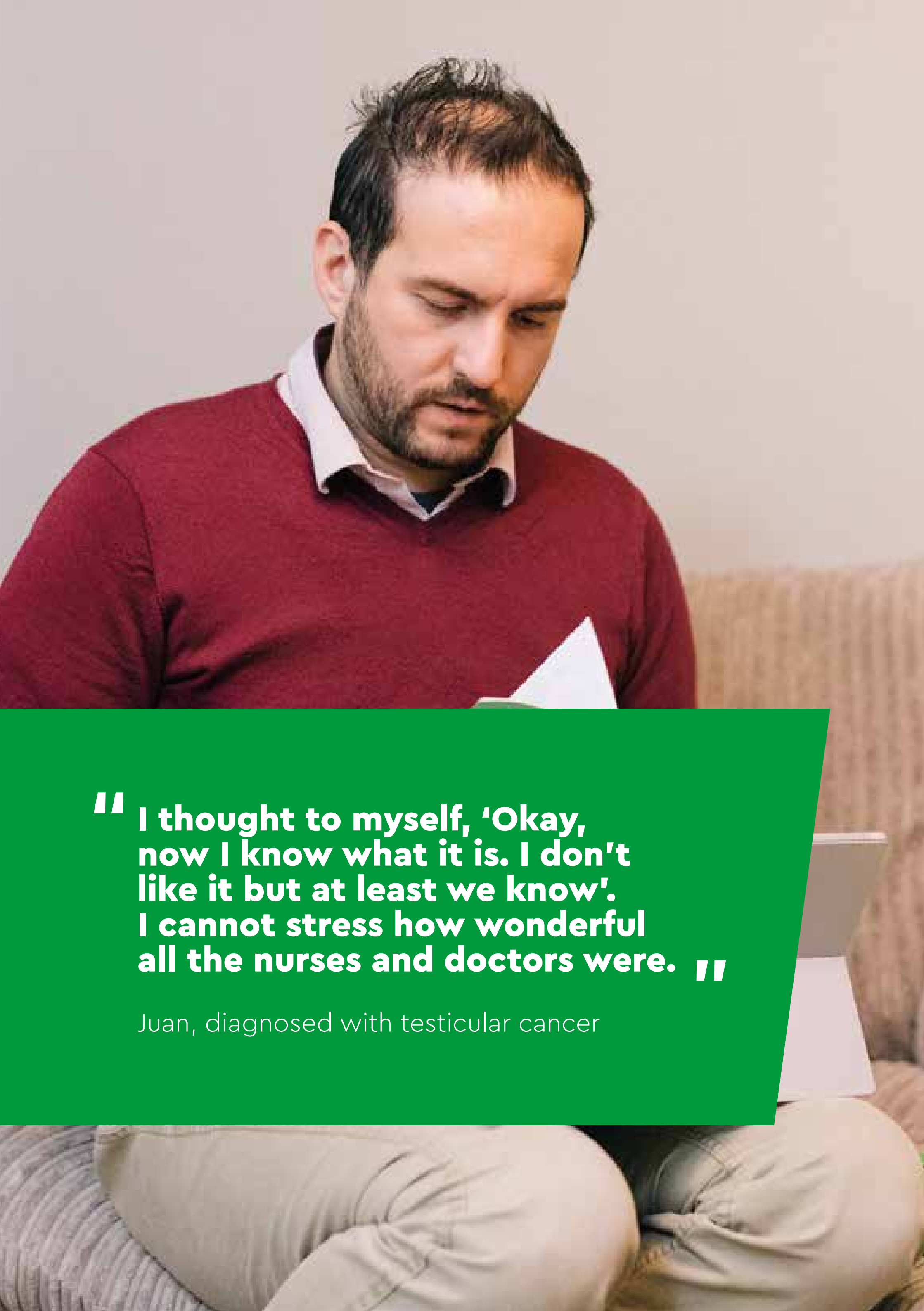
Understanding testicular cancer



> “I thought to myself, ‘Okay, now I know what it is. I don't like it but at least we know’. I cannot stress how wonderful all the nurses and doctors were.”

Juan, diagnosed with testicular cancer

About this booklet

This booklet is about testicular cancer. It is for anyone who has been diagnosed with testicular cancer.

There is also information for carers, family members and friends.

The booklet explains:

- what testicular cancer is
- the symptoms of testicular cancer
- how it is diagnosed
- the different treatments and possible side effects
- ways to cope with a diagnosis of testicular cancer.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 140 to 150, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 151 to 152).

Quotes

In this booklet, we have included quotes from people who have had testicular cancer, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes Juan, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

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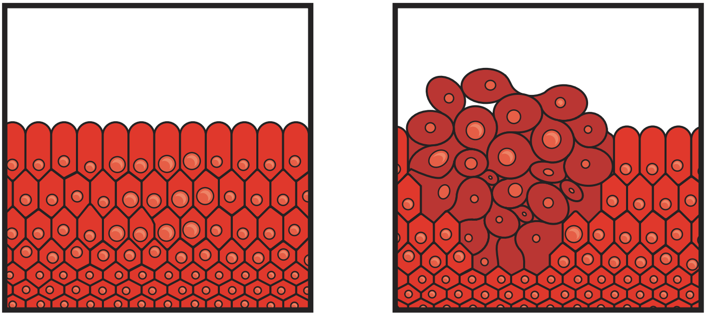
What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

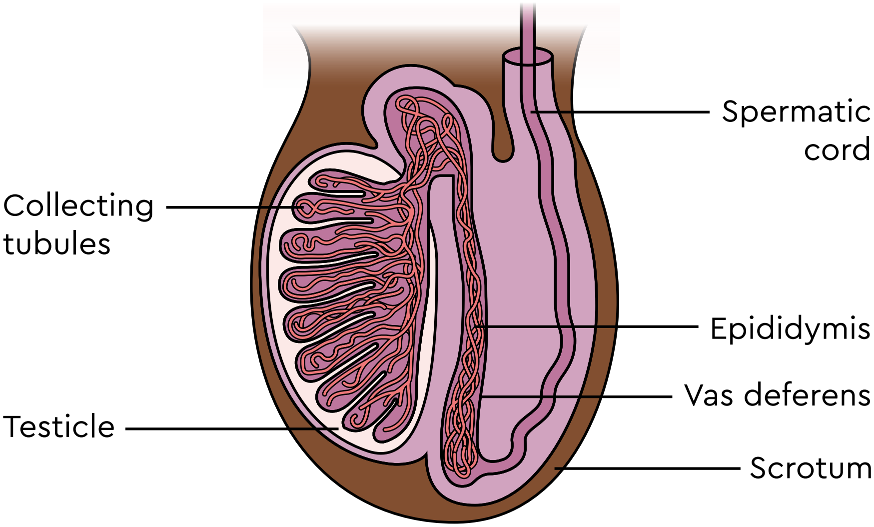
A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (pages 12 to 13). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The testicles

The testicles are 2 oval-shaped organs inside the scrotum. The scrotum is a pouch of skin behind the penis. The testicles hang below the penis. They are sometimes called the testes. They are the main part of the male reproductive system. Testicles produce sperm. Sperm can fertilise a female egg to make a baby.

The structure of the testicle

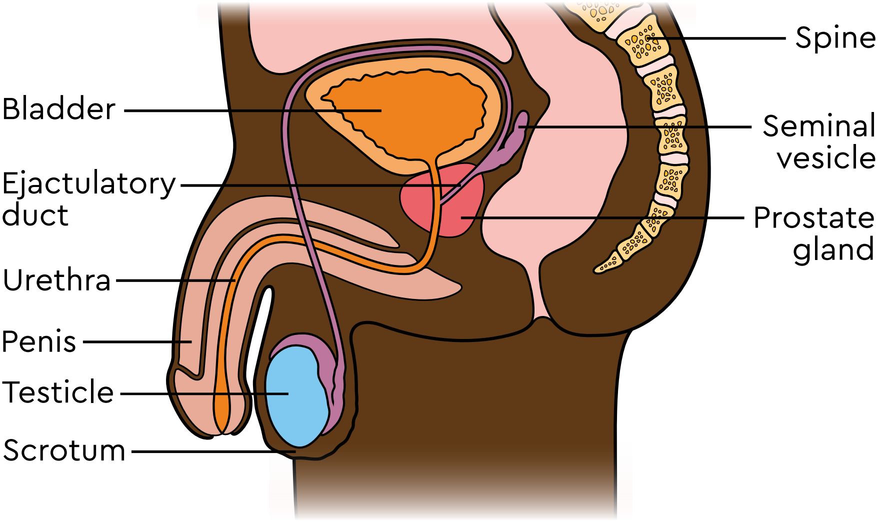


Sperm travels from the collecting tubules inside the testicle to a coiled tube called the epididymis. The epididymis feels like a soft swelling at the back of the testicle. The tube becomes a wider tube called the vas deferens, which is part of the spermatic cord.

This then joins a shorter tube, called the ejaculatory duct (page 10). The ejaculatory duct connects to a tube called the urethra, which goes from the bladder to the end of the penis.

Sperm mixes with fluid from the prostate and the seminal vesicles. These are glands that sit just under the bladder. The sperm and fluid is forced (ejaculated) along the urethra and out from the penis. The ejaculated fluid and sperm are called semen.

The male reproductive system



The testicles also make the hormone testosterone. Hormones are chemical messengers that help control different functions in our bodies.

Testosterone helps control:

- your sex drive (libido)
- getting an erection
- having a deep voice
- facial and body hair
- muscle development.

Testicular cancer

Testicular cancer starts in one of the testicles.

Each year in the UK, around 2,300 men are diagnosed with testicular cancer. This type of cancer can affect anyone who has testicles, including men, trans women and people assigned male at birth. It is most likely to happen between the ages of 25 and 40.

Testicular cancer is usually curable. Like other cancers, it is not infectious, and you cannot pass it on to other people.

The lymphatic system

Testicular cancer is usually only found in the testicle, but sometimes cancer cells from the testicles can spread to nearby lymph nodes. Lymph nodes are part of the lymphatic system.

