Understanding non-muscle-invasive bladder cancer

> **"I used the Macmillan website and information leaflets extensively. They were very helpful for understanding the technical side of things, and for information about dealing with the aftermath and side effects."**

Amuz, diagnosed with non-muscle-invasive bladder cancer

About this booklet

This booklet is about non-muscle-invasive bladder cancer (NMIBC). It is for anyone who is having tests or treatment for this type of cancer. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of bladder cancer, and how non-muscle-invasive bladder cancer is diagnosed and treated. It also has information about feelings, practical issues and money.

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.

This booklet does not have information about muscle-invasive and advanced bladder cancer. We have another booklet about this called **Understanding muscle-invasive and advanced bladder cancer** (page 104).

How to use this booklet

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

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

On pages 110 to 123, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (page 124).

Quotes

In this booklet, we have included quotes from people who have had bladder cancer, which you may find helpful. These are from people who have chosen to share their story with us. This includes Amuz, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

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

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

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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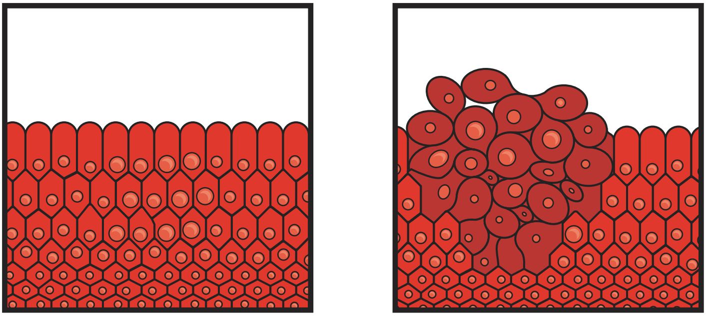
What is cancer?

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

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

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

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

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

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

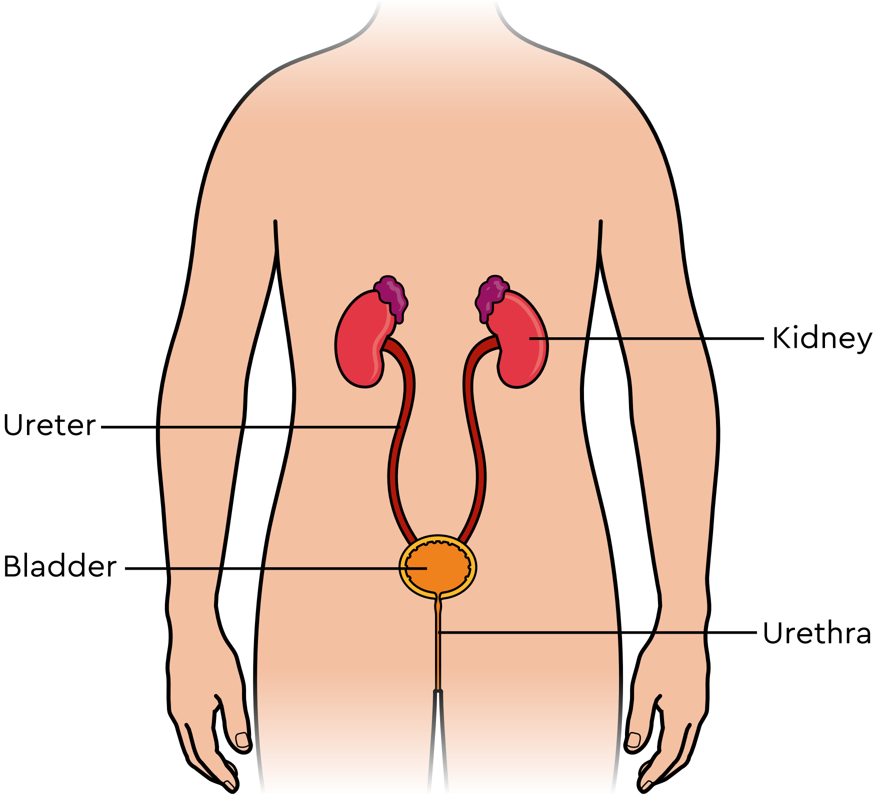
Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another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

The bladder

The bladder is a hollow and muscular organ that collects and stores pee (urine).

It is in the lower part of the tummy (abdomen), called the pelvis. This is the area between the hips.

The bladder in the body



What does the bladder do?

The bladder collects and stores pee. It can usually hold about 300 to 400ml of pee. Pee is made of water and waste products. It is made in the kidneys and moves from the kidneys to the bladder through long tubes called ureters.

As your bladder fills with pee it expands to store it. When it is full, it sends messages to the brain. These are called nerve signals. They make you feel like you need to pee (pass urine).

When you need to pee, the urine exits your bladder through a tube called the urethra. The urethra opens in front of the vagina, or at the tip of the penis.

The bladder and urethra are supported by the pelvic floor muscles. The muscle that wraps around the urethra is called the urethral sphincter. It works like a valve to keep the opening at the bottom of the bladder closed until you want to pee.

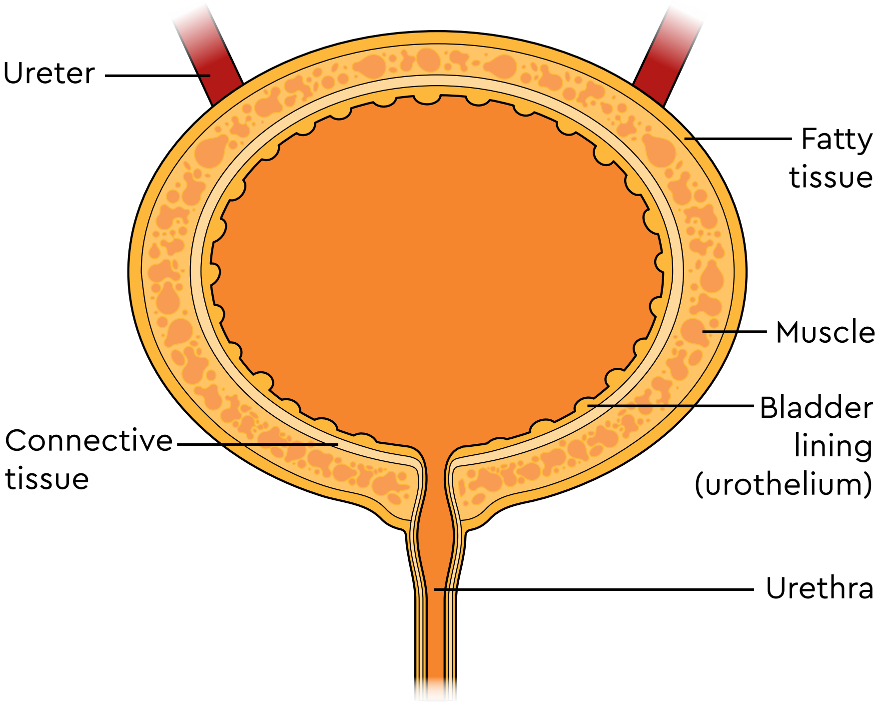
To empty your bladder, the pelvic floor muscles relax to open your urethral sphincter. At the same time, the bladder muscles tighten to push the pee out.

The layers of the bladder

The bladder wall is made of the following 4 layers:

- An inner lining made up of cells called urothelial or transitional cells. This is called the urothelium. It stops pee being absorbed back into the body.
- A layer of connective tissue.
- A layer of muscle, called the detrusor muscle.
- An outer layer of fatty tissue.

The bladder



Bladder cancer

Bladder cancer is often described using the following terms. These explain whether the cancer is only in the bladder lining or has spread through the wall of the bladder.

