



Understanding Testicular Cancer

A guide for people with cancer,
their families and friends

Cancer
information

For information & support, call

13 11 20



Understanding Testicular Cancer

A guide for people with cancer, their families and friends

First published 1997. This edition August 2020.

© Cancer Council Australia 2020. ISBN 978 1 925651 92 8

Understanding Testicular Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

Editor: Rosemary McDonald. Designer: Julia Gee. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative.

We thank the reviewers of this booklet: Prof Declan Murphy, Urologist and Director of Genitourinary Oncology, Peter MacCallum Cancer Centre, VIC; Gregory Bock, Urology Cancer Nurse Coordinator, WA Cancer and Palliative Care Network, North Metropolitan Health Service, WA; A/Prof Nicholas Brook, Senior Consultant Urological Surgeon, Royal Adelaide Hospital and The University of Adelaide, SA; Clinical A/Prof Peter Grimison, Medical Oncologist, Chris O'Brien Lifehouse and The University of Sydney, NSW; Dr Tanya Holt, Senior Radiation Oncologist, Radiation Oncology Princess Alexandra Hospital Raymond Terrace (ROPART), QLD; Brodie Kitson, Consumer; Elizabeth Medhurst, Genitourinary and Stereotactic Ablative Body Radiotherapy (SABR) Nurse Consultant, Peter MacCallum Cancer Centre, VIC; Rosemary Watson, 13 11 20 Consultant, Cancer Council Victoria. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

This booklet is funded through the generosity of the people of Australia.

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.



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

About this booklet

This booklet has been prepared to help you understand more about testicular cancer. Many people feel shocked and upset when told they have testicular cancer. We hope this booklet will help you, your family and friends understand how testicular 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, this information may answer some of your questions and help you think about what to ask your treatment team (see page 51 for a question checklist).

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 (see pages 52–55). 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 testicular cancer. It is based on international clinical practice guidelines for testicular cancer.^{1,2}

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. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

Contents

What is cancer?	4
The testicles	6
Key questions	8
What is testicular cancer?	8
How common is it?	8
What types are there?	9
What are the risk factors?	10
What are the symptoms?	12
Which health professionals will I see?	12
Diagnosis	14
Ultrasound	14
Blood tests	14
Surgery to remove the testicle	16
Further tests	20
Staging	22
Prognosis	23
Key points about diagnosing testicular cancer	24
Making treatment decisions	25
Treatment	27
Surveillance	28
Chemotherapy.....	28
Radiation therapy	33
Surgery to remove lymph nodes	36
Palliative treatment.....	38

Managing treatment effects	38
Effects on sexuality and intimacy.....	39
Effects on fertility.....	40
Effects on body image	41
Key points about treating testicular cancer.....	42
Looking after yourself	43
Life after treatment	45
Follow-up appointments	46
What if the cancer returns?	46
Seeking support	47
Support from Cancer Council	48
Useful websites	49
Caring for someone with cancer	50
Question checklist.....	51
Glossary	52
How you can help	56



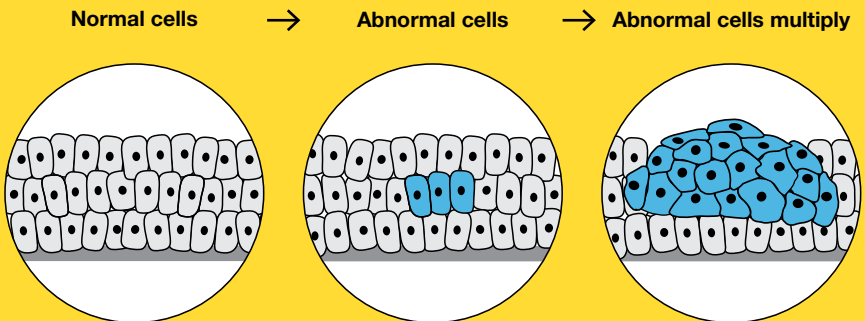
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as testicular cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer.

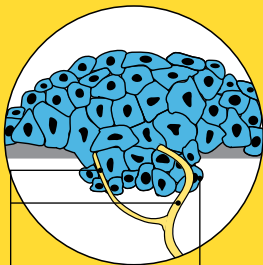
How cancer starts



Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If primary cancer 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, testicular cancer that has spread to the lungs is called metastatic testicular cancer, even though the main symptoms may be coming from the lungs.

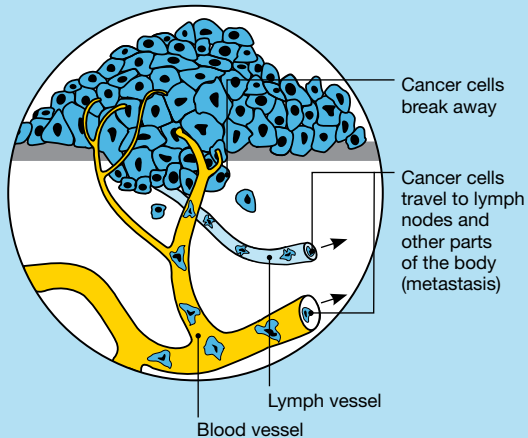
→ **Malignant cancer**



Grows own blood vessels (angiogenesis)

Invades surrounding tissue

How cancer spreads



Cancer cells break away

Cancer cells travel to lymph nodes and other parts of the body (metastasis)

Lymph vessel

Blood vessel



The testicles

The testicles are two oval glands that sit behind the penis in a pouch of skin called the scrotum. They are part of the male reproductive system and are also called testes (or a testis, if referring to one).

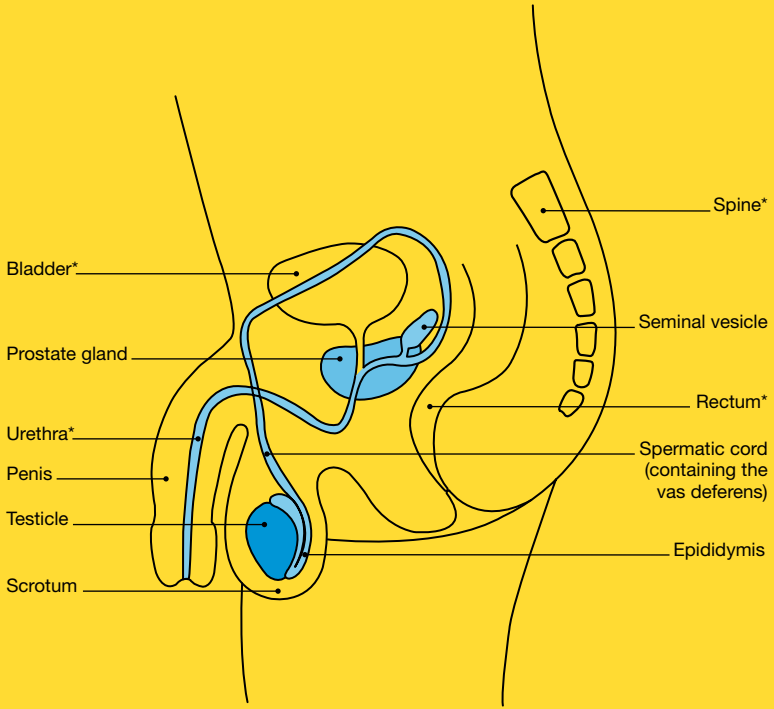
Role of the testicles – The testicles produce and store sperm. They also produce the sex hormone testosterone, which is responsible for the development of male characteristics, such as facial hair, a deeper voice and increased muscle mass, as well as sexual drive (libido).