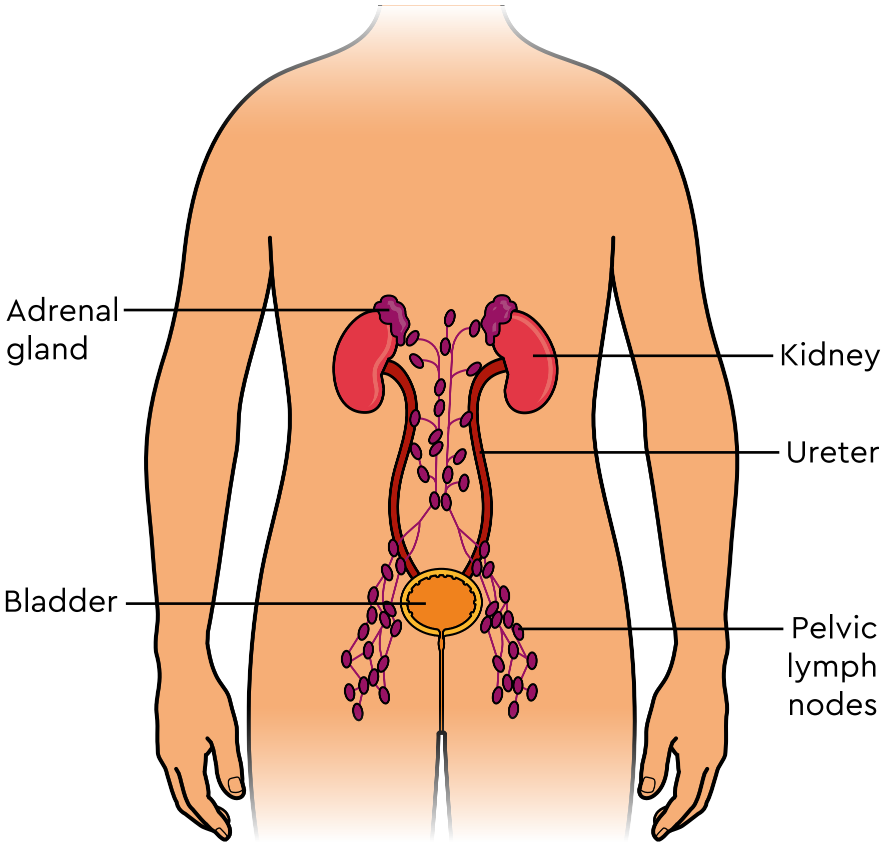
The lymphatic system helps protect us from infection and disease. It also drains lymph fluid from the tissues of the body, before returning it to the blood. The lymphatic system is made of fine tubes called lymphatic vessels. These lymphatic vessels connect to groups of lymph nodes throughout the body.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell to fight it.

The retroperitoneal lymph nodes

Sometimes, cancer cells from the testicles can spread to the lymph nodes at the back of your tummy (abdomen). These are called the retroperitoneal lymph nodes. They are behind your bowel and in front of your spine. You will have a CT scan (page 39) to check whether any of these nodes are larger than normal.

The retroperitoneal and pelvic lymph nodes



Risk factors and causes

Doctors do not yet know what causes testicular cancer. But we know some of the risk factors that may increase the chances of developing it.

Having one or more risk factors does not mean you will get testicular cancer. And if you do not have any risk factors, it does not mean you will not get testicular cancer.

We have listed some risk factors that may affect your chance of developing testicular cancer.

Undescended testicles (cryptorchidism)

The testicles develop inside the tummy (abdomen) of an unborn baby. Usually, they drop down (descend) into the scrotum at birth, or within the first year.

In some boys, this does not happen. This is called having undescended testicles (cryptorchidism). It can be just the one, or both the testicles that do not drop down. In this situation, surgery can be done to bring either the one or both testicles down into the scrotum. This surgery usually happens before the age of 2, and needs to be done before puberty.

Having an undescended testicle as a child increases your risk of testicular cancer. The risk may be higher if you did not have surgery for this.

If you had surgery to bring down the testicles as a child, you should check your testicles regularly (page 19). This is important so you can notice any changes early.

Family history

Having a brother or father who had testicular cancer gives you a slightly higher risk of getting it. Research is looking into whether certain genes may increase the risk.

Carcinoma in situ (CIS)

Carcinoma in situ (CIS) is when there are abnormal cells in the testicle. If it is not treated, it increases the risk of testicular cancer developing.

CIS is sometimes found after having a biopsy of the testicle – for example, to investigate infertility (being unable to start a pregnancy).

Treatment for CIS may include:

- surveillance
- radiotherapy
- surgery.

If the treatment involves removing the affected testicle, it should not affect your ability to get an erection or make someone pregnant, as long as your other testicle is healthy. This means you will still produce testosterone after the surgery.

Previous testicular cancer

If you have already had testicular cancer, there is slightly higher risk of developing cancer in the other testicle.

Ethnicity

Testicular cancer is more common in white men than in African Caribbean or Asian men. The reason for this is not known.

Human immunodeficiency virus (HIV)

If you are HIV-positive, you may have a slightly increased risk of developing testicular cancer.

Factors that do not increase the risk of testicular cancer

There is no evidence to suggest that injury to a testicle increases your risk of getting testicular cancer. But an injury to a testicle or the groin may bring possible symptoms of testicular cancer to your doctor's attention.

Having a vasectomy does not increase the risk of getting testicular cancer.

Symptoms

The most common symptom is a lump in a testicle. But there may also be other symptoms:

- swelling in a testicle – this is usually painless, but it may sometimes suddenly get bigger and become painful
- a dull ache, pain or a feeling of heaviness in the scrotum (pages 8 to 9).

If the cancer has spread to the lymph nodes or other parts of the body, it may cause:

- pain in the back or lower abdomen (tummy)
- weight loss
- a cough
- breathlessness
- feelings of being unwell
- a lump in the neck.

Rarely, the hormones the cancer makes can cause the nipples or breasts to feel tender. They can also cause breast swelling, which is called gynaecomastia.

Conditions other than testicular cancer may cause these symptoms. But it is always important to get your symptoms checked by your doctor.

How to check for testicular cancer

From puberty onwards, it is important to check your testicles regularly. It is usually possible to cure testicular cancer. But it is easier to treat when it is diagnosed early.

Checking for testicular cancer is sometimes called testicular self-examination. Doing this regularly means you will soon get to know what feels normal for you. A normal testicle should feel smooth and firm, but not hard.

It can be easier to check your testicles during, or right after, a warm bath or shower when the scrotal skin is relaxed. Hold your scrotum in the palm of your hand. Use your fingers and thumb to examine each testicle. You should feel for:

- lumps or swellings
- anything unusual
- differences between your testicles.

It is normal for the testicles to be slightly different in size. It is also normal for one to hang lower than the other.

The epididymis (tube that carries sperm) is behind the top of each testicle (pages 8 to 9). It feels like a soft, coiled tube. It is common to get harmless cysts or benign lumps in the epididymis. The treatment for these can vary.

Seeing a doctor

Other conditions can cause lumps or swellings, and most lumps are not cancer (non-cancerous). But it is important you get your doctor to check anything unusual as soon as possible.

Doctors are used to dealing with problems like this. If you feel embarrassed about seeing your GP, you can go to your local sexual health clinic. You can find your nearest clinic on the NHS website (page 144). Or you can look in the health section of your local phone book.

Trans and non-binary people

If you are a trans woman and have testicles, you may feel uncomfortable or upset about checking this part of the body. Talking to a healthcare professional about your body may also be especially difficult and complicated.

Try not to let this stop you checking regularly. It is important to get any changes checked. If you are not able to talk to your GP or local sexual health clinic, you can also contact a:

- gender identity clinic, if you attend one
- sexual health and well-being service that is trans and non-binary friendly. You can check if this is available in your area on Tranzwiki (page 149).

> "At first, I was embarrassed and was worried about having to go to the doctors, with it being a private part of the body.
> I told myself that they see this kind of stuff every day. I'm now glad I went and didn't leave it to get worse. „
>
> Jordan

Diagnosing testicular cancer

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How testicular cancer is diagnosed

Usually, you begin by seeing your GP, who will examine you. If your GP thinks your symptoms may be linked to testicular cancer, they will refer you to a hospital to be seen within 2 weeks.

At the hospital, you will see a urologist. This is a doctor who specialises in treating problems with the testicles, penis, prostate, bladder and kidneys. They will examine you and ask about your general health and any previous health problems you may have had.

They will arrange an ultrasound scan of the scrotum and testicles. They will also arrange blood tests. Sometimes, your GP will arrange for an ultrasound scan of the testicle before you visit the hospital.

You may also have a chest x-ray or a CT scan (page 39). This is to check that your lungs are not affected.

Some hospitals have testicular one-stop clinics. This means as well as seeing a urology doctor, you may have an ultrasound on the same day. You will also be seen by a specialist nurse.

Sometimes doctors diagnose testicular cancer during tests for symptoms in other areas of the body. For example, if a testicular cancer has spread, it may be diagnosed after a CT or MRI scan.

Ultrasound scan

An ultrasound scan uses sound waves to produce a picture of the inside of your testicles. This is done by putting gel onto the scrotum and then passing a device like a microphone over the area. It is a painless test, and only takes a few minutes. An ultrasound is the quickest and most accurate test for diagnosing testicular cancer. It can tell your doctor whether the lump is a harmless cyst (fluid-filled lump) or likely to be a cancer.

Blood tests

Some testicular cancers make certain chemicals called tumour markers (pages 36 to 37) that are released into the blood. You may have blood tests to see if you have raised levels of these chemicals. Even if these chemicals are not raised in the blood, you may still have testicular cancer. You will also have other blood tests to check your general health.

> **“I had noticed a lump on my left testicle and confided in my dad. He encouraged me to have it checked and drove me to have a scan.”**
>
> Conor

After the ultrasound scan

If the ultrasound scan shows the lump is very likely to be testicular cancer, the whole testicle needs to be closely examined. The only way to get a definite diagnosis is to have surgery to remove the whole of the affected testicle. This operation is called an orchidectomy. This is because taking just a small piece of tissue (biopsy) may miss a cancer.

On rare occasions, the surgeon will remove only part of the testicle. For example, this may happen when someone has only one testicle. Or it may happen if the scan does not show clearly how likely it is to be cancer.

A doctor called a pathologist will examine the removed tissue using a microscope. This is to see if there are any cancer cells. If there are, the sample will show which type of testicular cancer (pages 34 to 35) you have.

Removing the testicle (orchidectomy)

As well as confirming a diagnosis, removing the testicle removes the cancer. It is the main treatment for testicular cancer that has not spread. This may be the only treatment you will need if:

- the cancer has not spread outside the testicle
- there is low risk of the cancer coming back (recurrence).

