UNDERSTANDING TESTICULAR CANCER
My Macmillan nurse Paul helped me get through some difficult times, and has been a great support along with my family and friends.

PJ, diagnosed with testicular cancer
About this booklet

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

The booklet explains:
• what testicular cancer is
• the symptoms of testicular cancer
• how it is diagnosed
• the different treatments and possible side effects
• ways to cope with a diagnosis of testicular cancer.

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

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

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

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

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

How to use this booklet

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

You may want to skip parts of the booklet. You can always come back to them when you feel ready.

We have included quotes from people who have had testicular cancer, which you may find helpful. This includes PJ, who is on the cover of this booklet. Some quotes are from people who have chosen to share their story with us through the Macmillan Online Community (macmillan.org.uk/community). There are also some quotes from Healthtalk.org. Some names have been changed.
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# The Testicles and Testicular Cancer

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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.
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. 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 are two oval-shaped organs in the scrotum. The scrotum is a bag of wrinkly skin at the base of the penis. The testicles hang below the penis (see page 10). They are sometimes called the testes. They are the main part of the male reproductive system. Testicles produce sperm. Sperm can fertilise a female egg to make a baby.

The structure of the testicle
Sperm travel from the collecting tubules inside the testicle to a coiled tube called the epididymis (see opposite page). This feels like a soft swelling at the back of the testicle. The epididymis widens and becomes the vas deferens, which is part of the spermatic cord. This then joins a shorter tube, called the ejaculatory duct. The ejaculatory duct connects to the urethra. This is the tube that goes from the bladder to the end of the penis.

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

- Spine
- Rectum (back passage)
- Seminal vesicle
- Prostate gland
- Bladder
- Ejaculatory duct
- Urethra
- Penis
- Testicle
- Scrotum
The testicles also make the hormone **testosterone**. Hormones are chemical messengers that help control different functions 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 2,300 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. Testicular cancer is usually curable.

Like other cancers, it is not infectious and you cannot pass it 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 protect us from infection and disease. It also drains lymph fluid from the tissues of the body, before returning it to the blood. The lymphatic system is made of fine tubes called lymphatic vessels. These lymphatic vessels connect to groups of lymph nodes throughout the body.

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

The lymphatic vessels carry a fluid called lymph, which has 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 are just behind your bowel and in front of your spine. Sometimes, cancer cells from the testicles can spread to these nodes. You will have a CT scan to check whether any of these nodes are larger than normal.
The retroperitoneal and pelvic lymph nodes

- Right kidney
- Left kidney
- Bladder
- Lymph nodes
Risk factors and causes

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

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

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

Undescended 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 1 year old. In some boys, the testicle does not drop down. They usually have surgery to bring the testicle down into the scrotum. Men who had an undescended testicle as a child have a higher chance of getting testicular cancer. The risk may be higher if they did not have surgery. Surgery is usually done before the age of 2.

Having surgery to bring down the testicle means men can regularly check their testicles (see pages 20 to 21) and notice any changes early.
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 partly due to changes in certain genes. Research continues to look at what genes may increase the risk.

Carcinoma in situ (CIS)

This is when there are abnormal cells in the testicle that can develop into testicular cancer if they are not removed. CIS is sometimes found when men have a biopsy of the testicle. For example, they may have a biopsy to investigate infertility (being unable to have children). Treatment for CIS may include surveillance, radiotherapy or surgery. It depends on what certain blood tests show. Removing one testicle will not affect your sex life, if your other testicle is healthy. You will still be able to get an erection and have children.

‘My left testicle was undescended at birth. I had an operation to bring it down. It was always slightly different, so having a lump was nothing new. I had an ultrasound and surgery was advised.’

Tom
Cancer in the other testicle

A small number of men who have had treatment for testicular cancer will develop cancer in the other testicle.

Ethnicity

Testicular cancer is more common in white men than in African-Caribbean or Asian men.

Height

Men who are taller than average may have a higher risk of testicular cancer, but it is not clear why.

Human immunodeficiency virus (HIV)

Men who are HIV positive have an increased risk of developing testicular cancer. There is an especially increased risk of a type of testicular cancer called seminoma (see page 32).

Factors that do not increase the risk

There is 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 – this is usually painless, but can sometimes suddenly get bigger and become painful

• a dull ache or pain, or heaviness in the scrotum (see page 8).

The cancer can spread to the lymph nodes or other parts of the body. If this happens, symptoms may include:

• pain in the back or lower abdomen

• weight loss

• a cough

• breathlessness

• feeling unwell

• a lump in the neck.

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

Rarely, hormones that the cancer makes can cause nipple or breast tenderness. They can also cause breast swelling, which is called gynaecomastia.

It is usually possible to cure testicular cancer, even if it has spread when diagnosed.
Testicular self-examination

It is easier to treat testicular cancer when it is diagnosed early. So from puberty onwards, it is important for men check their testicles regularly. Doing this regularly means you will soon get to know what feels normal for you. A normal testicle should feel smooth and firm, but not hard.

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

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

It is normal for the testicles to be slightly different in size. It is also normal for one to hang lower than the other.
The epididymis (tube that carries sperm) is behind the top of each testicle (see page 8). It feels like a soft, coiled tube. It is common to get harmless cysts or benign lumps in the epididymis. Treatment for these may vary. Other conditions can cause lumps or swellings, and most lumps are not cancer (non-cancerous). But it is important you get your doctor to check anything unusual as soon as possible.

Doctors are used to dealing with problems like this. If you feel embarrassed about seeing your GP, you can go to your local sexual health clinic. You can find your nearest clinic on the NHS Choices website (see page 148). Or you can look in the health section of your local phone book.

Remember that testicular cancer is usually curable, especially when you find and treat it early.

‘I’ve always self-examined to check my testicles for cancer. I found a lump on my testicle. I had never felt anything like it before. I made an appointment the following day.’

Michael
DIAGNOSING TESTICULAR CANCER

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How testicular cancer is diagnosed

Usually, you begin by seeing your doctor (GP), who will examine you. If your GP thinks you may have testicular cancer, they will refer you to a hospital specialist for tests. Sometimes, your GP will ask for an ultrasound scan of the testicle.

The hospital specialist is usually a urologist. This is a doctor who has experience in treating testicular, penile, prostate, bladder and kidney problems. They will examine you and ask you about your general health. They will also ask about any previous health problems you have had. You will have an ultrasound scan of the scrotum and the testicles, and blood tests. You may also have a chest x-ray or a CT scan (see pages 36 to 37). This is to check that your lungs are not affected and are healthy.

Sometimes, men are diagnosed with testicular cancer that has spread when they have other tests for symptoms they have. These tests may include a CT scan or MRI scan.
Ultrasound

This scan can help doctors find out whether a lump is cancer. A lump may be due to other causes instead. For example, a cyst (harmless lump filled with fluid) could be causing the symptoms.

