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

For information & support, call 131120
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Understanding Cervical Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.


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The illustration on page 7 has been adapted from An abnormal Pap smear result – what this means for you (National Cervical Screening Program; ISBN 0 642 82958 6). Used by permission of the Australian Government.

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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 medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council
Cancer Council is Australia’s peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.

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

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

We cannot give advice 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 to ask your treatment team.

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

How this booklet was developed
This information was developed with help from a range of health professionals and people affected by cervical cancer. It is based on international clinical practice guidelines for cervical cancer.¹

If you or your family have any questions, call Cancer Council 13 11 20. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.
What is cancer?

Cancer is a disease of the cells, which are the body’s basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don’t grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).
The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis).

If cancerous cells grow and form another tumour at a new site, it 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 called metastatic cervical cancer, even though the person may be experiencing symptoms caused by problems in the lungs.

**How cancer spreads**

- Primary cancer
- Local invasion
- Angiogenesis – tumours grow their own blood vessels
- Lymph vessel
- Metastasis – cells invade other parts of the body via blood vessels and lymph vessels
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 external genitals).

Also called the neck of the uterus, the cervix connects the uterus to the vagina. It has an outer surface (lining) that opens into the vagina and an inner surface that faces into the uterus.

The functions of the cervix include:
- producing moisture to lubricate the vagina, which keeps the vagina clean
- producing mucus that helps sperm travel up to the fallopian tube to fertilise an egg that has been released from the ovary
- holding a developing baby in the uterus during pregnancy
- widening to enable a baby to be born via the vagina.

The cervix is covered by two kinds of cells:

**Squamous cells** – flat, thin cells that are found on the outer surface of the part of the cervix that opens into the vagina (ectocervix). Cancer of the squamous cells is called squamous cell carcinoma (see page 10).

**Glandular cells** – column-shaped cells that are found on the inner surface of the cervix (cervical canal or endocervix). Cancer of the glandular cells is called adenocarcinoma (see page 10).

The area where the squamous cells and glandular cells meet is called the transformation zone. This is where most cervical cancers start.
The female reproductive system

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

- Glandular cells
- Transformation zone
- Squamous cells
Cervical cell changes

Sometimes the squamous cells and glandular cells in the cervix start to change and no longer appear normal when they are examined under a microscope. These changes are called precancerous lesions. This means there is a lesion (area of abnormal tissue) that is not cancer but may lead to cancer.

Cervical cell changes may be found during a routine screening test (see pages 14–15).

For some women, these precancerous lesions will disappear without treatment. Other lesions can be treated before they develop into cervical cancer. Treatment may include large loop excision of the transformation zone (see page 18), laser surgery (page 19), a cone biopsy (page 19) or dilation and curettage (page 23). Only some women with precancerous changes of the cervix will develop cervical cancer.

There are different types of precancerous changes:

**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 cervical cancer or will get cancer. Atypia can be caused by an infection, such as HPV (see page 12), or irritation.

**Squamous abnormalities** – The squamous cells of the cervix are abnormal. This abnormality may be classified as low grade or high grade. Low-grade abnormalities usually disappear without
treatment. High-grade abnormalities are precancerous. Although they do not usually cause symptoms, high-grade abnormalities in the cervix have the potential to progress to early cervical cancer over about 10–15 years if they are not detected and treated.

**Glandular abnormalities** – The glandular cells of the cervix are abnormal. These abnormalities always require further testing, as they may be either precancerous or cancerous.

If the results from a screening test show that your cervix has any of the abnormal changes described above, your doctor will recommend one of the following options depending on the grade of the changes:
- another screening test in 6–12 months to monitor the cells
- a biopsy to look at the cells in more detail using an instrument called a colposcope (see pages 16–17)
- immediate treatment (see pages 18–20 and 23).

**Squamous abnormalities and CIN**
Squamous abnormalities are also called cervical intraepithelial neoplasia (CIN). They are graded according to how deep the abnormal cells are within the surface of the cervix. This is detected by taking a sample of tissue (biopsy, see page 17) from the surface of the cervix. Early changes are graded as CIN 1, and they will usually disappear without treatment. Further abnormal changes are graded as CIN 2 or CIN 3 and will require treatment (see pages 18–20).
Key questions

Q: What is cervical cancer?
A: Cervical cancer is the growth of abnormal cells in the lining of the cervix.

Cancer most commonly begins in the area of the cervix called the transformation zone (see page 6), but it may spread to tissues around the cervix, such as the vagina, or to other parts of the body, such as the lungs or liver.

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

- **Squamous cell carcinoma** – the most common type, accounting for about 70% of cases.

- **Adenocarcinoma** – a less common type, starting in the glandular cells of the cervix. Adenocarcinoma is more difficult to diagnose because it occurs higher up in the cervix and is harder to reach with the instruments a doctor uses during a screening test (see pages 14–15).

A small number of cervical cancers feature both squamous cells and glandular cells. These cancers are known as adenosquamous carcinomas or mixed carcinomas.

Other rarer types of cancer that can start in the cervix include small cell carcinoma and cervical sarcoma.
Q: How common is it?
A: About 800 women in Australia are diagnosed with cervical cancer every year. Cervical cancer accounts for about 1.5% of all cancers diagnosed in women.

The incidence of cervical cancer in Australia has decreased significantly since a national screening program was introduced in the 1990s.

Q: What are the symptoms?
A: In its early stages, cervical cancer usually has no symptoms. The only way to know if there are abnormal cells in the cervix, which may develop into cervical cancer, is to have a screening test (see pages 14–15).

If symptoms are present, they usually include:
- vaginal bleeding between periods, after menopause or after sexual intercourse
- pain during sexual intercourse
- an unusual vaginal discharge
- heavier periods or periods that last longer than usual
- excessive tiredness
- leg pain or swelling
- lower back pain.

These symptoms can also be caused by other conditions. See your general practitioner (GP) if you are worried or the symptoms are ongoing.
Q: What are the causes and risk factors?

A: Most cases of cervical cancer are caused by an infection called human papillomavirus (HPV). There are also other known risk factors (see pages 13–14).

**HPV** — Human papillomavirus is the name for a group of viruses. HPV is a common infection that affects the surface of different areas of the body, such as the cervix, vagina and skin.

There are more than 100 different types of HPV, including more than 40 types of genital HPV. Some types of HPV cause common warts on the hands and feet.

Genital HPV is usually spread via the skin during sexual contact. About four out of five people will become infected with genital HPV at some time in their lives. Most people will not be aware they have HPV as it is usually harmless and doesn’t cause symptoms.

In most women, the virus is cleared quickly by the immune system and no treatment is needed.