Your specialist doctor and nurse will explain why you need it and can talk through any concerns you may have. It is natural to be worried about having this operation and how it may affect your body image, sex life or fertility (pages 96 to 105).

If your other testicle is healthy, removing one testicle will not affect your fertility or ability to get an erection.

Testicular implant or prosthesis

During the operation, the surgeon can put an artificial testicle into your scrotum. This is called a testicular implant or prosthesis. If you are unsure about whether you want this at the time of your operation, you can have a prosthesis put in later. Your doctor will give you more details about the benefits and disadvantages of having an artificial testicle. They can explain how it will look and feel.

Before your operation

If you smoke, try to stop or reduce how much you smoke before your operation. This will help:

- lower your risk of chest problems, such as a chest infection
- help your wound heal after the operation
- reduce your risk of other health conditions.

The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live. Your GP or specialist nurse can also give you advice and information about local stop-smoking services.

Before your operation, you will meet a member of the surgical team and a specialist nurse or clinical nurse specialist (CNS). They will discuss the operation and you can ask any questions or talk over any concerns you have.

You will go to a pre-assessment clinic for some general checks such as blood tests and an ECG (a recording of your heart). This is part of the standard preparation before a general anaesthetic.

Fertility and storing sperm (sperm banking)

You may be worried that the cancer will affect your ability to make someone pregnant (your fertility). Removing one testicle will not usually affect your fertility, as long as the other testicle is healthy.

But you will usually be asked if you want to store (bank) sperm before your operation, as long as it does not delay treatment too much. This is because you may need to have further treatment after your surgery, such as chemotherapy (pages 63 to 67). This may affect your fertility.

Storing or freezing some of your sperm means you can use it in the future to help you start a pregnancy. You may want to store your sperm even if you are not in a relationship.

You may be asked to give a sample of sperm to check your sperm levels first. If there is no sperm in the sample you give, it may be possible to take a sample from your testicle during surgery. There are also other sperm collection techniques (page 105).

If your sperm count is low, or there is no sperm in the sample, that may be because the other testicle is small or making less sperm.

If you are offered further treatment, and have not stored any sperm, you can store sperm after surgery.

If you are trans or non-binary, this may feel even more overwhelming. But it is important for you to have the option of preserving your fertility so you can make an informed decision. Your cancer doctor or specialist nurse can talk to you about this before your treatment starts.

We have more information about sperm banking (page 103 to 105).

The operation

You have the operation as a day patient procedure. Before your operation, you will meet members of the surgical and nursing teams and the anaesthetist. The anaesthetist is the person who gives you the anaesthetic.

You usually have the operation done under a general anaesthetic. But you may have it done under a local anaesthetic. Your anaesthetist and surgeon will discuss which is the best option for you.

The surgeon will make a small cut (incision) into the groin on the affected side. They will then push the testicle up from the scrotum and remove it through the incision.

After the operation

When you have recovered from the effects of anaesthetic, you will be able to eat and drink. The hospital staff will encourage you to get up and start walking around as soon as possible.

As soon as you feel well enough and your doctor has checked you over, you can go home. This is usually the same day that you have the surgery. You will need someone to take you home and stay with you for the first 24 hours.

Recovering from surgery

You may have some discomfort, bruising and slight swelling around the scar for a couple of weeks. Taking regular painkillers will help this. The hospital will give you a temporary scrotal support garment. Or you may be advised to wear supportive underwear for about 2 weeks after your surgery. Wearing loose trousers may also help with any discomfort.

You may have numbness around the area, but this usually gets better slowly. But, for some people, there may be areas of numbness that never completely go away.

You usually have dissolving stitches. They can take a few weeks to dissolve. If you have non-dissolving stitches, they are usually removed about 5 to 10 days after your operation.

Driving and returning to work

Your doctor will advise that you only start driving when you feel comfortable enough. You should also be confident that you can do an emergency stop. Your specialist can give you more information about this.

Check with your insurance company to make sure that you are covered. You can discuss any concerns you have about driving after your orchidectomy with the Driver and Vehicle Licensing Agency (DVLA) if you live in England, Scotland or Wales. Visit **gov.uk/contact-the-dvla** or call **0300 790 6806**. If you live in Northern Ireland, contact the Driver and Vehicle Agency (DVA). Visit **nidirect.gov.uk** or call **0300 200 7861**.

Your specialist will also advise you not to do any heavy lifting for the first few weeks after your operation. The amount of time you need to take off work will depend on the type of work you do. Your hospital doctor can advise you more on this.

Sex

It is usually okay to have sex once your wound has healed. But you may not feel like having sex for a while after your surgery. This may happen if you are in some discomfort and feel anxious. You may be concerned about your sex life (pages 99 to 101) after the testicle has been removed. Any negative feelings will usually get better gradually.

If difficult feelings or problems with your sex life continue, talk to your doctor or nurse. There are also organisations that might also be able to help (pages 140 to 150).

If you are gay, bisexual or transgender

There may be times when members of your healthcare team ask about your sexual orientation or gender identity. You do not have to give your team this information. But it is an important part of who you are, and it may be helpful that they know. It can help your team give the right care and support to you and the people close to you. You may find it makes things easier or less stressful for you.

If the questions they ask do not fit who you are or how you identify, tell your team. If you are unsure or uncomfortable answering a question, it is okay to check why the person is asking. You can ask them why they need this information and why they think it is relevant to your care.

If your healthcare team have not asked, it is still important that you feel able to come out to them if you want to. You may choose to do this at your first meeting with anyone from your team. Or you may decide to wait until you find someone you feel comfortable with. If a healthcare professional is wearing a rainbow NHS badge, you could start by asking them about it. The badge means they should be open to talking about LGBTQ+ needs and able to offer support. Some healthcare professionals wear rainbow lanyards or other items to show they support the LGBTQ+ community.


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Types of testicular cancer

After surgeons have removed the testicle, the tissue is examined under a microscope. This will help doctors find out the type of testicular cancer you may have.

Germ cell tumours

Most testicular cancers develop from germ cells in the testicles. They are also called germ cell tumours (GCTs). Germ cells in the testicles produce sperm.

There are 2 main types of testicular germ cell cancer:

- seminomas
- non-seminomas.

Sometimes, testicular cancers are a combination of non-seminomas and seminomas. This is also called a **mixed germ cell tumour** cancer. Testicular cancer is the general term used for all types of testicular cancer.

Seminomas

Seminomas can happen between the ages of 15 and 50. But the average age at diagnosis is 35. About 40 to 45 in 100 (40 to 45%) testicular cancers are seminoma.

Non-seminomas

Non-seminomas usually occur between the ages of 15 and 35. About 40 to 45 in 100 (40 to 45%) testicular cancers are non-seminoma.

Non-seminomas are made of different types of cells. They can be made of just one cell type, or they may be made of a mixture. They include:

- teratomas
- embryonal tumours
- yolk sac tumours
- choriocarcinomas.

Rarer types

Sometimes, the cancer found in the testicle is not a germ cell tumour, but another type of cancer. These include rare types of cancer called Leydig cell tumours and Sertoli cell tumours. Another rare type of testicular cancer is a type of non-Hodgkin lymphoma. We have more information in our booklet **Understanding non-Hodgkin lymphoma** (page 134). You can also talk to our cancer support specialists.

Call the Macmillan Support Line free on
0808 808 00 00, 7 days a week, 8am to 8pm. ☎

Tumour markers

Some testicular cancers make chemicals or proteins that are released into the blood. These are called tumour markers. Doctors can measure tumour marker levels by taking a blood test.

Most non-seminomas and some seminomas have raised levels of tumour markers (pages 36 to 37). But not everyone with testicular cancer has raised markers.

There are 3 main tumour markers:

- Alpha-fetoprotein (AFP) – can be raised in non-seminomas but not in seminomas.
- Human chorionic gonadotrophin (HCG) – can be raised in non-seminomas and sometimes in seminomas.
- Lactic dehydrogenase (LDH) – can be raised in both seminomas and non-seminomas.

Tumour markers can be used to:

- help diagnose testicular cancer
- monitor you after surgery
- check how you are responding to treatment
- check that the cancer has not come back.

You have blood tests to measure tumour markers before surgery to remove the testicle (page 26). You have them measured again, usually a week after surgery. Even if you do not have raised levels of tumour markers before your surgery, you still have them checked afterwards and as part of your follow-up after treatment. You will have regular blood tests to check the levels of your tumour markers.

If the levels of tumour markers fall quickly after the operation, it can be a sign that all the cancer has been removed. This helps the doctors plan your treatment.

A CT scanner

Further tests

After testicular cancer is diagnosed, you may have further tests.

These are to find out if the cancer has spread to other parts of the body. The results help your doctors decide the best treatment for you.

Some people are diagnosed with a testicular cancer that has spread when they are having scans to investigate other symptoms they might have. If testicular cancer has spread, it is still usually possible to cure it.

General blood tests

You may have some general blood tests. These check for different things, including your iron (haemoglobin) levels and how your liver and kidneys are working.

CT scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring. We have more information about CT scans on our website. Visit **macmillan.org.uk/ct-scan**

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation (pages 140 to 150) can also provide support. Or you can talk to one of our cancer support specialists on **0808 808 00 00** 7 days a week, 8am to 8pm.

Staging

The stage of a cancer is a term used to describe:

- its size
- whether it has spread from where it started.

For testicular cancer, staging also includes levels of tumour markers (pages 36 to 37).

Knowing the stage helps doctors decide on the best treatment for you. Your cancer doctor or nurse can tell you more about the stage of your cancer.

The most commonly used staging systems for testicular cancers are the TNM and number staging systems.

TNM staging system

T describes the size of the tumour. It is numbered between 0 and 4 depending on the size and extent of the tumour.

- T0 means that there are no signs of a tumour.
- Tis means there are abnormal cells in the testicle that are pre-cancerous (carcinoma in situ).
- T1 means the tumour is inside the testicle and has not spread outside of the testicle.
- T2 means a tumour is inside the testicle but has spread to the outer layers within the testicle. It has not spread outside the testicle.
- T3 means a tumour has spread to the outer layers within the testicle and to the spermatic cord. It may also have started to spread outside of the testicle.
- T4 means a tumour has spread into the scrotum and may have spread to the lymphatic system.

