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MACMILLAN.  
CANCER SUPPORT

A practical guide to understanding cancer

# UNDERSTANDING TESTICULAR CANCER



# About this booklet

This booklet is for men who have been diagnosed with testicular cancer. We hope it answers some of your questions about diagnosis and treatment, and addresses some of the feelings you may have.

We can't advise you about the best treatment for yourself. This information can only come from your own doctor, who knows your full medical history.

There are useful addresses and websites at the end of this booklet (see pages 115–120). There's also a page to write down any notes or questions you have for your doctor or nurse (see page 121).

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

We've included some comments from men who have had testicular cancer, which you might find helpful. Quotes are from the Macmillan online community (**macmillan.org.uk/community**). Some names may have been changed. Some quotes are from PJ, who is on the cover of this booklet. He has chosen to share his story with us.



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# THE TESTICLES AND TESTICULAR CANCER

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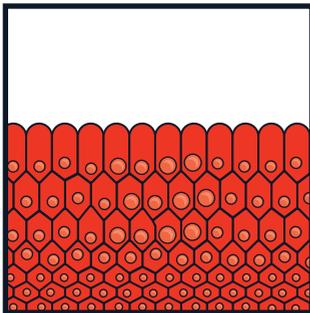
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# What is cancer?

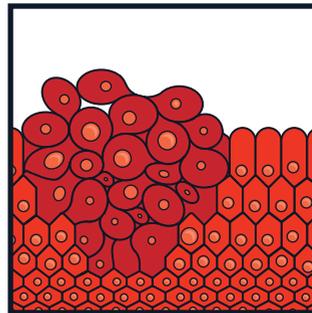
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (**tumour**). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



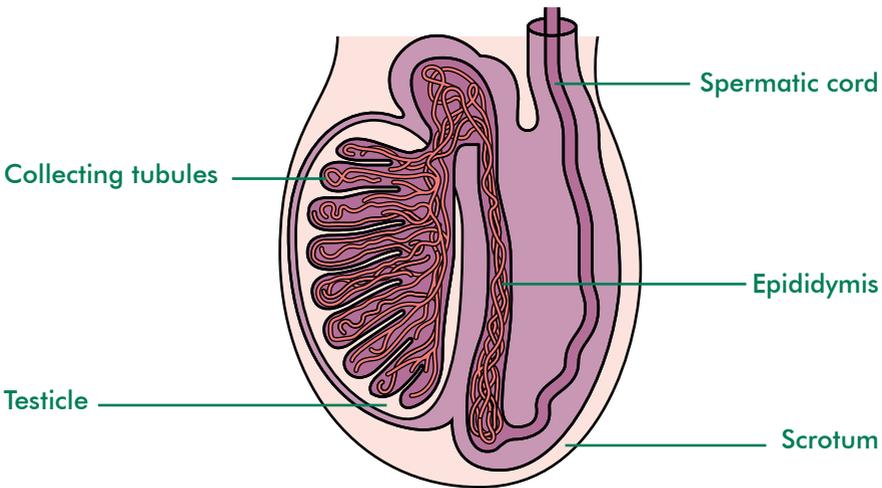
A lump that is not cancerous (**benign**) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (**the primary site**) to other parts of the body. They can travel through the blood or lymphatic system (see pages 11–12). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

# The testicles

The testicles are two small, oval-shaped organs, contained in a sac of skin called the scrotum. They hang below the penis (see next page). The testicles are sometimes called the testes. They are the main part of the male reproductive system. From puberty, the collecting tubules inside the testicles (see diagram below) produce sperm. They can fertilise a female egg to make a baby.

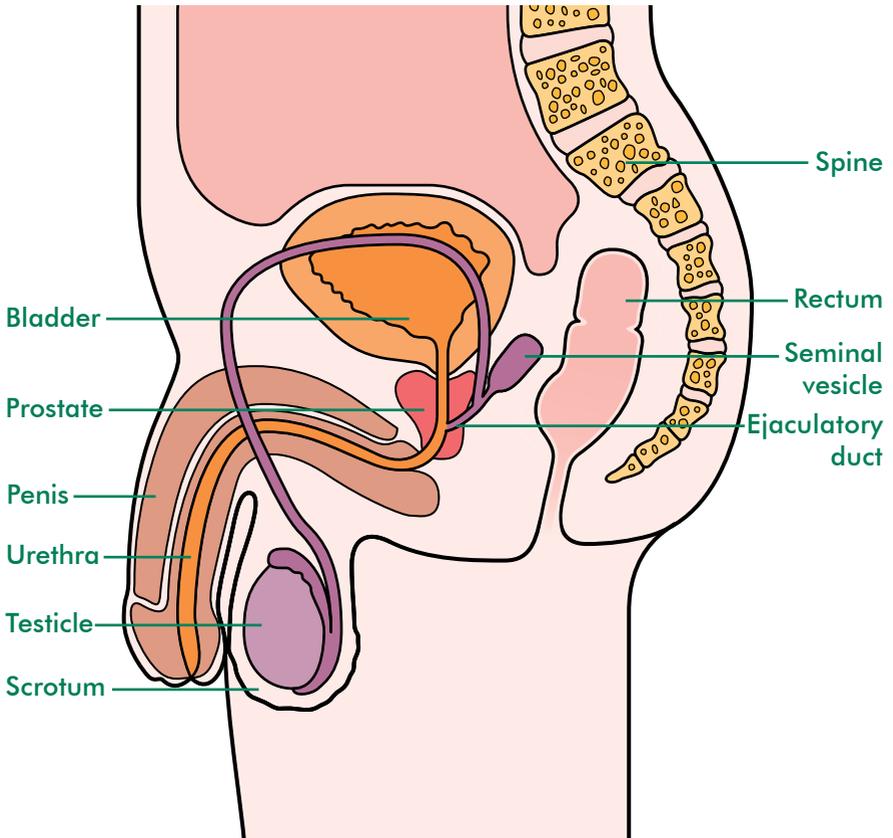
## The structure of the testicle



Sperm travels from the tubules to a coiled tube called the epididymis (see page 8). This feels like a soft swelling at the back of the testicle. The epididymis widens to become the spermatic cord (vas deferens). This joins a shorter tube called the ejaculatory duct. The ejaculatory duct connects to the urethra. This is the tube from the bladder to the end of the penis.

Sperm mixes with fluid from the prostate and seminal vesicles (glands that sit just under the bladder) before it 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 produce the hormone **testosterone**. Hormones are chemical messengers that help control different activities in our bodies. Testosterone helps with:

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

## Testicular cancer

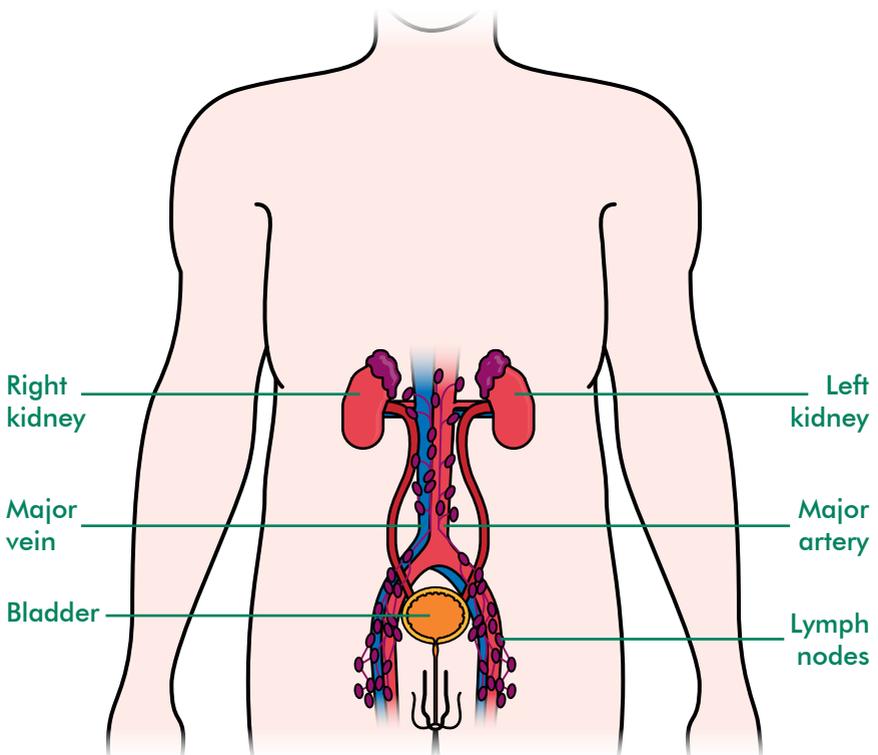
Each year in the UK, around 2,200 men are diagnosed with testicular cancer. It is more common in white men, and in younger to middle-aged men.

Treatment for testicular cancer is very effective and nearly all men are cured. Like other cancers, it isn't infectious and can't be passed on to other people.

# The lymphatic system

Sometimes, cancer cells from the testicles can spread to nearby lymph nodes. Lymph nodes are part of the lymphatic system. The lymphatic system helps to 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 up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

## The retroperitoneal and pelvic lymph nodes



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

The lymphatic vessels carry fluid called lymph, which contains cells that help us fight infection. Lymph fluid from your testicles travels to a collection of lymph nodes at the back of your tummy (abdomen). These are called the **retroperitoneal lymph nodes**. They lie just behind your bowel and in front of your spine. Sometimes, cancer cells from the testicles can spread to these nodes. You'll have a scan (CT scan) to check whether any of these nodes are larger than normal.

# Risk factors and causes

We don't yet know what causes testicular cancer. But we know some of the risk factors that may increase the chances of developing it.

