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CANCER SUPPORT

A practical guide to understanding cancer

UNDERSTANDING NON-INVASIVE BLADDER CANCER



About this booklet

This booklet is for people with non-invasive bladder cancer. We hope it answers some of your questions and helps you deal with some of the feelings you may have.

Non-invasive bladder cancer is cancer that is only in the inner lining of the bladder. It has not spread into the muscle of the bladder. Doctors may call this non-muscle invasive bladder cancer or superficial bladder cancer. In this booklet, we call it non-invasive bladder cancer.

Cancer that has grown into the muscle layer of the bladder is called invasive bladder cancer. This type of bladder cancer is treated differently to non-invasive bladder cancer. You can read more information in our booklet **Understanding invasive and advanced bladder cancer**.

In this booklet, we've included comments from people who have had bladder cancer, which you may find helpful. Some are from Alex, who is also on the cover of this booklet. Others are from our Online Community – [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

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

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

Turn to pages 77–83 for some useful addresses and websites. On pages 84–85 you can write down any notes or questions for your doctor or nurse.

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



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**'I'd suddenly
need the toilet,
and it had to
happen straight
away. I told the
GP something
was wrong,
I just didn't
know what.'**

Alex

ABOUT NON-INVASIVE BLADDER 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 bladder

The bladder is a hollow, muscular, balloon-like organ that collects and stores urine. It sits in the lower part of the tummy (abdomen), called the pelvis.

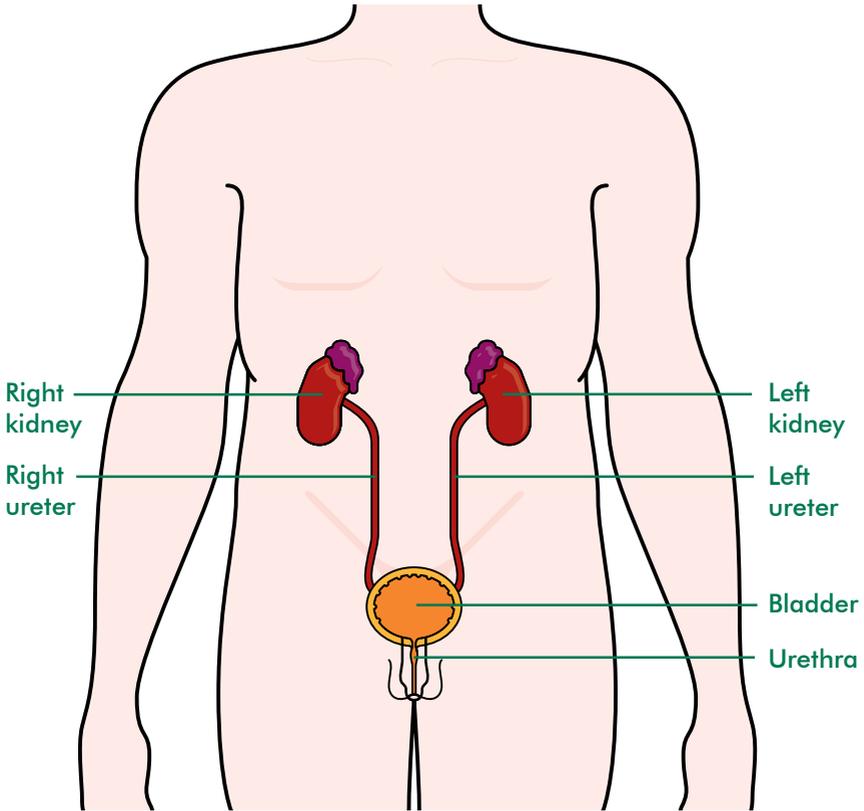
The inside of the bladder is covered with a urine-proof lining called the **urothelium**. This stops urine from being absorbed back into the body. The cells that make up this lining are called **urothelial cells** or **transitional cells**.

Urine is made in the kidneys. It travels to the bladder through tubes called **ureters** (see diagram on the next page). Urine is made up of water and waste products that the body doesn't need.

When the bladder is full, it sends messages (nerve signals) to the brain. This makes you feel like you need to empty your bladder.

The bladder muscle contracts and squeezes the urine out of the body through the **urethra**. In women, the urethra is a short tube that lies in front of the vagina. In men, the urethra is longer and passes through the prostate gland to the tip of the penis.

Position of the bladder in the body



Causes and risk factors

Each year, over 10,000 people in the UK are diagnosed with bladder cancer. Around 8 out of 10 (80%) of these people are diagnosed with non-invasive bladder cancer.

There are certain things that can affect the chances of developing bladder cancer. These are called risk factors. But having a risk factor doesn't necessarily mean a person will get bladder cancer. And people without risk factors can also develop bladder cancer.

Age

Bladder cancer is more common in people over 60. A few people under the age of 40 get bladder cancer.

Smoking

Smoking may cause about 4 in 10 (40%) of bladder cancers. Chemicals that can cause bladder cancer are present in cigarette smoke. These chemicals eventually pass into the urine through the blood. They can damage the cells that line the bladder. Over many years, this could cause bladder cancer.

The longer a person smokes and the more they smoke, the greater the risk.

There is more information about smoking and your health on page 55. We also have tips and advice in our booklet **Giving up smoking**.

Gender

Bladder cancer is more common in men than in women.

Exposure to chemicals at work

These include chemicals previously used in dye factories and industries such as rubber, leather, textile, printing, hairdressing, gasworks, plastic and paint. Many of these chemicals are now banned. But it can take more than 25 years after exposure to them for bladder cancer to develop.

If you think chemicals at your work may have caused the cancer, you may be able to claim Industrial Injuries Disablement Benefit. The Department for Work and Pensions (visit [gov.uk](https://www.gov.uk)) has more information about this benefit. If you live in Northern Ireland, see [nidirect.gov.uk](https://www.nidirect.gov.uk).

Infection

Repeated urinary infections and untreated bladder stones are linked with a less common type of bladder cancer, called squamous cell cancer.

People who are paralysed because of an injury to their spinal cord can have more bladder infections. This may be why they have a higher risk of bladder cancer.

Previous treatment for cancer

People who have had radiotherapy to the pelvis have an increased risk of bladder cancer. People who have had the chemotherapy drug cyclophosphamide also have an increased risk. But the benefits of cyclophosphamide treatment far outweighs the risk of bladder cancer.

Diabetes

Diabetes has been linked with an increased risk of bladder cancer. A drug called pioglitazone is likely to be the cause of this. Other medicines for diabetes are not linked with an increased risk of bladder cancer.

Family history

If you have a close relative who has had bladder cancer, your risk of developing it increases slightly. This may be due to sharing certain risk factors, such as smoking.

Rarely, an inherited gene may increase the risk of bladder cancer. But having a close relative that has also had bladder cancer does not mean an inherited gene has caused it. If you are worried about this, talk to your doctor or specialist nurse.

Bladder cancer isn't infectious and can't be passed on to other people.

Types of bladder cancer

Urothelial bladder cancer

This is the most common type of bladder cancer. It is also called **transitional cell carcinoma** or **TCC**. It starts in cells in the bladder lining (urothelial cells or transitional cells).

In non-invasive bladder cancer, the cancer cells are only in the inner lining of the bladder. They have not spread (invaded) into the muscle layer. Non-invasive bladder cancer can appear in different forms:

- A **papillary tumour** is usually a mushroom-like growth on the bladder lining.
- **Carcinoma in situ (CIS)** appears as flat, red patches on the bladder lining. Sometimes there is a papillary cancer as well as CIS.