Epididymis, spermatic cord and vas deferens – A tightly coiled tube at the back of each testicle called the epididymis stores immature sperm. The epididymis connects the testicle to the spermatic cord. The spermatic cord runs through the groin region into the pelvis and contains blood vessels, nerves, lymph vessels and a tube called the vas deferens. The vas deferens carries sperm from the epididymis to the prostate gland.

Seminal vesicles and prostate gland – Two small glands called seminal vesicles sit above the prostate gland. The seminal vesicles and prostate gland produce fluids that make up a large part of semen. Semen also contains sperm from the testicles and is ejaculated from the penis during sexual climax.

Lymph nodes and vessels – There are many lymph nodes (also called lymph glands) and lymph vessels around the testicles and in the abdomen. These are part of the lymphatic system and are important for resisting and fighting disease (immunity). The nodes and vessels also drain lymphatic fluid (lymph) from the tissues back into the bloodstream.

The male reproductive system



* Not part of the male reproductive system



Key questions

Q: What is testicular cancer?

A: Cancer that develops in a testicle is called testicular cancer or cancer of the testis (plural: testes). Usually only one testicle is affected, but in some cases both are affected. About 90–95% of testicular cancers start in the cells that develop into sperm – these are known as germ cells.

Sometimes testicular cancer can develop outside the testicle. It can also spread to lymph nodes in the abdomen or to other parts of the body.

Q: How common is it?

A: Testicular cancer is not a common cancer, but it is the second most commonly diagnosed cancer, after skin cancer, among young men aged 20–39.³ In Australia, about 850 men are diagnosed with testicular cancer each year, accounting for about 1% of all cancers in men. It occurs most often in men aged 25–40.⁴

Anyone with a testicle can get testicular cancer. Transgender women, male-assigned non-binary people or intersex people can also get testicular cancer if they have a testicle. For information specific to your situation, speak to your doctor.



Other types of cancer, such as lymphoma, can also involve the testicles. Call Cancer Council **13 11 20** or visit your local Cancer Council website for information about lymphoma.

Q: What types are there?

A: The most common testicular cancers are called germ cell tumours. There are two main types, seminoma and non-seminoma.

Germ cell tumours

seminoma

- tend to develop more slowly than non-seminoma cancers
- usually occur between the ages of 25 and 45, but can occur at older ages

non-seminoma

- tend to develop more quickly than seminoma cancers
- more common in late teens and early 20s
- there are four main subtypes: teratoma, choriocarcinoma, yolk sac tumour and embryonal carcinoma

Sometimes a testicular cancer can include a mix of seminoma cells and non-seminoma cells, or a combination of the different subtypes of non-seminoma cells (mixed tumours). When there are seminoma and non-seminoma cells mixed together, doctors treat the cancer as if it were a non-seminoma cancer.

A small number of testicular tumours start in cells that make up the supportive (structural) and hormone-producing tissue of the testicles. These are called stromal tumours. The two main types are Sertoli cell tumours and Leydig cell tumours. They are usually benign and are removed by surgery.

Intratubular germ cell neoplasia (ITGCN)

Some testicular cancers begin as a condition called intratubular germ cell neoplasia (ITGCN or IGCN). In this condition, the cells are abnormal, but they haven't spread outside the area where the sperm cells develop.

ITGCN is not cancer but it has about a 50% risk of turning into testicular cancer within five years. About 5–10% of men diagnosed with testicular cancer have ITGCN.

ITGCN has similar risk factors to testicular cancer. It is hard to diagnose because there are no symptoms and it can only be found by testing a tissue sample.

Once diagnosed, some cases of ITGCN will be carefully monitored (surveillance, see page 28). Other cases will be treated with radiation therapy (see pages 33–36) or with surgery to remove the testicle (see pages 16–20).

Q: What are the risk factors?

A: The causes of testicular cancer are unknown, but certain factors may increase your risk of developing it:

Personal history – If you have previously had cancer in one testicle, you are more likely to develop cancer in the other testicle. ITGCN is also a risk factor (see box above).

Undescended testicles – Before birth, testicles develop inside the abdomen. By birth, or within the first six months of life, the testicles should move down into the scrotum.

If the testicles don't descend by themselves, doctors perform an operation to bring them down. Although this reduces the risk

of developing testicular cancer, people born with undescended testicles are still more likely to develop testicular cancer than those born with descended testicles.

Family history – Sometimes gene mutations are passed on in families. If your father or brother has had testicular cancer, you are slightly more at risk of cancer. But family history is only a factor in a small number (about 2%) of people who are diagnosed with testicular cancer. If you are concerned about your family history of testicular cancer, you can ask your doctor for a referral to a specialist called a urologist.

Infertility – Having difficulty conceiving a baby (infertility) can be associated with testicular cancer. Testicular cancer can cause changes in your testosterone levels as well as genetic damage to sperm cells. As a result, infertility is considered a risk factor for testicular cancer.

HIV and AIDS – There is some evidence that people with HIV (human immunodeficiency virus) and AIDS (acquired immune deficiency syndrome) have an increased risk of testicular cancer.

Some congenital defects – Some people are born with an abnormality of the penis called hypospadias. This causes the urethra to open on the underside of the penis, rather than at the end. People with this condition are at an increased risk of developing testicular cancer. Likewise, there may also be an increased risk for people born with a lump in the groin known as an inguinal hernia, even when it has been repaired.

Q: What are the symptoms?

A: In some people, testicular cancer does not cause any noticeable symptoms, and it may be found during tests for other conditions. When there are symptoms, the most common ones are a swelling or a lump in the testicle (usually painless) and/or a change in a testicle's size or shape (e.g. hardness or swelling). These symptoms don't necessarily mean you have testicular cancer. They can be caused by other conditions, such as cysts, which are harmless lumps in the scrotum. If you find any lump, however, it's important to see your doctor for a check-up.

Occasionally, testicular cancer may cause other symptoms such as a feeling of heaviness in the scrotum; a feeling of unevenness between the testicles; pain or ache in the lower abdomen, testicle or scrotum; enlargement or tenderness of the breast tissue; back pain; or stomach-aches. If you are concerned about any of these symptoms, make an appointment to see your doctor.

Q: Which health professionals will I see?

A: Your general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist called a urologist. The urologist will arrange further tests. If testicular cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care.