N describes whether the cancer has spread to the lymph nodes.

- N0 means that no lymph nodes are affected.
- N1, N2 or N3 means there are cancer cells in the lymph nodes. The number depends on how many lymph nodes contain cancer cells, the size and where they are.

M describes whether the cancer has spread to another part of the body. This is called metastatic cancer.

- M0 means the cancer has not spread.
- M1 means the cancer has spread to distant lymph nodes or to organs such as the lungs.

Serum tumour markers

The levels of serum tumour markers (pages 36 to 37) are also included as part of the staging for testicular cancer.

- S0 means tumour marker levels are within normal limits.
- S1 means tumour markers are slightly raised.
- S2 means tumour markers are moderately raised.
- S3 means tumour markers are very high.

Number staging system

Stage 1

The cancer may be any size, and is only in the testicle.

Stage 1 cancers are divided into 2 groups depending on whether tumour markers are normal (or return to normal) or rise after surgery.

Stage 2

The cancer has spread to local lymph nodes in the tummy (abdomen) called the retroperitoneal lymph nodes (page 14).

Stage 2 cancers are divided into different groups depending on the size and number of lymph nodes affected.

Stage 3

The cancer has spread to distant lymph nodes in the chest, or higher up (pages 12 to 13). For example, this could be the lymph nodes in your chest, armpit or neck. Retroperitoneal lymph nodes may also be affected.

Stage 3 cancers are divided into different groups: 3a, 3b and 3c. In stage 3c, the cancer may have spread to other organs such as the liver or brain.

Your cancer doctor can give you more information about the stage of your cancer.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Treating testicular cancer

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Treatment overview

The 3 main treatments for testicular cancer are:

- surgery
- chemotherapy
- radiotherapy.

You usually have surgery to diagnose and remove the cancer. This is called an orchidectomy (page 26). After this, your doctors and other members of the multidisciplinary team (pages 58 to 59) will talk to you about the treatment options. They will explain what might be best for your situation.

They may talk to you about surveillance (pages 54 to 55). This is the option of monitoring you regularly in clinic. Or they may suggest having chemotherapy after surgery (pages 63 to 77). Occasionally, they may suggest radiotherapy (pages 86 to 90). Treatment options depend on:

- the stage of the cancer
- whether it is non-seminoma or seminoma (page 34 to 35)
- the risk of it coming back.

If testicular cancer comes back, it can usually be treated successfully.

Treating stage 1 testicular cancer

Stage 1 testicular cancer is cancer that has not spread outside the testicle.

Surgery

Surgery to remove the testicle (orchidectomy) may be the only treatment you need.

Surveillance

After surgery, your doctor will ask you to go to the clinic for regular physical examinations and have blood tests, including a test to check your tumour marker levels (pages 36 to 37). You may also have CT or MRI scans at the clinic. This is called surveillance (pages 54 to 55).
If the cancer comes back, the surveillance tests help to find it at the earliest stage. Further treatment can usually cure the cancer.

Adjuvant treatment

Your doctor may offer you chemotherapy treatment after surgery (page 63 to 77). This is called adjuvant treatment (page 64). You have it to reduce the risk of the cancer coming back.

Surveillance or adjuvant treatment

Your doctor will explain why they have suggested adjuvant treatment. After talking to your doctor, you may feel you do not want treatment that might not be necessary. You may decide not to have treatment, and to have surveillance instead.

And if you have the option of surveillance, you may decide to have chemotherapy treatment instead.

You can talk about the benefits and disadvantages of the treatment with your doctor (pages 56 to 57). Make sure you have enough information to help you make your decision.

Seminoma stage 1

If you have a stage 1 seminoma, your doctor may suggest you have surveillance. This is if there is a low risk of the cancer coming back. You usually need to have regular clinic appointments for several years.

Your doctors may also offer you a single dose of adjuvant chemotherapy, with a drug called carboplatin.

Your doctors will decide whether you will benefit from adjuvant treatment based on:

- the size of the tumour
- how it looks under a microscope
- the tumour marker levels (if present).

Non-seminoma stage 1

If you have a stage 1 non-seminoma, your doctor may suggest you have surveillance if there is a low risk of the cancer coming back. After a few years, you may only need to have regular blood tests, if scans show no signs of the cancer.

Your doctors may also offer you the option of adjuvant treatment. The chemotherapy drugs usually used for non-seminoma testicular cancer are bleomycin, etoposide and cisplatin. This combination of chemotherapy drugs is also called BEP chemotherapy (page 63). You usually have 1 session of treatment.

Doctors will offer treatment depending on:

- how the cancer looks under a microscope
- if it has spread to nearby blood vessels
- the size of the tumour
- the tumour marker levels (if present).

Treating stages 2 to 3 testicular cancer

Treatment will depend on the type and the stage of the cancer. Your doctors will talk to you about the treatment they feel is best for you.

If the cancer has spread outside your testicle, you will be offered chemotherapy after your orchidectomy. Occasionally, radiotherapy may be offered.

If testicular cancer has spread to other areas in the body and tumour markers are high, you may be offered chemotherapy before having surgery. This aims to reduce the size of the tumour before the operation or any other treatment.

Treatment for a non-seminoma

If you have a non-seminoma that has spread, you may need 3 or 4 sessions of chemotherapy. You may need more intensive chemotherapy. This will depend on the stage of cancer, certain risk factors and how you respond to the standard chemotherapy.

If you have chemotherapy, you may also need surgery to remove the retroperitoneal lymph nodes (pages 79 to 81). You may need this if the lymph nodes are still enlarged after chemotherapy treatment.

Treatment for a seminoma

If you have a seminoma that has spread, your doctor may offer you 3 or 4 courses of chemotherapy. You may have radiotherapy and chemotherapy treatment. If you are not able to have chemotherapy, you may have radiotherapy on its own. Your doctor will talk to you about the treatment they think is best.

If testicular cancer comes back

If testicular cancer comes back, treatment can usually cure it. This is even if the cancer has spread to other parts of the body. Treatment will depend on the type of testicular cancer, the areas affected and previous treatment.

Treatment and fertility

Treatments for testicular cancer may affect your ability to make someone pregnant. You usually are advised to store sperm (pages 103 to 104) before having an orchidectomy. You can also do this after surgery if you need further treatment.

Surveillance (monitoring)

If you have stage 1 testicular cancer (pages 40 to 43) with a low risk of it coming back after orchidectomy (page 26), your doctor may recommend surveillance. This is when you have regular monitoring for signs of the cancer coming back (recurrence). Your doctor and nurse will give you all the information you need to help you to decide if surveillance is right for you.

Surveillance aims to find any signs of cancer early, when it is easier to treat and cure. This means you avoid having adjuvant treatment (pages 49 to 51), such as chemotherapy, which you may not need. You only have treatment if your tumour marker levels increase (pages 36 to 37), or if scans show the cancer has come back.

Only a small number of testicular cancers come back. If it does come back, finding it early means there is still a high chance of curing it. But you may need a longer course of chemotherapy.

What does surveillance involve?

Your specialist doctor will tell you what kind of monitoring you will have. It usually involves:

- regular tumour marker (pages 36 to 37) checks and blood tests
- regular chest x-rays
- occasional CT or MRI scans
- a physical examination of your body (including checking your other testicle).

Your doctor will ask you how you have been feeling, and about any new or ongoing symptoms. Tell them if you are having emotional (pages 118 to 121) or sexual difficulties (page 96 to 101).

How long does surveillance last?

You usually need regular clinic appointments for several years. As time passes, the risk of the cancer coming back reduces. That means your appointments and tests will become less often.

It is important to go to your surveillance appointments. If your address changes, make sure the hospital knows your new address. It is also important to tell your doctor if you get any new symptoms or feel unwell between appointments. You can arrange an earlier clinic appointment if you need to. Some appointments can happen by telephone in the first instance. The sooner a possible recurrence is diagnosed, the easier it is to treat.

The benefits and disadvantages of treatment

With early-stage testicular cancer, surgery alone may cure the cancer. Adjuvant chemotherapy may be offered to reduce the risk of the cancer coming back. Or your doctors may ask you to choose what you want to do. They may ask whether you want to have adjuvant treatment or surveillance. Sometimes people find it hard to make a decision like this.

You may be worried about having adjuvant treatment because it is treatment you may not need and it has side effects. Or you may prefer to have any treatment that might reduce the risk of the cancer coming back.

It is important that you have all the information you need to make the right choice for you. Your doctor and nurse will talk to you about:

- the risk of the cancer coming back
- the benefits and side effects of the treatment
- ways to cope with side effects.

If early-stage testicular cancer comes back, it is usually still possible to cure it. It is also usually still possible to cure testicular cancer that has spread outside the testicle (page 40 to 43). If the cancer is very advanced or comes back after initial treatment, you may need intensive chemotherapy. But the aim will usually still be to cure the cancer.

Rarely, very advanced testicular cancer may not respond well to treatment. Or it may continue to come back despite treatment. In this case, you can have treatment to help control the cancer and improve symptoms. Occasionally, the treatment may not control the cancer or improve symptoms. This means you would have side effects without the benefit of treatment. In this case, you may decide not to continue the treatment.

Making decisions about treatment can be difficult. You may need to talk about it with your doctor and family or friends. If you choose not to have treatment for the cancer, you can still have treatment to control any symptoms.

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- A surgeon (urologist) – a doctor who treats problems with the kidneys, bladder and male reproductive system.
- An oncologist – a doctor who treats people who have cancer.
- A specialist urology nurse – a nurse who gives you information and support. They are sometimes called Macmillan specialist urology nurses
- A radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- A pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include other healthcare professionals such as dietitians, physiotherapists, occupational therapists, psychologists or counsellors.

After the meeting, your specialist doctor and nurse will talk to you about your treatment options. They will explain different treatments and their advantages and disadvantages.

The MDT will look at several factors when advising you on the best course of treatment. These may include:

- your general health
- the type and size of the tumour
- whether it has begun to spread.

If you are aged between 16 and 24, you should have the option of having your treatment at a Principal Treatment Centre (PTC). These centres provide cancer services for teenagers and young adults (TYA).

We have more information about making treatment decisions on our website.
Visit **macmillan.org.uk/making-treatment-decisions**

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment.
Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website.
Visit **macmillan.org.uk/getting-a-second-opinion**

Surgery

Orchidectomy

Removing the testicle (orchidectomy) helps your doctor make the diagnosis. This is usually the first treatment for testicular cancer. If the cancer is only in the testicle (stage 1), this operation may be the only treatment you need – pages 40 to 43.