An ultrasound is a painless test, and only takes a few minutes.

Once you are in a comfortable position, a gel is spread onto your scrotum and testes. A small, handheld device like a microphone is then passed over this area. This produces soundwaves that a computer turns into pictures. These show the inside of the testicles and structures near them.

Blood tests

Your doctor will also take some blood from you for testing. These blood tests will show if you have raised levels of certain chemicals in the blood, called tumour markers (see pages 34 to 35). Some testicular cancers make these chemicals and release them into the blood. You may still have testicular cancer even if these chemicals are not raised in the blood. You will also have other blood tests to check your general health.

‘The ultrasound is not uncomfortable at all. I could actually see the screen, and even I could see that there was a difference in the two testes.’

Tim
After your tests

The only way to get a definite diagnosis of testicular cancer 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 cancer spreading. You will only have the testicle removed if the ultrasound shows that the lump is highly likely to be cancer.

But occasionally, the surgeon will remove only part of the testicle. For example, this may happen if you only have one testicle. Or it may happen if the scan does not show clearly how likely it is to be cancer.

A doctor called a pathologist will examine the area removed, to see if there are cancer cells.

It is natural to be worried about having this operation. Your specialist will explain why you need it and will talk about it with you. They may also refer you to a specialist nurse who can give you information and support. If your other testicle is healthy, removing one testicle will not affect your sex life. It will not affect your ability to have an erection or have children. You will be able to return to your normal sex life once you have recovered from the operation.
If you are gay, bisexual or transgender

Sometimes, people may find their doctor or nurse assumes they are heterosexual. Or their doctor may not be aware that they are transgender. You may choose to let your doctor or nurse know about your sexuality, or the gender you identify with. If you are transgender, letting them know may make it easier when you have a physical examination. If you are gay or bisexual, and have a partner, it can make it easier for them to come to appointments with you. And having your relationship recognised can make you both feel more supported.

Removing the testicle (orchidectomy)

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

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

During the operation, the surgeon can put an artificial testicle into your scrotum. This is called a testicular implant or prosthesis. If you are unsure about whether you want this, you can have a prosthesis put in another time. Your specialist will give you more details about the benefits and disadvantages of having an artificial testicle. They can explain how it will look and feel.
Before your operation
If you smoke, try to give up or reduce how much you smoke before your operation. This will help lower your risk of chest problems, such as a chest infection. It will also help your wound heal after the operation. Your GP can give you advice, and you may find it helpful to read our booklet *Giving up smoking* (see page 140).

Before you have your operation, you will meet a member of the surgical team and a specialist nurse. They will discuss the operation with you and you will have a pre-assessment. This is to assess your general health. You may need to have some blood tests and an ECG (a recording of your heart). Make sure you ask any questions, or talk over any concerns you have about the operation.

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

If your doctor thinks the operation may affect your fertility, they may ask if you want to store sperm beforehand (see pages 102 to 103).

The operation
You will have the operation under general anaesthetic. The surgeon will make a small cut (incision) into the groin on the affected side. They will then push the testicle up from the scrotum, and remove it through the incision.
After the operation
When you have recovered from the effects of anaesthetic you will be able to eat and drink. The hospital staff will encourage you to get up and start walking around as soon as possible. As soon as you feel well enough and your doctor has checked you over, you can go home. This 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 once you are home.

You may have some discomfort, bruising and slight swelling around the scar for a couple of weeks. But you can usually control any discomfort with painkillers. Wearing supportive underwear and loose trousers might help you feel more comfortable. The hospital may give you a temporary scrotal support to wear if you feel very uncomfortable.

You may have numbness around the area, but usually this will gradually improve. 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 are usually removed about 5 to 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 need to take off work will depend on the type of work you do.
Sex

You can return to a 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 are in some discomfort and feel anxious. Some men are concerned about their appearance after they have had a testicle removed. For most men, any negative feelings gradually get better. But you can talk to your doctor or nurse if difficult feelings or problems with your sex life continue. They can suggest sources of help and support. There are organisations that might also be able to help (see pages 145 to 151).

Fertility (being able to father children)

You may be worried that the cancer will affect your ability to father a child. You will still be able to have children after an orchidectomy, if your other testicle is healthy. However, some men may have fertility problems. Or the other testicle may be small and may be making less sperm. In this case, men will usually have the option of sperm banking before their operation, if it does not delay treatment too much. Sperm banking means freezing some of your sperm. This is so you can use it in the future to help you and your partner have a child. You may want to do this, even if you are not in a relationship at the moment. Your cancer doctor or specialist nurse can talk to you about this before your treatment starts. If your other testicle is healthy, you may not be offered sperm banking.

We have more information about sperm banking (see pages 102 to 103).
Types of testicular cancer

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

Germ cell tumours

Most testicular cancers develop from germ cells in the testicles, so they are also called germ cell tumours (GCTs). In men, germ cells produce sperm. The term testicular cancer is for all types of testicular tumour.

There are two main types of testicular germ cell cancer, seminomas and non-seminomas.

Seminoma
Seminomas usually happen in men aged 15 to 55. About 40 to 45 in 100 (40 to 45%) of men with testicular cancer have a seminoma.

‘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.’

PJ
Non-seminoma
Non-seminomas most often affect men aged 15 to 35. They happen in about 40 to 45 in 100 (40 to 45%) of men with testicular cancer.

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

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

Sometimes, non-seminomas can be combined with seminomas.

Rarer types
Sometimes, the cancer found in the testicle is not a germ cell tumour, but another type of cancer. These include a type of cancer called non-Hodgkin lymphoma. Other rare types are Leydig cell tumours and Sertoli cell tumours.

We have more information about non-Hodgkin lymphoma in our booklet Understanding non-Hodgkin lymphoma and on our website (see page 140).

To find out more about these rarer types of testicular cancer and their treatment, contact our cancer support specialists (see page 142).
Tumour markers

Some testicular cancers make chemicals or proteins called tumour markers. These are released into the blood. Doctors can measure them with simple blood tests.

Not all men with testicular cancer have raised markers. Most non-seminomas and some seminomas (see pages 32 to 33) have raised levels of tumour markers. You will get used to having regular blood tests to check the levels of your tumour markers. Even if you do not have raised levels of tumour markers before your operation, you may still have them checked afterwards.

There are three main tumour markers:

- **Alpha-fetoprotein (AFP)** – can be raised in non-seminomas but not in seminomas.

- **Human chorionic gonadotrophin (HCG)** – can be raised in non-seminomas and sometimes in seminomas.