Health professionals you may see

urologist*	treats diseases of the male and female urinary systems and the male reproductive system, including testicular cancer; performs surgery
fertility specialist*	diagnoses, treats and manages infertility and reproductive hormonal disorders; may be a reproductive endocrinologist or urologist
medical oncologist*	treats cancer with drug therapies such as chemotherapy; supports you through regular check-ups and reviews (surveillance)
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
nurse	administers drugs and provides care, information and support throughout treatment
cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
anaesthetist*	administers anaesthetic before surgery and monitors you during the operation
psychologist, counsellor	help you manage your emotional response to diagnosis and treatment
physiotherapist, occupational therapist	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment

* Specialist doctor



Diagnosis

You will usually begin by seeing your GP, who will examine your testicles and scrotum for a lump or swelling. Some people may find this embarrassing, but doctors are used to doing these examinations and it will only take a few minutes.

If the GP feels a lump that might be cancer, you will have an ultrasound scan. If the lump looks like a tumour on the ultrasound, you will have a blood test and are likely to be referred to a specialist called a urologist. The urologist may recommend removal of the testicle (see pages 16–20) to confirm the diagnosis.

Ultrasound

An ultrasound is a painless scan that uses soundwaves to create a picture of your body. This is a very accurate way to tell the difference between fluid-filled cysts and solid tumours. It can show if a tumour is present and how large it is.

The person performing the ultrasound will spread a gel over your scrotum and then move a small device called a transducer over the area. This sends out soundwaves that echo when they meet something dense, like an organ or a tumour. A computer creates a picture from these echoes. The scan takes about 5–10 minutes.

Blood tests

Blood tests can check your general health and how well your kidneys and other organs are working. The results of these tests will also help you and your doctors make decisions about your treatment.

Tumour markers

Some blood tests look for proteins produced by cancer cells. These proteins are called tumour markers. If your blood test results show an increase in the levels of certain tumour markers, you may have testicular cancer.

Raised levels of tumour markers are more common in mixed tumours and non-seminoma cancers. However, it is possible to have raised tumour marker levels due to other factors, such as liver disease or blood disease. Some people with testicular cancer don't have raised tumour marker levels in their blood.

There are three common tumour markers measured in tests for testicular cancer. These are:

- **alpha-fetoprotein (AFP)** – raised in some non-seminoma cancers
- **beta human chorionic gonadotropin (beta-hCG)** – raised in some non-seminoma and seminoma cancers
- **lactate dehydrogenase (LDH)** – raised in some non-seminoma and seminoma cancers.

Doctors will use your tumour marker levels to assess the risk of the cancer coming back after surgery, and this helps them plan your treatment. If the diagnosis of testicular cancer is confirmed after surgery, you will have regular blood tests to monitor tumour marker levels throughout treatment and as part of follow-up appointments.

Tumour marker levels will drop if your treatment is successful, but they will rise if the cancer is active. If this happens, you may need more treatment.

Surgery to remove the testicle

After doing a physical examination, ultrasound and blood tests (see previous two pages), your urologist may strongly suspect testicular cancer. However, none of these tests can give a definite diagnosis. The only way to be sure of the diagnosis is to surgically remove the affected testicle and examine it in a laboratory. The surgery to remove a testicle is called an orchidectomy or orchiectomy.

For other types of cancer, a doctor can usually make a diagnosis by removing and examining some tissue from the tumour. This is called a biopsy. However, doctors don't usually biopsy the testicle because there is a small risk that making a cut through the scrotum can cause cancer cells to spread.

Tissue removed during the orchidectomy is sent to a laboratory. A specialist called a pathologist looks at the cells under a microscope and provides information about the cancer, such as the type, and whether and how far it has spread (the stage, see pages 22–23). This helps doctors plan further treatment (see pages 27–42).

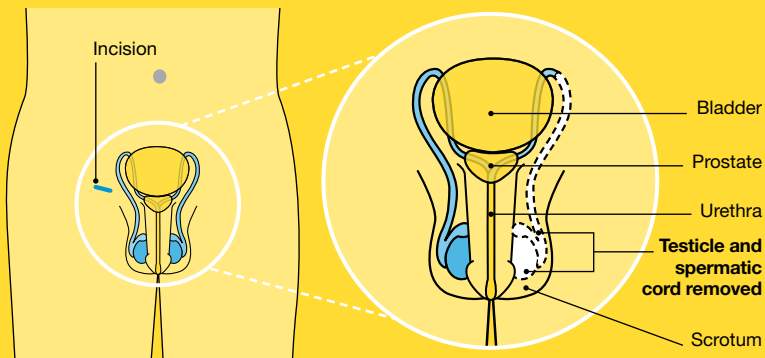
In most cases, only one testicle needs to be removed. It is rare for both testicles to be affected by cancer at the same time.

●● My doctor said to me, 'If you're going to get a cancer, this is the one to get. The cure rate is high, side effects are minimal, and life afterwards is pretty normal.' ●● *Mark*

Having an orchidectomy

An orchidectomy is an operation to remove a testicle. This is often done to confirm a diagnosis of testicular cancer. It is also the main treatment for testicular cancer that has not spread.

- You will be given a general anaesthetic before the orchidectomy.
- The urologist will make a cut (incision) in the groin above the pubic bone. This is shown below with a blue line.
- The whole testicle is pulled up and out of the scrotum through this cut.
- The spermatic cord is also removed because it contains blood and lymph vessels that may act as a pathway for the cancer to spread to other areas of the body.
- The scrotum is not removed but it will no longer contain a testicle. (You may choose to have an artificial testicle inserted to keep the shape. This is called a prosthesis, see page 20.)
- The operation takes about 30 minutes.
- After the orchidectomy, you can usually go home the same day, but you may need to stay in hospital overnight.
- You will need someone to take you home and stay with you for the first 24 hours.



What to expect after surgery

After an orchidectomy, you will need to take care while you recover. Talk to your treatment team about managing side effects



Having pain relief

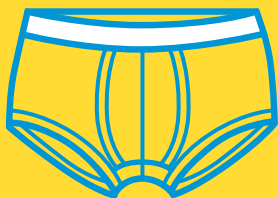
Your doctor can prescribe medicines to control any pain you have after the operation. Let the doctor or nurses know if the pain worsens – don't wait until it is severe before asking for more pain relief.

Stitches and bruising

You will have a few stitches to close the incision. These will usually dissolve after several weeks. There may be some bruising around the wound and scrotum. The scrotum can become swollen if blood collects inside it (intrascrotal haematoma). If this occurs, the swelling may make it feel like the testicle hasn't been removed. Both the bruising and the haematoma will disappear over time.

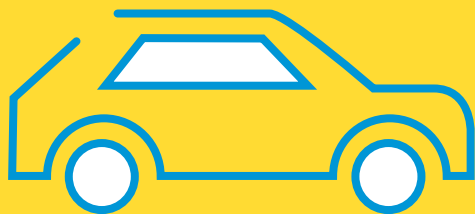
Avoiding strain

You'll probably be advised to avoid strenuous activities, such as heavy lifting and vigorous exercise, for about six weeks after the operation. It is usually okay to have sex 2–4 weeks after surgery. Your doctor will discuss these precautions with you.