We have more information on preparing for an orchidectomy (pages 26 to 28).

> **"With cancer in general, I had assumed that all chemotherapy was just the one drug and that was it. There are so many, and all specific, even within testicular cancer treatment."**
>
> Jon

Chemotherapy

Your doctor may suggest having chemotherapy treatment. Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs travel around the bloodstream, destroying possible cancer cells anywhere in the body.

You may have chemotherapy:

- after surgery, to reduce the risk of testicular cancer coming back (adjuvant chemotherapy)
- to treat testicular cancer that has spread outside the testicle, or come back after an orchidectomy (page 26)
- to treat testicular cancer that has come back after initial chemotherapy.

The drugs most commonly used to treat testicular cancer are:

- bleomycin
- etoposide
- cisplatin.

This combination is called BEP chemotherapy.

You may also have a chemotherapy drug called carboplatin.

We have more detailed information about chemotherapy in our booklet **Understanding chemotherapy**.

You can order our booklets and leaflets for free. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Adjuvant chemotherapy

You may have adjuvant chemotherapy to reduce the risk of testicular cancer coming back.

If you have an early (stage 1) non-seminoma, you may have 1 cycle of BEP. Each cycle is 3 weeks.

If you have an early (stage 1) seminoma, you may have a single treatment with carboplatin.

We have more information about BEP, carboplatin and other chemotherapy drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs**

If the cancer has spread or comes back during surveillance

The chemotherapy drugs you have will depend on stage of disease at diagnosis and previous treatment. You may have 3 or 4 cycles of BEP if testicular cancer has:

- spread outside the testicle
- come back during surveillance (pages 54 to 55).

Sometimes, bleomycin is left out. You may have 3 or 4 cycles of etoposide and cisplatin (EP) instead. Your oncology doctor will explain which is the best chemotherapy combination for you and how many treatments you may have.

Bleomycin may cause breathing problems if you smoke or already have a lung condition.

Intensive chemotherapy

If BEP does not get rid of the cancer, or the cancer comes back, you will usually have more intensive chemotherapy. Depending on the stage of the cancer (pages 40 to 43), you may have intensive chemotherapy straight away. Some drug combinations are:

- PEI (cisplatin, etoposide, ifosfamide) – this drug combination is also sometimes called VIP
- TIP (paclitaxel, ifosfamide, cisplatin)
- VeIP (vinblastine, ifosfamide, cisplatin).

High-dose chemotherapy with stem cell support (autologous stem cell transplant)

Occasionally, high-dose chemotherapy with stem cell support may be used for testicular cancer. You may have this as part of a clinical trial (pages 91 to 92).

Stem cells produce blood cells. The high-dose treatment destroys stem cells in the bone marrow, as well as the cancer cells. Because of this, doctors remove some stem cells before treatment. These are then stored to give back to you after treatment.

The stem cells are given back through a drip (infusion). This is called an autologous stem cell transplant. The cells go to your bone marrow and start to make blood cells again.

This type of treatment allows you to have higher than usual doses of chemotherapy. You usually have it if the cancer has not responded completely to previous treatment. Or you may have it if the cancer has come back after treatment. It is used to increase the chances of curing the cancer.

You may have high-dose treatment in hospitals with large cancer units that specialise in this type of treatment. This is an intensive treatment, and you will need to stay in hospital for several weeks.

We have more information about this treatment and its possible side effects on our website and in our booklet **Understanding stem cell transplants using your own cells (autologous)** – page 130.

How chemotherapy is given

You usually have chemotherapy as an outpatient. You have it as an injection or through a drip. This is called intravenous chemotherapy. You may have the drugs through a:

- cannula – a short, thin tube the nurse puts into a vein in your arm or hand
- central line – a fine tube that goes under the skin of your chest and into a vein close by
- PICC line – a fine tube that is put into a vein in your arm and goes up into a vein in your chest.

You have chemotherapy in cycles of treatment. A cycle usually takes 3 weeks.

If you are having BEP, you usually have to go to the hospital for 3 to 5 days as an outpatient. Sometimes you stay overnight. This is followed by weekly outpatient visits to have the rest of your cycle of treatment. Other combinations of chemotherapy drugs might mean you spend more time in hospital and have the drugs more often. Your doctor or nurse will tell you how many cycles of treatment you need, and how you will have it.

Fertility and storing sperm before treatment

Chemotherapy for testicular cancer usually causes infertility during treatment and for a time after. This is usually temporary, and your fertility will usually recover after treatment. But your doctor will advise you to consider storing sperm before having treatment (pages 103 to 104). How quickly your sperm count recovers varies from person to person. It generally starts to recover about 18 to 24 months after treatment. But it can take up to 5 years to recover.

If you have a low sperm count before chemotherapy treatment, sperm production can sometimes improve after treatment.

If you are having high-dose chemotherapy, you have a much higher risk of infertility. And infertility caused by this kind of treatment is usually permanent. If you are concerned about this, you can talk to a specialist.

Side effects

We explain the most common side effects of chemotherapy treatments that might be used for testicular cancer here. We also include some less common side effects.

You may get some of the side effects we mention, but you are unlikely to get all of them. If you are also having treatment with other cancer drugs, you may have some side effects that we have not listed here. Always tell your doctor, nurse or pharmacist about any side effects you have.

Your doctor can give you drugs to help control some side effects. It is important to take them exactly as your nurse or pharmacist explains. This means they will be more likely to work for you. Your nurse will give you advice about managing your side effects. After your treatment is over, most side effects start to improve.

Risk of infection

Chemotherapy treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

Bruising and bleeding

The treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

The treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

If you feel sleepy, do not drive or use machinery.

> **"Chemo never made me sick, but it zapped my energy. I walked every day to build my fitness back up. I wanted to feel good again. 50m one day, 100m the next, increasing until I could walk in the hills near where I live."**
>
> Ben

Sore mouth and throat

You may get a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

> **"Hair loss was the only thing I was really worried about. But I really liked the shaved head and might go back to it. It's a lot curlier now, after treatment."**
>
> Jon

Loss of appetite

Chemotherapy treatment can affect your appetite. Don't worry if you do not eat much for a day or two. But if your appetite does not come back after a few days, or if you are losing weight, tell your nurse or dietitian. They can give you advice. They may give you food or drink supplements. Or they may suggest changes to your diet or eating habits to help.

Hair loss

Carboplatin does not usually cause hair loss. But it is common to lose your hair with BEP chemotherapy. Your hair will usually start to fall out about 3 to 4 weeks after starting treatment. Hair usually falls out completely. Your eyelashes, eyebrows and other body hair may also thin or fall out.

Hair loss is usually temporary. Your hair will start to grow again after treatment has finished. It will be very fine at first, and may be a different colour or texture than before. You will usually have a full head of hair after 3 to 6 months.

Some people choose to shave their heads when they notice their hair is starting to fall out. You can cover up using hats such as baseball caps and beanies, or bandanas.

Choose something that suits your style and that you are comfortable with. You will probably have a variety of things you can wear, depending on the occasion and the weather. Your doctor or nurse can arrange for you to see a wig specialist if you want to use a wig. If you are an inpatient or are on income support, you can get a free wig on the NHS.

We have more information in our booklet **Coping with hair loss** (page 134).

Talk to your doctor if you are worried about this.

Effects on the kidneys

Cisplatin can affect how your kidneys work. You will have blood tests before and during treatment to check how well your kidneys are working.

Before and after each treatment, your nurses will give you extra fluids through a drip. This is to protect your kidneys. It is also important to drink at least 2 litres (3½ pints) of non-alcoholic fluid each day during treatment.

Tell your nurse or doctor if:

- you are not able to drink as much as you have been asked to – for example, if you feel sick
- you are being sick or have diarrhoea
- you are passing urine (peeing) less than usual.

Effects on the lungs

Bleomycin treatment can cause changes to the lungs. You may have tests to check your lungs before and during treatment. It is very important to tell your doctor if you develop:

- a cough
- wheezing
- breathlessness.

You should also tell them if any existing breathing problems get worse.

Smoking can increase the risk of your lungs being affected. If you smoke, talk to your doctor about stopping before you start treatment.

After treatment with bleomycin, breathing in high doses of oxygen for several hours can cause lung problems. If you need to have a general anaesthetic or oxygen therapy in the future, always tell the doctor that you have had bleomycin. Some people choose to wear a medical alert identifier.

You should not scuba dive for a year after treatment with bleomycin. After this, you will need to have tests to check whether scuba diving is safe for you. Your cancer doctor can give you more information about this.

Changes to your hearing

Cisplatin may affect your hearing. You may have ringing in the ears (tinnitus). Or you may lose the ability to hear some high-pitched sounds. Very occasionally, it may affect your sense of balance. Any hearing or balance changes usually get better after treatment ends. But sometimes they may be permanent. Tinnitus usually improves after treatment ends.

Tell your doctor or nurse if you notice any hearing loss or tinnitus. They will monitor this and arrange hearing tests if necessary.

Numbness or tingling in the hands or feet

Cisplatin affects the nerves, which can cause numb, tingling or painful hands or feet. This is called peripheral neuropathy. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes. But for some people, they may never go away.

Blood clot risk

Cancer and some cancer treatments can increase the risk of a blood clot. Symptoms of a blood clot include:

- throbbing pain, redness or swelling in a leg or arm
- suddenly feeling breathless or coughing
- sharp chest pain, which may be worse when you cough or take a deep breath.

If you have any of these symptoms, contact the hospital straight away on the 24-hour contact number you have been given. If you cannot get through to your doctor, call the **NHS urgent advice number** on **111**.

A blood clot is serious, but it can be treated with drugs that thin the blood (anticoagulants). Your doctor or nurse can give you more information.

You can help reduce the risk of developing a blood clot by:

- staying active during treatment
- drinking plenty of fluids, especially water.

You may be given anticoagulants to help prevent a clot.

Sex

If you have sex in the first few days of having chemotherapy, you need to use a condom. This is to protect your partner from any chemotherapy that might be in your semen.

Cancer cannot be passed on to your partner and sex will not make the cancer worse.

Contraception

Although treatment may affect your fertility, it is not always possible to know when this will happen. You may still be able to get someone pregnant. Your doctor will advise you not to make someone pregnant during treatment. This is because the chemotherapy drugs can temporarily damage your sperm, and possibly harm a developing baby.