- **Lactic dehydrogenase (LDH)** – can be raised in both seminomas and non-seminomas.
Tumour markers can be used to:
• diagnose testicular cancer
• monitor you after surgery
• check how you are responding to treatment
• check that the cancer has not come back.

Doctors will measure tumour markers before your operation and usually a week after it. If the tumour markers fall quickly after the operation, it can be a good sign that all the cancer has been removed. This helps the doctors plan your treatment.
Further tests

Once you have a definite diagnosis, 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 the best treatment for you.

Sometimes, men who are having scans to investigate their symptoms are diagnosed with a testicular cancer that has spread. If testicular cancer has spread when it is diagnosed, it is still usually possible to cure it.

Blood tests

As well as blood tests to measure tumour markers, you may have other blood tests to check how your liver and kidneys are working.

CT scan

You may have this scan 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 to 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 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 is 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 will 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 145 to 151, can also provide support. You can also talk things over with one of our cancer support specialists (see page 142).

‘You can feel isolated and slightly cut off from everybody else who is just carrying on normal life. And you’ve got this thing hanging over you. Every emotion seems to run at the same time.’

Antony
Staging

The stage of a cancer is a term used to describe:
• its size
• whether it has spread beyond its original site.

Knowing this 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. We have given a simple version of the system here.

Stage 1

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

Stage 1 cancers are divided further into different groups depending on whether tumour markers stay raised after surgery.
Stage 2

The cancer has spread to local lymph nodes in the tummy (abdomen), called the retroperitoneal lymph nodes (see pages 12 to 13). Stage 2 cancers are divided further into different groups depending on:

- the size of the tumour
- the lymph nodes affected
- the level of tumour markers.

Stage 3

The cancer has spread to lymph nodes in the chest, or higher up. For example, these could be lymph nodes in your armpit or neck.

Stage 3 cancers are divided further into different groups depending on:

- the size of the tumour
- the lymph nodes affected
- the level of tumour markers.

Stage 4

The cancer has spread to other parts of the body, such as the liver or lungs. When the cancer spreads, it is known as metastasis.

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

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

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at [macmillan.org.uk/cancerregistry](http://macmillan.org.uk/cancerregistry)
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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 is a non-seminoma or seminoma (see pages 32 to 33).

After surgery to diagnose the cancer and remove the testicle (orchidectomy) – see page 27, your doctor will talk to you about surveillance. Surveillance is the option of monitoring you regularly in clinic. Or they may suggest you have further treatment. This will depend on the type of testicular cancer you have and the risk of it coming back. If testicular cancer comes back, it can usually still be successfully treated.

Your doctor will talk you through the benefits and disadvantages of the treatment (see pages 56 to 57), and what might be best for your situation.
Treating stage 1 testicular cancer

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

**Surgery**
Surgery to remove the testicle (orchidectomy) may be the only treatment that some men need.

**Surveillance**
After surgery, your doctor will ask you to go to the clinic regularly for an examination. They will also measure your tumour markers, and you will have other tests. This is called surveillance (see pages 58 to 59). If the cancer comes back, the results from the scans and blood tests will help doctors find it early. Treatment can still usually cure the cancer.

Going to your surveillance appointments is important. If you move house, make sure the hospital knows your new address. It is also important to tell your specialist if you get any new symptoms or feel unwell between appointments. You can arrange an earlier clinic appointment if you need to.
As a family we knew this was what he wanted and we all agreed to rally around to help Joyce cope with his care.

Adrienne

Having chemotherapy
**Adjuvant treatment**
Your doctor may offer you chemotherapy treatment. This is known as adjuvant treatment (see page 63). You have it to reduce the risk of the cancer coming back.

Your doctor will explain why they have suggested adjuvant treatment. Some men may decide not to have treatment, and to have surveillance instead. They may want to avoid treatment that might not be necessary.

Sometimes, men who have the option of surveillance may have chemotherapy treatment instead. Talk about the treatments with your doctor. Make sure you have enough information to help you make your decision.

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

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

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

- the size of the tumour
- how it looks under a microscope
- the tumour marker levels (if present).
Non-seminoma stage 1
If you have a stage 1 non-seminoma, your doctor may suggest you have surveillance if there is a low risk of the cancer coming back. After a few years, if scans show no signs of the cancer coming back, you may only need regular blood tests.

You may also be offered the option of adjuvant treatment. The chemotherapy drugs usually used for non-seminomomal testicular cancer are bleomycin, etoposide and cisplatin. This combination of chemotherapy drugs is also called BEP chemotherapy. You may have one or two sessions. You can find more information about BEP on our website (see page 140).

Doctors will offer treatment depending on:
- how the cancer looks under a microscope
- if it has spread to nearby blood vessels
- the size of the tumour
- the tumour marker levels (if present).

Rarely, your doctor may suggest further surgery to remove some of the lymph nodes at the back of the abdomen (see page 61). These are called retroperitoneal lymph nodes.
Treating stages 2 to 4 testicular cancer

If the cancer has spread outside your testicle (see page 39), you will have chemotherapy or occasionally radiotherapy after your orchidectomy. This will depend on the type of cancer. Treatment can also depend on the stage of the cancer. Your doctors will talk to you about the treatment they feel is best for you.

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

• After chemotherapy, some men with a non-seminoma may need surgery to remove the retroperitoneal lymph nodes (see pages 83 to 92), if they are enlarged.

• If you have a seminoma that has spread, your doctor may offer you treatment with radiotherapy (see pages 78 to 82). Or they may offer you 3 or 4 courses of chemotherapy (see pages 62 to 77). Your doctor will talk with you about the treatment they think is best.
If testicular cancer comes back

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

Treatment and fertility

Treatments for testicular cancer can sometimes affect your ability to father a child. If you need treatment after having an orchidectomy, doctors may advise you to store your sperm (sperm banking) – see pages 102 to 103. You may have done this already before having an orchidectomy.
How treatment is planned

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

- a surgeon
- a medical oncologist (a doctor who specialises in treating cancer with chemotherapy)
- a clinical oncologist (a doctor who specialises in treating cancer with radiotherapy and chemotherapy)
- a radiologist (a doctor who specialises in reading scans and x-rays)
- a pathologist (a doctor who specialises in looking at cells under a microscope and diagnosing the cell type)
- a nurse specialist (a nurse who gives you information and support during treatment).

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

The MDT will look at several factors when advising you on the best course of treatment. These may include your general health, the type and size of the tumour, and whether it has begun to spread.
Your doctors may ask you to choose what you want to do. They may ask whether you want to have adjuvant treatment or surveillance. Sometimes people find it hard to make a decision like this. Your doctor will provide you with as much information as possible, including the risk of the tumour coming back. 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 do not understand or feel worried about. It may help to discuss the benefits and disadvantages of each option with your cancer specialist or nurse specialist. Or you can contact our cancer support specialists (see page 142).