The diagram on page 24 shows the different stages of non-invasive bladder cancers.

Less common types of bladder cancer

Less common types of bladder cancer include squamous cell cancer and adenocarcinoma. They start from different types of cells in the bladder lining and are usually invasive.

There is more information in our booklet

Understanding invasive and advanced bladder cancer.

Symptoms

Blood in the urine (haematuria)

This is the most common symptom of bladder cancer. It can happen suddenly and may come and go. Your urine may look pink, red or sometimes brown. Or you may see streaks or clots of blood in it. If you see blood in your urine, it is important to get it checked by your GP straight away.

Sometimes blood in the urine can't be seen and is found during a urine test. This is called non-visible or microscopic haematuria. If you have urinary symptoms (see below), your doctor will ask you to provide a sample of urine. They test this for non-visible blood.

Urinary symptoms

Some people have a burning feeling when they pass urine. Or, they feel the need to pass urine more often or urgently. These symptoms are usually caused by infection rather than cancer. Some people may need more tests to find out the cause of their urinary symptoms.

Pain in the lower part of the tummy or back

This is less common, but it may happen in some people.

There are different causes for the symptoms above, such as infection or stones in the bladder or kidney. But if you have any of these symptoms, it's important to get them checked by your GP. The earlier bladder cancer is diagnosed, the more likely it is to be cured.



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How it is diagnosed

Most people are diagnosed after going to see their GP when they notice symptoms. Your GP will talk to you about your symptoms and ask you for a sample of your urine. They can do a quick test to find out if there is any blood in your urine (haematuria). The sample is then sent to a laboratory to check for infection.

If you have blood in your urine, your GP will make sure there is no obvious reason for this, such as an infection.

Your GP should arrange for you to see a specialist if:

- you can see blood in your urine which can't be explained
- you can still see blood in your urine after having treatment for a urine infection
- a urine test finds blood in your urine and you have urinary symptoms but don't have a urine infection.

Most people are referred to a haematuria clinic for tests and to see a specialist. You can usually have most of the tests done on the same day.

Some people are referred to hospital to see a specialist. You may see a doctor who specialises in diagnosing and treating urinary, bladder and kidney problems (a urologist). Or you may see a nurse called a urology nurse specialist.

At the hospital

The urologist or urology nurse specialist will ask you about your symptoms and your general health. They will examine you by feeling your tummy (abdomen) and bladder. Then they will talk to you about the tests you need.

Having tests to diagnose bladder cancer can take a while and some may need to be repeated. This can be frustrating, but it's important your doctor has all the information they need to make the diagnosis. You'll usually have some of the following tests:

Blood tests

You will have samples of your blood taken. These are used to check your general health and number of blood cells in your blood (blood count). They can also show how well your kidneys are working.

Urine tests

A sample of your urine can be tested to look for cancer cells.

Some people may have a test which looks for substances in the urine that are present in bladder cancer. This is called molecular testing and is only occasionally done.

Flexible cystoscopy

This is the main test used to diagnose bladder cancer. A cystoscope is a thin tube with a camera and light on the end. A doctor or specialist nurse uses it to look at the inside of your bladder.

A cystoscopy to check for bladder changes is usually done under local anaesthetic using a flexible cystoscope. You may be asked to drink lots of fluids before the cystoscopy and to provide a sample of urine, which will be checked for infection.

The doctor or nurse will squeeze a jelly containing anaesthetic into the opening of your urethra (see the information on page 7). This is to make the procedure less uncomfortable. The anaesthetic starts to work after a few minutes.

The doctor gently passes the cystoscope through your urethra and into the bladder. They look at the whole lining of the bladder and urethra. The test takes a few minutes and you can usually go home after it's finished.

You may have some burning or mild pain when you pass urine for a couple of days after the test. You may also notice blood in your urine. This should clear up after a day or two. Your doctor will ask you to drink lots of fluids to help flush out your bladder.

'The procedure is nothing to worry about. It's slightly uncomfortable for a few seconds as the camera goes in, but then it's painless.'

Richard

If these symptoms don't go away or you have a high temperature, tell your doctor straight away. They can check to make sure you don't have an infection.

After the cystoscopy, the doctor will usually be able to tell you if they have seen a bladder tumour. If they have, they will arrange for you to come into hospital to have a rigid cystoscopy. This is done under general anaesthetic.

During this test, the doctor will pass instruments through the cystoscope to remove the tumour. Or they may take a small piece of tissue (biopsy). See page 32 for more information.

Blue light cystoscopy

During a cystoscopy, the doctor uses light to see inside the bladder. Sometimes the doctor uses a technique called blue light cystoscopy or photodynamic diagnosis (PDD). This is usually done under general anaesthetic as part of a rigid cystoscopy.

A light-sensitive drug is put into the bladder through the catheter. It is absorbed by cancer cells. During the cystoscopy, a blue light is used to show the inside of the bladder. The blue light makes areas of cancer glow pink. It can pick up small bladder tumours and carcinoma in situ (CIS – see page 23).

Narrow-band imaging (NBI)

Some people may have a newer type of cystoscopy called narrow-band imaging (NBI). Your doctor or specialist nurse can give you more information.

A healthcare professional in blue scrubs is adjusting a Siemens CT scanner. A patient is lying on the table, ready for a scan. The machine is white and has a Siemens logo on top. The patient is wearing a white hospital gown with a pattern. The healthcare professional is looking at the patient and adjusting the table. The machine has a small screen on top and a control panel on the right side. The background is a plain white wall with a ceiling vent.

Someone having a CT scan

Visit [macmillan.org.uk/ct-scan](https://www.macmillan.org.uk/ct-scan) to watch our video of someone having a CT scan.

Ultrasound scan

This scan can show up anything unusual in your urinary system. It uses sound waves to build up a picture of the inside of the body. You'll be asked to drink plenty of fluids before the test, so that your bladder is full and can be seen clearly.

Once you're lying comfortably on your back, a gel is spread over your tummy (abdomen). A small device that gives out sound waves is passed over the area. It picks the sound waves up again when they bounce back as echoes from the organs inside your body. The echoes are made into a picture by a computer. The scan is painless and takes about 15–20 minutes. Once it's over, you can empty your bladder.

CT (computerised tomography) urogram

A CT scan (see picture on opposite page) takes a series of x-rays, which builds up a three-dimensional picture of the inside of the body. A CT urogram is a CT scan of the bladder, ureters and kidneys. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

You are usually given an injection of a dye (contrast) that helps your bladder, ureters and kidneys to be seen more clearly. It may make you feel hot all over for a few minutes. Some people have a stronger reaction to the dye. Tell your doctor if you have asthma or an iodine allergy, as they increase the risk of a strong reaction. You should also tell your doctor if you have kidney problems or diabetes. You will need a blood test before the scan to check how well your kidneys are working.

You should be able to go home as soon as the scan is over.

Further tests

Some people may need to have further tests after surgery:

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc. You should also tell your doctor if you've ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you'll be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

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 77–82 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Staging and grading

Staging

The stage of a cancer describes its size, position and whether it has spread from where it started. Knowing the stage helps your doctors decide on the best treatment for you.

Test results provide some information about the stage of the cancer. But your doctor won't know the exact stage until after the cancer has been removed with surgery.

Doctors often use the TNM system to stage bladder cancer:

- **T** is how far the tumour has grown into the bladder
- **N** is whether the cancer has spread to the nearby lymph nodes and which nodes are involved.
- **M** is whether the cancer has spread to another part of the body. This is called secondary or metastatic cancer.

N and **M** are not used in non-invasive bladder cancer. This is because they are used to describe cancers that have spread.