It is usually best to use a barrier method of contraception, such as a condom, while you are having treatment.

It is also important to continue using effective contraception for about 1 year after chemotherapy. This allows time for your sperm to recover from any damage that treatment may have caused. You can talk to your doctor or nurse about this.

Juan, diagnosed with testicular cancer

Further surgery

Retroperitoneal lymph node dissection (RPLND)

Retroperitoneal lymph nodes (page 14) are the nodes at the back of your tummy (abdomen). Sometimes these nodes need to be removed after having chemotherapy. This is called a retroperitoneal lymph node dissection (RPLND).

The lymph nodes may shrink after having chemotherapy. But they may not disappear completely. After chemotherapy you have a CT scan (page 39). If this shows signs the lymph nodes might still contain cancer cells, you usually need an RPLND. This is because removing these lymph nodes is the only way to know for sure.

Rarely, these lymph nodes are removed with an early-stage non-seminoma when someone cannot have surveillance or adjuvant chemotherapy. An RPLND shows whether the cancer has spread and removes any nodes that might be affected.

Having an RPLND

Having an RPLND is a major operation. It is only done by experienced surgeons in specialist centres. Your surgeon and specialist nurse will explain what is involved, and the possible complications and side effects.

You have the operation done under a general anaesthetic. The surgeon makes a long cut from the top of your tummy (near your breastbone) to below your belly button.

The lymph nodes are in front of the spine. This means your surgeon has to move your bowel and other organs aside to reach them.

> **"I had an operation called a retroperitoneal lymph node dissection (RPLND). I was scared, but I was on the same ward as my friend Kieran so knew that we would get each other through."**
>
> Juan

Keyhole surgery for RPLND

Sometimes, surgeons can do this operation using keyhole surgery. For example, this may be an option if you have not previously had chemotherapy. This means you will have several small cuts (incisions) rather than one longer one. This is sometimes called laparoscopic or robotic retroperitoneal lymph node dissection. Keyhole surgery is very specialised, and only experienced surgeons should do it. There are only a few hospitals that can offer this type of surgery.

As keyhole surgery involves several small cuts, it can be quicker to recover from than standard surgery, where you have one longer cut.

Before your operation

If you smoke, try to give up or smoke less before your operation. This will help reduce your risk of chest problems, such as a chest infection. It will also help your wound to heal after the operation. Your GP can give you advice. You can also usually self-refer to a local stop-smoking service. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

You will meet a member of the surgical team and a specialist nurse to discuss the operation. This may be at a pre-operative assessment clinic before you are admitted for your operation. You may also meet the doctor who will give you your anaesthetic (anaesthetist). It is important to tell them if you have had bleomycin chemotherapy as a treatment.

Make sure you ask any questions and discuss any concerns you have about the operation. If you need help when you go home after surgery, tell your hospital team as soon as possible. For example, you may be a carer for someone else or live alone. This gives your team plenty of time to make arrangements to help you.

You may have tests before the operation, such as:

- a chest x-ray
- blood tests
- a urine test
- an ECG (a recording of your heart).

You will usually be admitted to hospital on the morning of the operation. You will then meet members of the surgical team and nursing team, including your anaesthetist. They will be able to answer any questions you have about the anaesthetic and about pain control after the operation.

After your operation

You may be looked after in a high-dependency or intensive care unit for the first few days. You will be monitored very closely after your operation.

You will have:

- fluids directly into a vein by an infusion (drip) until you can eat and drink normally
- a tube draining your bladder (catheter), attached to a bag to collect urine
- a drainage tube from your wound, to collect excess fluid and help the wound to heal.

You will only need the tubes for a short time. They will usually be taken out before you go home.

Your treatment team will encourage you to start moving about as soon as possible. This helps to reduce complications like chest infections or blood clots. You will also need to wear support stockings (TED stockings). These help prevent blood clots in your legs. A physiotherapist or specialist nurse may give you some gentle leg and breathing exercises to do.

If you have pain, let your nurse or doctor know. You will have painkillers regularly to control any pain. But if you still have pain, you can have a different painkiller or a higher dose.

Possible complications of surgery

This will depend on the type of operation you have. The most common complications after surgery are:

- a wound infection
- bleeding in the operation area
- a chest infection
- developing a blood clot.

The nurses will monitor you for these complications. Let them know straight away if you have:

- any bleeding, or feel unwell
- symptoms of an infection, such as a cough or feeling short of breath
- discharge from your wound
- swelling and redness in a limb.

Possible complications of RPLND

All operations have possible complications, and your surgeon will discuss these with you before. The most common complications are bleeding and a wound infection. The bowel may also take a while to start working normally again. Your doctors and nurses will do regular checks to look for signs of complications. This means that if any develop, they can treat them straight away.

Sometimes during surgery, the lymph nodes are found attached to a nearby structure, such as a kidney. If the surgeon cannot separate the lymph nodes from the kidney, they may need to remove both. But this is very rare.

Effects on fertility

A common side effect of this operation is dry ejaculation. You will still be able to ejaculate, but your semen will go into your bladder instead. This is known as retrograde ejaculation or dry climax. The semen will then leave your body harmlessly when you next pass urine (pee).

If you cannot ejaculate in the usual way, you will not be able to get someone pregnant without fertility treatment. But you should still be able to get an erection and have an orgasm.

This side effect is due to nerves being damaged during the operation. It is more likely if you have previously had radiotherapy to the lymph nodes at the back of the tummy. This can cause some scarring of the nerves. Sometimes, surgeons can adapt the surgery to use nerve-sparing techniques that try to protect the nerves.

Your doctor will advise you to store sperm before the operation, if this is appropriate for you (pages 103 to 104).

Going home

How long you need to be in hospital depends on how quickly you recover and whether you have any complications. It may take up to 10 days before you are ready to go home. If necessary, a district nurse can change your wound dressings at home. Most surgeons use dissolvable stitches, which they do not need to remove. You will have a long, vertical wound, which will be red and swollen at first. This will heal, but will leave a long scar that will gradually fade.

It may take a few months to fully recover from your operation. Your doctor will advise when you can lift heavy objects (such as bags of shopping), drive and return to work.

Surgery to other parts of the body

Occasionally, testicular cancer may spread to other parts of the body such as the lungs, brain or liver. If further surgery is needed, it is done in a specialist unit. If you need this type of operation, your doctor will explain more about it.

Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells.

You may have radiotherapy to treat a seminoma that has spread to the lymph nodes at the back of the tummy (abdomen). These are called the retroperitoneal lymph nodes. Radiotherapy aims to reduce the small risk of the cancer returning in this area of the body. You may have it after chemotherapy treatment if you have a stage 2 or 3 seminoma (pages 42 to 43).

If you are not able to have chemotherapy, you may have radiotherapy on its own.

If a seminoma comes back, you may have radiotherapy with chemotherapy.

More rarely, you may have radiotherapy to treat non-seminomas (page 35).

Having radiotherapy for testicular cancer

You usually have radiotherapy treatment in the hospital radiotherapy department. You have it as a series of short daily treatment sessions. The sessions usually happen between Monday to Friday, with a rest at the weekend. Each session takes 10 to 15 minutes. Your doctor will discuss the treatment and possible side effects with you.

A course of radiotherapy for seminoma may last about 2 to 3 weeks. You usually have treatment as an outpatient. The person who operates the machine is called a radiographer. They give you information and support during your treatment.

Radiotherapy does not make you radioactive. It is safe for you to be with other people, including children, throughout your treatment.

Temporary effects on fertility

Radiotherapy to the lymph nodes in the tummy will not affect your ability to have sex. It does not usually cause infertility. But a small dose of radiation may reach the remaining testicle. This may affect your sperm for a temporary period of time. So, your specialist doctor may advise you to think about storing sperm (pages 28 to 31) before treatment starts.

Contraception

There is no evidence that radiotherapy has any effect on children you may have (conceive) after treatment. But because radiotherapy may have a temporary effect on the sperm, you should use contraception during treatment and for 6 to 12 months after treatment. This allows time for your sperm to recover from any damage treatment may have caused.

Planning your radiotherapy treatment

You will have a hospital appointment to plan your treatment. You will usually have a CT scan (page 39) of the area to be treated. During the scan, you need to lie in the position that you will be in for your radiotherapy treatment.

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. If you are worried about them, talk to your radiographer.

Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully and make sure you are comfortable. During your treatment, you will be alone in the room. But you can talk to the radiographer, who will watch you from the next room.

Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Side effects

Radiotherapy to your tummy can cause side effects. But these can usually be controlled with medicines. Your doctor or specialist nurse will tell you more about what to expect. These side effects usually disappear gradually once your course of treatment has finished.

It is important to let your doctor know if you are having any problems with side effects. Most side effects are mild, and you can have medicines to treat them successfully.

Skin changes

If you have fair skin, the treated area may become red. If you have black or brown skin, it may become darker. But after your treatment finishes, these changes should go away. Your doctor can advise you how to look after your skin and prescribe cream if your skin is sore.

Feeling sick (nausea)

Radiotherapy to the tummy area may make you feel sick. Your doctor can prescribe anti-sickness medicine to prevent or stop this. Let your doctor know if the tablets are not working for you. There are other medicines they can prescribe.

Tiredness

Radiotherapy often makes people feel tired, especially towards the end of treatment. Try to pace yourself and avoid doing anything that you do not really need to do. Gentle exercise, such as short walks, can help to improve tiredness. It is good to balance this with plenty of rest.

Sometimes, tiredness can last about 8 weeks or longer after treatment finishes. Your energy levels should then slowly improve. We have more information in our booklet **Coping with tiredness (fatigue)** – page 134.

Diarrhoea

You might get diarrhoea, but your doctor can prescribe you medicines to control this. Let your doctor know if you have diarrhoea. It is important to drink plenty of fluids. Try to eat fewer high-fibre foods, such as fruit, vegetables, beans, pulses and wholewheat cereals.

Possible late effects

Effects on the heart

Radiotherapy to the lymph nodes at the back of the tummy may have an effect on your heart many years after treatment has finished.This is called a late effect (pages 106 to 108). This is because these lymph nodes are positioned near to the heart. You may have regular follow-up appointments to check your heart health after cancer treatment. The benefits of having treatment will usually far outweigh this risk. Your specialist doctor can tell you more about this.