Having a particular risk factor doesn't mean you will definitely get cancer – just as not having any risk factors doesn't mean you won't. Usually, cancer is the result of the combination of several risk factors.

Over the next pages are some risk factors that may affect a man's chance of developing testicular cancer.

## Undescended testicle (known as cryptorchidism)

The testicles develop inside the tummy (abdomen) of an unborn baby. Usually, they drop down (descend) into the scrotum at birth or by the time a boy is one year old. In some boys, the testicle doesn't drop down and surgery is carried out to bring the testicle down into the scrotum. Men who've had an undescended testicle as a child have a higher chance of getting testicular cancer.

## Family history

Men with a brother or father who have had testicular cancer have a slightly higher risk of getting it. Researchers have found that this is, in part, due to changes in certain genes. Research continues to find out which genes may increase the risk.

## **Carcinoma in situ (CIS)**

This is when there are abnormal cells in the testicle that, if left, can develop into testicular cancer. CIS tends to be found when men have a biopsy of the testicle to investigate infertility (inability to have children). Treatment is usually surgery to remove the testicle. Removing one testicle won't affect your sex life or your ability to get an erection or to have children, as long as your other testicle is healthy.

## **Cancer in the other testicle**

A small number of men who've previously been treated for testicular cancer will go on to develop a cancer in the other testicle.

## **Ethnicity and social status**

Testicular cancer is more common in white men than African-Caribbean or Asian men. It's also more common in wealthier social groups. The reason for this is not yet known.

## **Height**

Men who are taller appear to have a higher risk of testicular cancer, but it's not clear why.

## **Human immunodeficiency virus (HIV)**

There is an increased risk of developing testicular cancer in men who are HIV positive. In particular, there is an increased risk of a type of testicular cancer called seminoma (see page 26).

**There's no evidence to suggest that injury to a testicle increases your risk of getting cancer. However, an injury to a testicle or the groin may bring a 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.

Symptoms can include:

- swelling or a lump in a testicle, which is usually painless – occasionally the swelling may suddenly get bigger and become painful
- a dull ache or pain, or heaviness in the scrotum.

If the cancer has spread to the lymph nodes or other parts of the body, there may be some of the following symptoms:

- pain in the back or lower abdomen – if the cancer has spread to lymph nodes in the back of the abdomen
- a cough, breathlessness or difficulty swallowing – if the cancer has spread to lymph nodes in the chest area, or to the lungs
- nipple/breast tenderness or breast swelling (gynaecomastia) – this is rare but can be caused by hormones produced by the cancer.

These symptoms can be caused by conditions other than testicular cancer, but it's always important to have them checked by your doctor.

Testicular cancer can still usually be cured even if it has spread when it is diagnosed.

## Testicular self-examination

It is easier to treat testicular cancer when it is diagnosed early. So from puberty onwards, it's important that men check their testicles once a month. When you check them regularly, you'll soon get to know what feels normal for you. A normal testicle should feel smooth and firm, but not hard.

The best time to check your testicles is during, or right after, a warm bath or shower, when the scrotal skin is relaxed. Hold your scrotum in the palm of your hand, and use your fingers and thumb to examine each testicle.

Feel for lumps or swellings, anything unusual, or differences between your testicles. It's normal for the testicles to be slightly different in size and for one to hang lower than the other.

The epididymis (tube that carries sperm) lies at the top of the back part of each testicle. It feels like a soft, coiled tube. It's common to get harmless cysts or benign lumps in the epididymis.

Lumps or swellings can be caused by other conditions, and most lumps aren't cancer. But it's very important that you have anything unusual checked by your doctor 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 Choices website ([nhs.uk](https://www.nhs.uk)) or you can look in the health section of your local phone book.

Remember that testicular cancer is nearly always curable, particularly when it's found and treated early.

Waiting Area C



# DIAGNOSING TESTICULAR CANCER

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# How testicular cancer is diagnosed

Usually you begin by seeing your family doctor (GP), who'll examine you. If your GP suspects that you may have testicular cancer, you'll be referred to a hospital specialist for further tests. Sometimes your GP will request an ultrasound.

The specialist is usually a **urologist** – a doctor who is experienced in treating testicular, prostate, bladder and kidney problems. They will examine you and ask you about your general health and any previous health problems you may have had. You'll have an ultrasound examination of the scrotum and the testes, and blood tests. You may also have a chest x-ray to check that your lungs are healthy.

'I think a lot of people are uncomfortable with getting that area checked. But my doctor was very professional and you just feel safe and comfortable. It was easier than I thought it would be.'

**David**

Occasionally, men with testicular cancer that has spread are diagnosed when they have other tests to investigate their symptoms. These tests may include a CT scan or MRI scan (see opposite).

## Ultrasound

This test can help the doctors tell whether a lump is a cancer, or is due to other causes, like a cyst (a harmless lump filled with fluid). It's a painless test and only takes a few minutes.

Once you're in a comfortable position, a gel is spread onto your scrotum and testes. A small device, like a microphone, is then passed over this area. This produces soundwaves, which a computer converts into pictures of the inside of your testicle.

## Blood tests

Your doctor will also take blood from you. This is usually done when you see a urologist. This is to find out if you have raised levels of certain chemicals in the blood called **tumour markers** (see page 28). Some testicular cancers produce these chemicals and release them into the blood. You may still have testicular cancer even if these chemicals are not raised in the blood. Other blood tests will also be taken to check your general health.

## MRI (magnetic resonance imaging) scan

Occasionally, an MRI scan is used to diagnose testicular cancer. An MRI uses magnetism to build up a detailed picture of areas of your body. If an ultrasound doesn't clearly show whether a lump might be cancerous or not, an MRI scan is sometimes done to give a more detailed picture.

## After your tests

With testicular cancer, the only way to get a definite diagnosis is to do an operation to remove the whole of the affected testicle. This is because taking just a small piece of tissue (biopsy) may increase the risk of a cancer spreading.

The testicle is only removed if the ultrasound scan shows that the lump is highly likely to be cancer. After you've had the testicle removed, a doctor called a **pathologist** will examine it to see if there is a cancer.

It's natural to have concerns about having this operation. Your specialist will explain why you need it and will talk things over with you. You may also be referred to a specialist nurse who can give you information and support. Removing one testicle won't affect your sex life, your ability to get an erection, or have children, as long as your other testicle is healthy. You'll be able to return to your normal sex life once you've recovered from the operation. If your doctor has concerns that your fertility might be affected by the operation, they may offer you the chance to store your sperm (sperm banking) before the operation. There's more information on sperm banking on pages 80–81.

## Removing the testicle (orchidectomy)

As well as confirming a diagnosis, an orchidectomy removes the cancer. It is the main treatment for testicular cancer when it has not spread.

If the cancer hasn't spread outside the testicle, and there's a low risk of it coming back (recurrence), this may be the only treatment you'll need.

During the operation, the surgeon can insert an artificial testicle (known as an **implant** or **prosthesis**) into your scrotum. If you're unsure about whether you want this, you can have a prosthesis put in at a later date. Your specialist will give you more details about the benefits and disadvantages of having an artificial testicle, and how it will look and feel afterwards.

### Before your operation

If you smoke, try to give up or cut down before your operation. This will help reduce your risk of chest problems, such as a chest infection, and will help your wound heal after the operation. Your GP can give you advice, and you may find it helpful to read our leaflet **Giving up smoking**.

You may meet a member of the surgical team and a specialist nurse to discuss the operation. This may be at a pre-assessment clinic before you're admitted for your operation.

Make sure you ask any questions or talk over any concerns you have about the operation. You may have some tests before the operation, such as an ECG (a recording of your heart).

You'll usually be admitted to hospital on the morning of the operation. You'll meet a member of the surgical team and nursing team. You'll also meet the doctor who'll give you your anaesthetic (the anaesthetist). They'll be able to answer any questions you have about the anaesthetic and pain control after the operation. There's space for you to write down any questions you may have on page 121.

## **The operation**

Your operation will be done under a general anaesthetic. The surgeon will make a small cut (incision) in the groin on the affected side. The testicle is pushed up from the scrotum and removed through the incision.

## **After the operation**

Once the anaesthetic has worn off you'll be able to eat and drink. You'll be encouraged to get up and start walking around as soon as possible. As soon as you feel well enough and you've been checked over by your doctor, you can go home. This may be on the same day or you may need to stay in overnight. You will need someone to take you home and stay with you for the first 24 hours after going home.

It's not unusual to have some discomfort, bruising and slight swelling around the scar for a couple of weeks, but this can usually be controlled with painkillers. Wearing supportive underwear and loose trousers might help you feel more comfortable.

You may have numbness around the area, but usually this gradually improves. However in some men, it may always feel a little different to the unaffected side.

You usually have dissolving stitches. They can take a few weeks to completely dissolve. Non-dissolving stitches tend to be removed about 5–10 days after your operation.

Your specialist will advise you not to drive or do any heavy lifting for several weeks after your operation. The amount of time you'll need to take off work will depend on the type of work you do.

## Sex

You'll be able to get back to your normal sex life once your wound has healed. You may not feel like having sex for a while after your surgery. This may happen if you're in some discomfort and feel anxious. Some men are concerned about their appearance after they've had a testicle removed. Most men find that any negative feelings gradually go away. But if you continue to struggle with difficult feelings or problems with your sex life, talk to your doctor or specialist nurse. They can suggest sources of help and support. We have listed some useful organisations on pages 115–120.