Only a few types of genital HPV cause cervical cancer. Screening tests are used to detect these types of HPV or the precancerous cell changes caused by the virus. See pages 14–15 for more information on screening tests. There is also a vaccination against HPV.
Smoking and passive smoking – Chemicals in tobacco can damage the cells of the cervix, making cancer more likely to develop in women with HPV.

Weakened immune system – The immune system helps the body get rid of HPV. Women with a weakened immune system are at increased risk of cervical cancer. This includes women with HIV (the virus that causes AIDS) and women who take medicines that lower their immunity. Ask your doctor if this applies to you.

National HPV Vaccination Program

The HPV vaccine provides protection against two strains of HPV that are known to cause 70–80% of cervical cancers. The vaccine also offers some protection against other less common cancers in women, including vaginal, vulvar and anal cancers.

As part of the National HPV Vaccination Program, the vaccine is free for girls and boys aged 12–13 (the vaccine helps to protect males against penile and anal cancers).

Some older people who are already sexually active may still benefit from the HPV vaccine. Ask your GP for information.

The HPV vaccine cannot be given to treat precancerous changes or cervical cancer. It does not provide protection against all types of HPV, so it is important to continue having screening tests even if you’ve been vaccinated.

For more information, visit hpvvaccine.org.au.

Key questions
Taking an oral contraceptive (the pill) – Research has shown that women who have taken the pill for five years or more are at increased risk of developing cervical cancer.\textsuperscript{4} The reason for this is not clear. However, the risk is small and the pill can help protect against other types of cancer, such as uterine and ovarian cancers. Talk to your doctor if you are concerned.

Diethylstilbestrol (DES) exposure – DES is a synthetic (artificial) form of the female hormone oestrogen. DES was prescribed to pregnant women from the 1940s to the early 1970s to prevent miscarriage.

Studies have shown that the daughters of women who took DES have a small but increased risk of developing a rare type of cervical adenocarcinoma.\textsuperscript{5}

**Q:** What is a screening test?

**A:** Screening tests help to detect cancer in people who don’t have any symptoms. The Pap test (also called a Pap smear) has been used as a screening test for cervical cancer in Australia for several decades.

However, scientific evidence has found that screening women for HPV – the virus that causes cervical cancer – is a more effective way of preventing cervical cancer.\textsuperscript{6} For this reason, in December 2017, an HPV test will replace the Pap test as part of the National Cervical Screening Program.
The current program recommends two-yearly Pap tests for women aged 18–70 who are or have ever been sexually active. Under the new program, women aged 25–74 will be tested for HPV every five years.

During both the Pap test and HPV test, the doctor gently inserts an instrument called a speculum into the vagina to get a clear view of the cervix. The doctor uses a brush or spatula to remove some cells from the surface of the cervix. This can feel slightly uncomfortable, but it usually takes only a minute or two. The sample is placed onto a glass slide or put into a fluid and then sent to a laboratory for examination by a pathologist.

The results of the screening test are used to predict your level of risk for precancerous cell changes or cervical cancer. If the results show a higher risk, your GP may refer you to a specialist (gynaecologist) to discuss:

- whether you need further tests or treatment
- how you will be regularly monitored, including whether you will have another screening test immediately or more frequent screening tests in the future.

For more information about screening tests, call Cancer Council 13 11 20 or visit cervicalscreens.health.gov.au.

It is very important to continue having regular Pap tests every two years until the new HPV test is introduced in 2017.
Diagnosis

If your screening test results suggest that you have a higher risk of developing cervical cancer, or you have symptoms of cancer, you will be referred to a specialist for tests to confirm the diagnosis of precancerous changes or cervical cancer.

Some tests allow your doctor to see the tissue in your cervix and surrounding areas more clearly. Other tests tell the doctor about your general health and whether the cancer has spread. You probably won’t need to have all the tests described in this chapter.

Colposcopy

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

While you are lying on your back, the doctor will insert an instrument called a speculum into your vagina to get a clear view of your cervix and vagina. The doctor may coat your cervix and vagina with a fluid to highlight any abnormal areas.

Using an instrument called a colposcope, which has a light and looks like a pair of binoculars sitting on a large stand (see diagram opposite), the doctor can see a magnified picture of your cervix and vagina. The colposcope won’t be put inside you.

You may experience some mild discomfort for 10–15 minutes during the colposcopy. Some colposcopes are fitted with a camera that is connected to a TV screen so you have the option of watching what the doctor is doing.
A biopsy may be done during the colposcopy. A biopsy is when the doctor removes some tissue from the surface of the cervix and sends it to a laboratory for examination under a microscope. You will be given a local anaesthetic to numb the cervix so you won't feel any pain. You will be able to go home once the colposcopy and biopsy are over. The results will be available in about a week.

Side effects of a colposcopy with biopsy
During a biopsy, you may feel uncomfortable for a short time while the tissue sample is taken. After the procedure, it is common to experience cramping that feels similar to menstrual pain. You can ask for medicine to relieve any pain. You may also have some light bleeding or other vaginal discharge for a few hours.
To allow the cervix to heal and to reduce the risk of infection, your doctor will probably advise you not to have sexual intercourse or use tampons for 2–3 days after a biopsy.

**Large loop excision of the transformation zone (LLETZ)**

A LLETZ is a procedure to remove cervical tissue for examination and to treat some precancerous changes of the cervix.

A thin wire loop heated by an electrical current is used like a scalpel to remove the abnormal tissue from the transformation zone of the cervix. Sometimes the doctor can remove all visible abnormal cells.

A LLETZ is usually done under a local anaesthetic in the doctor’s office or, sometimes, under a general anaesthetic in hospital. It takes about 10 minutes. Sometimes it is done at the same time as a colposcopy and biopsy (see pages 16–17).

Once the tissue sample has been taken, it will be sent to a laboratory for examination under a microscope. The results will be available in about a week.

**Side effects of a LLETZ**

After a LLETZ, you may have some vaginal bleeding and cramping. This will usually ease in a few weeks. To give your cervix time to heal and to prevent infection, you should not have sexual intercourse or use tampons for 4–6 weeks after the procedure.
A LLETZ does not usually affect your ability to become pregnant, but it may slightly increase your risk of having the baby prematurely. Talk to your doctor before the procedure if you are concerned.

**Laser surgery**

A laser can be used to remove tissue from the cervix and to treat some precancerous changes in the cervix. Local anaesthetic is injected into the cervix and a laser beam is used to remove some tissue. Laser surgery is just as effective as LLETZ and may be a better option if the precancerous cells extend into the wall of the vagina or if the lesion on the cervix is very large. The side effects of laser surgery are similar to those of LLETZ.

**Cone biopsy**

A cone biopsy is done to determine how deeply cancer cells have spread into tissue beneath the surface of the cervix. It is also used to treat very small, early-stage tumours. It is called cone biopsy because a cone-shaped piece of tissue is removed from the cervix.

The cone biopsy is usually done under a general anaesthetic and involves a day or overnight stay in hospital. Results are usually available in a week.