It often helps to make a list of questions, and to take a relative or close friend with you. You can write down your questions and the answers you get.

You may find it helpful to read our booklet *Making treatment decisions* (see page 140).
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 straight away, 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 is 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 anxious at the idea of having cancer treatments, because of the side effects that can happen. Your doctor and nurse will talk to you about ways of coping with different side effects. Many of the side effects get better on their own, and some can be controlled with medicines.

In men with early testicular cancer, surgery alone may cure the cancer. Often, you have adjuvant chemotherapy to reduce the risk of the cancer coming back. You may be worried about having adjuvant treatment, because it is treatment you may not need and has side effects. Or you may prefer to have any treatment that reduces the risk of the cancer coming back. It is 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 is usually still possible to cure it in most men. It is also usually still possible to cure testicular cancer that has spread outside the testicle. Even if it is very advanced or comes back after initial treatment, you may have intensive chemotherapy with the aim of curing the cancer.
Rarely, very advanced testicular cancer may not respond well to treatment. Or it may continue to come back despite treatment. In this case, you can have treatment to help control the cancer, and improve symptoms and quality of life. Occasionally, the treatment may not control the cancer or improve symptoms. This means you would have side effects without the benefit of treatment. In this case, you may decide not to continue the treatment.

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

If the risk of your cancer coming back after surgery is low, your doctor may recommend surveillance. This is when the doctor regularly monitors you for signs of the cancer coming back. Surveillance aims to find and treat any signs of cancer early, when it is easier to cure. This means you avoid having adjuvant treatment (see page 63), which you may not need. You only have treatment if your tumour marker levels increase, or if scans show the cancer has come back.

It is extremely important to go to your surveillance appointments. Testicular cancer only comes back in a small number of men. If it does come back, finding it early means there is still a high chance of curing it. 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 will have. They will check your tumour markers regularly. You may also have regular chest x-rays and occasional CT scans (see pages 36 to 37). Your specialist will also do a physical examination and check your other testicle. They will ask you how you have been feeling, and about any new symptoms.

Over time, as the risk of the cancer coming back gets lower, you will have appointments and tests less often. Always tell your doctor if you are having problems with new or ongoing symptoms. Also tell them if you are having emotional or sexual difficulties. This helps them assess you properly and give you the best care and support. It is also an important way of being involved in your own healthcare. It is common to feel a range of emotions after a diagnosis of testicular cancer (see pages 120 to 124).
Surgery

Removing the testicle (orchidectomy) helps your doctor make the diagnosis. This is usually the first treatment for testicular cancer. If the cancer is only in the testicle (stage 1) – see page 38, this operation may be the only treatment you need.

We explain what to expect when you are having an orchidectomy in our section on diagnosis (see pages 24 to 41).
Removing retroperitoneal lymph nodes

The retroperitoneal lymph nodes (see page 13) are the ones at the back of your tummy (abdomen). Some men need further surgery after having chemotherapy. Sometimes, a CT scan shows the lymph nodes at the back of the tummy have enlarged (grown longer than 1cm). They may have shrunk after chemotherapy, but are still bigger than they should be. This might mean the lymph nodes have cells inside that could become cancerous in the future. Surgery to remove them is the only way of knowing for sure.

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

We have more information about removing the retroperitoneal lymph nodes. The operation is called a retroperitoneal lymph node dissection (RPLND) – see pages 83 to 92.

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. Experienced surgeons do these operations in specialist units. If you need this type of operation, your doctor will talk to you about it.
Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs travel around the bloodstream, reaching 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. You may have other combinations depending on the stage and type of the cancer, or if it has come back after treatment.

You may have chemotherapy:

• after surgery, to reduce the risk of testicular cancer coming back (adjuvant chemotherapy)

• to treat testicular cancer that has spread outside the testicle, or come back after an orchidectomy (see page 27)

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

We have more detailed information about chemotherapy in our booklet Understanding chemotherapy (see page 140).
Adjuvant chemotherapy

If you have an early (stage 1) non-seminoma, you may have 1 to 2 cycles of BEP. Each cycle is three weeks.

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

We have more information about BEP, carboplatin and other chemotherapy drugs on our website (see page 140).

‘I really struggled with the treatment decision, but I wanted to do everything to reduce my odds when I could. Remember – there is no wrong answer! Do what you feel comfortable with.’

Liam
If the cancer has spread or comes back during surveillance

If testicular cancer spreads outside the testicle, or comes back during surveillance (see pages 58 to 59), you may have 3 or 4 cycles of BEP. Sometimes, bleomycin is left out and you have 4 cycles of EP (etoposide and cisplatin) instead. Bleomycin may cause breathing problems in men who smoke, or who already have a lung condition (see page 73).

If BEP does not get rid of the cancer completely, or the cancer comes back again, you will usually have more intensive chemotherapy. Depending on the stage of the cancer, some men have more intensive chemotherapy straight away.

Some drug combinations are:

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

Occasionally, high-dose chemotherapy with stem cell support (see page 93) is used. This may be given as part of a clinical trial (see pages 90 to 91).
How chemotherapy is given

You usually have chemotherapy drugs as an outpatient. The chemotherapy drugs are given into a vein as an injection or 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 3 weeks. If you are having BEP, you will usually spend 3 to 5 days going to hospital as an outpatient. Sometimes you will stay overnight.

This is followed by weekly outpatient visits to have the rest of your treatment. Other combinations of chemotherapy drugs might mean you spend more time in hospital and have the drugs more often. Your doctor or nurse will tell you how many cycles of treatment they have planned for you. They will also explain how you will have the chemotherapy.
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
This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

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

Symptoms of an infection include:
• feeling shivery
• a sore throat
• a cough
• diarrhoea
• needing to pass urine often.

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

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time.
Anaemia (low number of red blood cells)
This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Bruising and bleeding
This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

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

Rob
Feeling sick
You may feel sick in the first few days after treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Feeling tired
Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.
Sore mouth
You may get a sore mouth or mouth ulcers. This can make you more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

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

Loss of appetite
This treatment can affect your appetite. Do not worry if you don’t eat much for a day or two. But if your appetite does not come back after a few days, tell your nurse or dietitian. They will give you advice. They may give you food or drink supplements.
As a family we knew this was what he wanted and we all agreed to rally around to help Joyce cope with his care.

Adrienne

Having a CT scan
Hair loss

It is common to lose your hair with chemotherapy treatments like BEP. Carboplatin, which is used to treat seminoma, does not normally cause hair loss. Your hair will usually start to fall out 3 to 4 weeks after starting treatment, although it may happen earlier. In most cases hair 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 treatment has finished. Your hair will be very fine at first, and may be a different colour or texture than before. You will probably have a full head of hair after 3 to 6 months.