Wearing supportive underwear

For the first couple of weeks, it's best to wear underwear that provides cupping support for the scrotum. This will offer comfort and protection as you recover and can also reduce swelling. You can buy scrotal support underwear at most pharmacies. It is similar to regular underwear and is not noticeable under clothing. You could also wear your usual underwear with padding placed under the scrotum.



Returning to driving and work

You should be able to drive after 2–4 weeks and go back to work when you feel ready.



Emotional effects

Losing a testicle may cause some people to feel embarrassed or depressed, or could lead to low self-esteem. It may help to talk about how you are feeling with someone you trust, such as a partner, friend or counsellor. See pages 47–49 for information about finding support services.

Effects on sexuality and body image

Your ability to get an erection and experience orgasm should not be affected by the removal of one testicle. However, some people find that it takes time to adjust to the changes to their body and this may affect how they feel about sex (see page 41). Some people choose to replace the removed testicle with an artificial one (prosthesis, see next page).



Fertility effects

As long as the remaining testicle is healthy, losing one testicle is unlikely to affect your ability to have children. However, some people may have fertility problems as the other testicle may be small and make less sperm. The urologist may advise you to store sperm at a sperm banking facility before the surgery, just in case you have fertility problems in the future (see page 40).

Testicular cancer usually occurs in only one testicle, so it is rare to need both testicles removed. However, people who have both testicles removed no longer produce testosterone and may need to see an endocrinologist who may prescribe testosterone replacement therapy. They will also be infertile.

Having a prosthesis

You may decide to replace the removed testicle with an artificial one called a prosthesis. The prosthesis is a silicone implant similar in size and shape to the removed testicle. There are different brands, and some feel firmer than others. Whether or not to have a prosthesis is a personal decision. If you choose to have one, you can have the operation at the same time as the orchidectomy or at another time. Your urologist can give you more information about your options.

Before you have any surgery, you should ask your doctor for a referral to a fertility specialist if you are wanting to have children in the future. You may be able to store sperm for later use (sperm banking).

Further tests

If the removal of your testicle and initial tests show that you have cancer, you will have further tests to see whether the cancer has spread to other parts of the body, such as lymph nodes or other organs. These tests may also be used during or after treatment to check how well the treatment has worked.

CT scan

You will have a computerised tomography (CT) scan of your chest, abdomen and pelvis. Sometimes this is done before the orchidectomy.

A CT scan uses x-rays to take pictures of the inside of your body and then compiles them into one detailed, cross-sectional picture. To make the scan pictures clearer and easier to read, you may have to fast (not eat or drink) for a period of time before your appointment.



All tests and scans have risks and benefits, and you should discuss these with your doctor. You should let your medical team know if you have diabetes or kidney disease. It is also important to tell them if you have had an allergic reaction to iodine or dye (the contrast) during a previous scan.

Before the scan, you may be given an injection of a dye into a vein in your arm to make the pictures clearer. This injection can make you feel hot all over for a few minutes. You might also feel like you need to urinate, but this sensation won't last long. You may be asked to drink a liquid instead of having an injection.

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 takes about 15 minutes.

MRI scan

In some circumstances, such as if you have an allergy to the dye normally used for a CT scan, you may instead have a magnetic resonance imaging (MRI) scan. An MRI uses a powerful magnet and radio waves to create detailed pictures of areas inside the body. Sometimes, a dye will be injected into a vein before the scan to help make the pictures clearer.

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. 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. The scan takes about 30 minutes, and most people are able to go home as soon as it is over.

PET-CT scan

In some circumstances, you may also be given a positron emission tomography (PET) scan combined with a CT scan. You will be injected with a small amount of a glucose (sugar) solution containing some radioactive material, then asked to rest for 30–60 minutes while the solution spreads throughout your body before you have the scan. Cancer cells show up more brightly 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-CT scan, but the scan itself usually takes about 15 minutes. The radioactive material in the glucose solution is not harmful and will leave your body within a few hours.

Staging

The tests described in this chapter will help to show whether and how far the cancer has spread (the stage). There are several staging systems for testicular cancer, but the most commonly used is the TNM system (see table opposite). The TNM scores and the levels of tumour markers in the blood (see page 15) are used to work out an overall stage for the cancer. Stage 1 means that the cancer is found only in the testicle (early-stage cancer). Stage 2 and above mean that the cancer has spread outside the testicle to the lymph nodes in the abdomen or pelvis, or to other areas of the body.

TNM staging system

T (tumour)	describes whether the cancer is only in the testicle (T1) or has spread into nearby blood vessels or tissue (T2, T3, T4)
N (nodes)	describes whether the cancer is not in any lymph nodes (N0) or has spread to nearby lymph nodes (N1, N2)
M (metastasis)	describes whether cancer has not spread to distant parts of the body (M0) or whether cancer has spread to distant lymph nodes, organs or bones (M1)

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor, but it is not possible for anyone to predict the exact course of the disease.

To assess your prognosis, your doctor will consider:

- your test results
- the type of testicular cancer you have
- the stage of the cancer
- other factors such as your age, fitness and medical history.

Testicular cancer has the highest survival rates of any cancer (other than common skin cancers).⁵ Regular monitoring and review (surveillance) is a major factor in ensuring good outcomes, so it's vital that you attend all your follow-up appointments (see page 46).



Key points about diagnosing testicular cancer

Initial tests

- Your doctor will examine your testicles and scrotum for a lump or swelling.
- An ultrasound will create a picture of your scrotum and testicles. This is a quick and painless scan.
- Blood tests will look for chemicals (tumour markers) in your blood that may indicate cancer. Some people with testicular cancer do not have raised tumour marker levels.

Surgery

- In most cases, the only way to diagnose testicular cancer with certainty is to remove the testicle. This operation is called an orchidectomy. This is also the main treatment for testicular cancer that has not spread.
- After an orchidectomy, you will have side effects such as pain and bruising. These will ease over time. Wearing scrotal support underwear will help.

Further tests and staging

- If the removal of the testicle shows that you have cancer, you will probably have more tests to see whether the cancer has spread. You may have a CT scan and other scans.
- The doctor will tell you the stage of the cancer, which describes whether and how far it has spread.
- Testicular cancer usually has high survival rates. It is very important, however, to attend regular follow-up appointments.



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, or you might be anxious to get started. Check with your specialist how soon treatment should begin – in general, treatment for testicular cancer should happen quickly. Ask the specialist to explain the options and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 12) and if the treatment centre is the most appropriate one for you. You may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes can help or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 51 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your

options. Specialists are used to people doing this. Your GP or specialist 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 second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

➤ See our *Cancer Care and Your Rights* booklet.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

➤ See our *Understanding Clinical Trials and Research* booklet.

Treatment

Your medical team will advise you on the best treatment for you.

They will consider:

- your general health
- the type of testicular cancer you have
- the size of the tumour
- the number and size of any lymph nodes involved
- whether the cancer has spread to other parts of your body. If testicular cancer does spread, it most commonly spreads to the lymph nodes in the pelvic and lower abdominal regions.