Second cancer

Radiotherapy may slightly increase the risk of developing another cancer later (pages 106 to 108). This does not mean that you will definitely develop another cancer. The benefits of having treatment will usually far outweigh this risk. Talk to your specialist doctor if you have any concerns about this.

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

> **“During treatment the most important things were resting, sleeping and being around the people I love.”**
>
> Juan, diagnosed with testicular cancer

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information on our website. Visit **macmillan.org.uk/information-and-support/clinical-trials**

Current research

Although current treatments for testicular cancer are very effective, different trials are being carried out to see if there are ways to improve them. For example, trials are looking at which genes may increase the risk of developing testicular cancer. Your doctors will be able to tell you about any trials that may be suitable for you.

Giving blood and tumour samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.


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Sex life and fertility

It is normal to worry about the possible effects of testicular cancer and its treatment on your sex life and fertility. This section explains how treatment may affect your sex life and fertility. There is also information on contraception during treatment, having children in the future, testosterone replacement and storing sperm (sperm banking).

Effects of treatment on sex life and fertility

Surgery

Orchidectomy

Removing a testicle will not affect your ability to get an erection or make someone pregnant. The healthy testicle will usually produce enough testosterone and sperm, unless it is very small.

Removing the retroperitoneal lymph nodes (RPLND)

Surgery to remove the retroperitoneal lymph nodes (pages 79 to 84) may damage the nerves involved in ejaculation. This can cause sperm to go backwards into the bladder instead of coming out through the penis when you orgasm. The sperm then passes out harmlessly when you next pass urine (pee). This is called retrograde ejaculation.

The operation does not stop you getting an erection, but your orgasm will feel different because it is dry (dry climax). Surgeons can use newer surgical techniques, such as keyhole and robotic surgery, to try and protect the nerves and reduce the risk of this. But your doctor may still advise you to think about storing sperm (pages 103 to 104) if you need this operation.

Urinary sperm retrieval

If you are unable to store sperm before your operation and you have retrograde ejaculation, sometimes specialists can collect the sperm from your pee. They will give you a drink that makes your urine less harmful to your sperm. You will be asked to pee and then masturbate. After you ejaculate, you will have to pee again. The sperm is quickly collected from the urine, prepared and stored.

Radiotherapy

Radiotherapy to the lymph nodes in the tummy (abdomen) does not affect your ability to have sex. It does not usually cause infertility. But your doctor might still suggest you store sperm.

Chemotherapy

Chemotherapy does not affect your ability to have sex. But side effects might lower your sex drive for a while.

Chemotherapy for testicular cancer usually causes infertility but it is usually temporary. Your doctor will talk to you about storing sperm before your treatment. High-dose chemotherapy with stem cell support has a much higher risk of causing infertility, which may be permanent (pages 65 to 66).

If you need to start chemotherapy straight away, there may be no time to give and store sperm samples. But you may be able to store sperm within the first few days of starting chemotherapy.

How quickly the sperm count recovers after chemotherapy can vary. It can depend on:

- your sperm count before having chemotherapy
- the type and amount of chemotherapy you have.

Your sperm count usually starts to return to normal about 18 months to 2 years after treatment. But it can take longer for some people. You can ask to have your sperm count checked.

If you have a low sperm count before starting chemotherapy, the treatment can sometimes improve sperm production.

If you are worried about infertility, you can speak to your cancer specialist doctor.

Sex life and sex drive

Treatments used for testicular cancer do not usually affect your ability to have sex. But a diagnosis of testicular cancer can cause a lot of feelings. This may affect your sex drive (libido) for a time.

Treatment side effects may also mean you have a lower sex drive. If you have a partner, let them know how you feel. It can take time to recover physically and emotionally.

If you find you have a low sex drive, this will usually improve as your feelings get easier to cope with and you recover from treatment.
If you are having sexual difficulties, there is support available (pages 140 to 150).

Testosterone replacement therapy

Removing one testicle does not usually affect your sex drive. The remaining testicle should make enough testosterone on its own.

Sometimes the remaining testicle does not produce enough testosterone. Or, rarely, both testicles have to be removed because of cancer.

A lack of testosterone can:

- affect your ability to get an erection
- reduce your sex drive
- cause tiredness, low mood and problems such as thinning of the bones (osteoporosis).

Tell your doctor if you are having these or any other symptoms. They can measure your testosterone level with a blood test. If it is low, your doctor may be able to prescribe testosterone replacement therapy to improve your symptoms. You can have it as a gel, an injection into a muscle, an implant, or a patch that you stick to the skin. Your doctor can give you more information about testosterone replacement therapy.

Sex and cancer

Sexual difficulties are very personal. A common worry is that you can pass cancer cells on during sex. Cancer is not infectious, so it is safe for you to have sex. Whatever feelings or concerns you have, it can help to talk to someone.

- **Talking to a partner** – if you have a partner, it can help to talk openly to them about any problems you are having. You might find that you understand each other better by having an honest conversation.

- **Talking to a potential partner** – if you are single, you may have some concerns about starting a new relationship or having sex with someone new. If you meet someone new, you may want to give yourself some time to feel comfortable in the relationship before talking about any concerns you may have.
- **Support from your healthcare team** – talk to your doctor or nurse about any sexual difficulties you have. You may feel embarrassed, but they have experience of speaking to others who have had similar problems. Many hospitals also have specialist nurses who can offer support. Some hospitals have counsellors who have had special training to help people who are having sexual difficulties. They are called sex and relationship therapists.
- **Talk to others in a similar situation** – sometimes it helps to talk to someone who is going through the same thing. You can find support in the Macmillan online community. Visit **macmillan.org.uk/community**
- **Support organisations** – ask your team about support groups. You can also contact support organisations such as Orchid and the College of Sexual and Relationship Therapists (page 140).

If you identify as gay, bisexual or transgender

Many sexual difficulties caused by testicular cancer are similar whatever your sexual orientation or gender identity. But you may have some specific questions. Having your sexual or gender identity acknowledged may help you feel better supported. It also means your healthcare team can give you the right information and advice.

If you feel unable to talk to your healthcare team about your sexuality, the LGBT Foundation (page 148) has a helpline that can give you confidential advice and support.

We have more information in our booklet **Cancer and your sex life** (page 134).

Fertility

Treatment for testicular cancer usually does not affect your ability to make someone pregnant (your fertility). But even if your chances of becoming infertile are low, your doctor usually advises you to store (bank) sperm. You usually do this before having an orchidectomy (pages 26 to 31). If this is not possible, it is important to do it before you have any further treatment.

If you are trans or non-binary, considering the possible effect on your fertility may feel even more overwhelming. But it is important to know your options about preserving fertility so you can make an informed decision. You can talk to your specialist doctor or nurse about any concerns you might have about this.

Having children after treatment

There is no evidence that cancer treatments can harm children you have (conceive) after treatment. It is usually possible to make someone pregnant if you have had treatment for testicular cancer, after you have recovered.

But doctors usually advise you to continue using contraception for about 1 year after radiotherapy and chemotherapy, to avoid making someone pregnant. This allows your sperm time to recover from any damage that treatment may have caused. If you are planning on having a family, you can talk to your doctor or nurse about having your sperm count checked. Your GP can also advise you on this.

Storing sperm (sperm banking)

Even if your chances of becoming infertile are low, your doctor will usually advise you to store some sperm. They will talk to you about this before you have your operation. If it is appropriate for you, you usually store sperm before you have an orchidectomy. But if this is not possible, it is important to do it before you have any further treatment. This is because this treatment could damage your sperm.

You will have counselling at the fertility clinic before you store your sperm. You also need to sign a consent form that states how your sperm will be used. You will have blood tests as well. These will check your general health, and for infections such as HIV or hepatitis.

Sperm banking is a safe technique that has been used for many years. It involves freezing your sperm. If you want to have a child later in life, your sperm can be used with fertility treatments. The usual period of time for storing sperm is 10 years. But, in some circumstances, you may be able to store it for longer. People affected by cancer may be able to store their sperm for up to 55 years.

Sometimes the NHS pays for sperm banking for people with cancer. But it varies across the UK, and in some hospitals you may have to pay for it yourself. Even if the hospital pays for storage to begin with, you may need to pay if you choose to store sperm for a longer period of time. The staff in the fertility clinic or your specialist doctor or nurse can explain more about this. If you have to pay, the average yearly cost is between £175 and £450 per year.

Sometimes treatment needs to start straight away, and there is no time to take sperm samples. If your doctor feels your treatment needs to start straight away, they will talk to you about this. You may still be able to store sperm if you do it in the first few days of starting chemotherapy.

If you are trans or non-binary, you may find the thought of giving a sperm sample very difficult. It may help to talk to a:

- gender identity clinic, if you attend one
- sexual health and well-being service that is trans and non-binary friendly. You can check if this is available in your area on Tranzwiki (page 149).

The fertility clinic at the hospital may also be able to give you advice and support.

Other sperm collection techniques

If you are not producing enough sperm, or you started treatment too quickly to give enough samples, you can still store sperm.

It is possible to collect sperm by taking a piece of testicular tissue or some fluid. Doctors can remove small amounts of testicular fluid or tissue by putting a fine needle into the testicle. Or they can make a small cut in the scrotum. They can do this using a local or general anaesthetic. The fluid or tissue is checked for sperm in the laboratory. The sperm is then removed and stored for future use. Your doctor or nurse at the fertility clinic can give you more information about these techniques.

We have more information about sexuality and cancer and cancer treatment and fertility in our booklet **Cancer and fertility information – for men** (page 134).

> **"I think fertility was our biggest concern. Having the back-up of the sperm bank is a massive relief."**
>
> Jon

Long-term or late effects of treatment

Some side effects that develop during treatment may take a long time to improve. Or some side effects may become permanent (long-term effects). Other effects can develop many years after treatment has finished (late effects). You may not have any of these effects at all. Or they may range from mild to severe.

Tell your doctor or nurse if you have any of these effects. They will monitor them and arrange any tests you need.

Changes in sensation in your hands and feet

You may get pins and needles or numbness in your hands and feet after having chemotherapy for testicular cancer. Or you may develop cold hands and pale fingers. This is called Raynaud's phenomenon. It is triggered by the cold, so keeping your hands and feet warm can help.

Chemotherapy may also cause changes in the nerves of the hands and feet. This is called peripheral neuropathy and it can be temporary but is sometimes permanent. If you have this, you may have a change in sensation in your hands or feet.