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

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

You may find our booklet *Coping with hair loss* useful (see page 140).
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.

You may have tests to check your lungs before and during treatment. Tell your doctor if you develop:

• a cough
• wheezing
• a fever (high temperature)
• breathlessness.

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

After treatment with bleomycin, breathing in higher doses of oxygen for several hours can cause lung problems. If you ever need a general anaesthetic or oxygen therapy, always tell the doctor that you have had bleomycin.

Scuba diving is not recommended after treatment with bleomycin.

‘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
Changes to your hearing
Cisplatin may affect your hearing. You may have ringing in the ears (tinnitus). Or you may lose the ability to hear some high-pitched sounds. Very occasionally, it may affect your sense of balance. Any hearing loss or changes to your balance 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 and arrange hearing tests if necessary.

Numbness or tingling in the hands or feet
Cisplatin affects the nerves, which can cause numb, tingling or painful hands or feet. This is called peripheral neuropathy. You may find it hard to fasten buttons or do other fiddly tasks. We have more information about this on our website (see page 140).

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

Changes in how your kidneys work
Cisplatin can affect how your kidneys work. You will have blood tests before and during treatment to check this.

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

If you pass less urine than usual, tell your nurse.
Blood clot risk
Cancer and some cancer treatments can increase the risk of a blood clot. Symptoms of a blood clot include:

• pain, redness or swelling in a leg or arm
• breathlessness
• chest pain.

If you have any of these symptoms, contact a doctor straight away.

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

Sex and protecting your partner

If you have sex in the first couple of days of having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in your semen.

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

Chemotherapy for men with testicular cancer often causes infertility during treatment and for a time after. This is usually temporary, and most men will recover their fertility after treatment. But your doctor will advise you to consider storing sperm before having treatment (see pages 102 to 103). How quickly your sperm count recovers varies from person to person. It generally starts to recover after about 18 to 24 months following treatment. But it can take up to 5 years to recover.

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.

Men having high-dose chemotherapy have a much risk of infertility and infertility is often permanent. If you are concerned about this, you can talk to specialist.
Preventing pregnancy

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

It is usually best to use a ‘barrier’ method of contraception, such as a condom, while you are having treatment. It is also important to continue using effective contraception for about a year after chemotherapy. This allows time for your sperm to recover from any damage that treatment may have caused. You can talk to your cancer doctor or nurse about this.
Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. You may have radiotherapy to treat seminomas and, more rarely, non-seminomas.

If you have a stage 2 seminoma (see page 39), you may have radiotherapy instead of chemotherapy or with chemotherapy. This aims to reduce the small risk of the cancer returning in the lymph nodes at the back of the abdomen.

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

A course of radiotherapy for seminoma may last 2 to 3 weeks. You usually have treatment as an outpatient.

Radiotherapy does not make you radioactive. It is safe for you to be with other people, including children, throughout your treatment.
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 will be alone in the room, but you can talk to the radiographer who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.
Side effects

Radiotherapy to your tummy (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 disappear gradually once your course of treatment has finished.

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

Skin changes
The skin in the treated area may become red (if you have white skin) or darker (if you have black or brown skin). But this will improve after your treatment finishes. You will get advice on looking after your skin. Your specialist can prescribe cream if your skin is sore or 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. They will probably advise you to take these medicines regularly during treatment. Let your doctor know if the tablets are not working for you. There are other medicines they can prescribe.
**Tiredness**
Radiotherapy often makes people feel tired, especially towards the end of treatment. Try to pace yourself, and avoid doing anything that you do not really need to do. Gentle exercise, such as short walks, can help to improve tiredness. It is good to balance this with plenty of rest.

Sometimes, tiredness can last up to 8 weeks or longer after treatment finishes. Your energy levels will then slowly improve.

We have more information about tiredness in our booklet *Coping with fatigue* (see page 140).

**Diarrhoea**
You might get some diarrhoea, but you can usually control this with medicines your doctor can prescribe. Let your doctor know if this is a problem. Make sure you drink plenty of fluids. Try to eat fewer high-fibre foods, such as fruit, vegetables, beans, pulses and wholewheat cereals.
Effects on fertility

Radiotherapy to the lymph nodes in the tummy will not affect your ability to have sex. It does not usually cause infertility. But your specialist may advise you to think about storing sperm before treatment starts (see pages 102 to 103).

Preventing pregnancy

During radiotherapy, a small dose of radiation reaches the remaining testicle. This may temporarily affect your sperm. So you will be advised to use effective contraception during treatment. There is no evidence that radiotherapy has any effect on children you have after treatment. But you are usually advised to use contraception for 6 to 12 months after treatment. This allows time for your sperm to recover from any damage that treatment may have caused.

You can talk to your doctor or specialist nurse about this.
Retroperitoneal lymph node dissection (RPLND)

This is an operation to remove the lymph nodes at the back of the tummy (abdomen) – see page 12. You may have this when testicular cancer has spread to these lymph nodes. It is a major operation that is only done by experienced surgeons in specialist centres. Your surgeon and specialist nurse will explain what is involved, and the possible complications and side effects.

The operation is done under a general anaesthetic. The surgeon makes a long cut from the top of your tummy (near your breastbone) to below your belly button. The lymph nodes are in front of the spine. This means your surgeon has to move your bowel and other organs aside to reach them. Sometimes, surgeons can do this operation using keyhole surgery. This can be quicker to recover from. But not many hospitals offer it.
Before your operation

If you smoke, try to give up or smoke less before your operation. This will help reduce your risk of chest problems, such as a chest infection. It will also help your wound to heal after the operation. Your GP can give you advice. You may also find it helpful to read our information about giving up smoking (see page 140).

You will 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 are admitted for your operation. It is important to tell the anaesthetist if you have had bleomycin chemotherapy as a treatment.

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

You may have tests before the operation, such as:

- a chest x-ray
- blood tests
- a urine test
- an ECG (a recording of your heart).
You will usually be admitted to hospital on the morning of the operation. You will then meet members of the surgical team and nursing team. You will also meet the doctor who will give you your anaesthetic (the anaesthetist). They will be able to answer any questions you have about the anaesthetic and about pain control after the operation.

You may need to wear elastic stockings (TED stockings) during and after the operation. These are to reduce the risk of developing blood clots in your legs.
After your operation

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

You will have fluids directly into a vein by an infusion (drip) until you can eat and drink normally. You will have a tube draining your bladder (catheter) attached to a bag to collect urine. This will be removed once you are able to sit or stand to pass urine normally. You may have drainage tubes from your wound to stop excess fluid collecting and help the wound heal. You will only need the tubes for a short time. They will usually be taken out before you go home.

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

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

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

**Immediate complications of surgery**

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

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

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

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

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. This means that if any occur, they can treat them straight away.