- Non-muscle-invasive bladder cancer – the cancer cells are in the inner lining or the connective tissue that surrounds the inner lining of the bladder. They have not spread into the muscle layer.
- Muscle-invasive bladder cancer – the cancer is in the muscle layer of the bladder or has spread through the muscle into the fat layer. It has not spread outside the bladder.
- Locally advanced bladder cancer – the cancer has spread outside the bladder into nearby tissues, the prostate, vagina, ovaries, womb or back passage (rectum). It may also be in lymph nodes in the pelvis, near the bladder.
- Advanced bladder cancer – the cancer has spread to other parts of the body.

We have information about other bladder cancer types in our booklet **Understanding muscle-invasive and advanced bladder cancer** (page 104).

Causes and risk factors

In the UK, over 10,000 people are diagnosed with bladder cancer each year. The actual number is likely to be higher than this because of the way this information is collected.

There are certain things that can affect the chances of developing bladder cancer. These are called risk factors.

Having a risk factor does not mean you will get bladder cancer. And not having risk factors does not mean that you will not get it.

Like other cancers bladder cancer is not infectious. You cannot catch it or pass it on to other people.

Age

Bladder cancer is more common in people over the age of 60. It is less common in people under the age of 40.

Smoking

Smoking may cause about 5 in 10 bladder cancers (50%). Chemicals that can cause bladder cancer are found in cigarette smoke. These chemicals eventually go into the pee (urine) through the blood. They can damage the cells that line the bladder. Over many years, this may cause bladder cancer.

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

Sex assigned at birth

Bladder cancer is more common in men than in women.

Exposure to chemicals at work

Exposure to certain chemicals can increase your risk of bladder cancer. 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 and health and safety guidelines at work have improved. But it can take more than 30 years after exposure to them for bladder cancer to develop.

You may be able to claim Industrial Injuries Disablement Benefit if you think chemicals at your work may have caused the cancer. The Department for Work and Pensions has more information about this. Visit **gov.uk/dwp** If you live in Northern Ireland, visit **nidirect.gov.uk** You can also call a Macmillan money adviser on **0808 808 00 00**.

Urinary tract infections (UTIs)

Repeated urinary tract infections (UTIs) and untreated bladder stones are linked to a less common type of bladder cancer called squamous cell cancer.

Bladder schistosomiasis

An untreated infection called schistosomiasis may cause bladder cancer. This infection is caused by a worm that lives in fresh water. This worm is a parasite. It is found in Africa, Asia, South America and the Caribbean. This infection is rare in the UK.

Catheters

Having a catheter in for a long time can increase your risk of bladder cancer.

Previous treatment for cancer

People who have had radiotherapy to the pelvis have a higher risk of developing bladder cancer. People who have had the chemotherapy drug cyclophosphamide also have an increased risk. But the benefits of cyclophosphamide treatment far outweigh the risk of developing bladder cancer. We have information about pelvic radiotherapy and chemotherapy drugs on our website (page 104).

Pioglitazone

A drug called pioglitazone is used to treat diabetes. It may increase the risk of developing bladder cancer. This risk is small and may depend on how long you have taken the drug for and at what dose. Talk to your doctor if you are concerned about this. Other medicines for diabetes are not linked to bladder cancer.

Family history

If you have a close family member who has had bladder cancer, you may have a slightly higher chance of developing it. This could be because people in the same family may share certain risk factors, such as smoking.

Types of bladder cancer

There are different types of bladder cancer. These are named after the cell they started in.

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

Less common types of bladder cancer include:

- squamous cell carcinoma
- adenocarcinoma
- small cell bladder cancer.

These start from different types of cells in the bladder lining. They are usually muscle-invasive bladder cancers. We have more information about this in our booklet **Understanding muscle-invasive and advanced bladder cancer**.

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

Symptoms of bladder cancer

Many people with these symptoms will not have bladder cancer. They can be caused by an infection or stones in the bladder or kidney. But if you have any symptoms, it is important to get them checked by your GP. The earlier bladder cancer is diagnosed, the more likely it is to be cured.

We understand that having any symptoms that could be cancer is worrying. The most important thing is to talk to your GP as soon as possible.

Blood in your pee (urine)

Blood in your pee is called haematuria. It is the most common symptom of bladder cancer. It can happen suddenly and may come and go. Your pee may look pink, red or sometimes brown. You may see streaks or clots of blood in it. If you see blood in your pee, it is important to get it checked by your GP as soon as possible.

Sometimes blood in your pee cannot be seen and is found during a urine test. This is called non-visible haematuria. If you have urinary symptoms your GP will ask you to give them a sample of urine. They test this for non-visible blood.

Urinary symptoms

You may:

- have a burning feeling when peeing (passing urine)
- need to pee more often
- need to rush to the toilet to pee
- have difficulty peeing
- feel like you have not completely emptied your bladder after peeing.

These symptoms are usually caused by an infection, an overactive bladder or an enlarged prostate rather than cancer. Some people may need more tests to find out the cause of their symptoms or because they have repeated urinary tract infections (UTIs).

Pain in the lower part of the tummy or back

Pain in the lower part of your tummy, below your belly button, is called pelvic pain. This type of pain, or pain in your lower back, are less common symptoms of bladder cancer. But it is important to get them checked by your GP.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"I was having discomfort and pain associated with going to the toilet. I would suddenly need the toilet, and it had to happen straight away. I dismissed it for a while. Then I went to see the GP and told them something was wrong. They sent me straight for a scan."

Alex, diagnosed with bladder cancer

How bladder cancer is diagnosed

If you have any symptoms, you should see your GP. They can test your pee (urine) for blood and send it to a lab to check for a urine infection (UTI). They may also send the pee away to be tested for cancer cells.

They may examine you internally. This is because the bladder is close to the bowel, and the prostate or womb. The doctor inserts a gloved finger into the back passage (rectum) or vagina. This is called an internal examination. They will feel to see if there are any obvious changes.

If your GP thinks you may have cancer or is not sure what is causing your symptoms, they will refer you to a urologist. This is a doctor who treats bladder and kidney problems. Or you may see a nurse called a urology nurse specialist.

If tests or symptoms suggest you could have bladder cancer, your GP will refer you urgently. This means you should get a specialist appointment as soon as possible.

Most people see the nurse or doctor at a haematuria clinic or at a hospital's urology department. You may have the following:

- A cystoscopy is the main test to check for signs of cancer inside the bladder (pages 24 to 26).
- The doctor or nurse may test your pee for cancer cells. It may also be tested for substances that are found in bladder cancer. This is called molecular testing.
- You may have another internal examination.
- You may have blood tests to check how well your kidneys and liver are working, and to show the number of blood cells in the blood.

Your doctor or nurse will arrange for you to have further tests if they think you need them.

"The diagnosis didn't really sink in. I went through diagnosis, surgery and treatment still trying to process it. Part of me wondered, why me? Something that helped was understanding I couldn't really affect the outcome. "

Amuz

Cystoscopy

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 the bladder.

There are different types of cystoscopy. Your doctor or nurse will talk to you about the type of cystoscopy you are having. They will explain how to prepare and what to expect after the test.

Sometimes extra imaging techniques are used to help to see if there is any cancer in the bladder. These may include the following:

- Narrow band imaging (NBI) – the doctor or nurse shines light at specific blue and green wavelengths on the inside of the bladder to look for bladder cancer.
- Blue light cystoscopy or photodynamic diagnosis (PDD) – a doctor or nurse puts a light-sensitive dye into the bladder through a tube called a catheter. This dye is absorbed by any cancer cells. During the cystoscopy, the doctor uses a special camera and a blue light to look for these cells.

These are not available at every hospital. Your doctor or nurse can give you more information.