In almost all cases, an orchidectomy is done to remove the affected testicle (see pages 16–20). If the cancer hasn't spread, this may be the only treatment you need. However, after the operation, you will need to have regular check-ups and tests to ensure that the cancer hasn't come back. This is called surveillance (see next page).

If additional treatments are needed, they may include chemotherapy, radiation therapy or a combination of treatments to kill any remaining cancer cells and prevent the cancer from coming back. If the cancer does not respond to chemotherapy, you may need further surgery to remove lymph nodes from the abdomen. This is called a retroperitoneal lymph node dissection (RPLND, see pages 36–37).

Fertility concerns

Chemotherapy, radiation therapy and RPLND can cause temporary or permanent infertility. If you may want to have children in the future, ask your doctor for a referral to a fertility specialist before treatment starts. You may be able to store sperm for later use.

➤ See our *Fertility and Cancer* booklet.

Surveillance

If you had an orchidectomy and the cancer was completely removed, you may not need any further treatment. Instead, you will have surveillance, with regular blood tests (checking tumour markers) and CT scans for 5–10 years.

Surveillance can help find if there is any cancer remaining (residual cancer). It can also help work out if the cancer has come back (recurrence, see page 46). How often you will need check-ups and tests will depend on whether you had seminoma or non-seminoma testicular cancer. Your doctor will tailor a surveillance schedule for your situation.



It's important to follow the surveillance schedule outlined by your doctor. While it may be tempting to skip appointments if you are feeling better or if you were diagnosed with stage 1 cancer, surveillance can help to find cancer early if it comes back.

Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. It aims to kill cancer cells or slow their growth, while causing the least possible damage to healthy cells.

When chemotherapy is given after surgery, it is known as adjuvant treatment. If the cancer is only in the testicle, it can usually be treated with surgery alone and chemotherapy may not be needed. Sometimes,

however, your treatment team assesses that there is a moderate risk of the cancer spreading or returning. In this case, a single dose (or two cycles) of chemotherapy will be recommended. After treatment, you will be monitored through surveillance with follow-up appointments and tests for 5–10 years (see page 46).

In rare cases, when the cancer has spread to other parts of the body, chemotherapy may be given before surgery as the primary treatment.

There are many types of chemotherapy drugs. Some people are given a drug called carboplatin, which is often used for early stage seminoma cancer after surgery. Other drugs commonly used for testicular cancer are bleomycin, etoposide and cisplatin. When these three drugs are used together, it is called BEP chemotherapy.

Chemotherapy is usually put into a vein (intravenously) through a drip. Bleomycin may also be given by injection into a muscle (intramuscularly). In either case, chemotherapy is given in cycles, which means you will receive the drugs for a period of time and then have a rest period of a few weeks before starting a new cycle.

The number of treatment cycles you have will depend on the type and stage of the cancer. Your doctor will give you more information. You will probably have to visit the hospital as an outpatient each time you have chemotherapy.

For ways to prevent or reduce the side effects of chemotherapy, see pages 31–33.

➤ See our *Understanding Chemotherapy* booklet for more details.



Bradley's story

I was 24 when I started feeling lethargic and developed a lot of pimples on my back, which was unusual for me. My left testicle was also increasing in size and felt hard.

At first, I thought it was some kind of hormonal change, but as the testicle was becoming heavy and uncomfortable, I told my dad. He took me straight to the doctor, who did a physical examination and sent me for an ultrasound.

After the ultrasound, the technician said to see my doctor right away. So, my dad and I went back to my GP, and he told me I had testicular cancer. I was shocked and emotional but tried to keep calm.

The GP referred me to a urologist, who said the testicle would need to be removed. Within 12 hours of seeing him, I'd had the operation. It was sent to the lab for testing and it was confirmed as stage 1 seminoma testicular cancer.

I had a little inflammation but otherwise I felt good. I only had to stay in hospital overnight.

A month after the surgery, I had two rounds of chemotherapy in case the cancer spread. The chemotherapy made me feel tired and left a funny taste in my mouth. These side effects passed quickly, and it helped to drink a lot of water.

My urologist suggested that I store some sperm before the chemotherapy began because there was a small chance it would make me sterile.

I saw my doctor for regular follow-up appointments and had blood tests as well as a CT scan and ultrasound. I also examined the other testicle regularly for any hardness. It's been five years now and there's been no recurrence of the cancer.

My life has now returned to normal and I don't really think about the cancer much.

Side effects of chemotherapy

Chemotherapy drugs damage cells as they divide. This makes the drugs effective against cancer cells, which divide more rapidly than most normal cells do. However, some normal cells – such as hair follicles, blood cells, and cells inside the mouth or bowel – also divide rapidly. Side effects can occur when chemotherapy damages these normal cells.

Everyone reacts differently to chemotherapy. Some people don't experience any side effects, while others have a few. Side effects are usually temporary, and there are medicines that can help reduce your discomfort. Talk to your doctor or nurse about any side effects you have and ways to manage them.

Fatigue – Most people feel tired during chemotherapy, particularly as treatment progresses.

Low white blood cell count – About a week after a treatment session, your white blood cell levels may drop, making you more prone to infections. If you feel unwell or have a fever higher than 38°C, call your doctor immediately or go to the nearest hospital emergency department.

Nausea and vomiting – It is common to feel ill or vomit within a few hours of chemotherapy treatment. Anti-nausea medicines can prevent or at least reduce this feeling. In most cases, an anti-nausea medicine will be injected at the same time as the chemotherapy is given. You may be given other anti-nausea medicines to take home in case nausea occurs. These are available in many forms, including tablets that you swallow, wafers that dissolve on the tongue and suppositories to put

into your bottom (rectum). Tell your medical team if you still feel sick as you may be able to try a different form of medicine.

Constipation – Sometimes chemotherapy drugs can affect the nerve endings in the bowel, making it hard to pass a bowel motion and causing constipation. More often, constipation occurs as a side effect of the anti-nausea medicines. Your medical team can prescribe medicines to help with constipation.

Hair loss – Chemotherapy often causes hair loss from the head and body, but hair usually grows back once treatment is over.

Erection problems – Chemotherapy can affect erections, but this is usually temporary. You may also find you have a lower sex drive (libido). For information about sexuality, see page 39.

Lower sperm production – The chemotherapy drugs may reduce the number of sperm you produce and their ability to move (motility). This can cause temporary or permanent infertility. Speak with your doctor about sperm banking before starting chemotherapy. You will still need to use contraception to protect your partner from any drugs in your semen and to avoid pregnancy (see box on opposite page).

Peripheral neuropathy – Some drugs affect the nerves, causing numb or tingling fingers or toes. This is called peripheral neuropathy. It usually improves after treatment is finished.

Ringling in the ears – Some types of chemotherapy drugs can cause short-term ringing or buzzing in the ears. This is known as tinnitus.

