MACMILLAN
CANCER SUPPORT

UNDERSTANDING NON-MUSCLE-INVASIVE BLADDER CANCER

‘It’s a case of getting back to normality now, which I’m doing slowly but surely.’

Alex, diagnosed with non-muscle-invasive bladder cancer in 2014

About this booklet

This booklet is about non-muscle-invasive bladder cancer. It is for anyone who is having tests for this type of cancer or has been diagnosed with it. This booklet may also be helpful for family members, friends or carers.

The booklet explains the symptoms of non-muscle-invasive bladder cancer. It also explains how it is diagnosed and treated, and ways to cope. This includes your feelings, relationships, work and finances.

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

How to use this booklet

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

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

In this booklet, we have included quotes from people who have been affected by non-muscle-invasive bladder cancer and have chosen to share their story with us. This includes Alex, who is on the cover of this booklet. To share your story, 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**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available.

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

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

Contents

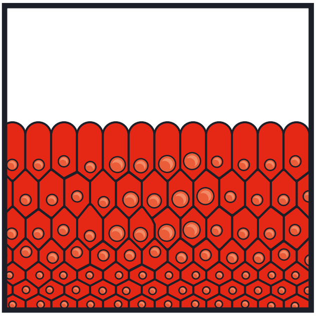
ABOUT NON-MUSCLE-INVASIVE BLADDER CANCER

What is cancer?

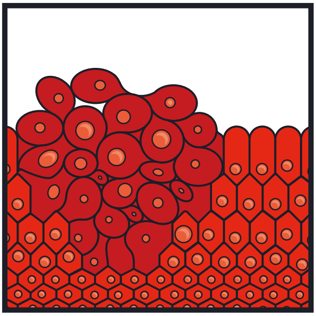
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop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

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour).

Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.



Normal cells



Cells forming a tumour

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

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system.

When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

The bladder

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

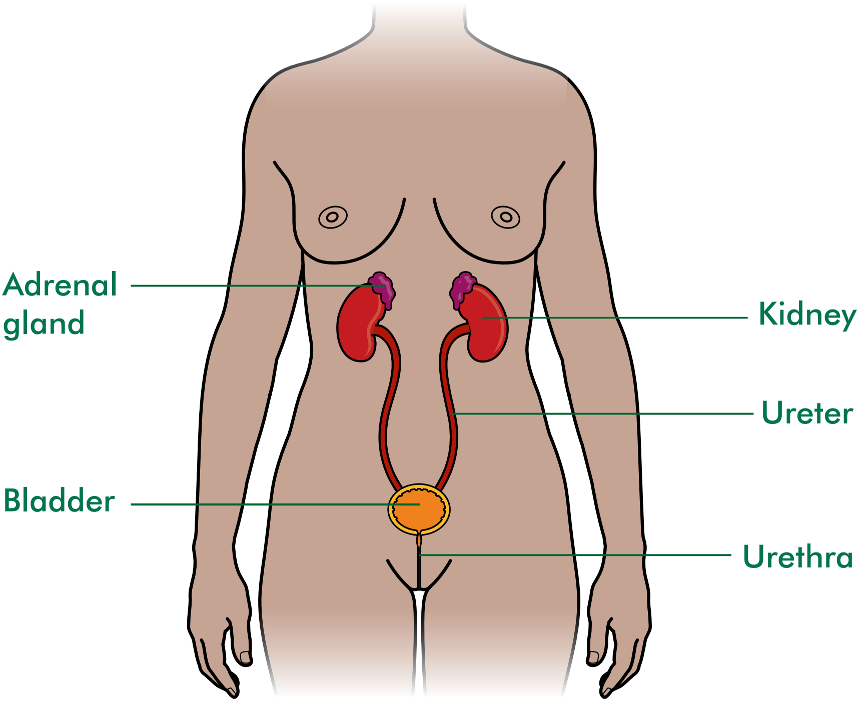
The inside of the bladder is covered with a lining. This lining is called the urothelium. It stops urine from being absorbed back into the body. The cells that make up this lining are called urothelial cells or transitional cells.

Urine is made of water and waste products. It is produced by the kidneys. Urine drains from your kidneys to your bladder through long tubes called ureters. As your bladder fills, it expands to store the urine. When it is full, it sends messages (nerve signals) to the brain. This makes you feel like you need to empty your bladder. The bladder muscle tightens and squeezes the urine out of the body through the urethra at the bottom of the bladder.