Flexible cystoscopy

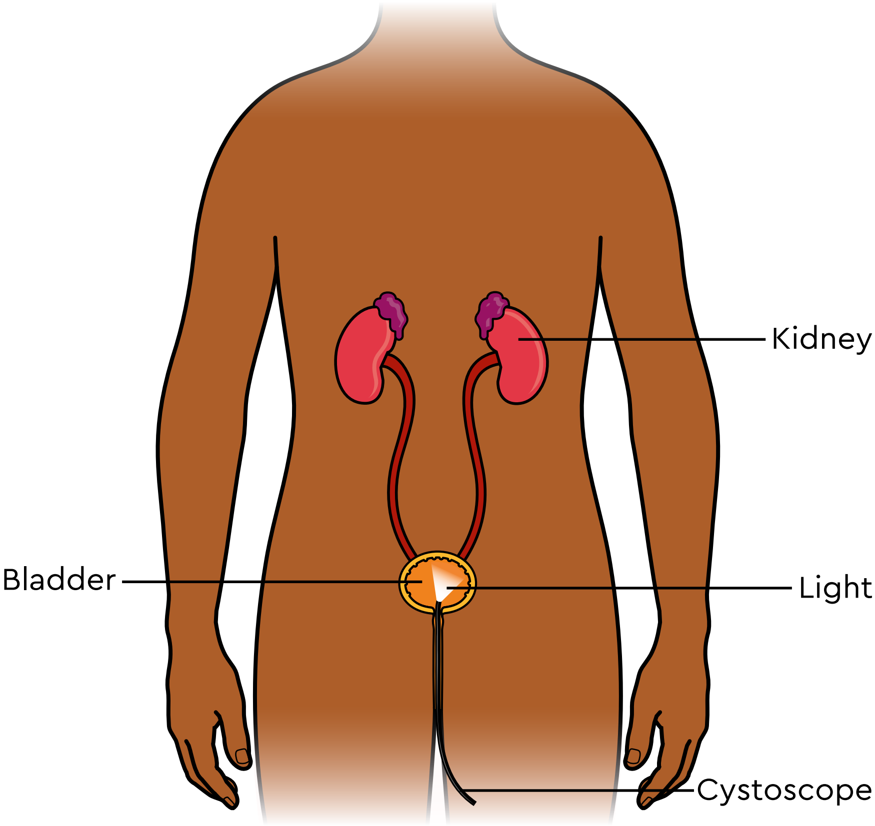
A flexible cystoscopy uses a cystoscope that can bend.

The doctor or nurse squeezes a numbing gel into the opening of your urethra. This is a local anaesthetic and makes the procedure less uncomfortable. The gel starts to work after a few minutes. The doctor or nurse then gently passes the cystoscope through the urethra into the bladder.

The light from the cystoscope helps them look closely at the lining of the bladder and urethra. They may also put sterile water into the bladder to help them see more clearly.

The test takes a few minutes. You may feel some discomfort during the procedure, but it should not be painful. Before you go home you have to pee (pass urine).

Cystoscopy



Rigid cystoscopy

A rigid cystoscope cannot bend. During this test, the doctor passes surgical instruments through the cystoscope to:

- remove a tumour in the bladder – this is called a transurethral resection of bladder tumour or TURBT (pages 52 to 59)
- take a small piece of tissue for tests – this is called a biopsy.

You may have this done:

- under a general anaesthetic, which means you are asleep
- using a spinal anaesthetic, which means the lower part of your body is numb – you are awake during the test, but you cannot feel anything.

After the cystoscopy you may be able to go home on the same day, or you may have to stay in hospital while you recover.

Cystoscopy side effects

You may have some burning or mild pain when you pee (pass urine) for a few days after the test. You may also notice some blood or blood clots in your pee. This should get better after 1 or 2 days. Your doctor will ask you to drink about 2 litres (3½ pints) of fluid. This will help flush out your bladder.

Tell your doctor straight away if these symptoms do not go away or if you have a high temperature, or smelly or cloudy pee. They can check to make sure you do not have an infection.

Ultrasound scan

An ultrasound scan uses sound waves to build up a picture of the inside of the body. It can show anything unusual in the urinary system. You will be asked to drink plenty of fluids so that the bladder can be seen more easily. This may be uncomfortable, but you will be able to pee (pass urine) as soon as the scan is over. If you have any concerns about this, talk to the person doing the scan.

For the scan you will lie on your back and the person doing the scan will try to make you comfortable. They spread a cold gel over your tummy (abdomen) and pass a small device that makes sound waves over the area. The sound waves are then turned into a picture by a computer. The scan is painless and takes about 15 to 20 minutes.

CT urogram

CT urogram uses a series of x-rays to build up a 3D picture of the bladder, ureters and kidneys. You will be told how to prepare for the test. Before the test, you can usually eat and drink normally. Just before the test you may be asked to empty your bladder.

You will be given an injection of a dye. The dye travels through the bloodstream to the kidneys. The doctor looks at a screen to see the dye passing through the kidneys and ureters. This helps them see your bladder, ureters and kidneys more clearly.

The dye 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, because you could have a stronger reaction to the injection.

You should also tell your doctor if you have kidney problems or diabetes, particularly if you take metformin. You will need a blood test before the scan to check how well your kidneys are working.

The scan is painless. It takes about 15 to 20 minutes. You may be in the department for about an hour.

You should be able to go home after the scan.

Other tests

You may also have scans such as a CT, MRI or PET-CT to check areas near the bladder, or to look for signs of cancer in other areas of the body.

MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of the body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips. Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of a dye called a contrast. This helps show certain areas of the body more clearly.

During the scan, you need to lie still on a bed inside a long cylinder (tube). If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan.

The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

We have more information about having an MRI scan on our website. Visit **macmillan.org.uk/mri-scan**

Preparing for a CT scan

CT scan

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

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

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

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information about having a CT scan on our website. Visit **macmillan.org.uk/ct-scan**

PET-CT scan

You may have a PET scan and a CT scan together. This is called a PET-CT scan. A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body. It can give more detailed information about cancer or abnormal areas seen on x-rays, CT scans or MRI scans.

We have more information about having a PET-CT scan on our website. Visit **macmillan.org.uk/pet-ct-scan**

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation can also provide support (pages 110 to 123). Or you can talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Staging and grading

Your cancer doctor needs certain information about the cancer to advise you on the best treatment for you. This includes the stage of the bladder cancer and its grade. They get this information from the tests you have. If you have surgery to remove bladder cancer, they may get information from this too.

Bladder cancer staging describes:

- how far it has grown into the bladder
- whether it has spread from where it first started.

Non-muscle-invasive bladder cancer means the cancer cells are either in the:

- inner lining called the urothelium
- connective tissue that surrounds the inner lining of the bladder.

The most commonly used bladder cancer staging system is the TNM system (pages 34 and 35).

TNM staging

The TNM staging system uses letters and numbers to describe the bladder cancer.

T stands for **t**umour – this explains how far the tumour has grown into the bladder, and how far it has spread into the surrounding tissue.

Non-muscle-invasive bladder cancer can be staged as carcinoma in situ (**CIS**), **Ta** or **T1**:

- Carcinoma in situ (CIS) is sometimes described as a flat tumour. The cancer cells are only in the inner layer of the bladder lining (urothelium).
- Ta means the tumour is a mushroom-like growth (papillary cancer). It is only in the inner layer of the bladder lining.
- T1 means the tumour has started to grow into the layer of connective tissue, beneath the bladder lining.