**Side effects of a cone biopsy**

You may have some light bleeding or cramping for a few days after the cone biopsy. Avoid doing anything strenuous for a few weeks, as this could cause the bleeding to become heavier or start again.
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 after the procedure.

A cone biopsy may weaken the cervix. If you would like to become pregnant in the future, talk to your doctor before the procedure. It is usually still possible to become pregnant, but you may be at a higher risk of having a miscarriage or having the baby prematurely. Some women who become pregnant after a cone biopsy have stitches inserted into the cervix to strengthen it. These stitches are usually removed before the baby is born.

Further tests
If any of the tests described on pages 16–20 show that you have cervical cancer, you may need to have further tests to
help the doctor work out whether the cancer has spread to other parts of your body. This is called staging (see page 24). You may have one or more of the tests described on the following pages.

**Blood test and chest x-ray**
You may have a blood test to check your general health and how well your kidneys and liver are working. You may also have an x-ray of your chest so the doctor can check your lungs for signs of cancer.

**CT scan**
A CT (computerised tomography) scan is a type of x-ray that takes detailed, three-dimensional pictures of the inside of the body. The scan can show whether the cancer has spread to lymph nodes in the abdomen or pelvis or to other organs in the body.

Before the scan, you may be given a drink or an injection of a dye. This may make you feel hot all over for a few minutes. You may also be asked to insert a tampon into your vagina. The dye and the tampon make the pictures clearer and easier to read.

The CT scanner is large and round like a doughnut. You will lie flat on a table that moves in and out of the scanner. The scan is painless and takes 5–10 minutes.

The dye used in a CT scan usually contains iodine. If you know you’re allergic to iodine or dyes, let the person performing the scan know in advance. You should also tell the doctor if you’re diabetic, have kidney disease or are pregnant.
**MRI scan**

An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to create detailed pictures of areas inside the body. Sometimes, dye will be injected into a vein before the scan to help make the pictures clearer.

During the scan, you will lie on a table that slides into a metal cylinder that is open at both ends. The machine makes a series of bangs and clicks and can be quite noisy. You will usually be given headphones to help block out the noise.

The scan is painless, but some people feel anxious lying in the narrow cylinder. Tell your doctor or nurse beforehand if you are prone to anxiety or claustrophobia. They can suggest breathing exercises or give you medicine to help you relax.

You will be asked to complete a checklist before the scan that asks whether you have any metal implants in your body, such as a pacemaker. If you do have any metal in your body, you may not be able to have an MRI scan.

The scan takes less than an hour, and most people are able to go home as soon as it is over.

**PET scan**

Before a PET (positron emission tomography) scan, you will be injected with a small amount of a glucose (sugar) solution containing some radioactive material. You will be asked to rest for 30–60 minutes while the solution spreads throughout your body.
Your body will then be scanned for high levels of radioactive glucose. Cancer cells show up brighter on the scan because they absorb more of the glucose solution than normal cells do.

It may take a few hours to prepare for a PET scan, but the scan itself usually takes about one hour. The radioactive material in the glucose solution is not harmful and will leave your body within a few hours.

**Examination under anaesthetic**
The doctor may want to examine your cervix, vagina, uterus, bladder and rectum to check whether the cancer has spread. For this procedure, you will need to have a general anaesthetic in hospital.

If the doctor sees any abnormal areas of tissue during the procedure, they will take a biopsy (see pages 17–18) and send the sample to a laboratory for examination.

**Pelvic examination** – The doctor will insert a speculum into your vagina to get a clear view of your cervix and vagina.

**Uterus** – The cervix will be dilated (stretched) and some of the cells in the lining of the uterus (endometrium) will be removed and sent to a laboratory for examination under a microscope. This is called a dilation and curettage (D&C). A D&C is also sometimes used to treat precancerous changes in the cervix (see pages 8–9).

**Bladder** – A thin tube with a lens and a light called a cystoscope will be inserted into your urethra (the tube that carries urine from the bladder to the outside of the body) to examine your bladder.
Rectum – The doctor will use a gloved finger to check for any abnormal growths inside your rectum. To examine your rectum more closely, the doctor may insert an instrument called a sigmoidoscope, which is a flexible tube with a camera attached.

You will most likely be able to go home from hospital on the same day as the examination under anaesthetic. You may have some light bleeding and cramping for a few days afterwards. Your doctor will talk to you about side effects you may experience.

Staging cervical cancer
The tests described in this chapter show whether you have cervical cancer, the size of the tumour and whether it has spread (the stage). Knowing the stage helps doctors plan the best treatment for you. One of the following stages will be used to describe the cancer:

<table>
<thead>
<tr>
<th>Stage I</th>
<th>The cancer is found only in the tissue of the cervix.</th>
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<tbody>
<tr>
<td>Stage II</td>
<td>The cancer has spread outside the cervix to the upper part of the vagina or other tissue next to the cervix.</td>
</tr>
<tr>
<td>Stage III</td>
<td>The cancer has spread to the tissue on the side of the pelvis (pelvic sidewall) and/or the lower part of the vagina.</td>
</tr>
<tr>
<td>Stage IV</td>
<td>The cancer has spread to the bladder or rectum, or beyond the pelvis to the lungs, liver or bones.</td>
</tr>
</tbody>
</table>
**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 the disease.

In general, the sooner cervical cancer is diagnosed, the better the prognosis. Most women with early-stage cervical cancer will go into remission, which is when signs and symptoms of the cancer reduce or disappear.

To work out your prognosis, your doctor will consider:
- your test results
- the type of cervical cancer you have
- the rate and depth of tumour growth
- how well you respond to treatment
- other factors such as your age, fitness and medical history.

**Which health professionals will I see?**

Your GP will arrange the first tests to assess your symptoms or investigate the results of an abnormal screening test. If these initial tests do not rule out cancer, you will be referred to a gynaecologist or gynaecological oncologist for more tests and treatment.

You will be cared for by a range of health professionals who will form a multidisciplinary team (MDT). The table on the following page describes the role of the people who may be in your MDT.
<table>
<thead>
<tr>
<th>Health professional</th>
<th>Role</th>
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</thead>
<tbody>
<tr>
<td>gynaecologist</td>
<td>specialises in treating diseases of the female reproductive system</td>
</tr>
<tr>
<td>gynaecological oncologist</td>
<td>treats women with cancers of the reproductive system (e.g. cervical, ovarian, uterine, vulvar and vaginal cancers)</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>prescribes and coordinates the course of radiotherapy</td>
</tr>
<tr>
<td>medical oncologist</td>
<td>prescribes and coordinates the course of chemotherapy</td>
</tr>
<tr>
<td>radiologist</td>
<td>reads and interprets diagnostic scans (e.g. CT, MRI and PET scans)</td>
</tr>
<tr>
<td>cancer nurse coordinator, cancer care coordinator</td>
<td>supports patients and families throughout treatment and liaises with other members of the treatment team</td>
</tr>
<tr>
<td>nurses</td>
<td>care for you during and after surgery; help administer drugs; and provide care, information and support throughout treatment</td>
</tr>
<tr>
<td>dietitian</td>
<td>recommends an eating plan to follow while you are having treatment and during recovery</td>
</tr>
<tr>
<td>social worker, psychologist</td>
<td>link you to support services; help with emotional problems associated with cancer and treatment</td>
</tr>
<tr>
<td>physiotherapist, occupational therapist</td>
<td>help with any physical or practical problems associated with cancer and treatment</td>
</tr>
</tbody>
</table>
Key points

• Changes in the cervix that may lead to cancer are detected by a screening test.