## Fertility (being able to father children)

You will still be able to have children after an orchidectomy. However, some men may already have fertility problems, or their unaffected testicle may be small and possibly producing less sperm. In this case, men may be offered sperm banking before their operation. Sperm banking involves freezing your sperm so that it can be used in the future to help you and your partner have a child. Your cancer doctor or specialist nurse can discuss this with you before your treatment starts. Sperm banking is explained in more detail on pages 80–81.

# Types of testicular cancer

Testicular cancers are also called **germ cell tumours** (GCTs). Germ cells in men produce sperm, and these tumours usually develop in the testicles.

In this booklet, we use the term testicular cancer for all types of testicular tumour. After you've had your testicle removed, the tissue is examined under a microscope to find out the type of testicular cancer you have. There are two main types of testicular cancer – **seminomas** and **non-seminomas**.

## Seminoma

These usually occur in men between the ages of 25–55. About 40–45 in 100 (40–45%) of men with testicular cancer have a seminoma.

## Non-seminoma

Non-seminomas usually affect younger men aged between 15–35 years old. They occur in about 40–45 in 100 (40–45%) of men with testicular cancer. Non-seminomas are made up of different types of tumour, such as teratomas, embryonal tumours, yolk sac tumours and choriocarcinomas. They can be made up of an individual cell type or mixture of cell types. Sometimes they are combined with seminomas. Although there are some minor differences, these tumours behave and are treated in similar ways.

## Rarer types

Sometimes, a type of cancer called **non-Hodgkin lymphoma** can occur in the testicles. Other rare types are **Leydig cell tumours** and **Sertoli cell tumours**.



To find out more about these rarer types of testicular cancer, contact our cancer support specialists on **0808 808 00 00**.

# Tumour markers

Some testicular cancers produce chemicals known as tumour markers. These are released into the blood and can be measured by simple blood tests.

Not all men with testicular cancer have raised markers. Most non-seminomas (see page 26) and some seminomas (see page 26) produce tumour markers.

If your cancer produces markers, you'll become used to having these measured. There are three main tumour markers:

- **Alpha-fetoprotein (AFP)** – often raised in non-seminomas
- **Human chorionic gonadotrophin (HCG)** – often 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:

- diagnose testicular cancer
- find out if it has spread
- monitor you after surgery
- watch how you're responding to treatment
- check that the cancer hasn't come back.

Tumour markers are measured before and usually a week after your operation. How quickly tumour markers fall gives doctors information about the risk of the cancer coming back. This helps them plan your treatment.



**'When I received my cancer diagnosis back in 2006, it was pretty devastating. I was 26 years old and considered myself young and fit, so to receive this news was difficult to deal with.'**

## Further tests

Once your diagnosis is definite, your specialist will arrange for you to 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 on the best treatment for you.

Occasionally, men who are having scans to investigate their symptoms are diagnosed with a testicular cancer that has spread. Testicular cancer can still usually be cured even if it has spread when it is diagnosed.

### Blood tests

After your orchidectomy, you're likely to have further blood tests to recheck the levels of any tumour markers, particularly if they were raised before your surgery. Other blood tests can check how well your liver and kidneys are working.

### CT (computerised tomography) scan

This may be done to check for any signs the cancer has spread to the lymph nodes in the abdomen or elsewhere in the body.

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.

## 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 of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 115–120, can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

# Staging

The stage of a cancer is a term used to describe its size and whether it has spread beyond its original site. Knowing the extent of the cancer helps the doctors decide on the best treatment for you.

There are several staging systems for testicular cancer. One commonly used system in the UK is the **Royal Marsden staging system**. Here is a simplified version of this system:

## Stage 1

The cancer may be of any size and is only in the testicle. Stage 1 cancers are further divided depending on whether tumour markers remain raised.

## Stage 2

The cancer has spread to local lymph nodes (see page 11) in the tummy (abdomen) called the retroperitoneal lymph nodes. Stage 2 cancers are further divided depending on the size of the tumour and lymph nodes affected and level of tumour markers.

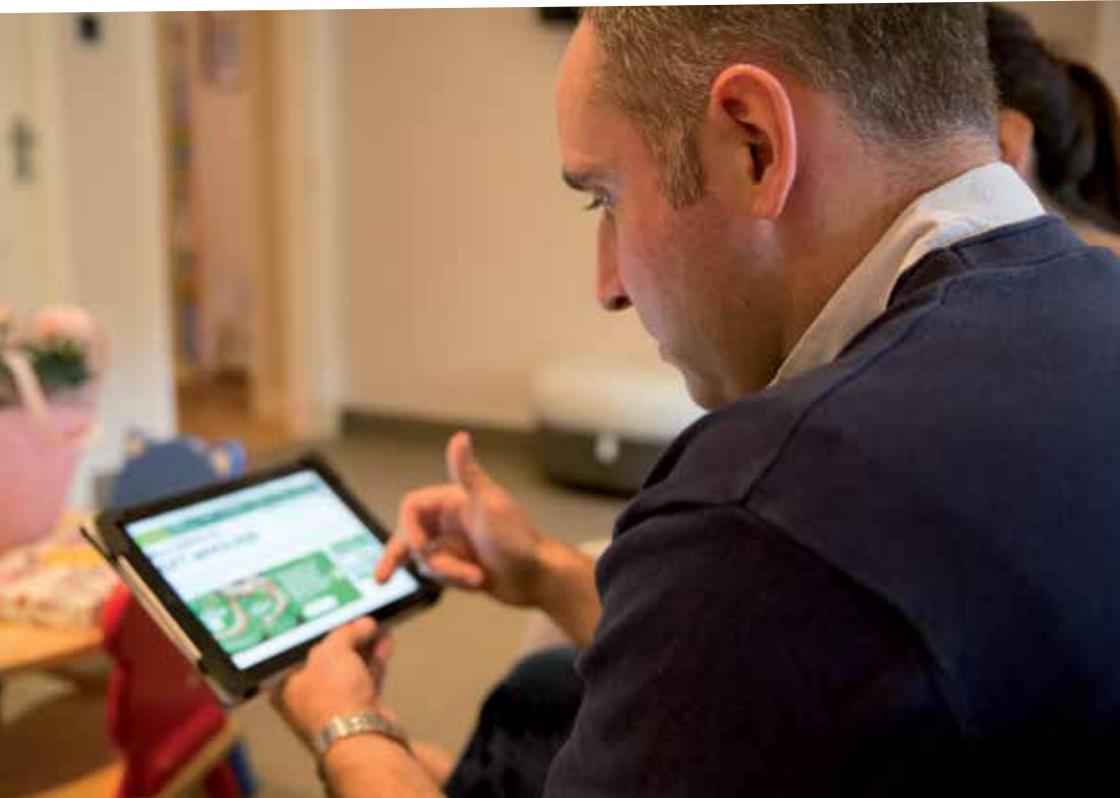
## Stage 3

The cancer has spread to lymph nodes in the chest or higher up, for example, lymph nodes in your armpit or neck. Stage 3 cancers are further divided depending on the size of tumour and lymph nodes affected and level of tumour markers

## Stage 4

The cancer has spread to other parts of the body, such as the liver or lungs. This is known as metastases.

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





# TREATING TESTICULAR CANCER

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# Treatment overview

The three main treatments for testicular cancer are **surgery**, **chemotherapy** and **radiotherapy**. Your treatment will depend on the stage of the cancer, and whether it's a non-seminoma or seminoma (see page 26).

## Testicular cancer that hasn't spread outside the testicle (stage 1)

### Surgery

For some men, surgery to remove the testicle (orchidectomy, see pages 23–25) may be the only treatment that's needed.

### Surveillance

After surgery, you'll be asked to go to the clinic regularly to have your tumour markers measured, as well as other tests. This is called surveillance (see page 44). If the cancer comes back, scans and blood tests will help your doctors pick it up early and treatment can usually cure it.

Attending your surveillance appointments is very important. If you move house, make sure the hospital knows your new address. It is also important to let your specialist know if you get any new symptoms or feel unwell between appointments. You can arrange an earlier clinic appointment if you need to.

## Adjuvant treatment

You may need treatment with chemotherapy (see pages 47–58) after surgery. This is known as **adjuvant treatment**. It's given to reduce the small risk of the cancer coming back.

- If you have a **non-seminoma**, you may have one or two sessions of adjuvant chemotherapy. The size of the tumour, how it looks under a microscope, and tumour marker levels (if present) help doctors decide whether you need adjuvant treatment.
- If you have a **seminoma**, you'll usually be offered a single dose of adjuvant chemotherapy.

Your doctor will explain why adjuvant treatment is advisable for you. Some men may decide not to have treatment and to have surveillance instead (see page 44). They may want to avoid treatment that might not be necessary. Talk about this with your doctor and make sure you have enough information to help you make your decision.

'The decision on treatment is a very personal thing but I chose to have it. I reckon that I would not be able to forgive myself if it recurred and I had not tried everything to prevent it.'

**Dougie**

## Testicular cancer that has spread outside the testicle (stages 2–4)

If the cancer has spread outside your testicle, you'll be given chemotherapy or occasionally radiotherapy after your orchidectomy. Treatment may depend on the exact stage of the cancer. Your doctors will discuss the treatment they feel is best for you.

- If you have a **non-seminoma** that has spread, you may need to have three or four sessions of chemotherapy. Some men need more intensive chemotherapy depending on the stage of their cancer, certain risk factors and how they respond to the initial chemotherapy.
- If you have a **seminoma** that has spread, treatment may be with three or four courses of chemotherapy, radiotherapy, or radiotherapy with a single dose of the chemotherapy drug carboplatin. Your doctor will discuss with you the treatment they think is best for you.

After chemotherapy, some men may need surgery to remove the retroperitoneal lymph nodes if they are enlarged (see page 45).