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

Effects on fertility (fathering a child)
Another common side effect of this operation is dry ejaculation. You will still be able to ejaculate, but your semen will go into your bladder. The semen will then leave your body harmlessly when you next pass urine (pee). This is known as retrograde ejaculation or dry climax. It means you cannot conceive (fertilise a female egg to make a baby) in the normal way. The operation should not physically affect you getting an erection or having an orgasm.

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

Your doctor will advise you to store sperm before the operation (see pages 102 to 103).
Keyhole surgery (laparoscopic or robotic retroperitoneal lymph node dissection)

Men who have not previously had chemotherapy may have the option of keyhole surgery to remove the retroperitoneal lymph nodes. This means you will have several small cuts rather than one longer one. Keyhole surgery is very specialised, and only experienced surgeons should do it. There are only a few hospitals that can offer this type of surgery.
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 is 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 do not 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.

If you would like more information, you may find our booklet Understanding cancer research trials (clinical trials) helpful – see page 140.

Current research

Although current treatments for testicular cancer are very effective, different trials are looking at ways to improve them. Your doctors will be able to tell you about any trials that may be suitable for you.
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.
High-dose chemotherapy with stem cell support

High-dose chemotherapy with stem cell support allows you to have higher than usual doses of chemotherapy to treat testicular cancer. You usually have it if the cancer has not responded completely to treatment. Or you may have it if the cancer has come back after treatment. It is used to increase the chances of curing the cancer.

You have high-dose treatment with stem cell support 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.

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

We have more information about high-dose treatment with stem cell support (see page 140). This explains more about the treatment and its possible side effects.
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Follow-up

After your treatment has finished, you will go to the hospital for regular check-ups. It is important to go to these appointments. Your doctors can check for any problems or signs that the cancer come back and deal with them straight away. If you cannot go, contact your doctor or clinic to arrange another appointment as soon as possible. Testicular cancer that comes back is often curable.

To begin with, check-ups may be every month, but they will gradually become less regular. At your appointments, your doctor will ask how you are feeling and examine you. They will check your remaining testicle.

You may have blood tests to check tumour markers (see pages 34 to 35). This is to make sure the cancer has not come back. You may also have regular chest x-rays and occasional CT or ultrasound scans (see pages 36 and 25).

In between your appointments, it is important that you check your remaining testicle every month (see pages 20 to 21). Getting a new primary cancer in the other testicle is rare. But men who have already had testicular cancer have a higher risk of this happening.
Let your doctor know if you are having any problems. These may include new or ongoing symptoms that are not getting better. Or you may be having emotional or sexual difficulties. Knowing this helps them assess you properly, and give you the best help and support.

It is important to ask for advice if you have new symptoms between appointments, or if anything is worrying you. You should contact your hospital doctor, nurse or GP as soon as possible.

**Being involved in your healthcare**

Having to attend follow-up appointments can feel stressful. Your healthcare team can help you understand more about testicular cancer and its treatment, which may help you to cope. 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.
Understanding testicular cancer

Sex life and fertility

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

We have more detailed information about this in our booklets Cancer and your sex life: information for men and Cancer treatment and fertility: information for men (see page 140).

Effects of treatment on sex life and fertility

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

Men who have an operation to remove the retroperitoneal lymph nodes (see pages 83 to 89) may get nerve damage. This can cause sperm to go backwards into the bladder instead of coming out through the penis. The sperm then passes out harmlessly in the urine. This is called retrograde ejaculation.

The operation does not stop you getting an erection, but your orgasm will feel different because it is dry (dry climax). Surgeons can use newer surgical techniques to try and protect the nerves and reduce the risk of this. However, your specialist may still advise you to think about storing sperm (see pages 102 to 103) if you need this operation.
Radiotherapy
Radiotherapy to the lymph nodes in the tummy (abdomen) does not affect your ability to have sex. It does not usually cause infertility. But your specialist might still suggest that you store sperm.

Chemotherapy
Chemotherapy does not affect your ability to have sex, but side effects might lower your sex drive for a while. Chemotherapy often causes infertility, so your doctor will talk to you about storing sperm before your treatment.

Infertility that chemotherapy may cause is usually temporary. How quickly the sperm count recovers can vary from person to person. It depends on things like your sperm count before chemotherapy, and the type and amount of chemotherapy you have. Your sperm count generally starts to return to normal around 18 months to 2 years after treatment. But it can take longer for some men. If you are planning to father a child, you can ask to have your sperm count checked.

Some men with testicular cancer have a low sperm count when they are diagnosed. Sometimes, successful treatment with chemotherapy improves sperm production.

High-dose chemotherapy has a much higher risk of causing infertility. Men having high-dose chemotherapy may become permanently infertile. If you are worried about this, you can speak to your cancer specialist.
Contraception during treatment
While you are having chemotherapy or radiotherapy, it is important to avoid making someone pregnant. This is because treatment can damage your sperm and possibly harm a developing baby conceived at this time. During treatment, it is best to use a barrier method of contraception, such as a condom. This will also protect your partner for the first couple of days after chemotherapy from any chemotherapy that might be in your semen.

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

Having children after treatment
There is no evidence that cancer treatments can harm children that are conceived after treatment. But doctors usually advise you to carry on using effective contraception for about a year after radiotherapy and chemotherapy, to avoid making someone pregnant. This allows your sperm time to recover from any damage that treatment may have caused. You can talk to your doctor or nurse about having your sperm count checked.

Many men who have had treatment for testicular cancer go on to have children after they have recovered.
**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 you need. Your specialist can give you more information about this.

Being told you have cancer, and that treatment may affect your fertility, can be very difficult. Fertility may not be the most important thing to you, as getting rid of the cancer is usually the priority. But you may find the possibility of losing your fertility 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 some sperm. They will talk to you about this before you have your operation. Storing sperm usually happens after you have had an orchidectomy, but before you have further treatment. This is because this treatment could damage your sperm. Occasionally, men may be offered the option of storing their sperm before they have an orchidectomy. This may be if they have fertility problems, or if their other testicle is small.

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

Sperm banking is a safe technique that has been successfully used for many years. It involves freezing your sperm. If you want to have a child later in life, your sperm can be used with fertility treatments. The standard period of time for storing sperm is normally 10 years. Men affected by cancer may be able to store their sperm for up to 55 years.
Sometimes, the NHS pays for sperm banking for men with cancer. But in some hospitals, you may have to pay for it yourself. You may also need to pay if you choose to store sperm for a longer period of time. The staff in the fertility clinic will explain more to you about this. If you have to pay, the average yearly cost is between £175 and £450 per year.

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

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

It is now possible to collect sperm by taking out a piece of testicular tissue or some fluid. Doctors can remove small amounts of testicular fluid or tissue by putting a fine needle into the testicle. Or they can make a small cut in the scrotum. They can do this using a local or general anaesthetic. The fluid or tissue is 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 these techniques.