• An examination of cervical tissue will show whether cells in the cervix are cancerous.

• During a colposcopy, the doctor examines the cervix and vagina using an instrument called a colposcope.

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

• A large loop excision of the transformation zone (LLETZ) or laser surgery are done to remove a sample of tissue from the cervix or treat precancerous changes.

• During a cone biopsy, a cone-shaped piece of tissue is removed from the cervix.

This is done in hospital under general anaesthetic. A cone biopsy may be used to treat early-stage cervical tumours.

• Further examinations or scans may be performed to check whether the cancer has spread to other parts of the body.

• Staging describes how far the cancer has spread in the body. Knowing the stage of the cancer allows the doctor to recommend the best treatment for you.

• Prognosis is the expected outcome of a disease. Generally, the sooner cervical cancer is diagnosed, the better the prognosis.

• You will be treated by a gynaecologist or gynaecological oncologist and other health professionals, who will work together in a multidisciplinary team.
Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that’s based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may 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 are confused or want clarification, you can ask questions – see page 62 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.
A second opinion
You may want to get a second opinion from another specialist to confirm or clarify your doctor’s recommendations or reassure you that you have explored all of your options. Specialists are used to people 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 might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial
Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of Understanding Clinical Trials and Research, or visit australiancancertrials.gov.au.
Treatment

Your doctor will advise you on the best treatment for you. Treatment options will depend on the results of your tests, the location of the cancer and whether it has spread, your age and general health, and whether you would like to have children in the future.

The most common treatment for cervical cancer is surgery and/or a combination of chemotherapy and radiotherapy (chemoradiation).

Surgery

Surgery is recommended for women who have small tumours that are confined to the cervix. The type of surgery you have will depend on how far within the cervix the cancer has spread.

Hysterectomy

A hysterectomy is when the uterus (womb) and other parts of the reproductive system are removed. There are two main types of hysterectomy, which are both done under a general anaesthetic:

**Total hysterectomy** – The uterus and cervix are removed. This can be done via keyhole surgery (laparoscopy) or by an open cut in the abdomen (laparotomy). Your surgeon will advise you on the best method for you.

**Radical hysterectomy** – The uterus, the cervix, the soft tissue around the cervix and about 2 cm of the upper vagina are removed. This surgery may cause nerve damage, which can affect bowel or bladder function (see pages 46–47).
You will spend up to a week in hospital after the hysterectomy, depending on the type of surgery you have.

**Bilateral salpingo-oophorectomy**
Depending on how far the cancer has spread, you may also need to have a bilateral salpingo-oophorectomy. This is when the ovaries and fallopian tubes are removed. They will be taken out at the same time as the hysterectomy.

For some women, the ovaries will be left in place to prevent the onset of early menopause. Ask your doctor if this might be an option for you.

Women who have a hysterectomy and/or bilateral salpingo-oophorectomy will become infertile, meaning they will no longer be able to have children naturally.

**Trachelectomy**
A trachelectomy is the removal of the cervix and some surrounding tissue. The uterus is left in place. This is not a common procedure, but it may be used in young women.

Your doctor will explain the side effects of your treatment to you. These can include infertility. If you would like to have children in the future, talk to your doctor before your treatment starts. For more information, see pages 51–52, call 13 11 20 for a free copy of *Fertility and Cancer* or download it from your local Cancer Council website.
with early-stage cancer (e.g. a tumour smaller than 2 cm) who would like the option of being able to have children in the future.

The side effects of a trachelectomy are similar to those of a hysterectomy (see Side effects of surgery below), but you will not experience menopause – you will still have periods (menstruate) and be able to become pregnant.

**Removing lymph nodes**
During a hysterectomy, your doctor may decide to remove some lymph nodes in the pelvic and/or abdominal area to see if the cancer has spread beyond the cervix. This is called a lymph node dissection or lymphadenectomy.

If cancer is found in the lymph nodes, your doctor may recommend you have additional treatment, such as radiotherapy (see pages 38–41).

A lymph node dissection may cause lymphoedema (see opposite). For ways to manage this condition, see pages 47–48.

**Side effects of surgery**
After surgery for cervical cancer, you may experience some of the following side effects. For more information on these side effects and ways to cope, see the Managing side effects chapter (pages 45–53).

**Pain and discomfort** – As with all major operations, you may be in pain after surgery. You will be given pain relief medicine
through a drip (intravenously) or via an injection into the spine (epidural). If you still have pain, your doctor or nurse can change your medicine to one that is more effective.

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 experience accidental or involuntary leakage of urine after surgery for cervical cancer. This is called urinary incontinence – see page 47 for ways to manage this.

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

Menopause – If you have a bilateral salpingo-oophorectomy and have not been through menopause, the removal of your ovaries will cause sudden menopause.

Sexuality issues – The physical and emotional changes you experience may affect how you feel about sex.

Internal scar tissue (adhesions) – Tissues in the body may stick together, which can sometimes be painful. In some rare cases, adhesions to the bowel or bladder may need to be treated with further surgery.
Sarah’s story

When I was 26, I went to see my GP for a prescription and asked if I could have a Pap test as well. Some of my Pap test results had been abnormal in the past, and I was conscious of needing to have regular tests.

A few days later, my GP called to tell me the results showed glandular abnormalities on my cervix. She referred me to a gynaecologist, who did a colposcopy. The colposcopy confirmed that there were abnormalities, so I was sent to hospital for a cone biopsy.

The results of the cone biopsy showed that I had cervical adenocarcinoma, which is a rare type of cervical cancer. I knew that some treatments for cervical cancer can lead to infertility, and I was worried that I would end up not being able to have children. My oncologist recommended I have IVF to store some of my eggs in case I became infertile.

About eight weeks after I had the Pap test, I was in hospital having surgery for cervical cancer. Because of my age and the fact I wanted the option to have children, I had a trachelectomy. This means that although my cervix was removed, my uterus wasn’t, and I’ll most likely be able to get pregnant naturally. The surgeon removed some lymph nodes from my pelvis as well.