Using contraception during treatment

Even if treatment lowers sperm production, there is still a chance your partner could become pregnant. Because chemotherapy and radiation therapy can damage sperm, you will need to use

contraception during treatment and sometimes for some months afterwards to prevent pregnancy. Your doctor will discuss this with you in more detail. See page 40 for more information.

Breathlessness, cough or unexplained symptoms – Some drugs can damage the lungs or kidneys. You may have lung and kidney function tests to check the effects of the drugs on your organs.

Risk of heart disease – Having chemotherapy for testicular cancer increases the risk of developing heart (cardiovascular) disease. You will have tests to check your heart function before and after treatment.

Risk of other cancers – People who have chemotherapy for testicular cancer are at a slightly higher risk of developing leukaemia, which is a blood cancer. This outcome is extremely rare, so the benefit of receiving treatment outweighs this risk. However, you will have regular check-ups after treatment to test for cancer.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill cancer cells or damage them so they cannot grow, multiply or spread. The radiation is usually in the form of focused, high-energy x-ray beams.

Radiation therapy is sometimes given to people with seminoma cancer after surgery to prevent the cancer from coming back and to destroy any cancer cells that may have already spread from the cancer to the lymph glands.

Treatment is carefully planned to ensure that any remaining cancer cells are destroyed while causing the least possible harm to normal tissue. During a radiation therapy session, you will lie under a machine called a linear accelerator. The radiation is directed at lymph glands in the back of the abdomen or in the pelvis. The unaffected testicle may be covered with a lead barrier to help preserve your fertility.

Radiation therapy is painless and can't be felt. It is just like having an x-ray taken. The treatment itself takes only a few minutes, but each session may last 10–15 minutes because of the time it takes to set up the equipment and place you in the correct position.

Most people have outpatient treatment sessions at a radiation therapy centre from Monday to Friday for 2–4 weeks. Your doctor will let you know how many sessions you need.

Side effects of radiation therapy

Radiation therapy can cause a range of side effects, including skin reactions, fatigue and stomach problems. Most side effects disappear within a few weeks of finishing treatment.

Skin reactions – In most cases, radiation therapy for testicular cancer won't irritate the skin in the treatment area. If the skin does

become red or sore, talk to your treatment team about using a moisturising cream, such as sorbolene.

Fatigue – Some people find they become very tired and lack energy for everyday tasks. Try doing some gentle exercise as this can help with fatigue. Plan your activities so you can rest regularly during the day. Talk to your family and friends about how they can help you. The tiredness often lasts for a few weeks after treatment is finished.

Stomach problems – If the treatment area includes your abdomen, you could have some minor stomach-aches, nausea or bloating. Your doctor may prescribe medicines to prevent these symptoms from occurring, or to treat them if they do occur.

Bowel problems – Radiation therapy sometimes causes diarrhoea and cramping. These bowel irritations are usually minor and do not need treatment, but if they are bothering you, talk to your doctor about adjusting your diet or taking medicines.

Hair loss – You may lose pubic and abdominal hair in the treatment area. After treatment, your hair will usually grow back.

Bladder irritation – In some people, the bladder and urinary tract may become irritated and inflamed. Drinking plenty of fluids will help, but you should avoid alcoholic or caffeinated beverages, as they can irritate the bladder further.

Infertility – Radiation therapy may reduce sperm production or damage sperm. The effect on sperm may be temporary or

permanent (see page 40). Speak with your radiation oncologist about sperm banking before starting radiation therapy. You will still need to use contraception (see box, page 33).

Risk of heart disease – People who have radiation therapy for testicular cancer have a higher risk of heart (cardiovascular) disease. You will have heart function tests before and after treatment.

Risk of other cancers – People who have radiation therapy for testicular cancer are at a slightly increased risk of a secondary cancer in the area exposed to radiation. If these cancers do occur, they appear many years after treatment. Because of this small risk, you will have regular check-ups after radiation therapy to test for cancer.

Your radiation oncologist will see you at least once a week to monitor and treat any side effects during the course of your treatment. You can also talk to a nurse if you are concerned about side effects.

➤ See our *Understanding Radiation Therapy* booklet.

Surgery to remove lymph nodes

In some cases, an operation called a retroperitoneal lymph node dissection (RPLND or lymphadenectomy) is done to remove lymph nodes at the back of the abdomen that may contain cancer cells.

Non-seminoma cancer – Your doctors may recommend an RPLND if scans after chemotherapy show that the lymph nodes have not returned to normal size, as this may mean that they still contain cancer cells.

Seminoma cancer – Chemotherapy or radiation therapy can usually destroy seminoma cancer cells in the lymph nodes, so an RPLND is rarely used. However, it may be offered for advanced seminoma cancer if there are no other treatment options.

An RPLND is a long, complex operation and should be performed by a surgeon with a lot of experience in the procedure. The standard approach involves open surgery, with a large cut made from the breastbone to below the bellybutton. The surgeon moves the organs out of the way, then removes the affected lymph nodes from the back of the abdomen (the retroperitoneum). Your surgeon can give you more information about this operation.

Side effects of RPLND

It can take many weeks to recover from an RPLND – at first, you will probably be very tired and may not be able to do as much as you are used to. The main side effects are pain and tenderness in the abdomen. Tell your doctor or nurses if you are in pain, as they can prescribe medicines to make you more comfortable.

An RPLND may also damage the nerves that control ejaculation. This can cause retrograde ejaculation, which is when semen travels backwards into the bladder, rather than forwards out of the penis. Your surgeon may be able to use a technique called nerve-sparing surgery that avoids damaging these nerves, but this is not always possible.

Although retrograde ejaculation is not harmful, it causes infertility. If having children is important to you, you can store some sperm before an RPLND. Talk to your surgeon for more information.

Palliative treatment

In the rare situation that testicular cancer is so advanced that treatment cannot make it go away, your doctor may talk to you about palliative treatment.

Palliative treatment helps to improve people's quality of life by managing symptoms of cancer without trying to cure the disease. Many people think that palliative treatment is only for people at the end of their life, but it can help people at any stage of advanced cancer. It is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of the cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment options may include radiation therapy, chemotherapy or other medicines.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, practical, emotional, spiritual and social needs. The team also supports families and carers.

- See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

Managing treatment effects

Treatments for testicular cancer can have short-term and longer-term side effects. Short-term side effects are discussed with each treatment earlier in this chapter. Some people find that their sexuality, fertility and body image are affected in the longer term. It may take time to adjust to any changes. The tables on the next three pages offer some tips.

Effects on sexuality and intimacy



Surgery	Chemotherapy	Radiation therapy
The removal of one testicle won't affect erections or orgasms but can affect testosterone levels. RPLND may damage nerves, causing semen to travel backwards into the bladder instead of forwards out of the penis. This still feels like an orgasm, but no semen will come out.	Chemotherapy drugs may remain in your system and be present in your semen for a few days. For a few weeks after chemotherapy, you may have some trouble getting and keeping an erection.	Radiation therapy to the pelvis may temporarily stop semen production. You will still feel the sensations of an orgasm but will ejaculate little or no semen (dry orgasm). In most cases, semen production returns to normal after a few months.

