day.

Visit your state or territory Cancer Council website

Cancer Council ACT  
www.actcancer.org

Cancer Council Northern Territory  
www.cancercouncilnt.com.au

Cancer Council NSW  
www.cancercouncil.com.au

Cancer Council Queensland  
www.cancerqld.org.au

Cancer Council SA  
www.cancersa.org.au

Cancer Council Tasmania  
www.cancertas.org.au

Cancer Council Victoria  
www.cancervic.org.au

Cancer Council Western Australia  
www.cancerwa.asn.au
For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.