Recovering from surgery in hospital was difficult. I had to stay in bed for three or four days afterwards – I couldn’t even get up to go to the toilet. I was young and active, and not being able to do much was hard.

I had a lot of support from family and friends, from when I was first diagnosed until after the surgery, and my doctors were fantastic. I haven’t needed any further treatment, and I’ve since had a normal Pap test result, which is a huge relief.
After the operation and recovering at home

When you wake up from surgery, you will be in a recovery room near the operating theatre, then you will be taken back to your bed on the hospital ward.

**Tubes and drips** – You will have several tubes in place. You may have an intravenous (IV) drip to give you fluid and medication, a tube 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 before you go home.

After the catheter is removed from your bladder, the nurses will perform a test to check that your bladder is emptying properly. This is done by measuring the amount of urine you pass each time you go to the toilet, and then using an ultrasound scan to check how empty your bladder is. It is a quick, painless test that is done on the hospital ward.

**Moving your legs** – While you are in bed, your doctors, nurses and physiotherapist will show you how to move your legs to prevent deep vein thrombosis (DVT) and help drain any lymph fluid. You will be encouraged to get out of bed and walk around as soon as you can.

You will be able to go home when the medical team is satisfied with your recovery and the results of your bladder function tests.

The illustration on pages 36–37 provides tips for recovering from surgery once you go home from hospital.
Taking care of yourself at home

Most women who have surgery for cervical cancer will feel better within six weeks, but recovery may take longer for some women. If you need home nursing care, ask hospital staff about services in your area. The following tips may help you during your recovery.

**Rest**
Take things easy for the first few weeks. Ask family or friends to help you with chores so you can rest as much as you need to.

**Lifting**
Avoid heavy lifting for at least a month. The length of time will depend on the type of surgery you have.

**Driving**
Avoid driving for a few weeks. Check with your car insurer whether there are any exclusions on your policy regarding major surgery and driving.
Sex
Avoid sexual intercourse for 4–6 weeks to give the wound time to heal properly.

Exercise
Walk regularly if your doctors say it is okay to do so. Speak to your doctor if you would like to do more vigorous exercise.

Diet
Drink plenty of water and eat lots of fresh vegetables and fruit to avoid becoming constipated.
Radiotherapy

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

Women with cervical cancer that has spread into the tissues or lymph nodes surrounding the cervix will usually have radiotherapy in combination with chemotherapy. This is called chemoradiation – see page 43. Some women may have radiotherapy treatment after surgery.

Many women with cervical cancer 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 the body that need treatment.

An initial planning session takes about 45 minutes. You will have a CT scan to work out where the x-ray beams should be directed.

You will probably have radiotherapy from Monday to Friday for 4–6 weeks as an outpatient. The actual treatment takes only a few minutes each time. 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 itself is painless and will not make you radioactive.
Internal radiotherapy (brachytherapy)

Brachytherapy is when a radiation source is placed inside the body on or near the cancer, making the radiation less likely to affect the surrounding organs. The most common type of brachytherapy for cervical cancer is high-dose-rate brachytherapy.

You will usually have 3–4 sessions of brachytherapy in total over 2–4 weeks. Each treatment takes a few hours and you can usually go home the same day.

You will be given a general anaesthetic or sedation and an epidural. An implant will be inserted into your vagina and cervix. Gauze padding may be put into your vagina, and a stitch may be put into the lips of your vulva (labia) to keep the implant in place. A small tube will be inserted into your bladder to drain urine (catheter).

After you wake up, you will have a CT scan, x-ray, ultrasound or MRI scan to check the location of the tumour and to work out the best dose of brachytherapy. During this test, a small ‘marker’ tube may be placed inside your rectum to help make the pictures clearer.

The radiation source will then be placed into the implant for 15–30 minutes. You may feel anxious during this time, but talking on the phone, watching TV, reading or listening to music can help

Once treatment is over and the brachytherapy implant is removed, you aren’t radioactive and you can safely interact with other people.
you pass the time. Nurses or other staff may come into the room during treatment, but while they are in the room, the treatment will be stopped. Once they leave the room, it will start again.

When the treatment is finished, the implant will be removed and you will be able to go home.

If you’ve had surgery to remove your cervix and uterus, an applicator will be placed inside your vagina to deliver radiotherapy. You will not need to have an anaesthetic, sedation or gauze padding.

**Side effects of radiotherapy**

Side effects vary depending on the dose of the radiotherapy and the length of the treatment. Most side effects occur during treatment or soon after it has finished. However, some women experience long-term side effects.

**Tiredness** – During radiotherapy, your body uses a lot of energy dealing with the effects of radiation on healthy cells. Tiredness usually builds up slowly during the course of the treatment, particularly towards the end.

**Loss of appetite** – You may lose your appetite during the course of radiotherapy. If you don’t feel like eating, you can replace some meals with nutritious high-kilojoule drinks available from the chemist. Talking to a dietitian can also be helpful.

**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. Radiotherapy will not cause you to lose hair from your head.

**Diarrhoea** – Radiation can affect bowel function, which can cause diarrhoea. For suggestions on managing diarrhoea, see page 46.

**Skin problems** – Radiotherapy may make the skin in the treatment area dry and itchy.

**Burning when passing urine (cystitis)** – Radiation passes through the bladder to reach the treatment area, which can cause cystitis. You may need to have a urine test to rule out infection, so talk to your doctor about your symptoms. Drinking water, cranberry juice and Ural® (available from chemists) can help relieve symptoms of cystitis. You may also be given pain relief.

**Menopause** – If your ovaries are still in place, radiotherapy will cause them to stop working permanently, causing menopause. See pages 48–49 for more information on menopause.

**Vaginal stenosis** – Radiotherapy may cause internal scar tissue to form, which sometimes shortens and narrows the vagina. This is called vaginal stenosis and can be prevented or reduced with a vaginal dilator (see *Coping with vaginal side effects*, page 50).
Chemotherapy

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

The drugs are 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 type of cervical cancer and any other treatment you may be having. If you have chemotherapy without radiotherapy, you will probably have treatment up to six times, and these will be scheduled every 3–4 weeks over several months.

Side effects of chemotherapy

The side effects of chemotherapy vary according to the drugs given, how often you have treatment, and your general health and fitness. You may experience nausea or vomiting, feel tired, or lose some hair from your body or head. Chemotherapy can also cause temporary or permanent menopause (see pages 48–49).

Chemotherapy may also reduce the number of blood cells in your body. Depending on the type of cells affected, you may feel very tired and be more prone to infections, such as colds. You will have regular blood tests during treatment to check your blood count.

Most side effects are temporary, and your treatment team can help you to prevent or reduce them. Cancer Council’s booklet Understanding Chemotherapy has more information.
Palliative treatment

Palliative treatment aims to reduce symptoms of cancer without trying to cure the disease. It can be given at any stage of advanced cancer to improve quality of life. It is not just for people who are about to die and does not mean you have given up hope. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy or other medication.