## If testicular cancer comes back

If testicular cancer comes back, treatment can usually cure it in most men, even if the cancer has spread to other parts of the body.

## Treatment and fertility

Treatments for testicular cancer can sometimes affect your ability to father a child (see page 75). If you need treatment after having an orchidectomy, you may be advised to store some of your sperm (sperm banking). We have more information about this on pages 80–81.

## How treatment is planned

In most hospitals, a team of specialists will talk to you about the treatment they feel is best for your situation. This **multidisciplinary team (MDT)** will include a:

- **surgeon** – who specialises in testicular cancers
- **medical oncologist** – a chemotherapy specialist
- **clinical oncologist** – a radiotherapy and chemotherapy specialist
- **nurse specialist.**

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

The MDT will take a number of factors into account when advising you on the best course of treatment, including your general health, the type and size of the tumour, and whether it has begun to spread.

Your doctors may ask you to choose what you want to do, such as whether to have adjuvant treatment or surveillance. Sometimes people find it hard to make a decision like this. Make sure that you have enough information about the different options, what is involved and the possible side effects. This will help you decide on the right treatment for you.

Remember to ask questions about anything that you don't understand or feel worried about. It may help to discuss the benefits and disadvantages of each option with your cancer specialist, nurse specialist or with our cancer support specialists on **0808 808 00 00**.

It often helps to make a list of questions and to take a relative or close friend with you. You can use the space on page 121 to write down your questions and the answers you receive.



You can find more information about making treatment decisions on our website. We also have a booklet called **Making treatment decisions** that we can send you.

## Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straightaway, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

## The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments because of the side effects that can occur. Your doctor and nurse will talk to you about ways of coping with different side effects. Many side effects can be controlled with medicines.

In men with early testicular cancer, surgery alone may cure the cancer. Often, adjuvant chemotherapy is given to reduce the risk of the cancer coming back. You may be concerned about having adjuvant treatment that you may not need, and that has side effects. Or you may prefer to have any treatment that reduces the risk of the cancer coming back. It's important that you have all the information you need, so that you can make the right choice for you. If early testicular cancer comes back, it can usually still be cured in most men.

Testicular cancer that has spread outside the testicle can also usually still be cured. Even if it's very advanced or comes back after initial treatment, intensive chemotherapy can be given with the aim of curing the cancer.

Rarely, very advanced testicular cancer may not respond well to treatment, or may continue to come back despite treatment. In this case, treatment can be given to help control the cancer, and improve symptoms and quality of life. Occasionally, this may have little effect on the cancer, and men will have side effects without the benefit of treatment.

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

# Surveillance (monitoring)

If the risk of your cancer coming back after your operation is very low, your doctor may recommend surveillance. This is when the doctor looks for signs of the cancer coming back so that it can be found and treated early, when it's easier to cure. This means you avoid having adjuvant treatment (see page 37), which you may not need. You only have treatment if your tumour marker levels increase or scans show that the cancer has come back.

It's extremely important to go to your surveillance appointments. If the cancer does come back (this only happens in a small number of men), it will be picked up early and still has a high chance of being cured by treatment. Men whose cancer comes back during surveillance may need a longer course of chemotherapy.

## What to expect

Your specialist will tell you what kind of monitoring you'll have. You will have your tumour markers checked regularly. You'll also have regular chest x-rays and occasional CT scans. Your specialist will also do a physical examination, check your other testicle, and ask you how you've been feeling.

Over time, as the risk of the cancer coming back decreases, your appointments and tests will be less frequent. Always let your doctor know if you're having problems with new or ongoing symptoms, or if you're having emotional or sexual difficulties. This helps them to assess you properly and give you the best care and support. It's also an important way of being involved in your own healthcare.

# Surgery

Removing the testicle (orchidectomy) helps your doctor make the diagnosis. This is usually the first treatment for testicular cancer. If the cancer is completely contained in the testicle (stage 1, see page 32), this operation may be the only treatment you will need.

We explain what to expect when you're having an orchidectomy in our section on diagnosis (see pages 23–25).

## Removing the lymph nodes at the back of the tummy (retroperitoneal lymph nodes)

Some men need further surgery after they have had chemotherapy. Sometimes a CT scan shows that the lymph nodes at the back of the tummy (abdomen) are enlarged (greater than 1cm in diameter). This means the nodes may contain cells that could become cancerous in the future. Surgery to remove them is the only certain way of finding this out.

Rarely, these lymph nodes are removed in men with an early-stage non-seminoma who are unable to have surveillance appointments or adjuvant chemotherapy. This will show whether the cancer has spread and remove any nodes that might be affected.

We have more information about removing the retroperitoneal lymph nodes, known as a retroperitoneal lymph node dissection (RPLND) on pages 65–68.

## Surgery to other parts of the body

Occasionally, after chemotherapy, some men may develop signs of cancer in areas such as the lungs, brain or liver. They may need to have further surgery. These operations are done by experienced surgeons in specialist units. If you need this type of operation, your doctor will talk it over with you.



# Chemotherapy

Chemotherapy is the use of anti-cancer (**cytotoxic**) drugs to destroy cancer cells. The drugs travel around the bloodstream and can reach cancer cells anywhere in the body.

The drugs most commonly used to treat testicular cancer are **bleomycin, etoposide** and **cisplatin**. This combination is known as **BEP chemotherapy**. Other combinations of drugs are also used depending on the stage and type of the cancer, or if it's come back after treatment.

Chemotherapy for testicular cancer is given:

- 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
- to treat testicular cancer that has come back after initial chemotherapy.



We have more detailed information about chemotherapy and its side effects on our website. We also have a booklet called **Understanding chemotherapy** that we can send to you.

'I was given the chemotherapy by a Macmillan nurse. Once I was hooked up she just stayed and chatted with me. She was fantastic.'

David

## Adjuvant chemotherapy

If you have an early (stage 1) non-seminoma, you'll normally have one to two cycles of BEP, usually given three weeks apart.

If you have an early (stage 1) seminoma, you'll usually have a single treatment with a drug called carboplatin.



We have more information about BEP, carboplatin and other chemotherapy drugs at [macmillan.org.uk/chemotherapy](https://www.macmillan.org.uk/chemotherapy)



## If the cancer has spread or comes back during surveillance

If testicular cancer has spread outside the testicle, or comes back during surveillance (see page 44), you may have three or four cycles of BEP. Occasionally, the bleomycin is left out and four cycles of EP (etoposide and cisplatin) are given instead. Bleomycin may cause breathing problems in men who already have a lung condition (see page 56).

If your cancer doesn't completely respond to BEP, or it comes back again, you'll usually be given more intensive chemotherapy. Some men, depending on the stage of their cancer, are given more intensive chemotherapy straightaway.

Some drug combinations that may be used are:

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

Occasionally, high-dose chemotherapy with stem cell support is given (see page 64). This may be given as part of a clinical trial (see pages 69–71).

## How chemotherapy is given

You usually have the chemotherapy drugs as an outpatient. The chemotherapy drugs are usually given into a vein as an injection or as a drip. This is called intravenous chemotherapy. The drugs may be given through:

- a thin, flexible tube inserted into a vein in the back of your hand (**cannula**)
- a plastic line called a **central line**, which is put into a vein in your chest
- a thin tube inserted into a vein in your arm near the bend of your elbow (**PICC line**).

Chemotherapy is given in cycles of treatment. A cycle usually takes three weeks. If you're having BEP, you'll usually spend 3–5 days going to hospital as an outpatient. Sometimes you'll stay overnight.

This is followed by weekly outpatient visits to have the rest of your treatment. Other combinations of chemotherapy drugs may involve spending more time in hospital and having the drugs more often. Your doctor or nurse will tell you how many cycles of treatment are planned for you and explain how you'll be given the chemotherapy.



We have more information on central lines and PICC lines on our website.

## Side effects

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well controlled with medicines and will usually go away once treatment has finished. Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that's planned for you. The main side effects are described here as well as some ways to reduce or control them.

### Risk of infection

Chemotherapy can reduce the number of white blood cells, which help fight infection. If your white blood cell count is low you'll be more prone to infections. A low white blood cell count is called **neutropenia**.

Always contact the hospital immediately on the 24-hour contact number you've been given and speak to a nurse or doctor if:

- your temperature goes over 37.5°C (99.5°F) or over 38°C (100.4°F), depending on the advice given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you feel shivery and shaky
- you have any symptoms of an infection, such as a cold, sore throat, cough, passing urine frequently (urine infection), or diarrhoea.

If necessary, you'll be given antibiotics to treat any infection. You'll have a blood test before each cycle of chemotherapy to make sure your white blood cells have recovered. Occasionally, your treatment may need to be delayed if the number of your white blood cells is still low.

## **Anaemia (low number of red blood cells)**

Chemotherapy may reduce the number of red blood cells (haemoglobin) in your blood. A low level of red blood cells is known as **anaemia**, which can make you feel very tired and lethargic. You may also become breathless.

Anaemia can be treated with blood transfusions. This should help you to feel more energetic and ease the breathlessness.

'The week after chemotherapy wasn't the nicest week of my life, but I was over the worst of it after 3–4 days. Think of it as a bad hangover with a touch of cold thrown in.'

**Rob**

## **Bruising or bleeding**

Chemotherapy can reduce the production of platelets, which help the blood to clot. Tell your doctor if you have any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin. You can have a platelet transfusion if your platelet count is low.

## Nausea and vomiting

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take. We have information about nausea and vomiting that we can send you.

## Tiredness (fatigue)

You're likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want to do or that need doing. Balance rest with some physical activity – even going for short walks will help increase your energy levels. Our booklet **Coping with fatigue** has more helpful tips.