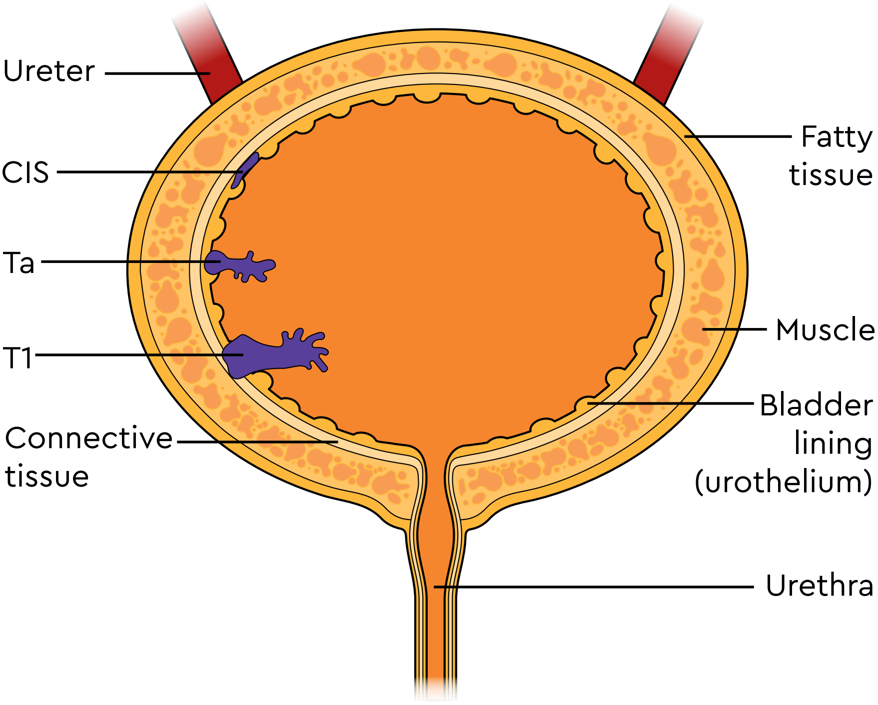
Some people may have both Ta papillary cancer and CIS.

N stands for **n**odes – this explains whether the tumour has spread to lymph nodes.

M stands for **m**etastasis – this is whether the tumour has spread to another part of the body. This is called secondary or metastatic cancer.

Your doctor or specialist nurse can tell you more about the stage of the bladder cancer you have.

Staging non-muscle-invasive bladder cancer



Grading

Bladder cancer grading is about how the cancer cells look under a microscope compared with normal cells. With non-muscle-invasive bladder cancer, grading is used to help your doctor plan your treatment.

Bladder cancer grades are:

- grade 1 – the cancer cells look very similar to normal bladder cells, they are usually slow-growing and are less likely to spread
- grade 2 – the cancer cells look less like normal cells and are slightly faster growing
- grade 3 – the cancer cells look very different to normal cells and usually grow more quickly.

Your doctor may combine the stage and grade of the tumour when talking about your results. For example, they may say you have a **TaG1** tumour. This means it is stage **Ta** and a grade 1 tumour.

Doctors may also use another bladder cancer grading system:

- low-grade – the cancer cells are slow-growing and are less likely to spread
- high-grade – the cancer cells grow more quickly and are more likely to spread.

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

Your doctor may combine the 2 grading systems. They can tell you more about grading.

> “It was only when I spoke to my Macmillan nurse that I fully understood that I had bladder cancer. I'd never even heard of bladder cancer before. The nurse was able to break it down for me in really simple terms.”

Ali, diagnosed with bladder cancer

Risk levels

Your doctor will look at what risk level the tumour is. This means the risk of the cancer spreading into the muscle of the bladder or the risk of it coming back. To decide the risk level, your doctor looks at:

- the size of the tumour
- how far the tumour has grown into the bladder (T stage)
- how many tumours there are
- the grade of the tumour
- if you have already had non-muscle-invasive bladder cancer in the last year.

Non-muscle-invasive bladder cancer can be grouped into:

- low-risk
- intermediate-risk
- high-risk.

Your doctor or specialist nurse can give you more information about risk groups.

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 (page 123).

Treating bladder cancer

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Treatment overview

Treatment for non-muscle-invasive bladder cancer usually depends on what risk level the tumour is (page 38). This means the risk of the cancer spreading into the muscle of the bladder or the risk of it coming back.

Your cancer doctor or nurse will talk to you about the different treatment options and things to think about when making treatment decisions.

Take some time to think about the information you have and ask more questions if you need to. You may find it helpful to look at our information on making decisions about bladder cancer treatment (pages 47 and 48).

> **"Reading through the Macmillan Online Community gave me hope. Reading other peoples experiences and seeing them express how they felt let me know I wasn't alone."**
>
> Amuz

Surgery

Surgery during a cystoscopy is the main treatment for non-muscle-invasive bladder cancer. Most people have an operation called a transurethral resection of the bladder tumour (TURBT) – pages 52 to 59.

You usually have chemotherapy into the bladder (intravesical) immediately after surgery (pages 61 to 65). You can usually go home on the same day as your operation or 1 to 3 days after.

Further treatment

If you have a low-risk tumour, you will have a TURBT and chemotherapy into the bladder (intravesical) straight after this. You will not need any further treatment.

If you have an intermediate-risk or high-risk tumour, you usually need further treatment with chemotherapy or an immunotherapy drug called BCG. Both are given into the bladder. High-risk bladder cancer is usually treated with BCG.

Your doctor may suggest having surgery to remove the bladder if you have a high-risk cancer or further treatments are not working. This surgery is called a cystectomy. This can be a difficult decision to make. It is important to talk to your doctor about all your treatment options and what support is available to you.

Other treatments

Sometimes other treatments are used to treat non-muscle-invasive bladder cancer. Your doctor or nurse will tell you if they are suitable for your situation.

Stop smoking

If you smoke, your doctor will usually advise you to stop. If you do not stop smoking, this should not affect the treatment plan your doctors offer you. But stopping smoking can:

- make your treatment more effective
- reduce the side effects of treatment
- reduce the risk of bladder cancer coming back.

Your hospital doctor or GP can offer different treatments to help you stop. Your hospital doctor, nurse or GP can refer you to a stop-smoking service in your area.

How treatment is planned

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

The MDT look at national treatment guidelines or the latest evidence for bladder cancer. If you have any treatment preferences, your doctor or nurse will share them with the MDT.

The MDT will usually include the following professionals:

- Urologist – a doctor who treats problems with the kidneys, bladder and male reproductive system.
- Oncologist – a doctor who treats people who have cancer.
- Urology specialist nurse – a nurse who gives information about cancer and support during treatment and follow up.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include:

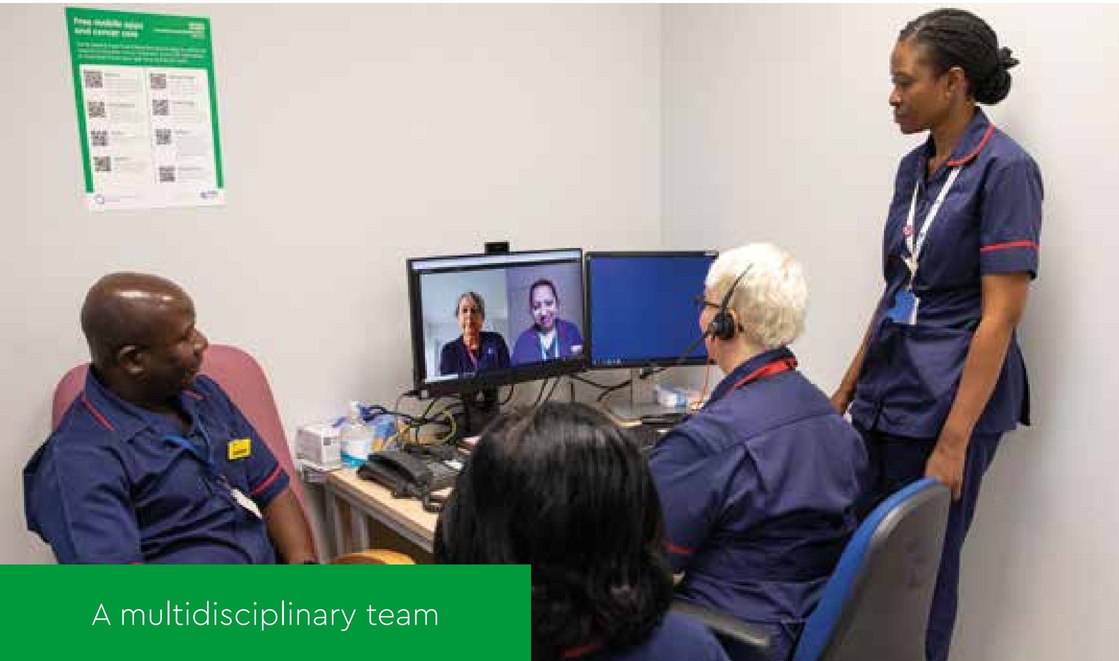
- a dietitian
- a physiotherapist
- an occupational therapist (OT)
- a psychologist or counsellor.