Managing changes to sexuality and intimacy

- Protect your partner from any drugs in your semen by using barrier contraception, such as condoms, during chemotherapy and radiation therapy and for a number of days afterwards, as advised by your doctor. See the next page for information about avoiding pregnancy.
 - Accept that tiredness and worry may lower your interest in sex and remember that sex drive usually returns when treatment ends.
 - Be gentle the first few times you are sexually active after treatment. Start with touching, and tell your partner, if you have one, what feels good.
 - Talk openly with your doctor or sexual health counsellor about any challenges. They may be able to help and reassure you.
- See our *Sexuality, Intimacy and Cancer* booklet.

Effects on fertility



Surgery

Most men who have had one testicle removed can go on to have children naturally. Men who have both testicles removed (rarely required) will no longer produce sperm and will be infertile. Men who experience retrograde ejaculation after RPLND (see page 37) will also be infertile.

Chemotherapy Radiation therapy

Both chemotherapy and radiation therapy can temporarily decrease sperm production and cause unhealthy sperm. It may take one or more years before there are enough healthy sperm to conceive a child. In some cases, infertility may be permanent.

Managing fertility changes

- Use sperm banking to store sperm before cancer treatment for use at a later date. Samples can be stored for many years. Although there is a cost involved, most sperm-banking facilities have various payment plans to make it more affordable. Ask your cancer specialist to refer you to a fertility specialist so you can find out more about your options.
 - Avoid pregnancy until sperm are healthy again by using contraception during and after chemotherapy or radiation therapy for about 6–12 months, as advised by your doctor. You may need a sperm analysis test to determine this.
 - If infertility appears to be permanent, talk to a counsellor or family member about how you are feeling. Infertility can be very upsetting for you and your family, and you may have many mixed emotions about the future.
- See our *Fertility and Cancer* booklet.

Effects on body image



Surgery

If you have had a testicle removed, it may affect how you feel about yourself as a man. You may have less confidence and feel less sexually desirable. Some men adjust quickly to having one testicle, while others find that it takes some time.

Chemotherapy Radiation therapy

Any type of 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, particularly if your body has changed physically. Some people find that their sense of identity or masculinity is affected by their cancer experience.

Adjusting to appearance changes

- Give yourself time to get used to any changes to your body. Try to see yourself as a whole person (body, mind and personality) instead of focusing on the parts of you that have changed.
- Talk to other people who have had a similar experience. You can call Cancer Council **13 11 20** to find out about our peer support programs or visit the Cancer Council Online Community (see page 48).
- Let your partner, if you have one, know how you are feeling. Show your partner any changes and let them touch your body, if you are both comfortable with this.
- If you continue to be concerned about your appearance, you may wish to speak to your medical team about getting an artificial testicle (prosthesis, see page 20).
- You may also find it helpful to talk to a psychologist if you are having trouble adjusting to any changes – ask your GP for a referral.



Key points about treating testicular cancer

Treatment options

Your medical team will advise you on treatment based on the type of testicular cancer, its stage, your general health and your preferences.

Surveillance

After surgery to remove the testicle (orchidectomy), you may not need further treatment. Instead, you will need regular check-ups, blood tests and CT scans. This surveillance has to be continued for 5–10 years. It will help detect any return of the cancer early.

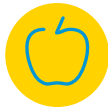
Further treatments

Some people also have chemotherapy, radiation therapy, more surgery or a combination.

- Chemotherapy uses drugs to kill cancer cells or slow their growth. Most side effects are temporary, but can include a risk of infection, fatigue, nausea, hair loss and erection problems.
- Radiation therapy uses targeted radiation to damage or kill cancer cells. Common side effects include fatigue and stomach pain.
- A retroperitoneal lymph node dissection (RPLND) is an operation to remove lymph nodes from the abdomen. It may be used if the cancer has spread to those lymph nodes.
- Palliative treatment can be used at any stage of advanced cancer to control symptoms and stop the cancer from spreading further.

Treatment effects

Treatment for testicular cancer can affect sexuality, fertility and body image, but there are ways to manage changes.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening and do the same for those around you.

➤ See our *Emotions and Cancer* booklet.

Sexuality – 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.

➤ See page 39 and our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See page 40 and our *Fertility and Cancer* booklet.



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 that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

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.

➤ See our *Living Well After Cancer* booklet.

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 medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline **13 11 14** or visit lifeline.org.au.

Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any side effects and check that the cancer hasn't come back or spread. During these check-ups, you will usually have a physical examination and you may have blood tests, x-rays or scans.

Treatment for testicular cancer usually has a good outcome and the majority of people with early stage cancer will be cured. Only about 2–3% of people who have had cancer in one testicle develop cancer in the other testicle. However, some people have a recurrence of cancer in another part of the body. It's important to go to all your follow-up appointments, as tests can detect cancer recurrence early.

When a follow-up appointment or test is approaching, many people may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety. Check-ups will become less frequent if you have no further problems. Between follow-up appointments, it's important to let your doctor know immediately of any symptoms or health problems.

What if the cancer returns?

Sometimes testicular cancer does come back after treatment. This is why it's important to have regular check-ups. There is still a good chance that a recurrence may be successfully treated. Treatment will depend on whether the cancer is in the other testicle, where it has spread to, and what type of testicular cancer it is. People with recurrent cancer may have surgery, chemotherapy, radiation therapy or a combination of treatments. Your doctor will discuss options with you.



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live. Some services will be free, but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ My family members don’t really understand what it’s like to have cancer thrown at you, but in my support group, I don’t feel like I have to explain. ” *Sam*

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit cancercouncil.com.au/OC.



Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council Australia	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
ANZUP Cancer Trials Group	anzup.org.au
Beyond Blue	beyondblue.org.au
Cancer Australia	canceraustralia.gov.au
CanTeen (support for ages 12–25)	canteen.org.au
Carer Gateway	carergateway.gov.au
Department of Health	health.gov.au
e-TC: Get Back on Track after Testicular Cancer (online program)	e-tc.org
Healthdirect Australia	healthdirect.gov.au
Healthy Male Andrology Australia	healthymale.org.au
MensLine Australia	mensline.org.au
Radiation Oncology Targeting Cancer	targetingcancer.com.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
Testicular Cancer Resource Network (US)	tc-cancer.com



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Australia – Carers Australia provides information and advocacy for carers, and is the national peak body representing them to the Australian Government. Visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of testicular cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- Should I be treated in a centre that specialises in testicular cancer?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will my fertility be affected? What are my options for preserving fertility?
- Will the treatment affect my sex life?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

After treatment

- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?



Glossary

abdomen

The part of the body between the chest and hips, which includes the stomach, pancreas, liver, gall bladder, bowel, bladder and kidneys.

adjuvant therapy

A treatment given after the main treatment to lower the risk that the cancer will come back.

alpha-fetoprotein (AFP)

A chemical found in the blood of some people with non-seminoma testicular cancer.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

benign

Not cancerous or malignant.

beta human chorionic gonadotropin (beta-hCG)

A chemical found in the blood of some people with either seminoma or non-seminoma testicular cancer.

biopsy

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

cells

The basic building blocks of the body. A human is made of billions of cells that perform different functions.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

congenital defect (birth defect)

A problem that happens while a baby is still developing in the womb. This may affect how the body looks or functions or both.