## Sore mouth

Chemotherapy can cause mouth problems such as a sore mouth, mouth ulcers or infection. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush can help to reduce the risk of this happening. Your chemotherapy nurse will explain how to look after your mouth to reduce the risk of problems. They can give you mouthwashes, medicines and gels to help.

We have more information about mouth care during chemotherapy. It has some useful tips on coping with a sore mouth.

## Loss of appetite

Some people lose their appetite while they're having chemotherapy. This can be mild and may only last a few days. If you don't feel like eating during treatment, you could try replacing some meals with nutritious drinks or a soft diet. If it doesn't improve you can ask to see a dietitian.

## Hair loss

It's common to lose your hair with chemotherapy treatments like BEP, although carboplatin (used to treat seminoma) doesn't usually cause hair loss. Your hair will usually start to fall out 3–4 weeks after starting treatment, although it may occur earlier. Hair usually falls out completely. Your eyelashes, eyebrows and other body hair may also thin or fall out. This is temporary and your hair will start to grow again once the treatment has finished.

Some men shave their heads once they notice their hair is starting to fall out. You can cover up using hats (baseball caps and beanies) or bandanas.

'In terms of hair loss, the speed at which it came out was certainly a surprise. I expected a gradual loss over a few weeks, but once it started, it fell out in clumps.'

PJ

Choose something that suits your personal style and that you're comfortable with. You'll probably end up with a variety of things that 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're an inpatient or are on income support, you can get a free wig from the NHS.



We have more information about coping with hair loss on our website. We also have a booklet called **Coping with hair loss**, which we can send you.

## Changes to the lungs

Bleomycin can cause some changes to the lungs. This can happen during treatment or afterwards. Your doctor can tell you more about this side effect.

Tell your doctor if you smoke, or if you notice any wheezing, coughing or breathlessness. You'll probably have a chest x-ray before starting bleomycin treatment, and you may have regular chest x-rays during your treatment.

If you need an operation after having bleomycin, always tell the anaesthetist that you've had bleomycin treatment.

If sub-aqua diving is an activity you're involved in, you may need to be careful doing it for a while after treatment with bleomycin, so talk to your doctor about this.

## Changes to your hearing

Cisplatin may affect your hearing. You may have ringing in the ears (tinnitus) and lose the ability to hear some high-pitched sounds. Very occasionally your sense of balance may be affected. Any hearing loss (and balance changes if they occur) may be permanent. Tinnitus usually improves when treatment ends.

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

## **Numbness or tingling in the hands or feet**

Cisplatin can affect the nerves in your hands or feet. This can cause tingling, numbness, or muscle weakness called **peripheral neuropathy**. You may notice that you have difficulty fastening buttons or doing similar fiddly tasks. Your hands and feet may also become more sensitive to the cold. It's important to report your symptoms as they may be controlled by slightly lowering the dose of the drug.

This side effect usually improves slowly, a few months after the treatment has finished. Sometimes symptoms can continue – talk to your doctor if this happens.

We have more information about peripheral neuropathy which we can send you. You can also find this information on our website.

## **Changes in the way your kidneys work**

Chemotherapy (cisplatin in particular) can affect your kidneys, so you'll have regular blood tests to check how well they're working. You'll also be given lots of fluid through a drip before and after having cisplatin.

## **Risk of blood clots**

Cancer can increase your risk of developing a blood clot (thrombosis), and having chemotherapy may increase this risk further. A blood clot may cause symptoms such as pain, redness and swelling in a leg, or breathlessness and chest pain.

Blood clots can be very serious so it's important to tell your doctor straightaway if you have any of these symptoms. However, most clots can usually be successfully treated with drugs to thin the blood. Your doctor or nurse can give you more information about blood clots.

## Contraception

It's not advisable to father a child while having any of the chemotherapy drugs used to treat testicular cancer, as the drugs may harm the developing baby. It's important to use an effective barrier method of contraception. Condoms are usually recommended during your treatment and for at least a few months afterwards. You can discuss this with your doctor or nurse.

It's also safest to either avoid sex or use a condom for about 48 hours after chemotherapy treatment, to protect your partner. This is because it's not known whether chemotherapy drugs are present in the semen.

## Fertility

Chemotherapy for men with testicular cancer often causes infertility during treatment and for a time after. This is usually temporary, but your doctor will advise that you consider storing sperm before having treatment (see pages 80–81). The rate at which the sperm count recovers varies from person to person, but it generally returns to normal from around 18 months after treatment.

Some men with testicular cancer have a low sperm count before they start treatment. Treatment with chemotherapy can sometimes improve sperm production, once the sperm count has recovered after treatment.

In men having high-dose chemotherapy, the risk of infertility is much higher and infertility is often permanent.



# Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells. Radiotherapy may be used to treat seminomas and more rarely, non-seminomas.

If you have a stage 2 seminoma, you may have radiotherapy instead of chemotherapy. In this situation, the aim of treatment is to reduce the small risk of the cancer coming back in the lymph nodes at the back of the abdomen.

The treatment is normally given in the hospital radiotherapy department as a series of short daily sessions. The treatments are usually given from Monday–Friday, with a rest at the weekend. Each treatment takes 10–15 minutes. Your doctor will discuss the treatment and possible side effects with you.

A course of radiotherapy for seminoma may last 2–3 weeks. Treatment is usually given as an outpatient.

Radiotherapy doesn't make you radioactive, and it's perfectly safe for you to be with other people, including children, throughout your treatment.



Our booklet **Understanding radiotherapy** gives more detailed information about this treatment and its side effects. You can also find this information on our website.

## Planning your radiotherapy

Radiotherapy has to be carefully planned to make sure it's as effective as possible. It's planned by a cancer specialist (clinical oncologist) and it may take a few visits.

On your first visit to the radiotherapy department, you'll be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated.

You may need some small marks made on your skin to help the radiographer (who gives you your treatment) position you accurately and to show where the rays will be aimed at. These marks need to be able to be seen throughout your treatment, so permanent marks (like tiny tattoos) are usually used. These are extremely small, and will only be done with your permission. It may be a little uncomfortable while they are done.

### Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment you'll 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 (abdomen) 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, gradually disappear once your course of treatment has finished.

### Skin changes

The skin in the area being treated may become red (if you have white skin) or darken (if you have black or brown skin), but this will improve after your treatment finishes. You'll be given advice on looking after your skin and your specialist can prescribe cream if your skin is uncomfortable.

### Feeling sick (nausea)

Radiotherapy to the tummy area may make you feel sick. Your doctor will prescribe anti-sickness medicine to prevent or stop this. You'll probably be advised to take these medicines regularly during treatment. Let your doctor know if the tablets aren't working for you, as 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 things that don't really need to be done. Gentle exercise, such as short walks, can help to improve tiredness. It's good to balance this with plenty of rest.

Sometimes tiredness can last up to eight weeks or longer after treatment finishes. Your energy levels will then gradually improve.

## Diarrhoea

You might get some diarrhoea but this can usually be controlled with medicines, which your doctor can prescribe. Let your doctor know if this is a problem and make sure you drink plenty of fluids and cut down on foods that are high in fibre, such as fruit, vegetables, beans, pulses and wholewheat cereals.

It's important to let your doctor know if you're having any problems with side effects. Most of the side effects are mild and can be treated successfully with medicines.

## Effect on fertility

Radiotherapy to the lymph nodes in the tummy won't affect your ability to have sex and doesn't usually cause infertility. But your specialist may advise you to think about storing sperm before your treatment starts (see pages 80–81).

## Contraception

During radiotherapy, a small dose of radiation reaches the remaining testicle. This may affect your sperm, so it's advisable to use effective contraception during your treatment. There's no evidence that radiotherapy has any effect on children fathered after treatment, but you're usually advised to use contraception for 6–12 months afterwards. You can talk this over with your doctor or specialist nurse.

# High-dose chemotherapy with stem cell support

High-dose chemotherapy with stem cell support allows you to have much higher doses of chemotherapy than usual to treat testicular cancer. It's usually given if the cancer hasn't responded completely to treatment or the cancer has come back after treatment. It's used to increase the chances of curing the cancer.

High-dose treatment with stem cell support is given to try and destroy any remaining cancer cells. Stem cells produce blood cells. The treatment destroys stem cells in the bone marrow, as well as destroying the cancer cells. Because of this, some of your stem cells are taken and stored before you have high-dose treatment.

After high-dose treatment, the stored stem cells are given back to you through a drip (infusion). The cells go to your bone marrow and start to make blood cells again.

High dose treatment is given in hospitals with large cancer units that specialise in giving this treatment. This is an intensive treatment, and you'll need to stay in hospital for several weeks.



You can find more information about this on our website. We also have a booklet called **Understanding high-dose treatment with stem cell support**, which we can send you. It explains more about this treatment and its possible side effects.

# Retroperitoneal lymph node dissection (RPLND)

This is an operation to remove the lymph nodes at the back of the tummy (abdomen). This may be occasionally used for testicular cancer. It's a major operation that is carried out by experienced surgeons in specialist centres. Your surgeon and specialist nurse will explain what's involved, and the possible complications and side effects of this operation.

The operation is done under a general anaesthetic. Your surgeon will make a long cut from the top of your tummy (near your breastbone) to below your belly button. As these lymph nodes are behind the spine, your surgeon has to move your bowel and other organs aside to reach them.

## Before your operation

If you smoke, try to give up or cut down before your operation. This will help reduce your risk of chest problems, such as a chest infection, and will help your wound heal after the operation. Your GP can give you advice, and you may find it helpful to read our leaflet **Giving up smoking**.