Stages of non-invasive bladder cancer

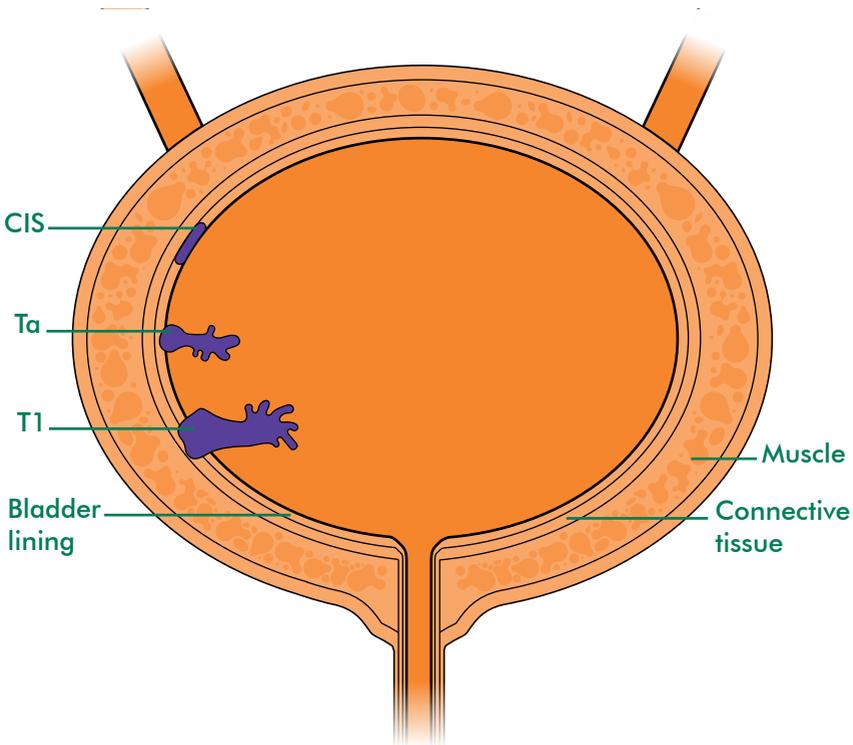
Non-invasive bladder cancer will be staged as **CIS**, **Ta** or **T1**:

Carcinoma in situ (CIS) – this is sometimes described as a flat tumour. The cancer cells are only in the very inner layer of the bladder lining.

Ta – the cancer is a mushroom-like growth (papillary cancer) that is only in the inner layer of the bladder lining.

T1 – the cancer has started to grow into the layer of connective tissue beneath the bladder lining.

The stages of non-invasive bladder cancer



Invasive and advanced bladder cancer

In stage **T2**, **T3** and **T4** tumours, the cancer has grown into the muscle layer of the bladder (invasive bladder cancer) and may have spread further.

You can read more about these stages in our booklet **Understanding invasive and advanced bladder cancer**.

Grading

Grading is how the cancer cells look under the microscope compared with normal cells. The grade helps your doctor to decide if you need further treatment after surgery. You are likely to need further treatment if the cancer is grade 2 or 3.

Grade 1 – the cancer cells look a lot like normal bladder cells. They are usually slow-growing and are less likely to spread.

Grade 2 – the cancer cells look more abnormal and grow slightly more quickly than grade 1 cancer.

Grade 3 – the cancer cells look very abnormal. They are more likely to grow more quickly.

Your doctor may combine the stage and grade of the tumour when talking about your results. For example, TaG1 is a stage Ta tumour which is grade 1.

Doctors may also use another grading system for bladder cancer:

- **Low grade** – the cancer cells are slow-growing and less likely to spread
- **High grade** – the cancer cells grow more quickly and are more likely to spread

Your doctor may combine the two grading systems together.

Carcinoma in situ (CIS) is always classed as high-grade.



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Treatment overview

Surgery (see pages 32–37) is the main treatment for non-invasive bladder cancer. Tumours in the bladder can be removed using a cystoscope (see pages 18–19). Some people may only need surgery to cure the cancer.

After surgery

After surgery, your doctor will use the size, number, stage and grade of the tumour to decide the risk level. This refers to the chance of the cancer coming back in the bladder lining or spreading into the muscle layer.

Non-invasive bladder cancer can be **low, intermediate** or **high risk**. If you have a low risk tumour, you won't need any further treatment after surgery. If you have an intermediate or high risk bladder tumour, you usually need further treatment after surgery. Grade 3 tumours and CIS (see page 23) are always treated as high risk.

Once your doctors know what the risk level is, they can talk to you about the best treatment for you. They will describe the risks and benefits of each treatment and help you to reach a decision about treatment together.

Treatment is usually with chemotherapy (see pages 38–42) or a vaccine called BCG (see pages 43–46) given directly into the bladder.

If you have a high risk bladder cancer, sometimes your specialist will talk to you about deciding between BCG treatment or an operation to remove the bladder (cystectomy – see page 37).

In some people, bladder cancer can come back but still be successfully treated. There is more information about treatment if the cancer comes back on page 51.

If you smoke, your doctor or nurse will explain the benefits of stopping smoking. Stopping smoking may reduce the side effects of treatment and can reduce the risk of bladder cancer coming back. There is more information about giving up smoking on page 55.

Planning your treatment

In most hospitals, a team of specialists will meet to discuss and agree on the plan of treatment they feel is best for you. This multidisciplinary team (MDT) will normally include:

- a **urologist**, who is a surgeon experienced in bladder surgery
- a **specialist urology nurse**, who gives information and support
- **oncologists**, who are doctors that have experience in bladder cancer treatment using chemotherapy, immunotherapy and radiotherapy
- **pathologists**, who advise on the type of cancer and its extent
- **radiologists**, who analyse x-rays and scans.

Other staff are also available to help you if needed. They include physiotherapists, counsellors and psychologists.

Your doctor will talk to you about the best treatment for your situation. If you have any questions about your treatment, don't be afraid to ask the doctor or nurse looking after you. It often helps to make a list of the questions you want to ask. You could also take a close relative or friend with you to help you remember what is discussed.

The benefits and disadvantages of treatment

For most people with non-invasive bladder cancer, surgery is done with the aim of curing the cancer or controlling it for many years. You may also have treatment after surgery to reduce the risk of the cancer coming back.

If you have been offered treatment that aims to cure the cancer, deciding whether to accept it may not be difficult. But some people may want to know more about the benefits of further treatments when weighed up against the side effects.

Your specialist will talk about this with you, so that you know the advantages and any possible disadvantages.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide on the best treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask 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.

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's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions. You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

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

Surgery

Surgery is the main treatment for non-invasive bladder cancer. During the operation, the surgeon inserts a cystoscope into your bladder (see pages 18–19). They then remove the tumour or tumours using instruments that are passed through the cystoscope. They may use a mild electrical current (cauterisation) to stop any bleeding.

Sometimes, blue light cystoscopy (PDD) or narrow band imaging (see page 19) are used during surgery to help your doctor remove the tumour or tumours. They will then be examined to check the stage and grade (see pages 23–25).

The operation is called a transurethral resection of a bladder tumour (TURBT). Transurethral means through the urethra (see information on page 7).

Some people may have another TURBT operation two to six weeks after the first. Your doctor may recommend this if:

- you have a high-risk non-invasive bladder cancer – to make sure all of the tumour has been removed
- biopsy samples taken during your first operation didn't contain cells from the bladder muscle layer.

When the results of your first operation are ready, your doctor will explain if you need a further TURBT operation.