CT scan

Computerised tomography scan. This scan uses x-rays to create detailed cross-sectional pictures of the body.

dry orgasm

Sexual climax without the release of semen from the penis (ejaculation).

epididymis

A tightly coiled tube located at the back of each testicle. It stores immature sperm and connects the testicle to the spermatic cord, which contains the vas deferens.

fertility

The ability to conceive a child.

germ cells

Cells that produce sperm in males and eggs in females. Germ cell cancers can occur in the testicles and ovaries.

groin

The area between the abdomen and thigh on either side of the body. The adjective is inguinal (e.g. inguinal hernia).

gynaecomastia

Enlargement of male breast tissue. It can be a symptom of testicular cancer.

haematoma

A collection of blood that clots to form a solid swelling.

HIV (human immunodeficiency virus)

The virus that causes AIDS (acquired immune deficiency syndrome).

hormones

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

hypospadias

A birth defect in which the opening of the urethra is not in its normal place.

infertility

The inability to conceive a child.

inguinal hernia

A bulge in the groin caused when some bowel or fatty tissue comes out through a weak spot in the abdominal muscles.

intrascrotal haematoma

Blood that collects in the scrotum.

intratubular germ cell neoplasia (ITGCN or IGCN)

A non-invasive condition that may turn into testicular cancer.

lactate dehydrogenase (LDH)

A chemical found in the blood of some people with seminoma or non-seminoma testicular cancer.

libido

Sex drive and sexual desire.

lymphadenectomy

See retroperitoneal lymph node dissection (RPLND).

lymphatic system

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

lymph nodes

Small bean-shaped structures that collect and destroy bacteria and viruses.

lymph vessels

Thin tubes that carry the clear fluid known as lymph all over the body.

malignant

Cancerous. Malignant cells can spread (metastasis) and eventually cause death if they cannot be treated.

metastasis (plural: metastases)

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

MRI scan

Magnetic resonance imaging scan. A scan that uses magnetic fields and radio waves to take detailed cross-sectional pictures of the body.

nerve-sparing surgery

A type of surgery to save the nerves that affect ejaculation and urination.

non-seminoma cancer

A type of testicular cancer. Main subtypes are teratoma, choriocarcinoma, yolk sac tumour and embryonal carcinoma.

orchidectomy

An operation to remove a testicle and spermatic cord through a cut (incision) in the lower abdomen.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms.

pathologist

A doctor who interprets the results of tests (such as blood tests and biopsies).

PET-CT scan

Positron emission tomography scan combined with a CT scan. The person is injected with a radioactive solution to help find cancerous areas.

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.

prognosis

The expected outcome of a particular person's disease.

prostate

A gland in the male reproductive system. It produces fluid that makes up part of semen.

prosthesis

An artificial replacement for a lost or damaged body part.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

remission

When the signs and symptoms of the cancer reduce or disappear.

residual cancer

Cancer that remains after treatment.

retrograde ejaculation

A condition where the semen travels backwards into the bladder, instead of forwards out of the penis.

retroperitoneal lymph node dissection (RPLND)

Surgery to remove the lymph nodes from the abdomen. Also called lymphadenectomy.

retroperitoneal lymph nodes

Lymph nodes in the area outside or behind the peritoneum (the tissue that lines the wall of the abdomen).

scrotum

The external pouch of skin behind the penis that contains the testicles.

semen

The fluid ejaculated from the penis during sexual climax. It contains sperm from the testicles and fluids from the prostate and seminal vesicles.

seminal vesicles

Two small glands that lie very close to the prostate and produce fluid that forms part of semen.

seminoma cancer

A type of testicular cancer.

side effect

Unintended effect of a drug or treatment. Most side effects can be managed.

sperm

The male sex cell, which is made in the testicles and is required for reproduction.

spermatic cords

A pair of cord-like structures that run from the testicles to the abdomen. The spermatic cords contain tubes called vas deferens, as well as blood vessels, nerves and lymph vessels.

staging

Performing tests to work out how far a cancer has spread.

stromal tumour

A rare type of testicular tumour that is not usually cancerous. Includes Sertoli cell and Leydig cell tumours.

surveillance

Regular check-ups for several years after the cancer is removed to make sure it hasn't returned.

testicles

Two oval-shaped glands that produce sperm and the male sex hormone testosterone. They are found in the scrotum. Also called testes.

testosterone

Major male sex hormone produced by the testicles. Testosterone promotes the development of male sex characteristics.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

tumour marker

Chemical produced by cancer cells and released into the blood. It may suggest the presence of a tumour.

Markers can be found by blood tests or by testing tumour samples.

ultrasound

A non-invasive scan that uses soundwaves to create a picture of part of the body. An ultrasound scan can be used to measure the size and position of a tumour.

urethra

The tube that carries urine from the bladder to the outside of the body. In the male reproductive system, the urethra also carries semen.

vas deferens

A pair of tubes that carry the sperm from the testicles to the prostate.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary

References

1. MP Laguna et al., *European Association of Urology (EAU) Testicular Cancer Guidelines*, retrieved from uroweb.org/guideline/testicular-cancer, 17 March 2020.
2. J Oldenburg et al., "Testicular seminoma and non-seminoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 24 (suppl. 6), 2013, pp. vi125–vi132.
3. Australian Institute of Health and Welfare (AIHW), *Cancer incidence projections: Australia, 2011 to 2020*, AIHW, Canberra, 2012.
4. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Testicular cancer*, AIHW, Canberra, 2018.
5. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2019*, AIHW, Canberra, 2019.



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 other Pink events, 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

13 11 20

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.

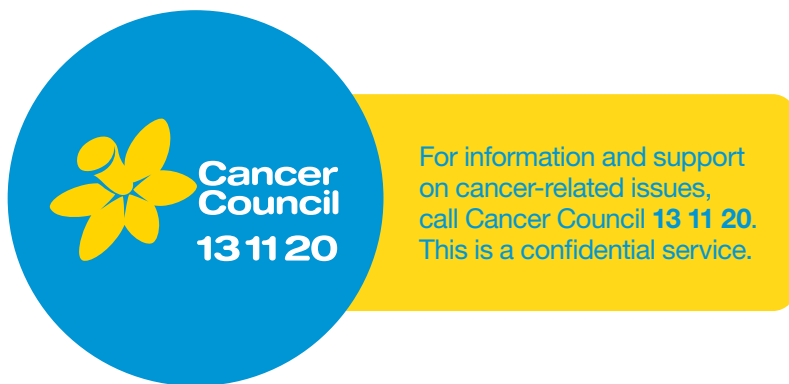
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.
To support Cancer Council, call your local Cancer Council or visit your local website.*