You'll meet a member of the surgical team and a specialist nurse to discuss the operation. This may be at a pre-assessment clinic before you're admitted for your operation. Make sure you ask any questions or talk over any concerns you have about the operation. If you think you may need help when you go home after your surgery, for example because you live alone or are a carer for someone else, bring this up as soon as possible. This will help the staff make arrangements in plenty of time.

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'll usually be admitted to hospital on the morning of the operation. You'll meet a member of the surgical team and nursing team. You'll also meet the doctor who'll give you your anaesthetic (the anaesthetist). They'll be able to answer any questions you have about the anaesthetic and pain control after the operation.

You may be given elastic stockings (TED stockings) to wear during and after the operation, to prevent blood clots in your legs.

## **After your operation**

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

You'll be given fluids into a vein by an infusion (drip) until you're able to eat and drink normally. You may have drainage tubes from your wound to stop any excess fluid collecting, and to help the wound heal. The tubes will only be needed for a short time and will be taken out before you go home.

You'll be encouraged to start moving about as soon as possible. This helps to reduce complications like chest infections or blood clots. You'll also need to wear support stockings, which help to prevent blood clots in your legs. A physiotherapist or specialist nurse may give you some gentle leg and breathing exercises to do.

You'll be given painkillers regularly to control any pain. If you still have pain, let your nurse or doctor know. They can increase the dose of your painkiller or change it.

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're ready to go home. If necessary, a district nurse can change your wound dressings at home. Most surgeons use dissolvable stitches, which don't need to be removed. You'll 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 you about when you can lift heavy objects such as bags of shopping, drive and return to work.

## Possible complications

All operations have possible complications and your surgeon will discuss these with you beforehand. 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, so that if any occur they can be treated straightaway.

Occasionally during surgery, the lymph nodes are found to have become attached to a nearby structure, such as the kidney. If the lymph nodes cannot be separated from the kidney, the kidney may also need to be removed.

### **Effect on fertility**

Another common side effect of this operation is infertility. This is due to nerves being divided during the operation. You'll still be able to ejaculate, but your semen will go into your bladder and pass out harmlessly the next time you pass urine. This is known as retrograde ejaculation or dry climax. However, this is becoming less of a problem as surgeons use new nerve-sparing techniques to help protect the nerves.

This operation does not usually have any physical effect on your ability to get an erection or have an orgasm. Your doctor will advise you to store sperm before the operation (see pages 80–81).

### **Keyhole surgery (laparoscopic retroperitoneal dissection)**

Men who have not had previous chemotherapy may be offered keyhole surgery to remove the retroperitoneal lymph nodes. This involves having several small cuts rather than one longer one. Keyhole surgery is very specialised and should only be done by experienced surgeons. There are only a few hospitals that can offer this type of surgery.

# Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, radiotherapy, or other treatment is better than what is already available.

## Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments. Or the treatments may have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.



Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. We can send you a free copy.

## 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 men developing testicular cancer. Your doctors will be able to tell you about any trials that may be suitable for you.



Our website [macmillan.org.uk/clinicaltrials](http://macmillan.org.uk/clinicaltrials) has information about current clinical trial databases.

## Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.





# AFTER YOUR TREATMENT

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## Follow-up

After your treatment has finished, you'll be seen at the hospital for regular check-ups. It's extremely important to attend these appointments, as any problems or signs that cancer has come back can be dealt with straightaway. Testicular cancer that comes back can often be cured.

To begin with, check-ups may be every month but they'll gradually become less frequent. At your appointments, your doctor will ask how you're feeling and examine you. Your remaining testicle will be checked. You may have blood tests taken to check tumour markers. This is to make sure the cancer hasn't come back. You may also have regular chest x-rays and occasional CT or ultrasound scans.

Let your doctor know if you're having any problems, such as new or ongoing symptoms, or any emotional or sexual difficulties. This helps them to assess you properly and give you the best help and support. If you have new symptoms in between your appointments, or if there's anything worrying you, it's important to contact your hospital doctor, nurse or GP for advice.

# Sex and fertility

It's normal to worry about the effects of testicular cancer and its treatment on your sex life, and your ability to father a child. This section explains the effects of treatment and how your sex drive may be temporarily affected. There's 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

Removing a testicle won't affect your ability to get an erection or father children. The healthy testicle (unless it's very small) will produce more testosterone and sperm to make up for the testicle that's been removed.

Men who have an operation to remove the retroperitoneal lymph nodes (see pages 65–68) may get nerve damage. This can cause sperm to go backwards into the bladder instead of coming out through the penis. This is called retrograde ejaculation. The sperm is then passed out harmlessly in the urine.

The operation doesn't stop you from getting an erection but your orgasm will feel different because it's 'dry' (dry climax). Fortunately, new surgical techniques mean that this problem is now less common. However, your specialist may still advise you to think about storing sperm if you need this operation (see pages 80–81).

## Chemotherapy

Chemotherapy won't affect your ability to have sex, but the side effects might reduce your sex drive for a while. Chemotherapy often causes infertility, so your doctor will talk to you about storing sperm before your treatment (see pages 80–81). High-dose chemotherapy has a much higher risk of causing infertility.

Infertility caused by chemotherapy is usually temporary. How quickly the sperm count recovers varies from person to person. It generally starts to return to normal around 18 months after treatment. Some men with testicular cancer have a low sperm count when they're diagnosed. Sometimes, successful treatment with chemotherapy improves sperm production.

Men having high-dose chemotherapy may become permanently infertile. If you are worried about this, you can speak to your cancer specialist about your concerns.

## Radiotherapy

Radiotherapy to the lymph nodes in the tummy does not affect your ability to have sex and does not usually cause infertility. But your specialist might still suggest that you store sperm.

## Contraception during treatment

While you're being treated with chemotherapy or radiotherapy, it's important to avoid getting someone pregnant. This is because treatment can damage your sperm and possibly harm a baby conceived at this time.

## Effects of treatment on children fathered (conceived) after treatment

There's no evidence that cancer treatments can harm children that are conceived after treatment. But doctors usually advise you to carry on using contraception for about a year after treatment to avoid fathering a child. This allows time for your sperm to recover from any damage that treatment may have caused.

Many men who've been treated for testicular cancer go on to have families after they've recovered.

## Your sex drive (libido)

Being diagnosed with testicular cancer brings up a lot of different emotions, such as fear, anxiety and anger (see pages 94–98). Some men may find that it affects their feelings of masculinity. It's also common for the side effects of treatment, such as tiredness or sickness, to have an effect on your libido.

Coping with all of this can make you feel less interested in having sex. This is understandable. You'll rediscover your sex drive when your feelings are easier to cope with and you're recovering from treatment.



## Support with sexual difficulties

A common worry is that cancer cells can be passed during sex. Cancer isn't infectious, so it's perfectly safe for you to have sex.

Sexual difficulties are very personal. If you have a partner, talking openly to them about any problems you may be having can help. This can be difficult, but you might find that you understand each other better by having an open and honest conversation.

You can also talk to your doctor or nurse about any sexual difficulties you are worried about. You may feel embarrassed, but they'll have experience of talking to other men who have gone through similar problems. They will be able to talk about what support is available for you.

Some hospitals also have counsellors who are specially trained to help people having sexual difficulties. Your doctor can refer you to a counsellor. Many hospitals also have specialist nurses who can offer support.

## Testosterone replacement therapy

Removing one testicle doesn't usually affect your sex drive as long as the other testicle makes enough testosterone to make up for it.

Sometimes the remaining testicle won't produce enough testosterone, or (rarely) a man has to have both testicles removed because of cancer. A lack of testosterone can affect your ability to get an erection and reduce your sex drive. It can also cause tiredness, low mood and problems such as thinning of the bones (osteoporosis).

It's important to let your doctor know if you're having these or other symptoms. Your testosterone level can be measured by a blood test. If it's low, your doctor can prescribe **testosterone replacement therapy**. This will help improve problems such as a low sex drive and feeling constantly tired. It can be given as a gel, an injection into a muscle, an implant, or a patch that is stuck on the skin. Your doctor can give you more information about testosterone replacement therapy.

We have more information about sexuality and cancer on our website. We also have a booklet called **Sexuality and cancer – information for men**, which has lots more helpful information. We can send you a copy. There is also a list of useful support organisations on pages 115–120.

## Storing sperm (sperm banking)

Most men are still able to father a child after testicular cancer treatment. However, treatment can affect some men's fertility. This may depend on the type and amount of treatment needed. Your specialist will be able to give you more information about this.

Being told you have cancer and that treatment may affect your fertility can be very difficult. Your fertility may not be the most important thing to you – getting rid of the cancer is often the priority. But some men may find that the threat of losing their fertility is as difficult to accept as the diagnosis of cancer.

Even if your chances of becoming infertile are low, your doctor will usually advise you to store 2–3 samples of your sperm. Sperm storage usually happens after you've had an orchidectomy, but before you have further treatment. This is because this treatment could damage your sperm. Occasionally, some men may be offered sperm storage before an orchidectomy if they have fertility problems or if their unaffected testicle is small.

You'll have counselling at the fertility clinic before you have sperm banking. You'll also have to sign a consent form that states how your sperm is to be used. Blood tests are taken as well, to check whether you have any abnormalities or infections, such as HIV or hepatitis.

Sperm banking is a safe technique that's been successfully used for many years. It involves freezing your sperm. If you want to have a child later in your life, your sperm can be thawed and used with fertility treatments. Sperm samples can be kept frozen until you're 55. The NHS often pays for sperm banking for men with cancer, but in some hospitals you may have to pay for it yourself.