Before your operation

Before your surgery, your urologist and specialist nurse will explain the operation to you. They will tell you what to expect after the surgery. This is a good opportunity to ask any questions you have about the operation. You can also tell your doctor about any medications you are taking.

It's important to discuss the operation fully with your surgeon beforehand so that you understand what it involves. Remember, no operation or procedure will be done without your consent.

Usually, you will have a pre-operative assessment at an outpatient clinic a few days before the operation. You will have a medical examination to check your general health. This will include a blood test and sometimes a tracing of your heart (ECG) and a chest x-ray. This is to make sure that you're fit enough to have an anaesthetic. The anaesthetist will also see you to explain about the anaesthetic.

You usually go into hospital on the day of your operation. Most people have a general anaesthetic for their surgery, but some people have the operation done under a spinal anaesthetic.

For a spinal anaesthetic, the doctor injects an anaesthetic drug through a needle into the back. This numbs the nerves from the waist down. Although you're awake during the operation, you won't feel anything. If you are having a spinal anaesthetic, you may also have a sedative to help you relax.

After your operation

The nurses will encourage you to get out of bed and walk around once you feel well enough. This helps to prevent complications, such as chest infections or blood clots forming in your legs. You are usually given stockings to wear to help prevent blood clots.

Most people are given chemotherapy into the bladder immediately after surgery (see pages 38–42).

You will have a tube (catheter) in your bladder to drain your urine into a bag, but you can walk around with this.

There will be blood in your urine at first. You will be encouraged to drink plenty of fluids to help flush out your bladder and reduce the risk of developing a urine infection.

Sometimes, large bags of fluid are connected to the catheter to flush out the bladder until the bleeding clears. This helps prevent blood clots from forming and blocking the urethra. If you feel your bladder is full or the catheter is not draining, tell the nurses straight away.

When your urine looks clear, a nurse will remove your catheter. This may feel a little uncomfortable but isn't painful. If your urine is no longer bloodstained and you can pass urine, you can usually go home. This may be one to three days after the operation.

After the nurse removes the catheter, you may need to pass urine more often or more urgently. Sometimes you may leak urine. You may also have some blood in your urine. These symptoms usually settle down in a day or two but may continue for several weeks. Tell your doctor if they continue. Drinking at least two litres (three and a half pints) of fluids every day can help to reduce the symptoms.

There is more information about looking after your bladder and what you can do to help on pages 54–55.

'Recovery is an individual thing, but you have to listen to your body and not overdo things.'

Christine

Possible risks of surgery

Removing non-invasive bladder cancers is generally a safe procedure. However, there are some possible risks.

Urine infection

Some people may get a urine infection while they are in hospital or after they go home. Signs of an infection include:

- feeling cold, shivery, hot or sweaty
- feeling generally unwell
- your urine getting smelly or cloudy.

If you think you have an infection, you can take a urine sample to your doctor for testing.

Bleeding

Some people may have bleeding for about 10–14 days after the TURBT. Tell your doctor or specialist nurse straight away if:

- the bleeding becomes heavier
- you see any blood clots
- you have difficulty passing urine or have severe tummy pain.

If the bleeding continues, you may need another operation under general anaesthetic to stop it. About 2 in 100 people may need a blood transfusion.

Damage to the bladder

There is a small risk of a hole (perforation) being made in the bladder during surgery. If this happens, the catheter is left in the bladder for about 3–10 days. This allows the hole to heal. Rarely, you may have an operation may be done to seal the hole.

Going home

Your urologist or nurse will explain when you can safely start doing normal activities such as driving, going back to work and carrying shopping. If you have any questions, ask your doctor or nurse.

Surgery to remove the bladder (cystectomy)

A cystectomy is an operation to remove the bladder. It is sometimes recommended if you have a high risk non-invasive bladder cancer that has come back.

Being advised to have your bladder removed when you have a non-invasive bladder cancer can be hard to accept. Your doctors will weigh up the benefits of treatments that aim to keep the bladder against the risk of the cancer spreading before suggesting a cystectomy.

If you do have your bladder removed, the surgeon will create a new way for you to pass urine (urinary diversion). Your urologist or specialist nurse can give you more information about what this involves.

Having your bladder removed is major surgery. But with support from family, friends, health professionals and support organisations (see pages 77–83), people usually manage to cope well with a cystectomy.

There is more information about cystectomy and urinary diversion in our booklet **Understanding invasive and advanced bladder cancer**.

Chemotherapy

After surgery, you usually have chemotherapy into your bladder to reduce the risk of the cancer coming back. This is called **intravesical chemotherapy**.

Chemotherapy drugs work by destroying cancer cells. When you have it into the bladder, the drug comes into direct contact with any cancer cells in the bladder lining.

Hardly any of the drug is absorbed into the blood, so it rarely affects the rest of the body. This means you don't get some side effects, such as feeling sick or hair loss.

Having chemotherapy into the bladder

Most people have a one-off treatment of intravesical chemotherapy after surgery. If you have a low risk of the cancer coming back, you won't usually need chemotherapy after this.

If you have an intermediate risk of the cancer coming back, you may have chemotherapy once a week for about six weeks.

How it is given

When you have chemotherapy into your bladder after surgery, you will be in hospital with a urinary catheter in place. The chemotherapy is usually given soon after surgery. In some hospitals, it is given when you are still in the operating theatre or recovery room. If you've had a lot of blood in your urine, chemotherapy may be delayed until the following day. If your bladder has been damaged during surgery, it may be delayed for longer.

If you need more chemotherapy after this, you will have it in the hospital outpatient department. Your nurse or doctor will give you information about preparing for your treatment.

You may be asked to limit the amount of fluids you drink before having chemotherapy as drinking too much can make your bladder feel uncomfortably full. Drinking less also helps to increase the concentration of the chemotherapy drug in your bladder.

People who take water tablets (diuretics) should take them later in the day, after the treatment. Let your doctor know about any other medicines you're taking. You won't be given chemotherapy if you're feeling unwell or have a urine infection. Your nurse will check a sample of your urine to make sure there is no infection.

When you are lying down, the nurse passes a tube (catheter) into your bladder. They put the liquid chemotherapy drug directly into your bladder through the catheter. The drug most often used is **mitomycin-C**. Sometimes a chemotherapy drug called **gemcitabine** is given. Rarely, **epirubicin** or **doxorubicin** are used.

Once the drug is in your bladder, the nurse usually removes the catheter. They will ask you not to pass urine for at least an hour. This can be uncomfortable, but it gives the chemotherapy time to work. You can go to the toilet when the treatment is finished.

Sometimes the nurse leaves the catheter in and clamps it to keep the chemotherapy in your bladder. You can walk around during this time. The nurse then removes the clamp. The chemotherapy drug drains into a urine bag before the nurse removes the catheter. For six hours after treatment, you need to take certain precautions. This protects you and others from coming into contact with the chemotherapy drug.

You will usually be asked to:

- avoid splashing urine on the toilet seat – you should sit down to pass urine
- wash the skin in your genital area carefully with soap and water after you pass urine – this removes any traces of the drug that may have splashed onto your skin
- put the lid down after you have finished and flush the toilet twice
- wash your hands carefully afterwards
- drink at least two to three litres (three and a half to five pints) of fluid a day for at least 48 hours after each treatment, to help flush the drug out of your bladder.

Your nurse will explain what you need to do after treatment.

Side effects

You may have some side effects after your treatment. These include:

- needing to pass urine often
- pain or stinging when you pass urine
- blood in the urine.

Most side effects are caused by inflammation in the bladder lining (cystitis). These can take up to a week to improve.