For more information, call 13 11 20 or visit your local Cancer Council website to download Understanding Palliative Care.
Key points

- Surgery is a common treatment for cervical cancer. The type of surgery you have will depend on how far the cancer has spread.

- A hysterectomy is the surgical removal of the cervix and uterus. Some women also need a bilateral salpingo-oophorectomy, which is an operation to remove the ovaries and fallopian tubes.

- A trachelectomy removes only the cervix. This is not a common procedure and is used more often for young women with early-stage cervical cancer.

- Sometimes the lymph nodes in the pelvic region are removed. This is called a lymphadenectomy.

- After surgery, you will need to rest as much as possible while you recover. This may take many weeks.

- Radiotherapy uses x-rays to kill or damage cancer cells. You may have external or internal radiotherapy (brachytherapy), or both.

- Chemotherapy is the use of drugs to kill or damage cancer cells. Chemotherapy is usually given intravenously every 3–4 weeks, or weekly if combined with radiotherapy.

- Chemoradiation is a combination of chemotherapy and radiotherapy. It is usually given to treat advanced cervical cancer.

- Treatment for cervical cancer can cause temporary or permanent side effects. The side effects you experience will depend on the treatment you have. Your medical team can help you manage these.

- Palliative treatment can treat symptoms and side effects at any stage of advanced cancer.
Managing side effects

It may take some time to recover from treatment for cervical cancer. As well as causing physical changes, you may find that cancer affects you emotionally.

Side effects of treatment vary from person to person. Some women don’t experience any side effects; others may experience a few. Side effects may last from a few weeks to a few months or, in some cases, many years or permanently. Fortunately, there are ways to reduce or manage the discomfort that side effects cause.

Tiredness

Many women who are treated for cervical cancer find that tiredness is a major issue, particularly if they have radiotherapy and chemotherapy. The tiredness may continue for several months, or even a year or two, after treatment has finished.

Coping with tiredness

- Plan your day so you have time to rest regularly.
- Talk with your family and friends about how you’re feeling and discuss things they can help you with, e.g. housework and shopping.
- Do some light exercise, such as walking or stretching, to help increase your energy levels. Ask your doctor if these activities are suitable for you.
- Read Cancer Council’s booklets *Living Well After Cancer* and *Cancer, Work & You* for more tips. Call 13 11 20 or download them from your local Cancer Council website.
Feeling tired is not only a side effect of the treatment itself. Travelling to hospitals and clinics for treatment can be exhausting. If you work during your treatment or if you have a family to care for, this can make you feel especially tired.

It may be frustrating if other people don’t understand how you’re feeling. See pages 58–59 for information about support services.

**Bowel problems**

After surgery or radiotherapy, some women notice changes in their bowel habits. You may experience constipation or diarrhoea, or feel pain in your abdomen.

The following tips may help you to manage these side effects:

- Drink peppermint or chamomile tea to reduce abdominal or wind pain.
- Drink plenty of liquids (except alcohol and caffeinated drinks) to replace fluids lost through diarrhoea or to help soften stools if you are constipated.
- Limit spicy and greasy foods, as these can make diarrhoea and constipation worse.
- Talk to your doctor or a dietitian about making changes to your diet, or to ask whether taking medication is an option.

For more information, call Cancer Council 13 11 20 for a free copy of the booklet *Nutrition and Cancer*, or download a digital version from your local Cancer Council website.
**Bladder problems**

Bladder control may change after surgery or radiotherapy. Some women find they need to pass urine more often or in a hurry. Others may experience involuntary loss of urine when they cough, sneeze, laugh, strain or lift. This is called urinary incontinence.

There are ways to manage and treat urinary incontinence. Ask your doctor to refer you to a continence nurse or physiotherapist at your hospital. You can also call the National Continence Helpline on 1800 33 00 66 or visit continence.org.au.

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**Lymphoedema**

If lymph nodes have been damaged or removed during surgery, lymph fluid may not drain properly from your legs. This causes the fluid to build up and the legs to swell, which is called lymphoedema. This can occur during treatment or after treatment has finished.

It is important to manage lymphoedema symptoms as soon as possible. Gentle exercise, compression stockings, and a type of massage called manual lymphatic drainage can all help to reduce the swelling. A physiotherapist trained in lymphoedema management will be able to give you further advice.
To find a practitioner who specialises in the management of lymphoedema, visit the Australasian Lymphology Association website at lymphoedema.org.au/the-register/find-a-practitioner. Cancer Australia’s booklet *Lymphoedema – what you need to know* is also a good source of information. Download a copy at canceraustralia.gov.au/publications-and-resources.

**Menopause**

If you’ve had radiotherapy to your ovaries or surgery to remove them, your body will no longer produce the hormones oestrogen and progesterone. When these hormones are no longer made by the body, women stop menstruating (having periods). This is called menopause. For most women, menopause is a natural and gradual process that starts between the ages of 45 and 55.

Symptoms of menopause include:
- hot flushes
- mood swings
- trouble sleeping (insomnia)
- tiredness
- vaginal dryness.

The symptoms of sudden menopause are usually more severe than a natural menopause, because the body hasn’t had time to get used to a gradual decrease in the levels of oestrogen and progesterone.

For information about dealing with the symptoms of menopause, talk to your doctor or call Cancer Council 13 11 20.
**Osteoporosis and heart disease**

Menopause may cause other changes in the body. For example, over time, your bones may become weak and brittle, and break more easily. This is called osteoporosis. Your cholesterol levels may rise, which can increase your risk of heart disease.

The table below outlines ways to help prevent osteoporosis and heart disease. For more information, talk to your doctor, or visit osteoporosis.org.au and heartfoundation.org.au.

<table>
<thead>
<tr>
<th>Osteoporosis</th>
<th>Heart disease</th>
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<tbody>
<tr>
<td>• Eat 3–5 serves of calcium-rich food daily (e.g. yoghurt, milk, tofu, green vegetables).</td>
<td>• Ask your doctor to check your cholesterol levels. If they are high, ask about medication and/or dietary changes.</td>
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<tr>
<td>• Vitamin D helps the body absorb calcium. The main source of vitamin D is sun exposure. Visit your local Cancer Council website or download the SunSmart app for safe times to go out in the sun in your location.</td>
<td>• Eat lots of fruit, vegetables and fibre.</td>
</tr>
<tr>
<td>• Ask your GP whether a calcium or vitamin D supplement might help you.</td>
<td>• Reduce your saturated fat intake. Sources of this fat include processed meats and takeaway foods.</td>
</tr>
<tr>
<td>• Do weight-bearing exercise, such as walking, dancing or team sports. Ask your GP what is suitable for you.</td>
<td>• Exercise regularly. Your doctor can suggest exercises that are suitable for you.</td>
</tr>
<tr>
<td></td>
<td>• If you smoke, talk to your doctor about quitting or call the Quitline on 13 7848.</td>
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Sexuality issues
Having cervical cancer can affect your sexuality in different ways. The effects you experience depend on many factors, such as your treatment and its side effects, whether you have a partner, and your overall self-confidence.