For some men, treatment needs to start immediately and there's no time to take sperm samples. If your doctor feels that your treatment needs to start straightaway, they will discuss this with you.

We have more detailed information about cancer treatment and fertility for men.

'After being told by the oncology nurse that the chemo would definitely permanently impair my fertility, I was feeling very low for several days. Going out with my mates from the running club and doing a few miles on a sunny Sunday made a big improvement to my state of mind.'

Alex

## Newer fertility techniques

If you aren't producing many sperm, or if your treatment started quickly and you couldn't provide all the samples, your sperm can still be stored. A fertility treatment called **ICSI (intra-cytoplasmic sperm injection)** is now often used. This only needs a single sperm to fertilise an egg.

It's also now possible to collect sperm by extracting a piece of testicular tissue or fluid. This can be done using a local or general anaesthetic. Small amounts of testicular fluid or tissue are removed by inserting a fine needle into the testicle, or by making a small cut in the scrotum. The fluid or tissue is examined 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 this technique.

# After treatment

After treatment is over, you'll probably be keen to get back to doing all the things you did before your cancer. But you may still be coping with the side effects of treatment, such as tiredness, and the emotional effects.

Recovering from cancer and its treatment takes time. You'll usually find that the day-to-day things that occupied you before your diagnosis will gradually start to take over again. Going back to work (see page 104) and getting back to the interests you had before can be big steps forward.

Some people feel that although they wouldn't have chosen to go through this experience, it's changed them in positive ways and helped them to think about their priorities. They may decide to focus more on relationships with family and friends or on doing the things they've always wanted to do.

## Positive lifestyle choices

Some people want to make changes to their lifestyle after cancer. You might choose to make just a few changes or completely change the way you live. Adopting a healthy lifestyle doesn't have to be very difficult or expensive.

Living a healthy lifestyle can sometimes appear to be a lot of hard work and as if you will be denying yourself all of the pleasures in life. However, it is about making small, achievable changes to the way you live that will improve your health and well-being. Your healthy lifestyle will be individual to you, and 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 and being involved in your healthcare. You will need to think about any side effects of treatment when planning changes to your diet and exercise. Don't try to do too much too soon.

A well-balanced diet should include:

- plenty of fresh fruit and vegetables (at least five 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.

Before making major changes to your diet, it's a good idea to discuss your plans with your specialist or a dietitian at the hospital.

If you're a smoker, stop. Stopping has many health benefits and reduces your risk of other diseases, such as heart disease and stroke.

Exercise does not have to be particularly strenuous. 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, such as walking, hiking, cycling or swimming. Activities like gardening, dancing and playing sport are also good to try.



We have a booklets called **Healthy eating and cancer** and **Giving up smoking** which we can send you. We also have booklets on physical activity and weight management.

## Being involved in your healthcare

It is very important to always attending your surveillance (see page 44) or follow-up appointments. If you can't attend, contact your doctor or clinic to arrange another appointment as soon as possible.

Check your remaining testicle every month (see page 17). Men who've already had testicular cancer have an increased risk of getting a new primary cancer in the other testicle.

Understanding more about testicular cancer and its treatment can also help you to cope. It means you can discuss treatment, tests and check-ups with your doctors and nurses, and be involved in making decisions. This can make you feel more confident and give you back a feeling of control.

Let your doctor know of any new symptoms or ongoing symptoms that aren't improving.

## Long-term or late effects of treatment

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

## Changes in sensation in your hands and feet

Some men who have had chemotherapy for testicular cancer find that they experience pins and needles or numbness in their hands and feet, and their hands become cold and fingers go pale. This is known as **Raynaud's phenomenon**. It's triggered by being in a cold environment, 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 (see page 57), and it can be temporary or sometimes permanent. If you have this, you may have altered sensation in your hands or feet.

## Hearing changes

The chemotherapy drug cisplatin can cause permanent hearing problems, particularly with high-pitched sounds (see page 56).

## Heart and lung problems

Some chemotherapy drugs may increase your risk of developing heart or lung problems (see page 56). Things that can help are doing regular exercise, eating healthily, keeping to a healthy weight and if you smoke, stopping or cutting down on smoking.

Always let your doctors know if you have any of these effects. Your doctor will monitor them and arrange any necessary tests.

## Risk of developing another cancer

Research has shown that men who have radiotherapy or chemotherapy treatment for testicular cancer have a slightly increased risk of developing another cancer later in life. This doesn't mean that they will definitely develop another cancer. For most men, the benefits of having treatment will far outweigh this risk.



## Dealing with stress

The way people manage stress varies. You may want to think about what works for you or try out new ways to deal with stress.

Exercise and a healthy diet can help to reduce stress and anxiety. Some people find that complementary therapies, relaxation techniques or even taking up a new hobby can help. Others find talking about their feelings or having contact with other people who have been through a similar experience can also help.

## Complementary therapies

Complementary therapies may help you to feel better, reduce stress and anxiety, and improve some treatment side effects. Relaxation, counselling and psychological support are available at many 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.



Our booklet **Cancer and complementary therapies** tells you about different therapies and gives advice on choosing a therapist.

## Talking to someone or sharing your experience

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

## Support groups

Self-help or support groups offer 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 don't feel able to talk about your feelings with people around you. Not everyone finds talking in a group easy, so it might not be for you. Try going along to see what the group is like before you decide.

You can call us on **0808 808 00 00** or visit our website **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** for information about cancer support groups across the UK.

'I eventually got some counselling from my local Maggie's Centre, which helped me to accept and understand the way in which I was overreacting to stress and lose the guilt. I also did a course in mindfulness, which helped me to get control back.'

**Michael**

## Online support

Many people now get support through the internet. There are online support groups, social networking sites, forums, chatrooms and blogs for people affected by cancer. You can use these to ask questions and share your experience.

Our online community at **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)** is a social networking site where you can talk to people in our chat rooms, blog your journey, make friendships and join support groups.

## Specialist help

It's 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're feeling so that they can support you. Talking about your feelings isn't always easy.



You can read some helpful tips about this in our booklet **Talking about your cancer**.

Often it's easier to talk to someone who's not directly involved with your illness. You can ask your hospital consultant or GP to refer you to a doctor or counsellor who is a specialist in the emotional problems of people with cancer and their relatives.

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.

'One thing that helped me was the Macmillan forum – from reading others' experiences, asking when I had questions, and leaning on people on a couple of occasions.'

**Greg**



# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

## Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

*'My Macmillan nurse, along with my family and friends, have really helped me get through some difficult times and have been a great support.'*

**PJ**

## Fear and anxiety

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

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.



## Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

## Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

## Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people going through the same thing on our online community at **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

## If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.



**Our booklet *How are you feeling? The emotional effects of cancer* discusses the feelings you may have in more detail, and has suggestions for coping with them.**

# If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's 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, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Lost for words – how to talk to someone with cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.



We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)



# Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

## Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website [riprap.org.uk](http://riprap.org.uk) which has been developed especially for teenagers who have a parent with cancer.



# WORK AND FINANCIAL SUPPORT

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# Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

## Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.



Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. There's also lots more information at [macmillan.org.uk/work](http://macmillan.org.uk/work)

# Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- **contributory** – you can get this if you have made enough national insurance contributions
- **income-related** – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

**Personal Independence Payment (PIP)** is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called **Disability Living Allowance (DLA)** in England, Scotland and Wales.

**Attendance Allowance (AA)** is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

## Help for carers

**Carers Allowance** is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

## More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Scotland and Wales) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 118) or Citizens Advice (see page 118). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Our booklet **Help with the cost of cancer** has more detailed information.

## Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 118–119.



Our booklets **Insurance** and **Getting travel insurance** may also be helpful.



SHARE OUR EXPERIENCES



GOOD DAY?



# FURTHER RESOURCES

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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 leaflets or booklets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

All of our information is also available online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

**org.uk/cancerinformation**

There you'll also find videos featuring real-life 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](https://www.macmillan.org.uk/otherformats)

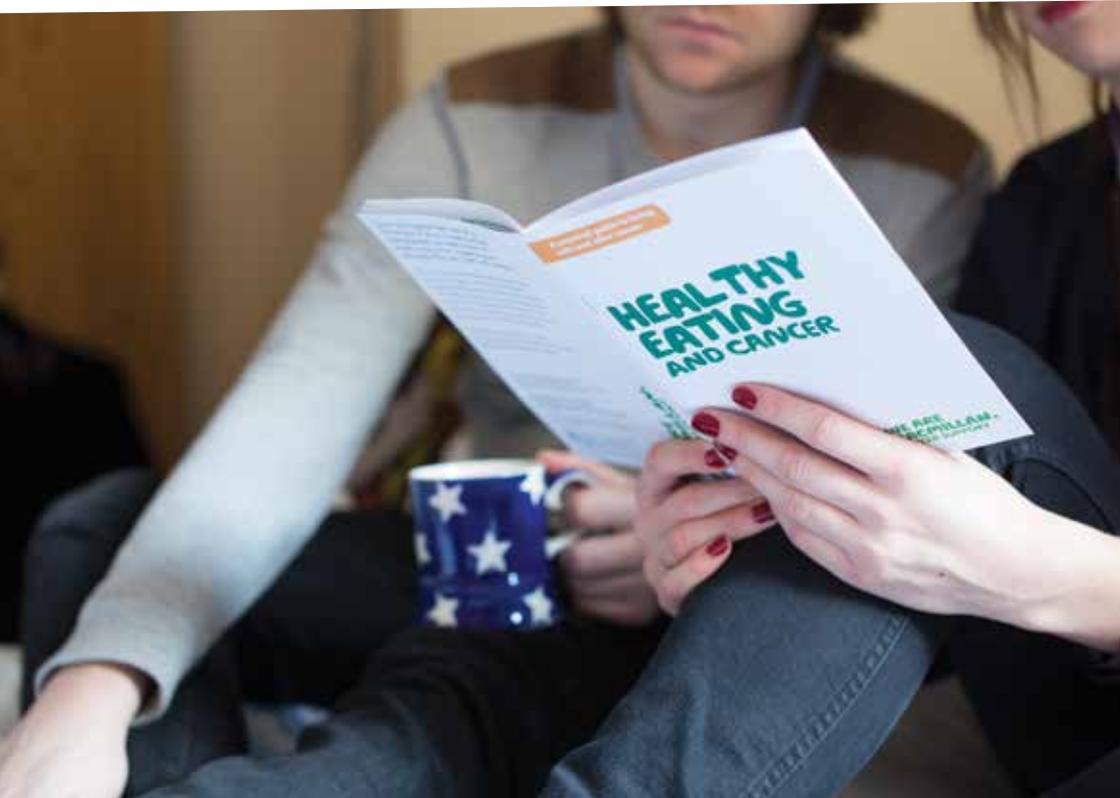
If you'd like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk) You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

## 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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

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

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres.