Drinking lots of fluid will ease the irritation. Try to drink about two to three litres (three and a half to five pints) each day. Taking mild painkillers will also help. There is more information about looking after your bladder during and after treatment on pages 54–55.

Some people get a red rash on their hands or genital area. Some people may get a rash on the rest of their body. If this happens, let your nurse or doctor know straight away.

Contact your doctor straight away if:

- the side effects don't improve after a day or two
- you have a raised temperature
- your urine is smelly or cloudy.

These symptoms may mean you have a urine infection.

Rarely, a person may find it difficult to pass urine or have severe tummy pain. If you're a man, you may have pain around your penis. Call your doctor or specialist nurse straight away if you have any of these symptoms.

Sex after treatment

Men should use a condom during sex for the first 48 hours after chemotherapy. If you're a woman having treatment, your partner should use a condom. This protects your partner from any of the drug that may be present in semen or vaginal fluid.

Your doctor will tell you not to become pregnant or father a child while having chemotherapy to treat bladder cancer. This is because the drugs may harm a developing baby. You should use effective contraception during your treatment. Talk to your doctor or specialist nurse about this.



BCG treatment

BCG is a type of immunotherapy drug used to treat some non-invasive bladder cancers. It is given directly into the bladder (intravesical). Most people know BCG as a vaccine used to prevent tuberculosis (TB). BCG may make the bladder react in a way that triggers the immune system to get rid of cancer cells.

When BCG is used

BCG helps prevent the cancer from coming back in the bladder lining. It also reduces the risk of the cancer becoming invasive. Doctors usually advise it if you have high-risk bladder cancer or sometimes if you have an intermediate-risk bladder tumour.

After you've had surgery, there needs to be a gap of at least two weeks before you can have BCG treatment. This is to let the bladder heal after surgery.

You usually have BCG treatment once a week for six weeks. This is followed by a six-week break. After the break you may have BCG once a week for one to three weeks. If the BCG is working well, you may be offered maintenance treatment.

Treatment times vary. Your doctor will explain what is best for you.

Recently there have been some difficulties with the availability of BCG. Your urology doctor or specialist nurse can explain if this is likely to affect your treatment.

How it is given

You have treatment with BCG in the hospital outpatient department. It takes up to three hours. You can usually go home as soon as it is finished.

You are usually asked to limit the amount of liquid you drink before treatment. This helps to increase the concentration of BCG in your bladder. And drinking too much beforehand can make your bladder feel uncomfortably full. If you normally take water tablets (diuretics), take them later in the day. Your nurse or doctor will give you advice about preparing for your treatment.

When you're lying down, the nurse passes a tube (catheter) into your bladder (see diagram on page 8). The BCG is then put directly into your bladder through the catheter. You can get up and walk around after that.

Try not to pass urine for two hours afterwards. This can be difficult, but it gives the BCG treatment time to work. Sometimes the nurse leaves the catheter in and clamps it for the two hours. This is to keep the drug in your bladder.

When the treatment is over, you can go to the toilet. If you have a catheter, the nurse removes the clamp and the BCG is drained into a urine bag. The nurse can then remove the catheter.

After treatment, you need to take some precautions for the next six hours. This is because BCG is a live vaccine and other people shouldn't be exposed to it.

You will be asked to:

- avoid urine splashing on the toilet seat – you should sit down to pass urine
- avoid getting urine on your hands
- after passing urine, put undiluted bleach into the toilet bowl to destroy any vaccine – leave it for 15 minutes and then flush the toilet with the lid down
- wash your hands carefully after using the toilet.

Your nurse will explain what you need to do after treatment.

Side effects

The most common effects of BCG are:

- needing to pass urine often
- pain when you pass urine
- blood in the urine
- flu-like symptoms such as tiredness, general aching and a raised temperature.

These effects should settle down in a day or two. If they don't get better after this time, contact your doctor. You should drink lots of fluids. Try to drink about two to three litres (three and a half to five pints) per day. This will help flush the drug out of your bladder and reduce some of the side effects. Taking painkillers will also help.

Rare side effects can include a continuing high temperature (fever), pain in your joints and a cough. If you have any of these symptoms or feel generally unwell, contact your doctor straight away. It could be a sign of a more serious infection due to BCG that needs urgent treatment. If this happens, you'll be treated with antibiotic drugs used to treat TB.

Sex after treatment

Men should use a condom if they have sex during the first week after having BCG treatment. If you're a woman having the treatment, your partner should use a condom during this time. This protects your partner from any vaccine that may be present in semen or vaginal fluid.

Doctors don't yet know how BCG may affect an unborn baby. They will recommend you do not become pregnant or father a child while having it. You should use effective contraception during treatment. You can discuss this with your doctor or specialist nurse.

Newer treatments

Some newer treatments are being tested for non-invasive bladder cancer. Because these are experimental, they're usually only available in clinical trials (see pages 48–49). If your urologist thinks a clinical trial may be helpful for you, they can refer you to the hospital doing the trial.

Heated intravesical chemotherapy

This treatment combines intravesical chemotherapy with heat. A fine probe applies microwave heat to the bladder lining. At the same time, chemotherapy is given into the bladder.

Another type of this treatment uses a machine to heat the chemotherapy before it goes into the bladder. The chemotherapy is then given into the bladder through a catheter. Trials are trying to find out if using heat makes chemotherapy given into the bladder work better.

Electromotive intravesical chemotherapy

Some trials involve giving the chemotherapy drug mitomycin into the bladder with a technique called electromotive stimulation. An electrical current is passed through the bladder so that the cells absorb more of the chemotherapy drug. Your doctor or nurse may also call this electromotive drug administration.

Sometimes this treatment is combined with a course of BCG treatment into the bladder. Your doctor or nurse will explain about this.

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, hormone therapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

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

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

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

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

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.

Current research

Research is looking at newer ways of treating the inside of the bladder in non-invasive bladder cancer (see page 47). Our website [macmillan.org.uk/clinicaltrials](https://www.macmillan.org.uk/clinicaltrials) also has links to clinical trial databases.

Follow-up

The most important test for follow-up is cystoscopy. Some people may also have their urine checked for cancer cells.

After your treatment has finished, you will have regular cystoscopies (see pages 18–19) to monitor how well treatment has worked. These also check that no new cancers are growing in the bladder. They will usually be every three to six months at first. The cystoscopy will be done in the outpatient department under local anaesthetic. You may attend a specialist nurse-led clinic for follow-up.

Your doctor or specialist nurse will explain how often you will have a cystoscopy. This will depend on what risk level of bladder tumour you have. If you have an intermediate or high risk bladder tumour, you will have a cystoscopy more often than if you have a low risk bladder tumour. Most people have cystoscopy follow up for several years after treatment.

If you have any new symptoms or symptoms that come back between appointments (especially blood in your urine), let your doctor or specialist nurse know straight away.

'If you are worried about any ache or pain, go and see your GP and get it checked out. It may be nothing to worry about, but it's always good to get it checked for peace of mind rather than live with the pain and worry.'

Christine

If the cancer comes back

It's not uncommon for bladder cancer to come back in the lining of the bladder. If this happens, it can usually be removed with an operation. Some people may be given chemotherapy or BCG into the bladder. Non-invasive bladder cancer that comes back in the bladder can usually be cured or controlled for a long time.

In some people, the cancer may start to grow into the muscle layer of the bladder (invasive bladder cancer). If this happens, the urologist may recommend an operation to remove the bladder (cystectomy).

They may also advise a cystectomy if treatment with BCG isn't working or if the cancer keeps coming back. If you have high risk non-invasive bladder cancer, it might be suggested instead of BCG treatment.