Knowing the potential challenges and addressing them early may help you to adjust to these changes. Sexual intercourse may not always be possible, but closeness and communication are vital to a healthy relationship. Talking to a counsellor may help.

Vaginal changes – The main side effect of treatment will be to the 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 easily during sexual intercourse.

Coping with vaginal side effects
- Your doctor may suggest you use a vaginal dilator to help keep the walls of the vagina open and supple. A dilator is a tube-shaped device that is designed to gently stretch the vagina. Used with lubricant, it is inserted into the vagina for short periods of time. Ask your nurse or radiation therapist for more information about vaginal dilators.
- Having regular gentle sexual intercourse can also help widen the vagina.
- Ask your doctor about short-term hormone replacement therapy (HRT), which may help with vaginal dryness.
Radiotherapy can also cause the vagina to narrow or shorten (vaginal stenosis). Although vaginal stenosis can make sexual intercourse uncomfortable, it should not affect your ability to reach orgasm. See the box opposite for ways to keep your vagina open and more elastic.

**Low libido** – A lack of interest in sex or loss of desire is common because of the physical and emotional effects of treatment.

If you do not feel like having sexual intercourse, or if you find it uncomfortable, let your partner know. It normally takes some time for sex to be comfortable again. You can also explore other ways to be intimate, such as massage and cuddling.

For more information about sexuality issues, call 13 11 20 for a free copy of the booklet *Sexuality, Intimacy and Cancer*, or download it from your local Cancer Council website.

**Infertility**

Because cervical cancer affects the reproductive organs, some treatments, such as hysterectomy and radiotherapy, will cause infertility. This means it is no longer possible to become pregnant.

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 or future relationships. Even if your family is complete or you were not planning to have children, you may feel some distress.
If you have a partner, talk to them about your feelings. Speaking to a counsellor or gynaecological oncology nurse may also help.

For some women, there may be options for having children after treatment. Before treatment starts, ask your doctor or a fertility specialist about what options are available to you. The following list explains some ways you may be able to have children after treatment for cervical cancer.

- If you have not already been through menopause, ask about ways to preserve your fertility. One option may be to store eggs or embryos for use in the future.

- 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 outside your pelvis and into your abdomen. This is called ovarian transposition or relocation, and it may help to prevent the ovaries being affected by radiation.

- Having a trachelectomy, where only the cervix is removed, is an option for some women with early-stage cervical cancer (see pages 31–32). It will still be possible to become pregnant after this procedure, but you will be at higher risk of having a miscarriage and having the baby prematurely. Your doctor can discuss these risks with you.

You can find more information in Cancer Council’s booklet *Fertility and Cancer*. Call 13 11 20 for a free copy, or download it from your local Cancer Council website.
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 from a few weeks to many years or permanently.

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

• Bowel and bladder problems may occur after treatment. Your doctor can refer you to a continence nurse or physiotherapist to help you manage these problems.

• Surgery or radiotherapy to the ovaries can cause menopause. Chemotherapy may also cause temporary or permanent menopause. The symptoms of menopause include hot flushes, mood swings and insomnia. Talk to your doctor about ways to help reduce these symptoms.

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

• Sexuality issues following treatment are common. Addressing any challenges early can help you adjust. It can be helpful to talk to a counsellor.

• Some women are not able to have children after treatment for cervical cancer. This is called infertility and can be very distressing. If you would still like to be able to have children, speak to your doctor before treatment starts about options for preserving your fertility.
Looking after yourself

Cancer can cause physical and emotional strain. It’s important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor’s advice. Cancer Council’s *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or download it from your local Cancer Council website.
Relationships with others
Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life. Give yourself time to adjust to what’s happening, and do the same for others. People may deal with the cancer in different ways, for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality, intimacy and fertility
Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

See pages 50–52 for more information about coping with sexuality issues after treatment, and options for preserving fertility.
Life after treatment

For most people, the cancer experience doesn’t end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say they feel pressure to return to ‘normal life’, but they don’t want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

Dealing with feelings of sadness

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, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medicines – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Go to beyondblue.org.au or call 1300 22 4636 to order a fact sheet.
Follow-up appointments
After your treatment, you will need regular check-ups to confirm that the cancer hasn’t come back. At these appointments, you may have a screening test (Pap test or HPV test), blood tests, x-rays, a CT scan or PET scan. Your doctor will discuss your follow-up schedule with you.

It is important to go to all of your follow-up appointments. These check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any health problems or symptoms.

What if cervical cancer returns?
For some women, cervical cancer does come back after treatment, which is known as a recurrence. This is why it’s important to have regular check-ups.

If cervical cancer does return, you will usually be offered treatment with chemotherapy or surgery. You may not be able to have further radiotherapy if you had it the first time you had treatment.
Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

**Practical and financial help**
There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can’t afford to pay – call 13 11 20 to ask if you are eligible.

**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.

People often feel they can speak openly and share tips with others who have gone through a similar experience.
In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren’t trying to protect their loved ones.

“I felt really alone when 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.” *Amanda*

**Types of support**
There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.
You may be reading this booklet because you are caring for someone with cancer. Being a carer can be 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 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 groups and organisations 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 Associations in each of the states and territories. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers’ services and to get a free copy of the *Caring for Someone with Cancer* booklet, or download it from your local Cancer Council website.
Useful websites

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

**Australian**

Cancer Council Australia..................................................cancer.org.au
Cancer Australia..................................................canceraustralia.gov.au
Cancer Connections.............................................cancerconnections.com.au
Carers Australia..................................................carersaustralia.com.au
Department of Health.............................................health.gov.au
Department of Human Services.................humanservices.gov.au
healthdirect Australia.................................healthdirect.gov.au
beyondblue..................................................beyondblue.org.au
Australian Cervical Cancer Foundation.................accf.org.au
Gynaecological Awareness Information Network ...........gain.org.au
HPV Vaccine..................................................hpvvaccine.org.au
National Cervical Screening Program..................cervicalscreenscreen.health.gov.au
HPV School Vaccination Program.......................hpv.health.gov.au
Continence Foundation of Australia...............continence.org.au
Australasian Lymphology Association...............lymphoedema.org.au

**International**

American Cancer Society.................................cancer.org
Macmillan Cancer Support.................................macmillan.org.uk
Cancer Research UK...........................................cancerresearchuk.org
National Cancer Institute........................................cancer.gov
HysterSisters: Woman-to-Woman
Hysterectomy Support...........................................hystersisters.com
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, ask for clarification.