We have more information about fertility in our booklet Cancer treatment and fertility: information for men (see page 140).
Your sex drive (libido)

Being diagnosed with testicular cancer brings up a lot of different emotions, such as fear, anxiety and anger (see pages 120 to 124). Some men may find it affects their feelings of masculinity. It is also common for treatment side effects, such as tiredness or sickness, to affect your libido.

It is understandable that trying to cope with everything can make you feel less interested in having sex.

If you have a partner and do not feel interested in sex, let them know how you feel. It can take time to recover physically and emotionally.

You will rediscover your sex drive when your feelings are easier to cope with, and you start recovering from treatment.

‘It helped me to get in my mind that, although I’ve only got one testicle, I’m still the same person and it’s not going to affect me.’

Rahul
After your treatment

Testosterone replacement therapy

Removing one testicle does not usually affect your sex drive, if the remaining testicle makes enough testosterone to make up for it.

Sometimes, the remaining testicle does not produce enough of the hormone testosterone. Rarely, a man may need 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 is important to let your doctor know if you are having these or any other symptoms. They can measure your testosterone level with a blood test. If it is low, your doctor can prescribe testosterone replacement therapy. This will help improve problems such as a low sex drive and always feeling tired. You can have it as a gel, an injection into a muscle, an implant, or a patch that you stick onto the skin. Your doctor can give you more information about testosterone replacement therapy.

We have more information about sexuality and cancer in our booklet Cancer and your sex life: information for men (see page 140).
Support with sexual difficulties

A common worry is that you can pass cancer cells on during sex. Cancer is not infectious, so it is safe for you to have sex.

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

If you are single, you may have some concerns about starting a new relationship, or having sex with someone new. It can be difficult to decide what to tell a new partner, and when to tell them. If you want to make a strong commitment to a new partner, you may want discuss your situation. This may be especially important if the cancer has affected your fertility. It may involve a period of adjustment for you and your partner.

If you have difficulty getting an erection, this can affect your body image. If you have had an orchidectomy, you may feel it has affected your masculinity. Some men can feel embarrassed or angry, which can affect their confidence and sexuality. Usually, these feelings go away gradually.

Whatever feelings you have, it can help to talk about them. You could join a cancer support group (see pages 142 to 143) or our Online Community (see page 143). That way, you can share your experiences with people in similar situations.
You can also talk to your doctor or nurse about any sexual difficulties you might be worried about. You may feel embarrassed, but they have experience of talking to others who have gone through similar problems. They will be able to talk about the support available for you. Many hospitals also have specialist nurses who can offer support. Your doctor can also refer you to a counsellor. Some hospitals have counsellors who have had special training to help people who are having sexual difficulties. They are called sex and relationship therapists. You can also get support from other organisations (see pages 145 to 151).

If you identify as gay, bisexual or transgender, you may worry that your healthcare team will treat you insensitively. Many sexual difficulties that may be caused by testicular cancer are similar whatever your sexuality or gender identity. But you may have some specific questions. Having your sexual or gender identity acknowledged may help you feel better supported. It also means your healthcare team can give you the right information and advice.

If you feel unable to talk to your healthcare team about your sexuality, the LGBT Foundation has a helpline that can give you confidential advice and support (see page 151).
After treatment

After treatment is over, you will probably want to get back to doing all the things you did before cancer. But you may still be coping with the side effects of treatment, such as tiredness, as well as the emotional effects.

Recovering from cancer and its treatment takes time. You may find that the day-to-day things you focused on before your diagnosis slowly start taking over again. Going back to work and getting back to your usual interests can be big steps forward (see pages 136 to 137).

Some people feel that, although they would not have chosen this experience, it has changed them in positive ways. It may have helped them to think about their priorities. They may decide to focus on relationships with family and friends, or do things they have always wanted to do.
Positive lifestyle choices

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

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

A healthy lifestyle can include:

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

You will need to think about any side effects of treatment when planning changes to your diet and exercise. Try not to do too much, too soon.
Diet and exercise
A well-balanced diet should include:
• plenty of fresh fruit and vegetables (at least 5 portions a day)
• foods high in fibre, such as beans and cereals
• plenty of water or other non-alcoholic fluids.

Try to reduce your intake of:
• red meat and animal fats
• alcohol
• salted, pickled and smoked foods.

Talk to your specialist or a dietitian at the hospital before making major changes to your diet. It is a good idea to discuss your plans with them. You may find our booklet Healthy eating and cancer helpful (see page 140).

If you smoke, try to stop. Stopping has many health benefits and reduces your risk of other diseases, such as heart disease and stroke. We have more information that may help in our booklet Giving up smoking (see page 140).

Exercise does not have to be too tiring. You can start gently and build up the amount of physical activity you do. Whatever your age or physical health, there will be some kind of exercise you could try. For example, you may want to do walking, hiking, cycling or swimming. Activities like gardening, dancing and playing sport are also good to try. It may help to read our booklet Physical activity and cancer treatment (see page 140).
Reducing stress
Finding ways to reduce and manage stress can help you live a healthy lifestyle. The way people manage stress varies. You may want to think about what works for you, or try out new ways to manage stress. Exercise and a healthy diet can help to reduce stress and anxiety. It can also help to find some time for yourself every day when you can fully relax. Some people find that complementary therapies, relaxation techniques or even starting a new hobby can help.

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

We have more information about complementary therapies (see page 140).
Juan, diagnosed with testicular cancer
Long-term or late effects of treatment

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

Changes in sensation in your hands and feet

Some men get pins and needles or numbness in their hands and feet after having chemotherapy for testicular cancer. Or their hands become cold and their fingers go pale. This is known as Raynaud’s phenomenon. It is 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 and it can be temporary or sometimes permanent. If you have this, you may have a change in sensation in your hands or feet. We have more information about peripheral neuropathy on our website (see page 140).

Hearing changes

The chemotherapy drug cisplatin can cause permanent hearing problems (see page 74), particularly with high-pitched sounds.
Heart and lung problems

Some chemotherapy drugs may increase your risk of developing heart problems or lung problems. Things that can help are doing regular exercise, eating healthily and keeping to a healthy weight. If you smoke, try to stop or reduce the amount.

Always let your doctors know if you have any of these effects. Your doctor will monitor them and arrange any necessary tests. We have more information about these possible heart problems in our booklet *Heart health and cancer treatment* (see page 140).