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.



A multidisciplinary team

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor decide together on the best treatment plan for you. Your doctor is an expert in bladder cancer treatments. But you know your preferences and what is important to you.

Doctors sometimes ask you to choose between different treatments. This is usually when 2 treatments work equally well.

It can help to talk to your family or friends about your treatment options. Your doctor or nurse can also help. You do not usually need to decide straight away.

You may also want to talk to other people who have had treatment. Your cancer doctor or nurse may know whether there is a local cancer support group, where you can talk to someone who has had similar treatment. Or you can visit the bladder cancer forum on Macmillan's Online Community to talk with people affected by bladder cancer, share your experience, and ask an expert your questions. Visit **community.macmillan.org.uk/cancer_types/bladder-cancer-forum**

You could write a list of benefits and disadvantages for each treatment. When choosing a treatment, you may want to think about:

- how long you need to have it for
- how it may affect your everyday life
- how much time you will need to spend in hospital
- the different side effects and how they are likely to affect you.

Your doctor or nurse may give you printed information or show you videos about your treatment options. They may also show you online tools to help you make your decision. These may be called decision-making aids. Depending on the treatments you are offered, the information below may also help.

Choosing between BCG or cystectomy

If you have high-risk non-muscle-invasive bladder cancer, your doctor may talk with you about deciding between BCG treatment (pages 66 to 71) or surgery to remove the bladder. This is called a cystectomy (page 60) .

Before suggesting you have a cystectomy, doctors consider other treatments that aim to keep the bladder. They look at the benefits of these treatments, compared to the risk of the cancer spreading. Talking to your doctor or nurse can help you understand the benefits and any possible disadvantages of each treatment. Make sure you have the information you need. This will help you to feel more confident about making the right decision for you. You may also want to talk it over with a partner, family member or friend.

> **"BCG treatment and other alternatives were explained to me by my urologist after 2 operations to remove tumours from the bladder."**
>
> Noel, diagnosed with bladder cancer

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (pages 46 and 47).

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

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment.

Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

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

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion.

Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

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

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

TURBT surgery

Transurethral resection of a bladder tumour (TURBT) is an operation used to take a biopsy or remove cancer from inside the bladder. Transurethral means through the urethra. A TURBT is the main treatment for non-muscle-invasive bladder cancer.

During a TURBT, the surgeon puts a thin, rigid tube called a cystoscope through the urethra into the bladder. They remove the tumour (or tumours) using surgical instruments that are passed through the cystoscope. They may use a mild electrical current to stop any bleeding. This is called cauterisation.

Any tumours removed for biopsy are sent away to the laboratory to be looked at under a microscope. This tells your doctor more about the stage and grade of the cancer (pages 33 to 36).

Getting the results of your TURBT usually takes 2 to 3 weeks. When the results are ready, they are discussed at an MDT meeting (pages 45 to 47). Your doctor will then tell you if you need further treatment.

Before your operation

Before your operation, you will have a pre-operative assessment. You will be allocated a keyworker who will be able to answer any questions you have. You usually have tests to check your general health. These can include:

- blood tests
- a recording of your heart, called an ECG
- a chest x-ray.

The nurse or doctor may ask you for a sample of your urine (pee) to check for any infection. If you have a urine infection, your doctor will give you antibiotics to treat it before surgery.

The nurse or doctor will explain the operation and tell you if there is anything you should do before the operation. This can include instructions about medications or eating and drinking. This is a good time to ask any questions, or to talk about any worries you may have.

> **"Surgery was a success, the surgeon managed to remove 2 tumours from my bladder. These were sent away for testing. A few weeks later my results were back and non-muscle-invasive bladder cancer was confirmed."**
>
> Katherine, diagnosed with bladder cancer

On the day of your operation

A member of the surgical team will talk to you about having a general anaesthetic or a spinal anaesthetic. For a general anaesthetic you are given medicines to make you sleep through the operation. For a spinal anaesthetic, the doctor injects a drug through a thin needle into your back. This numbs the nerves from the waist down. You will be awake during the operation, but you will not feel anything.

You will be asked to wear a hospital gown and elastic stockings called TED stockings during the operation. The stockings help to prevent blood clots in your legs. You will be asked to wear these for some time after the operation.

Having a TURBT takes about 15 to 90 minutes depending on the size and number of tumours in the bladder.

Sometimes, blue-light cystoscopy or narrow-band imaging are used during surgery to help your doctor remove the tumour (or tumours).

Once the cystoscope is removed, a tube called a catheter is put through the urethra into the bladder. This drains urine from the bladder into a collection bag.

After your operation

After your surgery, the nurses will encourage you to start moving as soon as possible. They will also encourage you to do regular leg movements and deep breathing exercises. This helps to prevent problems such as chest infections or blood clots.

You will see blood in your urine at first. This is common and your nurse will monitor it. Drinking fluids will help to flush out your bladder and reduce the risk of getting a urine infection.

Sometimes, a large bag of fluid is connected to the catheter. This flushes out the bladder and helps to stop blood clots forming. The inside of the catheter tube is split so fluid can flow into and out of the bladder at the same time, through different channels. A drainage bag collects urine and fluid as it flows out of the catheter.

If you feel your bladder is full, your tummy feels uncomfortable or if the catheter stops draining, tell your nurse straight away.

Your nurse will take the catheter out when your urine has less blood in it. This may feel a little uncomfortable, but it should not be painful. After the nurse removes the catheter, you may find it uncomfortable to pass urine at first, but this will get better. You may also:

- need to pass urine more often
- need to pass urine urgently
- leak urine
- have some blood in your urine.

These symptoms usually get better in 1 to 2 days. Tell your doctor if they do not get better. Drinking at least 2 litres (3 ½ pints) of fluid every day can help to reduce these symptoms.

Further treatment

Most people have chemotherapy into the bladder straight after a TURBT (pages 61 to 65). This is given through the catheter.

You may have another TURBT 3 to 6 weeks after the first one if:

- you have a high-risk, non-muscle-invasive bladder cancer – this is to make sure all of the tumour has been removed
- your surgeon was unable to remove all of the tumour at your first TURBT
- samples taken during your first operation did not contain cells from the bladder muscle layer – this is to check the cancer has not started to spread into the muscle.

> **"My recovery was good. I was soon getting up and about. Waiting for the test results to find out if the tumour was cancerous was certainly the longest and hardest wait. That was the first time that I used the Macmillan Online Community."**
>
> Alex, diagnosed with bladder cancer

TURBT surgery risks

Having a TURBT is usually a safe procedure. But there are some possible risks or complications.

Urine infection

Some people may get a urinary tract infection (UTI). This can happen in hospital or after you go home. Signs of an infection include:

- pain or burning feeling when you pass urine (pee)
- needing to pass urine more often
- smelly or cloudy urine
- needing to pass urine straight away
- needing to pass urine more often
- blood in your urine
- lower tummy or back pain
- feeling cold, shivery, hot or sweaty.

Tell your doctor if you think you have a urine infection. They can test your urine and give you antibiotics if you need them.

Bleeding

Some people may have bleeding for about 7 to 14 days after the operation. Tell your doctor or specialist nurse straight away if:

- the bleeding becomes heavier
- you see any blood clots in your urine or on toilet paper
- you have difficulty passing urine
- you have tummy pain.

If the bleeding continues, you may need another operation under general anaesthetic to stop it and to remove any clots.

Damage to the bladder

There is a small risk of a hole being made in the bladder during surgery. This is called a perforation. If this happens, your surgeon will explain what treatment you may need. This may be:

- leaving the catheter in the bladder to allow the hole to heal, and then removing it
- an operation to close the hole.