It can be hard to accept advice to have your bladder removed to treat non-invasive cancer. Before suggesting this, your urologist will consider the different treatments available to let you keep your bladder. With support from family, friends, health professionals and support organisations, people usually manage to cope well with a cystectomy.

The aim of a cystectomy is to treat the cancer before it spreads into the muscle layer, and possibly to other parts of the body (secondary or metastatic bladder cancer). When bladder cancer has spread to other parts of the body, it can no longer be cured.

You can read more about cystectomy in our booklet **Understanding invasive and advanced bladder cancer**.



'About three months after treatment was the first time I slowed down and really took stock of what had happened.'

Alex

COPING DURING AND AFTER YOUR TREATMENT

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Coping during and after treatment

Bladder health

During your treatment, you may have symptoms such as wanting to pass urine more often or urgently, or a burning sensation when you go to the toilet. For most people, these symptoms last a few days after treatment. Your urologist or specialist nurse can suggest ways to help and prescribe medication if needed. If the symptoms continue after your treatment finishes, they may suggest a referral to a continence adviser. They can help with bladder problems and give practical advice. The Bladder and Bowel Foundation (page 78) can also help.

What you can do to help

Drink plenty of fluids

Try to drink at least two litres (three and a half pints) of fluids per day. This is about eight glasses. If it's hot or you are exercising, you will need to drink more. It may help to drink less in the evening, if you find you have to get up in the night to pass urine. If you don't drink enough, it can make the symptoms worse.

Some fluids can irritate the bladder and make symptoms worse. Try to reduce or avoid:

- drinks that contain caffeine (such as tea, coffee, green tea, cola and cocoa)
- fizzy drinks
- drinks with artificial sweeteners (diet or light drinks)
- alcohol.

Give up smoking

If you're a smoker, giving up is one of the healthiest decisions you can make. The chemicals in cigarette smoke irritate and damage the lining of the bladder and can make your symptoms worse. There is lots of support available to help you stop.

Some studies suggest that stopping smoking may decrease the risk of non-invasive bladder cancer coming back in the bladder.

Smoking is a major risk factor for bladder cancer and other cancers such as lung cancer. It also increases the risk of heart disease.

We have a booklet called **Giving up smoking** that you may find helpful.

Just Can't Wait toilet card

Some treatments for bladder cancer can make you want to go to the toilet more often. You may also feel that you can't wait when you do want to go. Carrying a Just Can't Wait card may help you get access to a toilet more quickly when you're out. You can show it to staff in places like shops or pubs. The card allows you to use their toilets without them asking awkward questions. You can get the cards from the Bladder and Bowel Foundation – see page 78 for details.

Macmillan also has a toilet card that can help you access toilets. Call us on **0808 808 00 00** or visit **[be.macmillan.org.uk](https://www.be.macmillan.org.uk)** to request one.

The National Key Scheme (NKS) offers access to about 9,000 locked public toilets across the UK. You can buy a key from Disability Rights UK (see page 82). They can also send you details of where the toilets are located.

Well-being and recovery

Most people with non-invasive bladder cancer will be cured or will have their cancer controlled for many years. You may find that the cancer doesn't affect your life very much after the treatment is over.

Keeping in contact with friends and doing day-to-day things can reassure you that life hasn't changed too much. An experience of cancer may help some people decide on new priorities in their lives. This may mean spending more time with family, going on a special holiday or taking up a new hobby. Just thinking about these things and making plans can help you realise you still have choices.

There are also other things you can do to help improve your well-being and recovery.



Looking after yourself and making positive choices

After cancer treatment, you need time to recover. Looking after yourself is an important part of this. You may have had a healthy lifestyle before cancer, but some people might choose to make lifestyle changes. You may feel you want to focus more on making the most of your health.

We've included some information on the next couple of pages that may help you.

Keep to a healthy weight

If you feel you need to lose weight, you can ask your GP for advice and find out what your ideal weight is. Keeping to a healthy weight reduces the risk of some other cancers, heart problems and illnesses such as diabetes.

Here are some tips to help you lose weight:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less fat and sugar
- be more physically active.

Our booklet **Managing weight gain after cancer treatment** has some helpful tips.

Eat healthily

Eating healthily will give you more energy and help you recover. Try to eat plenty of fresh fruit and vegetables (five portions a day). If you eat meat, reduce the amount of red meat and eat more chicken and fish.

There's more information in our booklet **Healthy eating and cancer**.

Get physically active

Being physically active helps you feel less stressed and will give you more energy. It also keeps your weight healthy and reduces the risk of other health conditions.

We have a booklet called **Physical activity and cancer**, which has more information.

Stick to sensible drinking guidelines

Current guidelines recommend that men and women should drink no more than 14 units of alcohol in a week. They also suggest you should spread any alcohol units you drink over three or more days. It's a good idea to have a couple of alcohol-free days each week.

'This has made me realise that maybe I should take life more easily. It's something that I really watch out for now.'

Alex

Getting more information about your treatment

Understanding the cancer and its treatment helps many people to cope. It can help you discuss plans for treatment, tests and check-ups with your doctors and nurses. This means you can play a real part in the decisions that are made. Being involved in these choices builds confidence and can help you get back control of your life.

Complementary therapies

Finding a complementary therapy that helps you to relax can also be a positive way of dealing with anxiety and stress. We have a booklet called **Cancer and complementary therapies** that we can send you.



Who can help?

Many people are available to help you and your family, if you need them.

Various people can offer support in the community. **Continence nurses and physiotherapists** can help with bladder problems. Your urologist or GP can refer you for assessment. **District nurses** work closely with GPs and make regular visits to some patients and their families at home. Let your GP know if you're having any problems so that more home care can be arranged if needed. The **hospital social worker** can give you information about social services and other benefits you may be able to claim while you're having treatment.

If you find that the impact of the cancer has left you feeling anxious or depressed, let your doctor or nurse know. They can refer you to a doctor or counsellor experienced in helping with the emotional problems of people affected by cancer.

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

If you find it difficult to talk about your cancer, you might find it helpful to read our booklet **Talking about your cancer**.

Your relationships

The experience of cancer may have improved your relationships with people close to you. The support of family and friends may have helped you cope. But cancer is stressful, and this can have an effect on relationships. Any problems usually improve over time, especially if you can talk openly about them.

Your partner

Some couples become closer through a cancer experience. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between couples who've been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse.

Even couples that are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help you understand each other. Our booklet **Cancer, you and your partner**, may help.

Treatment for bladder cancer may affect your sex life. You may have pain or discomfort in your bladder or urethra. This can make sex uncomfortable. Following the bladder health advice (pages 54–55) can help. If you have any worries about sex, talk to your urologist or specialist nurse. They can help with advice and support.

Our booklets **Sexuality and cancer – information for women** and **Sexuality and cancer – information for men** have more information that can help.

Family and friends

Your family and friends may not always understand if you aren't feeling positive about getting on with things, and may not know how big an effect treatment is having on your life. Talking about how you feel will help them give you the support you need.

Our booklet **Talking about cancer** has more useful tips.

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. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **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 may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

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

Talking to children

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

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

Teenagers

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

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



WORK AND FINANCIAL SUPPORT

Financial help and benefits

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Work

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Financial help and benefits

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

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

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

There are two different types of ESA:

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

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

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

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

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

Help for carers

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

More information

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

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 81). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at [macmillan.org.uk/gettingfinancialhelp](https://www.macmillan.org.uk/gettingfinancialhelp) useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 81–82.