Risk of developing another cancer

Research shows men who have radiotherapy or chemotherapy for testicular cancer have a slightly increased risk of developing another cancer later. This does not mean that they will definitely develop another cancer. For most men, the benefits of having treatment will far outweigh this risk.
Talking to someone or sharing your experience

Talking about your feelings can help reduce stress, anxiety and isolation. There are lots of different ways to communicate, and 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 (see pages 142 to 143). They may be facing the same challenges as you. Joining a group can help if you live alone or feel unable to talk about your feelings with those 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.

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

Greg
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 (see page 143) is a social networking site. Here, you can talk to people in our forums, blog your journey, make friendships and join support groups.

Further help

Most people find that any difficult feelings during and after the treatment get better as they recover. Some people get support from family or friends. Others find it easier to talk to someone who is not directly involved with their illness. If you continue to have difficult feelings after your treatment, it can be helpful to speak to a counsellor. You can ask your hospital consultant or GP to refer you to a counsellor who specialises in emotional problems of people with cancer.

Our cancer support specialists (see page 142) can tell you more about counselling and tell you about services in your area.
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. You can also talk to other people going through the same thing on our Online Community (see page 143).

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 (see page 140).
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 to find out more.

Our booklet Talking with someone who has 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 can find more information in out booklet Looking after someone with cancer. It’s based on carers’ experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer (see page 140).
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 which has been developed especially for teenagers who have a parent with cancer (see page 147).

We have more information that you may find useful in our booklet Talking to children and teenagers when an adult has cancer (see page 140).
WORK AND FINANCIAL SUPPORT

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Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working. If you would like more information, you could read our financial guidance information (see page 140).

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to gov.uk if you live in England, Wales and Scotland (see page 151) or nidirect.gov.uk if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.
Employment and Support Allowance (ESA)
This benefit is for people under state pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment
This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance
This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules
If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.
Help for carers

Carer’s Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

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

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.
Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call 0808 808 00 00.

We have more information in our booklets Insurance and Travel and cancer (see page 140). Our Online Community forum Travel insurance may also be helpful. Visit macmillan.org.uk/travelinsurancegroup

More information

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

You can also get information about benefits and other types of financial help from Citizens Advice (see page 150).

Our booklet Help with the cost of cancer has lots more information (see page 140).
Work

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

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

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 is also lots more information on our website (see page 140).
Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

We have more information in our booklet *Your rights at work when you are affected by cancer* (see page 140).
FURTHER INFORMATION

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About our information

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

Order what you need

You may want to order more leaflets or booklets like this one. Visit 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.

Online information

All of our information is also available at macmillan.org.uk/information-and-support
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
If you’d like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on 0808 808 00 00.
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 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.

Talk to us

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

**Macmillan Support Line**

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

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

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

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

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 guidance
Our financial team can give you guidance 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 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

My Organiser app

Our 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.

Testicular cancer support organisations

The College of Sexual and Relationship Therapists (COSRT)
Tel 020 8543 2707
Email info@cosrt.org.uk
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
Helpline 0808 802 0010
Tel 0203 745 7310 (Mon to Fri, 9am to 5.30pm)
Email info@orchid-cancer.org.uk
www.orchid-cancer.org.uk
National Male Cancer Helpline 0808 802 0010
Microsite for testicular cancer: www.yourprivates.org.uk

Funds research into men’s cancers, their diagnosis, prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid male cancer information nurses:
Email nurse@orchid-cancer.org.uk

Relate
Tel 0300 100 1234
Email relate.enquiries@relate.org.uk
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)
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.

Shine Cancer Support
Tel 07804 479413
(Mon to Fri, 10am to 6pm)
Email hi@shinecancersupport.org
www.shinecancersupport.org
Supports adults in their 20s, 30s and 40s who have had a cancer diagnosis. Provides peer support and offers a range of activities, which includes, lunches, drinks evenings, getaways, workshops, online networking and mentoring.

General cancer and support organisations

Cancer Black Care
Tel 020 8961 4151
Email info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland
Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.
Cancer Research UK
Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland
Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email info@
cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie’s Centres
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Riprap
www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.
Tenovus
Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

Healthtalk
Email
info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-peoples-experiences
(site for young people)
Has information about cancer, and videos and audio clips of people’s experiences. Also provides advice on topics such as making decisions about health and treatment.

General health information

Health and Social Care in Northern Ireland
www.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS Choices
www.nhs.uk
The UK’s biggest health information website. Has service information for England.

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

NHS Inform
Helpline 0800 22 44 888
(Daily, 8am to 10pm)
www.nhsinform.scot
NHS health information site for Scotland.
Patient UK
www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health-and illness-related websites.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at itsgoodtotalk.org.uk

UK Council for Psychotherapy (UKCP)
Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind
Helpline 0300 123 3393
Text 86463
Email info@mind.org.uk
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.
Understanding testicular cancer

**Samaritans**

**Helpline** 116 123  
**Email** jo@samaritans.org  
**www.samaritans.org**
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

**Financial or legal advice and information**

**Benefit Enquiry Line Northern Ireland**

**Helpline** 0800 220 674  
(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)  
**Textphone** 028 9031 1092  
**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. Use their online webchat or find details for your local office in the phone book or one of these websites:

**England**

**Helpline** 03444 111 444  
**Email** debt.advice@citizensadvice.co.uk  
**www.citizensadvice.org.uk**

**Wales**

**Helpline** 03444 77 2020  
**www.citizensadvice.org.uk/wales**

**Scotland**

**www.citizensadvice.org.uk/scotland**

**Northern Ireland**

**Helpline** 0800 028 1181  
**Email** debt.advice@citizensadvice.co.uk
Civil Legal Advice
Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm, Sat, 9am to 12.30pm)
Minicom 0345 609 6677
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 (DWP)
Personal Independence Payment (PIP)
Helpline 0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)
Carer’s Allowance Unit
Tel 0345 608 4321
Textphone 0345 604 5312
(Mon to Thu, 8.30am to 5pm, and Fri, 8.30am to 4.30pm)
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.

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

LGBT-specific support

LGBT Foundation
Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, and Sat, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.
YOUR NOTES AND QUESTIONS
Disclaimer

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

Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Jim Barber, Consultant Clinical Oncologist.

With thanks to: Mr Erik Mayer, Consultant Surgeon; Professor Andrew S Protheroe, Consultant Medical Oncologist; Asif Muneer, Consultant Urological Surgeon; Clare Akers, Clinical Specialist Nurse; and Catherine Pettersen, Urology Clinical Nurse Specialist. Thanks also to the people affected by cancer who reviewed this edition and those who shared their stories.

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

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk


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.

**5 WAYS YOU CAN HELP SOMEONE WITH CANCER**

**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
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

Valid from     Expiry date

Issue no     Security number

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

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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

If you’d rather donate online go to 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

27530
This booklet is about testicular cancer. It is for men who have been diagnosed with testicular cancer. There is also information for carers, family members and friends.

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

We’re here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we’re right there with you. For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk

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

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