Going home

You can usually go home when you can pass urine without the catheter. This may be on the same day as your operation or 1 to 3 days after. Some people may notice blood in their urine about 10 to 14 days after the surgery. If this bleeding is very heavy, or if you pass blood clots, tell your nurse or doctor straight away.

When you are at home, it is important to follow the advice given by your specialist nurse. You may need to avoid lifting or carrying anything heavy for 2 to 3 weeks. You can try to do some light exercise, such as walking. This can help to build up your energy, so you can slowly get back to your normal activities.

If you work, your doctor or nurse can give you advice about when to go back.

Cystectomy (bladder removal surgery)

A cystectomy is an operation to remove the bladder. Urologists will always consider the different treatments available to try to keep your bladder. But you may be offered a cystectomy for non-muscle-invasive bladder cancer if:

- you have a high-risk, non-muscle-invasive bladder cancer
- BCG treatment (pages 66 to 71) is not working
- the cancer keeps coming back even after treatment.

Sometimes it is possible to have a partial cystectomy. This is not common but means only part of the bladder is removed.

Usually the surgeon removes the whole bladder. This is called a radical cystectomy. They may also remove nearby areas. If the whole bladder is removed, the surgeon also makes a new way for you to pass urine. This is called a urinary diversion. There are different types of urinary diversion. You may have a urostomy, bladder reconstruction or continent urinary diversion.

Your surgeon or specialist nurse will talk to you about which type may be best for you. Having your bladder removed is major surgery. With help and support from family members, friends, health professionals and support organisations, people usually manage to cope with life after a cystectomy well. But it is important to understand what the operation involves.

We have more information about this surgery and having a urinary diversion on our website, and in our booklet **Understanding muscle-invasive and advanced bladder cancer** (page 104).

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells.

Chemotherapy for non-muscle-invasive bladder cancer can be given directly into the bladder. This is called intravesical chemotherapy.

Having intravesical chemotherapy

You usually have intravesical chemotherapy after a transurethral resection of a bladder tumour (TURBT) – pages 52 to 59. The chemotherapy helps to reduce the risk of the cancer coming back in the bladder lining.

If you have a low risk of the cancer coming back, you usually do not need more chemotherapy after this.

If you have an intermediate risk of the cancer coming back, you may have more intravesical chemotherapy. This is usually given once a week for 6 weeks.

After this, you may be offered more intravesical chemotherapy. These are called maintenance doses.

You have chemotherapy into the bladder through a tube called a catheter. This tube goes through the urethra and into the bladder.

The chemotherapy drug used most is mitomycin-C. Sometimes, other chemotherapy drugs may be used, such as gemcitabine or epirubicin. We have more information about these drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs**

After surgery

After surgery to remove a bladder tumour, you will usually have a catheter draining urine (pee) from your bladder into a collecting bag. Your nurse will give the chemotherapy through this tube.

This may happen when you are still in the operating theatre or recovery room. Or you may have it when you go back to the ward.

Your doctor may decide to delay the chemotherapy if either:

- you have a lot of blood in your urine
- there has been any injury to your bladder during surgery.

As an outpatient

You have intravesical chemotherapy in the hospital outpatient department. Your nurse or doctor will give you advice on preparing for your chemotherapy. For example, they will ask you to limit the amount of fluids you drink directly before chemotherapy. This can:

- make it easier for you to keep the chemotherapy in your bladder for the required time – this stops you needing to pass urine (pee) too early
- increase the concentration of the chemotherapy drug in your bladder.

Tell your doctor if you take any medications. People who take water tablets should take them after the treatment. These are called diuretics.

When you arrive for your appointment you will be asked for a sample of urine. Your nurse will check the sample for infection. You will not be given chemotherapy if you are feeling unwell or have a urine infection.

To have the chemotherapy, a nurse passes a tube called a catheter through the urethra and into the bladder. They then slowly put the chemotherapy through the catheter directly into the bladder. The nurse usually then takes the catheter out and asks you not to pass urine for about an hour. This gives the chemotherapy time to work. You can get up and walk around while waiting for the treatment to finish. Your bladder may feel full and a bit uncomfortable, but you can go to the toilet as soon as the treatment is finished.

Sometimes, the nurse leaves the catheter in and clamps it to keep the chemotherapy in your bladder. When the treatment is over, the nurse removes the clamp and the chemotherapy drains into a urine bag. Your nurse then takes the catheter out.

After treatment

Your nurse may ask you to take certain precautions after treatment. This can include things like washing your hands and the skin around your genital area with soap and water after you pass urine. These precautions can be different depending on your hospital. You should follow the advice given by your nurse.

For about 2 days after each treatment, you will usually be asked to drink at least 2 to 3 litres (3½ to 5 pints) of fluid a day. This helps to flush the drug out of your bladder.

You are usually advised not to have sex for at least 48 hours after the treatment as it may be uncomfortable.

Small amounts of chemotherapy can get into your body fluids. This includes fluid made in the vagina and the fluid that contains sperm. To protect any partners, your cancer doctor may advise that for a few days after this treatment you use:

- a condom for vaginal or anal sex
- a condom or a latex barrier such as a dental dam for oral sex.

Your cancer doctor or specialist nurse can give you more information about this.

Your doctor will tell you not to become pregnant or make someone pregnant 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. Your doctor or specialist nurse can give you more information about this.

Side effects of intravesical chemotherapy

Intravesical chemotherapy can irritate the bladder lining. This is called cystitis and may include the following side effects:

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

Cystitis can take up to a week to get better. Drinking 2 to 3 litres (3½ to 5 pints) of fluid a day and taking mild painkillers can help.

Other side effects of intravesical chemotherapy include:

- flu-like symptoms for 2 to 3 days after treatment
- a red rash on your skin – your doctor or nurse can give you creams and advise on how to help
- finding it difficult to pass urine or severe tummy pain
- a urinary tract infection (UTI) – tell your doctor straight away if you have symptoms of a UTI.

Symptoms of a UTI include:

- pain or a burning feeling when you pass urine
- needing to pass urine more often
- smelly or cloudy urine
- needing to pass urine straight away
- blood in your urine
- lower tummy or back pain
- feeling cold, shivery, hot or sweaty.

Tell your doctor straight away if you have these symptoms.

BCG treatment

BCG is short for Bacillus Calmette Guérin. It is a type of immunotherapy drug. Immunotherapy drugs encourage the body's immune system to fight cancer cells. Some people may know BCG as a vaccine used to prevent tuberculosis (TB). But it is also a main treatment for non-muscle-invasive bladder cancer.

For bladder cancer, BCG is given directly into the bladder (intravesical). This can make the bladder react in a way that makes the immune system get rid of cancer cells.

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

When is BCG treatment used?

You may have BCG directly into your bladder after a transurethral resection of a bladder tumour (TURBT) – pages 52 to 59. There are usually at least 2 weeks between the TURBT and the start of BCG treatment. This is to give your bladder enough time to heal from the surgery.

Doctors usually suggest this treatment if you have a high-risk bladder cancer (page 38). It is sometimes used if you have an intermediate-risk bladder cancer. This treatment helps prevent the cancer from coming back in the bladder lining. It also reduces the risk of the cancer becoming muscle-invasive (page 11).

You usually have BCG treatment once a week for 6 weeks. This is called the induction course. Some people then have more BCG treatments. This is called maintenance treatment.

Your doctor will explain how many treatments you will have.

Having BCG treatment

You have this treatment in the hospital outpatient department. Your nurse or doctor will give you advice on preparing for your treatment. For example, they will ask you to limit the amount of fluids you drink 4 to 6 hours before BCG treatment. This can:

- make it easier for you to keep the BCG in your bladder for the required time – this stops you needing to pass urine (pee) too early
- increase the concentration of the BCG in your bladder.

Tell your doctor if you take any medications. People who take water tablets should take them after the treatment. Water tables are also called diuretics.