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



Work

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

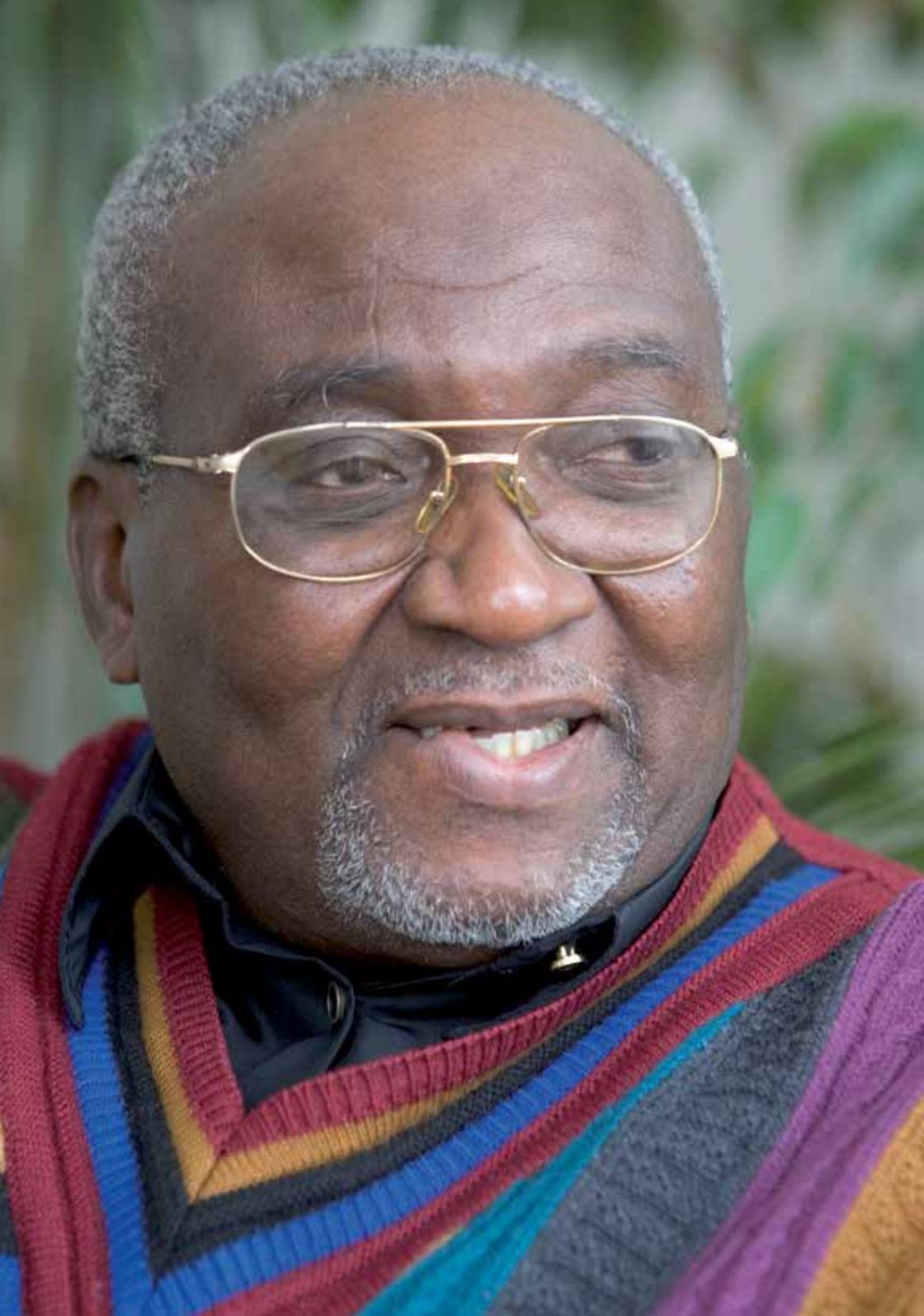
Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

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

Employment rights

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

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



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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.

All of our information is also available online at **macmillan.org.uk/cancerinformation**. There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- ebooks
- large print
- translations.

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

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. No one should face cancer alone.

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

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

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

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** or call us on **0808 808 00 00**.

Talk to others

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

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)



Macmillan's My Organiser app

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

Other useful organisations

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

Bladder cancer support organisations

Action on Bladder Cancer (ABC)

6 Trull Farm Buildings,
Tetbury,
Gloucestershire GL8 8SQ

Email

info@actiononbladder
cancer.org

www.

actiononbladdercancer.org

Works with healthcare professionals, patients, carers and the general public to help improve the care of people with bladder cancers.

Fight Bladder Cancer

The Loft,
Robert House,
19 Station Road,
Chinnor,
Oxfordshire OX39 4PU

Email

info@fightbladdercancer.co.uk

www.

fightbladdercancer.co.uk

A national charity providing information and support to all people affected by bladder cancer. Also supports research into causes, treatments and better patient aftercare.

Organisations that help with bladder problems

Bladder and Bowel Foundation

SATRA Innovation Park,
Rockingham Road,
Kettering,
Northants NN16 9JH

Helpline 0845 345 0165

Email info@bladderandbowel
foundation.org

www.bladderandbowel foundation.org

A UK-wide charity that provides information, advice and support for a range of symptoms and conditions related to the bladder and bowel.

Urostomy Association

4 Demontfort Way,
Uttoxeter ST14 8XY

Tel 01889 563 191

Email

secretary.ua@classmail.co.uk

www.

urostomyassociation.org.uk

Aims to help anyone who has had surgery that's resulted in a urinary diversion, such as a urostomy, continent urinary pouch or neo-bladder.

General cancer support organisations

Cancer Black Care

79 Acton Lane,
London NW10 8UT

Tel 020 8961 4151

Email

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

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

Cancer Focus

Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX

Tel 0800 783 3339

(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

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

Cancer Support Scotland

Calman Cancer Support Centre,
75 Shelley Road,
Glasgow G12 0ZE

Tel 0800 652 4531

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.

Irish Cancer Society

43–45 Northumberland Road,
Dublin 4,
Ireland

Tel 1800 200 700

(Mon–Thu, 9am–7pm,
Fri, 9am–5pm)

Email helpline@irishcancer.ie

www.cancer.ie

National cancer charity offering information, support and care to people affected by cancer. Has a helpline staffed by specialist cancer nurses. You can also chat to a nurse online and use the site's message board.

Maggie's Centres

1st Floor,
One Waterloo Street,
Glasgow G2 6AY

Tel 0300 123 1801

Email

enquiries@maggiescentres.org

www.maggiescentres.org

Maggie's Centres provide information about cancer, benefits advice, and emotional or psychological support.

Tenovus

Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD

Tel 0808 808 1010

(Mon–Sun, 8am–8pm)

www.tenovus.org.uk

Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

Counselling and emotional support**British Association for Counselling and Psychotherapy (BACP)**

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

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Samaritans

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

Tel 08457 90 90 90

Email jo@samaritans.org

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

UK Council for Psychotherapy (UKCP)

2nd Floor,
Edward House,
2 Wakley Street,
London EC1V 7LT

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.

Organisations that help with sexual difficulties

College of Sexual and Relationship Therapists

PO Box 13686,
London SW20 9ZH
Tel 020 8543 2707

Email info@cosrt.org.uk

www.cosrt.org.uk

The national specialist charity for sex and relationship therapy. Previously known as the British Association for Sexual and Relationship Therapy.

The Institute of Psychosexual Medicine

Building 3,
Chiswick Park,
566 Chiswick High Rd,
London W4 5YA

Tel 020 7580 0631

Email admin@ipm.org.uk

www.ipm.org.uk

Provides a list of accredited doctors who accept psychosexual referrals. The list gives details of doctors and clinics, both private and NHS-run throughout the UK.