- What type of cervical cancer do I have?
- How far has the cancer spread? What stage is it?
- What treatment do you recommend and why?
- Do I have more than one treatment option? If not, why not?
- What are the risks and possible side effects of each treatment? Are the side effects temporary or permanent?
- How will cervical cancer and treatment affect my sex life?
- Will I still be able to get pregnant after treatment? Who can I talk to about my fertility?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cervical cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?
**abdomen**
The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

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

**adenosquamous carcinoma**
A rare type of cervical cancer that features both squamous cells and glandular cells. Also called mixed carcinoma.

**advanced cancer**
Cancer that has spread into the surrounding tissues or away from the original site (metastasised).

**anaemia**
A reduction in the number or quality of red blood cells in the body.

**anaesthetic**
A drug that stops a person feeling pain during a medical procedure.

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

**benign**
Not cancerous or malignant.

**bilateral salpingo-oophorectomy**
Surgical removal of both 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 radiotherapy where radioactive material is placed inside tubes that are inserted into the vagina and cervix close to cancerous cells.

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

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

**cervix**
The lower part of the uterus that connects the uterus to the vagina. Also called the neck of the uterus.

**chemoradiation**
Combined chemotherapy and radiotherapy treatment. Also called chemoradiotherapy.

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

**colposcope**
An instrument that enables the doctor to see a magnified view of the cervix and vagina from outside the body.

**colposcopy**
Examination of the cervix using a colposcope.

**cone biopsy**
The removal of a cone-shaped piece of the cervix for examination under a microscope.

**CT scan**
A computerised tomography scan. This scan uses x-rays to create
a three-dimensional picture of the inside of the body.

**cystitis**
Inflammation of the bladder lining, usually caused by a bacterial infection.

**cystoscope**
A thin viewing instrument with a light that is inserted into the urethra to examine the bladder.

**deep vein thrombosis (DVT)**
A blood clot that forms in the veins of the legs.

**dilation and curettage (D&C)**
A procedure where the cervix is dilated and the lining of the uterus (endometrium) is scraped out. D&C is sometimes used to treat precancerous changes of the cervix.

**ectocervix**
The outer surface of the part of the cervix that opens into the vagina.

**endocervix**
The inner surface of the cervix. Also called the cervical canal.

**endometrium**
The lining of the uterus.

**epidural**
An injection of anaesthetic drugs directly into the spinal column.

**fallopian tubes**
The two long tubes that extend from the uterus to the ovaries. The fallopian tubes carry fertilised eggs from the ovary to the uterus.

**glandular cell**
A type of cell found in the inner surface of the cervix (endocervix).

**grade**
A score that describes how quickly a tumour is likely to grow.

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

**hormones**
Chemicals in the body that send information between cells to bring about changes in the body.

**HPV test**
A test that can detect the HPV virus in cervical cells.

**human papillomavirus (HPV)**
A group of viruses that can cause infection on different surfaces of the body, including the genitals. HPV is a risk factor for cervical cancer.

**hysterectomy**
The surgical removal of the uterus and cervix.

**keyhole surgery**
See laparoscopy.

**labia**
The lips of the vulva.

**laparoscope**
A tiny telescope through which structures within the abdomen and pelvis can be seen during a laparoscopy.
laparoscopy
Surgery done through small cuts in the abdomen using a laparoscope for viewing. Also called keyhole surgery.

laparotomy
An operation in which a long cut is made in the abdomen to examine and remove internal organs.

large loop excision of the transformation zone (LLETZ)
A procedure to remove cervical tissue for examination and to treat some precancerous changes of the cervix.

laser surgery
The use of a laser beam to remove tissue and treat some precancerous changes of the cervix.

lesion
An area of abnormal tissue.

ligament
A band of tissue that connects bones and holds organs in place.

lymphadenectomy
Removal of the lymph nodes from a part of the body.

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

lymph nodes
Small, bean-shaped glands that form part of the lymphatic system. The lymph nodes collect and destroy bacteria and viruses. Also called lymph glands.

lymphoedema
Swelling caused by a build-up of lymph fluid.

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

menopause
When a woman stops having periods (menstruating). This can happen naturally, because of chemotherapy or radiotherapy treatment, or because the ovaries have been removed.

menstruation
A woman’s monthly bleed from the vagina. Also called periods.

metastasis
A cancer that has spread from another part of the body. Also known as secondary cancer.

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

oestrogen
The primary female sex hormone produced mainly by the ovaries that helps mature and regulate the female reproductive cycle.

osteoporosis
Thinning and weakening of the bones that can lead to bone pain and fractures.

outpatient
A person who receives medical treatment without being admitted into hospital.

ovarian transposition or relocation
The surgical relocation of one or both ovaries from the pelvis into the
abdomen. This procedure is used to protect the ovaries from radiotherapy. Also called oophoropexy.

**ovary**
A female reproductive organ that contains eggs (ova). It produces the hormones oestrogen and progesterone.

**Pap test (Pap smear)**
A test that can detect changes in cervical cells.

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

**PET scan**
A positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution. Cancerous cells show up brighter in the scan because they take up more of the glucose.

**precancerous**
A term used to describe a condition that may or is likely to become cancer.

**primary cancer**
The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

**progesterone**
A hormone produced by the ovaries that prepares the lining of the uterus (endometrium) for pregnancy.

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

**remission**
When the symptoms and signs of the cancer reduce or disappear. A partial remission is when there has been a significant reduction in symptoms but some cancer is still present. A complete remission is when there is no evidence of active cancer. This does not necessarily mean the cancer is cured.

**screening tests**
Help to detect cancer in people who don’t have any symptoms.

**speculum**
An instrument used to hold open the walls of the vagina.

**squamous cell**
A type of cell found in the outer surface of the cervix (ectocervix).

**squamous cell carcinoma**
Cancer that starts in the squamous cells of the cervix.

**staging**
Performing tests to determine how far a cancer has spread.

**trachelectomy**
The surgical removal of the cervix and some surrounding tissue.

**transformation zone**
The area in the cervix where the squamous cells and the glandular cells meet.

**tumour**
A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).
ultrasound
A non-invasive scan that uses soundwaves to create a picture of part of the body.

urethra
The tube that carries urine from the bladder to the outside of the body.

uterus
The organ in which a fertilised egg (ovum) grows and a foetus is nourished until birth. Also called the womb.

vaginal dilator
A cylinder-shaped device that is inserted into the vagina to keep the walls of the vagina open and supple.

vaginal stenosis
Shortening and narrowing of the vagina.

vulva
The external sexual organs of a woman.

womb
See uterus.

References
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.
Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn’t just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area. 13 11 20 is charged at a local call rate throughout Australia (except from mobiles).