When you arrive for your appointment you will be asked to pass urine. Your nurse will check this for infection. You will not be given BCG if you are feeling unwell or have a urine infection.

To have the treatment, a nurse passes a tube called a catheter through the urethra and into the bladder. They then slowly put the BCG through the catheter directly into the bladder.

Once the drug is in the bladder, the nurse usually takes the catheter out. They ask you not to pass urine for 2 hours. This gives the BCG time to work.

You can get up and walk around during this time. Your bladder may feel full and a bit uncomfortable but you can go to the toilet as soon as the treatment is finished.

“BCG through a catheter into the bladder was relatively painless. It takes no longer than 2 minutes. I was told after each treatment to go home, relax and not pass urine for 2 hours after. This helps to increase the concentration and effectiveness of the BCG whilst in your bladder.„

Noel, diagnosed with bladder cancer

Some hospitals will let you go home after the BCG has been put into your bladder and the catheter has been taken out. You are still asked not to pass urine for 2 hours. Once the 2 hours have passed you can go to the toilet at home.

Sometimes, the nurse leaves the catheter in and clamps it to keep the BCG in your bladder. When the treatment is over, the nurse removes the clamp and the BCG drains from your bladder into a urine bag. Your nurse then takes the catheter out.

After BCG treatment

It is important to remember that BCG is a live vaccine and other people should not be exposed to it. The nurse will ask you to take certain precautions for 6 hours after treatment. This will protect you and others from coming into contact with the BCG.

You will be asked to do the following:

- Sit down to pass urine. This avoids splashing urine on the toilet seat.
- Wash your hands and skin in and around your genital area with soap and water after you pass urine. This cleans any drops of BCG that may have splashed on to your skin.
- Put undiluted bleach into the toilet bowl after you have passed urine and leave it for 15 minutes before flushing.

For the first few days after each treatment, try to drink 2 to 3 litres (3½ to 5 pints) of fluid a day. This helps to flush the drug out of your bladder.

Talk to your nurse if you are worried. They will tell you what you need to do after treatment.

You are usually advised not to have sex for at least 48 hours after the treatment as it may be uncomfortable.

Small amounts of BCG can get into your body fluids. This includes fluid made in the vagina and the fluid that contains sperm. To protect any partners, your cancer doctor may advise that for a week after this treatment you use:

- a condom for vaginal or anal sex
- a condom or a latex barrier such as a dental dam for oral sex.

Your cancer doctor or specialist nurse can give you more information about this.

Doctors do not yet know how BCG may affect an unborn baby. They will recommend you do not become pregnant or make someone pregnant while having it. You should use effective contraception during treatment. Your doctor or specialist nurse can give you more information about this.

Side effects of BCG treatment

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

- 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 get better in 48 to 72 hours. Tell your doctor straight away if they do not. Taking painkillers can help.

Rare side effects include:

- a continuing high temperature (fever)
- vomiting
- skin rash
- a cough
- a condition called reactive arthritis – this can cause symptoms such as painful joints, symptoms of a urinary tract infection (UTI) and red and sore eyes.

If you have any of these or feel generally unwell, tell your doctor straight away. It could be a sign of a more serious infection due to BCG that needs treatment straight away. If this happens, you will be treated with antibiotic drugs used to treat tuberculosis (TB).

> **"After each treatment of BCG I felt a bit wobbly and maybe even a bit tired. I took the advice to rest. The following day I was up and about."**
>
> Noel, diagnosed with bladder cancer

Other treatments

Sometimes other treatments are used to treat non-muscle-invasive-bladder cancer. Your doctor or nurse will tell you if they are suitable for your situation. These treatments may only be available at some hospitals.

Heated intravesical chemotherapy

For this treatment, a thin tube with a rounded end called a probe applies heat to the bladder lining while chemotherapy is given into the bladder. Or a machine is used to heat the chemotherapy before it goes into the bladder.

Electromotive intravesical chemotherapy

For this treatment, a small electrical current is given into the bladder at the same time as the chemotherapy. This helps the cancer cells absorb more of the chemotherapy drug. This treatment is also called electromotive drug administration (EMDA).

A nurse puts a catheter into the bladder. This catheter contains a wire which is attached to a small machine. Your doctor or nurse usually puts 2 electrode pads on the skin of the tummy (abdomen). These are also attached to the small machine. The chemotherapy is put into the bladder through the catheter. After this, they switch on the machine and it delivers the electrical current.

Sometimes, this treatment is combined with having BCG into the bladder (pages 66 to 71).

Tumour ablation

This treatment uses a laser called an infra-red light during a flexible cystoscopy to burn any areas of cancer away.

This treatment is only available for certain non-muscle-invasive bladder tumours. Your doctor will refer you if they think this treatment may work for you.

Immunotherapy

You may be offered immunotherapies as part of a clinical trial. Immunotherapy drugs use the body's immune system to find and attack cancer cells. You have these drugs into a vein (IV). This type of treatment is being tested for non-muscle-invasive bladder cancer as part of clinical trials. If your urologist thinks a clinical trial may be helpful for you, they can refer you to the hospital doing the trial.

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

Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

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

Taking part in a clinical trial

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

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Taking a blood sample

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part – page 50. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

Follow-up

After treatment for bladder cancer, you will have regular follow-up appointments with your cancer doctor or nurse. At first, these will usually be every 3 to 6 months. If you have any problems or notice new symptoms between appointments, let your doctor or nurse know as soon as possible.

The most important test for follow-up is a cystoscopy (pages 24 to 26). How often you have a cystoscopy depends on the risk of the cancer coming back. High-risk and intermediate-risk tumours need to be monitored more often than low-risk tumours.

You may also have your pee (urine) checked for cancer cells.

It is not uncommon for non-muscle-invasive bladder cancer to come back. If this happens it can usually be cured or controlled for a long time. It can usually be treated with a TURBT to remove it again. Some people may also have chemotherapy or BCG into the bladder.

Your doctor may talk to you about having an operation to remove the bladder (cystectomy). This may be when:

- the cancer keeps coming back and further treatments are not working
- the cancer starts to grow into the muscle layer of the bladder – this is called muscle-invasive bladder cancer.

Coping during and after treatment

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Coping with side effects and symptoms during and after your treatment

Your doctor or nurse will talk to you abut any side effects of treatment. During any treatment for non-muscle-invasive bladder cancer, you may have symptoms such as:

- passing urine (peeing) more often
- rushing to the toilet to pass urine
- blood in your urine (pee)
- a burning sensation when you pass urine.

For most people, these symptoms last for a few days after treatment. Your doctor or nurse can talk to you about things you can do to help. They will give you medication if needed.

Some people can have problems controlling their bladder during and for some time after treatment. This is called urinary incontinence. This can be a rare side effect of having lots of cystoscopies.

It is important that you talk to your doctor or nurse if this is a problem for you. They may refer you to a continence adviser or specialist physiotherapist who can give you advice. The Bladder and Bowel Community can also help (page 110).

Drink plenty of fluids

Try to drink at least 2 litres (3½ pints) of fluids every day. This is about 8 glasses. If it is hot or you are exercising, you will need to drink more. If you find you have to get up at night to pass urine, it may help to drink less in the evening. If you do not drink enough, it can make some symptoms worse.

Any type of drink counts as fluids. But some drinks can irritate the bladder and make symptoms worse. Try to reduce or avoid:

- drinks that contain caffeine, such as tea, coffee, cola and hot chocolate
- fizzy drinks
- drinks with artificial sweeteners – for example diet or 'light' drinks
- alcohol.

Living well

You may think about making changes to your lifestyle and want to find out more about being healthy. You may have already followed a healthy lifestyle, but now want to focus more on making the most of your health.

There are things you can do to help improve your long-term health and well-being. It can also help you feel more in control of your situation.

Living a healthy lifestyle can help your body recover after treatment. There are things you can do to help your body recover and improve your well-being. Certain changes may reduce the risk of other illnesses and some cancers. Many people find making positive health choices helps give them back a sense of control.