There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## 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's why we help to bring people together in their communities and online.

## Support groups

Whether you are someone living with cancer or a carer, 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](https://www.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](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

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.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

## Help with money worries

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

### Financial advice

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

### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### 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 a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're 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](https://www.macmillan.org.uk/work)



### Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

There are lots of other organisations that can give you information or support.

## **The College of Sexual and Relationship Therapists (COSRT)**

PO Box 13686,  
London SW20 9ZH  
Tel 020 8543 2707  
Email [info@cosrt.org.uk](mailto:info@cosrt.org.uk)

**[www.cosrt.org.uk](http://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**

St Bartholomew's Hospital,  
London EC1A 7BE

**Tel** 0203 465 5766  
(Mon–Fri, 9am–5.30pm)

### **Email**

[info@orchid-cancer.org.uk](mailto:info@orchid-cancer.org.uk)

**[www.orchid-cancer.org.uk](http://www.orchid-cancer.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**

Premier House, Carolina Court,  
Lakeside, Doncaster DN4 5RA

**Tel** 0300 100 1234

**[www.relate.org.uk](http://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)**

Suite 301, Emblem House,  
London Bridge Hospital,  
27 Tooley Street,  
London SE1 2PR  
**Helpline** 020 7486 7262  
(Mon, Wed, Fri, 9am–5pm)

**Email** info@  
sexualadviceassociation.co.uk

**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.

**General cancer and support organisations**

**Cancer Black Care**

79 Acton Lane,  
London NW10 8UT  
**Tel** 020 8961 4151

**Email**  
info@cancerblackcare.org.uk

**www.cancerblackcare.org.uk**

Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

**Cancer Support Scotland**

The Calman Centre,  
75 Shelley Road,  
Glasgow G12 0ZE

**Tel** 0800 652 4531

**Email** info@  
cancersupportscotland.org

**www.cancersupport  
scotland.org**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

**Irish Cancer Society**

43–45 Northumberland Road,  
Dublin 4, Ireland

**Helpline** 1800 200 700

(Mon–Thu, 9am–7pm,  
Fri, 9am–5pm)

**Email** helpline@irishcancer.ie  
**www.cancer.ie**

Operates Ireland's only freephone cancer helpline, which is staffed by qualified nurses trained in cancer care.

### **Maggie's Cancer Caring Centres**

1<sup>st</sup> Floor, One Waterloo Street,  
Glasgow G2 6AY

**Tel** 0300 123 1801

#### **Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Offers free, comprehensive support for anyone affected by cancer. You can access information, benefits advice, and emotional or psychological support.

### **Teenage Cancer Trust**

3<sup>rd</sup> Floor, 93 Newman Street,  
London W1T 3EZ

**Tel** 020 7612 0370

(Mon–Fri, 8.30am–5.30pm)

**[www.teenagecancertrust.org](http://www.teenagecancertrust.org)**

Builds cancer units for teenagers and young adults in hospitals, and organises support and information services for patients, their families, schools and health professionals.

### **Tenovus**

9<sup>th</sup> Floor, Gleider House,  
Ty Glas Road, Llanishen,  
Cardiff CF14 5BD

#### **Freephone helpline**

0808 808 1010

**Email** [post@tenovus.com](mailto:post@tenovus.com)

**[www.tenovus.com](http://www.tenovus.com)**

Provides a variety of services to people with cancer and their families, including counselling and a freephone cancer helpline.

### **Cancer Focus**

#### **Northern Ireland**

40–44 Eglantine Avenue,  
Belfast BT9 6DX

**Tel** 0800 783 3339

(Mon–Fri, 9am–1pm)

**Email** [hello@cancerfocusni.org](mailto:hello@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

## Financial or legal advice and information

### Benefit Enquiry Line Northern Ireland

Tel 0800 220 674

(Mon–Wed and Fri, 9am–5pm,  
Thu, 10am–5pm)

Textphone 0800 243 787

[www.nidirect.gov.uk/  
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

**England and Wales**  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

**Scotland**  
[www.cas.org.uk](http://www.cas.org.uk)

**Northern Ireland**  
[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)

You can also find advice online in a range of languages at [adviceguide.org.uk](http://adviceguide.org.uk)

### Civil Legal Advice

Tel 0845 345 43 45

(Mon–Fri, 9am–8pm,

Sat, 9am–12.30pm)

Minicom 0345 609 6677

[www.gov.uk/  
civil-legal-advice](http://www.gov.uk/civil-legal-advice)

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

### Department for Work and Pensions

#### Disability Benefits Helpline

08457 123 456

(Textphone 0845 722 4433)

#### Personal Independence Payment Helpline

0845 850 3322

(Textphone 0845 601 6677)

#### Carer's Allowance Unit

0845 608 432

(Textphone 0845 604 5312)

[www.gov.uk/  
browse/benefits](http://www.gov.uk/browse/benefits)

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

### **Personal Finance Society – ‘Find an Adviser’ service**

42–48 High Road,  
South Woodford,  
London E18 2JP

**Tel** 020 8530 0852

**www.findanadviser.org**

The UK’s largest professional body for independent financial advisers. Use the ‘Find an Adviser’ website to find qualified financial advisers in your area.

### **Turn2Us**

Hythe House,  
200 Shepherd’s Bush Road,  
London W6 7NL

**Helpline** 0808 802 2000  
(Mon–Fri, 8am–8pm)

**Email** [info@turn2us.org.uk](mailto:info@turn2us.org.uk)

**www.turn2us.org.uk**

Provides an online service to help people in financial need in the UK. Its website has information about the benefits and grants available from both statutory and voluntary organisations. You can often apply for support directly from the website.

### **Unbiased.co.uk**

**Email** [contact@unbiased.co.uk](mailto:contact@unbiased.co.uk)

**www.unbiased.co.uk**

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.

### **Counselling and emotional support**

#### **British Association for Counselling and Psychotherapy (BACP)**

BACP House,  
15 St John’s Business Park,  
Lutterworth,  
Leicestershire LE17 4HB

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

**www.bacp.co.uk**

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

## Samaritans

Freepost RSRB-KKBY-CYJK,  
Chris, PO Box 9090,  
Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** [jo@samaritans.org](mailto: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.

## Support for young people

### Youth Access

1–2 Taylors Yard,  
67 Alderbrook Road,  
London SW12 8AD

**Tel** 020 8772 9900

(Mon–Fri, 9.30am–1pm  
and 2–5.30pm)

### Email

[admin@youthaccess.org.uk](mailto:admin@youthaccess.org.uk)

**www.youthaccess.org.uk**

A national organisation providing counselling and information for young people. Support is given through local young people's services. Find your local service via the website.



You can search for more organisations on our website at [macmillan.org.uk/organisations](http://macmillan.org.uk/organisations), or call us on 0808 808 00 00.



## 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 photographs 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 Jim Barber, Consultant Clinical Oncologist.

With thanks to: Dr Vijay Agarwal, Medical Oncologist; Lesley Cooper, Renal and Testicular Clinical Nurse Specialist; Professor Alan Horwich, Consultant Clinical Oncologist; and Mr Roger Kockelbergh, Consultant Urological Surgeon. Thanks also to the people affected by cancer who reviewed this booklet, and those who shared their stories.

## Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at [bookletfeedback@macmillan.org.uk](mailto:bookletfeedback@macmillan.org.uk)

American Cancer Society. *Treatment options for testicular cancer, by type and stage*. [www.cancer.org/cancer/testicularcancer/detailedguide/testicular-cancer-treating-by-stage](http://www.cancer.org/cancer/testicularcancer/detailedguide/testicular-cancer-treating-by-stage) (accessed 4 June 2015).

European Association of Urology. *Guidelines on testicular cancer*. 2015.

European Society for Medical Oncology (ESMO). *Testicular seminoma and non-seminoma: ESMO Clinical Practice Guidelines*. 2013.

Medscape. *Nonseminoma testicular cancer treatment protocols*.

[www.emedicine.medscape.com/article/2006613-overview](http://www.emedicine.medscape.com/article/2006613-overview) (accessed 4 May 15).

Scottish Intercollegiate Guidelines SIGN. 124. *Management of adult testicular germ cell tumours*. 2011.

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



## **Share your cancer experience**

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

## **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.

## **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?

## **Raise money**

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

## **Give money**

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

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## 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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Issue no

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Security number

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Signature

Date / /

## Don't 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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit [macmillan.org.uk](http://macmillan.org.uk)

Hard of hearing? Use textphone

0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.

Braille and large print versions on request.

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