The Sexual Advice Association

Tel 020 7486 7262

Email info@sexualadviceassociation.co.uk

www.sda.uk.net

Aims to help improve the sexual health and well-being of men and women.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Tel 0800 220 674

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

Textphone 0800 243 787

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

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

Citizens Advice

Gives advice on financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

England and Wales
www.citizensadvice.org.uk

Scotland
www.cas.org.uk

Northern Ireland
www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk**

Department for Work and Pensions Disability Benefits Helpline

08457 123 456

(Textphone 0845 722 4433)

Personal Independence Payment Helpline

0845 850 332

(Textphone 0845 601 6677)

Carer's Allowance Unit

0845 608 432

(Textphone 0845 604 5312)

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

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

GOV.UK

www.gov.uk

Has comprehensive information about social security benefits and public services.

Personal Finance Society – ‘Find an Adviser’ service

www.findanadviser.org

Use the website to find qualified financial advisers in your area.

Unbiased.co.uk

Email

contact@unbiased.co.uk

www.unbiased.co.uk

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

Equipment and advice on living with a disability

British Red Cross

UK Office,

44 Moorfields,

London EC2Y 9AL

Tel 0844 871 11 11

Email

information@redcross.org.uk

www.redcross.org.uk

Offers a range of health and social care services such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

12 City Forum,

250 City Road,

London EC1V 8AF

Tel 020 7250 3222

Email

enquiries@disabilityrightsuk.org

www.disabilityrightsuk.org

Provides information on social security benefits and disability rights.

Disabled Living Foundation (DLF)

380–384 Harrow Road,

London W9 2HU

Tel 0845 130 9177

(Mon–Fri, 10am–4pm)

Email helpline@dlf.org.uk

www.dlf.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

Support for older people

Age UK

Tavis House,
1–6 Tavistock Square,
London WC1H 9NA
Tel (England and Wales)
0800 169 6565

Tel (Scotland)
0845 125 9732

Tel (Northern Ireland)
0808 808 7575
(Daily, 8am–7pm)

www.ageuk.org.uk

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

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)

Tel (England) 0844 800 4361

Tel (Scotland) 0141 221 5066

Tel (Wales) 0292 009 0087

Email support@carers.org

www.carers.org and

www.youngcarers.net

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Tel (England, Scotland, Wales)
0808 808 7777

Tel (Northern Ireland)
028 9043 9843

(Wed–Thu, 10am–12pm
and 2–4pm)

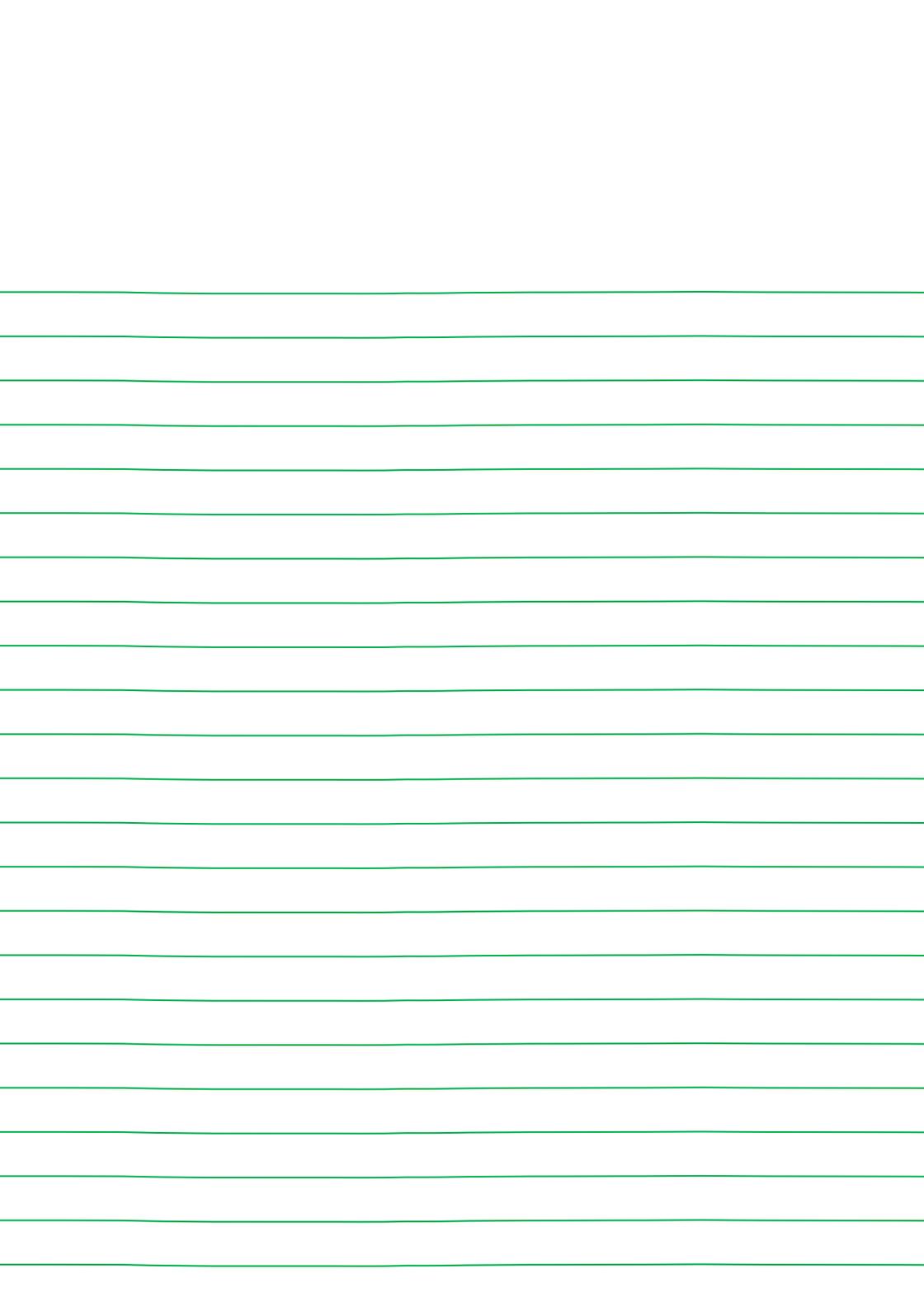
Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.



You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.



Disclaimer

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

With thanks to: Paula Allchorne, Uro-Oncology Nurse Specialist; Sue Amery, Clinical Nurse Specialist for Bladder Cancer; Mark Fenely, Consultant Urological Surgeon; Param Mariappan, Consultant Urological Surgeon; Hugh Mostafid, Consultant Urological Surgeon; and Kay Thomas, Consultant Urological Surgeon. Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

Sources

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

European Association of Urology. *Guidelines on Non-muscle-invasive Bladder Cancer (Ta, T1 and CIS)*. 2015.

Nargund et al. *Urology Oncology*. Springer. 2008.

National Institute of Health and Care Excellence (NICE). *Bladder Cancer: diagnosis and management*. NG2. February 2015.

National Institute of Health and Care Excellence (NICE). *Suspected cancer: recognition and referral*. NG12. June 2015.

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Signature

Date / /

Don't let the taxman keep your money

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

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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



If you'd rather donate online go to macmillan.org.uk/donate

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

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

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

Together, we are all Macmillan Cancer Support.

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

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available. Braille and large print versions on request.

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CANCER SUPPORT**