Some hospitals have cancer information centres where staff can talk to you about well-being and groups in your local area to help with this.

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

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Stopping smoking can:

- make your treatment more effective
- reduce the side effects of treatment
- reduce the risk of bladder cancer coming back.

Your cancer doctor or GP can offer different treatments to help you stop. Your hospital doctor, nurse or GP can refer you to a stop-smoking service in your area.

> “I didn't expect much from myself after surgery. I just wanted to keep my mind active. I went back to the gym to see my friends.”

Amuz

Keep to a healthy weight

Keeping to a healthy weight reduces the risk of cancer, heart and kidney problems, and illnesses such as diabetes. Your GP can tell you what the ideal weight for your height is.

If you feel you need to lose weight, ask your GP for advice. Some hospital teams can refer you to local services.

Here are some tips to help you keep to a healthy weight:

- Eat a healthy diet with lots of fruit and vegetables, less fat and less sugar.
- Be more physically active.

If you have lost weight during treatment, your GP or a dietitian can give you advice about gaining weight.

Eat a healthy diet

Eating well helps you keep your strength, gives you more energy and improves your well-being. A well-balanced diet includes:

- plenty of fresh fruit and vegetables
- less red or processed meats
- more chicken, fish, beans and pulses
- carbohydrates
- less sugary food and drinks.

If you have had radiotherapy, you may have been advised to make changes to your diet to help with any bowel effects. Follow any advice you have been given by a dietitian or specialist nurse. Our booklet **Healthy eating and cancer** may be helpful.

Be active

Keeping active helps you:

- maintain a healthy weight
- reduce stress and tiredness
- reduce the risk of other health conditions.

Some hospitals can refer you to local exercise or fitness groups, for all abilities. You may find our booklet **Physical activity and cancer** helpful.

Stick to sensible drinking guidelines

NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in a week
- spread the amount you drink in a week over 3 or more days
- try to have several alcohol-free days every week.

There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

Reduce stress

Think about ways to reduce the stress in your life. You could make time to do things that you enjoy or that make you laugh. Some people find it relaxing to meditate. Other people start a new hobby or evening class. You may wish to order our booklets **Cancer and complementary therapies** and **Life after cancer treatment**.

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

> **“Macmillan helped me to access a toilet card. Now I'm confident to go shopping as I know there'll be somewhere to go nearby.”**

Ali, diagnosed with bladder cancer

Using public toilets

If you have problems with bladder control, you may feel worried about going out. Planning ahead can help you feel more confident.

Toilet card

A toilet card is a card that you can show quickly and easily to staff in shops, pubs and other places. It explains that you have a medical condition and need urgent access to a toilet. Sometimes it is also called a bladder and bowel card or a 'no waiting' toilet card.

You can order our **Macmillan toilet card** to carry and use when you are out in public (page 104). It also comes with a fob version that can be attached to a key ring. We cannot guarantee that it will work everywhere. But we hope it helps you get access to a toilet without any awkward questions.

The Bladder and Bowel Community also offers a free Just Can't Wait toilet card and toilet card app (page 110).

Plan ahead and find a public toilet

If you are going somewhere new, it is a good idea to plan ahead and find out where toilets are before you go. Many areas have lists or maps of the local public toilets. These are often on local authority websites. Try:

- typing 'public toilets' and the name of the place you are visiting into a search engine, such as Google
- visiting the website **toiletmap.org.uk** to see a map with details of public toilets
- downloading a toilet app for your phone that can help you find a public toilet.

Use disabled toilets

Disabled toilets often have more privacy and space. The National Key Scheme (NKS) offers access to over 9,000 locked disabled toilets in the UK. You can buy a key online from places such as Disability Rights UK. You can also order a guide that tells you where the toilets are. Visit **disabilityrightsuk.org**

Who can help?

There are people available to help you and your family.

Continence nurses and physiotherapists can help with bladder problems. Your urologist or GP can refer you.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares.

The social worker may also be able to arrange childcare for you during and after treatment.

Your feelings and relationships

Your feelings 92

Relationships 94

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet **How are you feeling? The emotional effects of cancer** (page 104).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help.

For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups** Or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on pages 106 to 109 about other ways we can help you.

> "I learned that accepting feelings instead of denying them gives them much less power over us, and that talking about issues helps the issue to become smaller."

Amuz

Relationships

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

We have more information about relationships online and in our booklets **Talking about cancer** and **Cancer and relationships: support for partners, families and friends** (page 104).

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet **Talking with someone who has cancer**.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet **Looking after someone with cancer** (page 104).

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 104).

> **“Leading up to surgery I told my kids that I needed to go into hospital to have something fixed.”**
>
> Amuz

Work and financial support

Help with money and benefits 98

Work 101

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 104).

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

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

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

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (pages 116 and 117).

Our booklet **Help with the cost of cancer** has lots more information (page 104).

Macmillan Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line.

Insurance

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

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

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

> "My work put me on sick leave and kept in touch. But I decided to hand my notice in. At the moment I'm taking a break to process everything."

Katherine, diagnosed with bladder cancer

Work

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer** (page 104).

There is also lots more information online at **macmillan.org.uk/work**

Further information

About our information 104

Other ways we can help you 106

Other useful organisations 110

Your notes and questions 124

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

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

The language we use

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

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and see the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

Help with work and cancer

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

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Bladder cancer support organisations

Action Bladder Cancer UK

www.actionbladdercanceruk.org
Works to support bladder cancer patients, raise awareness, improve early diagnosis and outcomes, and support research into bladder cancer.

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
www.bladderandbowel.org
Provides information, advice and support for a range of symptoms and conditions related to the bladder and bowel.

Fight Bladder Cancer

Tel **0184 435 1621**
www.fightbladdercancer.co.uk
A UK-based charity providing information, support and advice to everyone affected by bladder cancer.

Help with sexual well-being

College of Sexual and Relationship Therapists

Tel **0208 106 9635**
www.cosrt.org.uk
A national specialist charity for sex and relationship therapy. Provides information about sexual and relationship issues.

Institute of Psychosexual Medicine

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.
Find a specialist at **www.ipm.org.uk/25/find-a-doctor**

Sexual Advice Association

www.sexualadviceassociation.co.uk
Helps and supports people with all forms of sexual problems. You can download their app for information and support.

General cancer support organisations

Cancer Black Care

Tel **0208 961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

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

Cancer Research UK

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

Macmillan Cancer Voices

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

Maggie's

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

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

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

General health information

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

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

UK Council for Psychotherapy (UKCP)

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

Emotional and mental health support

Mind

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

Samaritans

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

Financial support or legal advice and information

Advice NI

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

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
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.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

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

England

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

Scotland

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

Wales

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

Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these 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.

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250**
Textphone **0800 587 1297**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Law Centres Network

www.lawcentres.org.uk
Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel **0344 892 0902**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity

Helpline **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

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

OUTpatients (formerly called Live Through This)

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

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
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

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **0289 043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
www.phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Disclaimer

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

Thanks

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

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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 **informationproductionteam@macmillan.org.uk**

Sources

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

Mottet N, Bellmunt J, Briers E, et al. Non-muscle-invasive bladder cancer (TaT1 and CIS). European Association of Urology [Internet], 2021. Available from http://uroweb.org/guideline/non-muscle-invasive-bladder-cancer/ [accessed September 2021].

National Institute for Health and Care Excellence (NICE). Bladder cancer: diagnosis and management. NG2. 2015

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

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

Card number
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Valid from
☐☐ ☐☐

Expiry date
☐☐ ☐☐

Issue no
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Security number
☐☐☐

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

This booklet is about non-muscle-invasive bladder cancer. It is for anyone who is having tests or treatment for this type of cancer. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of bladder cancer, and how non-muscle-invasive bladder cancer is diagnosed and treated. It also has information about feelings, practical issues and money.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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