Hearing changes

The chemotherapy drug cisplatin can sometimes cause hearing problems, particularly with high-pitched sounds. Hearing changes usually get better after treatment ends. But some can be permanent. Tell your doctor if you notice any changes in your hearing. You may have a hearing test before you start treatment.

Heart and lung problems

Some chemotherapy drugs may increase your risk of developing heart or lung problems. Radiotherapy to the lymph nodes at the back of the abdomen (retroperitoneal lymph nodes) may also increase the risk of developing heart problems (pages 86 to 90). Some people will have regular follow-up appointments to check their heart health after cancer treatment.

Things that can help to keep your heart and lungs healthy include:

- doing regular exercise
- eating healthily
- keeping to a healthy weight
- stopping smoking.

It is important to get any new symptom checked by your doctor. Sometimes the symptoms of heart and lung problems are like the symptoms of other conditions. But always tell your doctor if you:

- have chest discomfort, pain or tightness
- have pain that spreads to your arm, neck, jaw, stomach or back
- feel short of breath or have a persistent cough
- feel unusually tired or weak (fatigued)
- have swelling in your feet, ankles, tummy or lower back
- have palpitations, which might feel like a thumping or fluttering in your chest
- have blackouts (fainting)
- feel dizzy or light-headed.

Your doctor will monitor them and arrange any necessary tests.

Risk of developing another cancer

Research shows that people who have radiotherapy or chemotherapy for testicular cancer have a slightly increased risk of developing another cancer later. This does not mean that they will definitely develop another cancer. The benefits of having treatment will usually far outweigh this risk.

Follow-up

You will have regular check-ups at the hospital after your treatment finishes. How often you go to the hospital will depend on the type and stage of testicular cancer. Your doctor will examine you and check your remaining testicle.

You may have regular tumour marker blood tests (pages 36 to 37). Other tests may include:

- regular chest x-rays
- occasional CT or ultrasound scans.

Sometimes you may have other scans such as an MRI or PET scan.

It is important to go to these appointments. If you cannot go to an appointment, make another one straight away.

If you have new symptoms between your appointments, contact your hospital doctor, nurse or GP. It is important that you check your remaining testicle every month (page 19). It is rare to develop a new cancer in the other testicle, but having already had testicular cancer increases the risk of this happening.

Being involved in your healthcare

Having to attend follow-up appointments can feel stressful. Your healthcare team can help you to cope with any problems you might have after treatment and help you find support. This can make you feel more confident and give you back a feeling of control.

Juan, diagnosed with testicular cancer

After treatment

Recovering from cancer and its treatment can take time. You may still have side effects, such as tiredness, and be coping with the emotional effects for a while after treatment.

But in time, you may find you slowly start to focus more on the day-to-day things you did before your diagnosis. Going back to work and getting back to your usual interests can be positive steps. We have more information in our booklet **Work and cancer** (page 134).

Positive lifestyle choices

Some people want to make lifestyle changes after cancer. You might choose to just make a few changes, or completely change the way you live. Following a healthy lifestyle does not need to be difficult or expensive.

Living a healthy lifestyle can sometimes seem hard work. You might think you need to deny yourself all the pleasures in life. But it is about making small, achievable changes to your life that will improve your health and well-being. Your healthy lifestyle will be individual to you. What is right for you may not be right for someone else.

A healthy lifestyle can include:

- having a well-balanced diet
- getting some exercise
- reducing stress
- being involved in your healthcare.

You will need to think about any side effects of treatment when planning changes to your diet and exercise. Try not to do too much, too soon.

Diet and exercise

A well-balanced diet should include:

- plenty of fresh fruit and vegetables (at least 5 portions a day)
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic fluids.

Try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

Talk to your doctor or a dietitian at the hospital before making major changes to your diet. It is a good idea to discuss your plans with them. We have more information in our booklet **Healthy eating and cancer**.

If you smoke, try to stop. Stopping has many health benefits and reduces your risk of other diseases, such as heart disease and strokes. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

Exercise does not have to be too tiring. You can start gently and build up the amount of physical activity you do. Whatever your age or physical health, there will be some kind of exercise you could try. For example, you may want to do walking, hiking, cycling or swimming. Activities like gardening, dancing and playing sport are also good to try. We have more information in our booklet **Physical activity and cancer**.

Reducing stress

Finding ways to reduce and manage stress can help you live a healthy lifestyle. The way people manage stress varies. You may want to think about what works for you, or try out new ways to manage stress. Exercise and a healthy diet can help to reduce stress and anxiety. It can also help to find some time for yourself every day when you can fully relax. Some people find that complementary therapies, relaxation techniques or even starting a new hobby can help.

Complementary therapies

Complementary therapies may help you feel better, reduce stress and anxiety, and improve some treatment side effects. Relaxation, counselling and psychological support are available at some cancer treatment hospitals. Some hospitals also offer visualisation, massage, reflexology, aromatherapy and hypnotherapy. Therapies are sometimes available through cancer support groups or your GP. Many complementary therapists have private practices.

We have more information in our booklet **Cancer and complementary therapies**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Talking to someone or sharing your experience

Talking about your feelings can help reduce stress, anxiety and isolation. There are lots of different ways to communicate, and they can all help people feel less alone.

Self-help or support groups offer you a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone or do not feel able to talk about your feelings with the people around you. Not everyone finds it easy to talk in a group, so it might not be for you. Try going along to see what the group is like before you decide. Some hospitals have cancer information centres that provide support or can tell you where to find more support.

Online support

Many people now get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by testicular cancer. You can use these to ask questions and share your experience. Your doctor or nurse can tell you if your hospital runs any face-to-face or online 'moving on' courses. You can ask your nurse for advice if you are unsure which sites might be useful.

Our online community is a social networking site where you can talk to people in our chat rooms, blog about your journey, make friends and join support groups. Visit **macmillan.org.uk/community**

Specialist help

It is common to still have difficult feelings after treatment is over. But most people find these get better as they recover. Some people only experience a few of these feelings and may be able to deal with them easily. Others may have more, and find them harder to cope with. Try to let your family and friends know how you are feeling so they can support you. Talking about your feelings is not always easy.

Often it is easier to talk to someone who is not directly involved with your illness. You can ask your doctor, specialist nurse or GP to refer you to a specialist doctor or counsellor who can help.

Our cancer support specialists on freephone **0808 808 00 00** can tell you more about counselling and let you know about services in your area.

> **"I called Macmillan's support line and they were brilliant. I know a lot of my male friends think it's a sign of weakness to ask for help. But I don't know what I would have done without Macmillan's support."**
>
> Pete

Your feelings and relationships

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Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information in our booklet **How are you feeling? The emotional effects of cancer**.

You can order our booklets and leaflets for free. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information online about relationships and in our booklet **Talking about cancer** (page 134).

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information in our booklet **Talking with someone who has cancer** (page 134).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (page 134).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer**.

You can order our booklets and leaflets for free. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Work and financial support

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Work 130

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 134).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (page 146 to 147).

Our booklet **Help with the cost of cancer** has lots more information (page 134).

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not usually affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit **macmillan.org.uk/grants**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful, visit **macmillan.org.uk/community**

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer** (page 134).

We have more information about work on our website. Visit **macmillan.org.uk/work**

Further information

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About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to find out more about Macmillan Grants.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Testicular cancer support organisations

The College of Sexual and Relationship Therapists (COSRT)

Tel **020 8106 9635**
www.cosrt.org.uk
A national specialist charity for sex and relationship therapy. Has a list of qualified practitioners and clinics providing sex or relationship therapy in the UK.

Orchid

Tel **0203 745 7310**
www.orchid-cancer.org.uk
National Male Cancer Helpline **0808 802 0010**
Microsite for testicular cancer: **www.yourprivates.org.uk**
Funds research into men's cancers, their diagnosis, prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid male cancer information nurses.

Relate

Tel **0300 100 1234**
www.relate.org.uk
Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support – face to face, by phone and through the website.

The Sexual Advice Association (formerly the Sexual Dysfunction Association)

www.sda.uk.net
Aims to improve people's sexual health and well-being, and to raise awareness of how sexual conditions affect the general population.

Shine Cancer Support

Tel **0780 447 9413**
www.shinecancersupport.org
Supports adults in their 20s, 30s and 40s who have had a cancer diagnosis. Provides peer support and offers a range of activities, which includes, lunches, drinks evenings, getaways, workshops, online networking and mentoring.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

online.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Tel **0800 232 1271**
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on 0800 232 1271 to check you are getting all the benefits you are eligible for.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).
You should be able to find your local council's contact details in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.gov.uk/authorities

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.
Support for older people

Age UK

Helpline **0800 678 1602**

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage.
Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

TranzWiki

www.gires.org.uk/tranzwiki
A comprehensive directory of non-commercial groups and organisations supporting or assisting trans and gender-diverse individuals, their families and friends across the UK.

Advanced cancer and end-of-life care

Hospice UK

Tel **020 7520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **0207 654 8000**
www.ndrs.nhs.uk
Tel (Ireland) 0214 318 014
www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **02920 104278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/

Northern Ireland Cancer Registry

Tel **0289 097 6028**
www.qub.ac.uk/nicr

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Ursula McGovern, Consultant Clinical Oncologist.

With thanks to: Clare Akers, Clinical Nurse Specialist; Charlotte Etheridge, Clinical Nurse Specialist; and Dr Jahangeer Malik, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our testicular cancer information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

The British Association of Urological Surgeons (BAUS) Guidelines on Testicular Cancer. March 2015. Available from: **www.baus.org.uk/professionals/sections/testicular_cancer.aspx** (accessed April 2022).

European Association of Urology (EAU) Guidelines on Testicular Cancer 2022. Available from: **d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Testicular-Cancer-2022.pdf** (accessed April 2022).

European Society for Medical Oncology (ESMO). Testicular seminoma and non-seminoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Last updated 2022.

European Society for Medical Oncology (ESMO). Testicular seminoma and non-seminoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Last updated 2022. Available from: **www.annalsofoncology.org/article/S0923-7534(22)00007-2/fulltext** (accessed April 2022).

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number
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Valid from
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Issue no
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Security number
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Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

FR Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about testicular cancer. It is for anyone who has been diagnosed with testicular cancer. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of testicular cancer, how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

Trusted Information Creator
Patient Information Forum

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