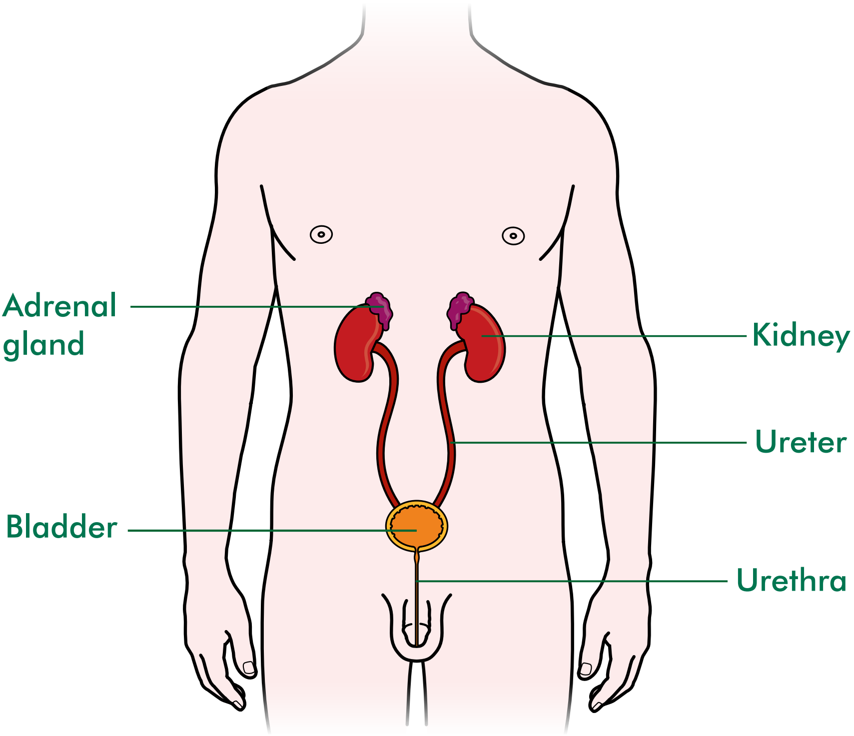
The urethra has rings of muscle called the external and internal sphincter. These sphincters help to keep the urethra closed. This stops urine leaking out.

The bladder is supported by a group of muscles that sit at the bottom of the pelvis (the area between the hips). They are called the pelvic floor muscles. In women, the urethra is a short tube that lies in front of the vagina (see the illustration opposite). In men, the urethra is longer and passes through the prostate gland to the end of the penis (see the illustration on page 10).

The bladder in women



The bladder in men



Causes and risk factors

In the UK, over 10,000 people are diagnosed with bladder cancer each year.

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 a person will get bladder cancer. People with no risk factors can also develop bladder cancer.

Age

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

Smoking

Smoking may cause about 4 in 10 (40%) bladder cancers. 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. You may find our booklet **Giving up smoking** helpful (see page 96).

Gender

Bladder cancer is more common in men than in women.

Exposure to chemicals at work

These include chemicals previously used in dye factories and industries such as:

- rubber
- leather
- textile
- printing
- hairdressing
- gasworks
- plastic and paint.

Many of these chemicals are now banned. But it can take more than 25 years after exposure to them for bladder cancer to develop.

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 benefit. Visit **gov.uk/industrial-injuries-disablement-benefit** If you live in Northern Ireland, visit **nidirect.gov.uk**

Infection

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

People who are paralysed because of an injury to their spinal cord can have more bladder infections. They may have a higher risk of developing bladder cancer.

An untreated infection called schistosomiasis, which is caused by a worm (parasite) that lives in fresh water, may cause bladder cancer. The parasite is found in Africa, but also lives in parts of the Middle East. This infection is rare in the UK.

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.

Diabetes

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

Family history

If you have a close relative 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.

Bladder cancer is not infectious and cannot be passed on to other people.

Types of bladder cancer

Urothelial bladder cancer

This is the most common type of bladder cancer. It is also called transitional cell carcinoma (TCC). It starts in cells in the bladder lining (see the illustrations on pages 9 and 10). These cells are called urothelial or transitional cells. Bladder cancer may be non-muscle-invasive, muscle-invasive or advanced.

In muscle-invasive bladder cancer, the cancer has spread into or through the muscle layer of the bladder. Advanced bladder cancer is when the cancer has spread to other parts of the body. This information is about non-muscle-invasive bladder cancer.

Non-muscle-invasive bladder cancer is when the cancer cells are only in the inner lining of the bladder. They have not spread (invaded) into the muscle layer.

Non-muscle-invasive bladder cancer can be mushroom shaped, which is called a papillary tumour (Ta). It can also be flat and red, which is called carcinoma in situ (CIS) – see pages 28 to 32. Some people may have both papillary cancer and CIS.

Less common types of bladder cancer

Less common types of bladder cancer include:

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

These start from different types of cells in the bladder lining and are usually muscle-invasive.

We have more information in our booklet **Understanding muscle-invasive and advanced bladder cancer** (see page 96).

Symptoms

Most 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.

Blood in the pee (haematuria)

This is the most common symptom of bladder cancer. It can happen suddenly and may come and go. Your pee (urine) 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 or microscopic 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

Some people may:

- have a burning feeling when they pee (pass urine)
- need to pee more often
- need to rush to the toilet to pee.

These symptoms are usually caused by an infection or an overactive bladder rather than cancer. Some people may need more tests to find out the cause of their urinary symptoms.

Pain in the lower part of the tummy or back

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

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

Alex

DIAGNOSING NON-MUSCLE-INVASIVE BLADDER CANCER

How bladder cancer is diagnosed

Most people are diagnosed after going to see their GP when they notice symptoms (see pages 16 to 17). Your GP will ask you about your symptoms. They will arrange for you to have your pee (urine) tested. They can do a quick test to find out if there is any blood in your pee. Blood in the pee is known as haematuria.

If you have blood in your pee, your GP will make sure there is no obvious reason for this, like an infection. They send your urine sample to a laboratory to check for an infection.

Your GP will usually refer you to a specialist if:

- you can see blood in your pee which cannot be explained
- you can still see blood in your pee after having treatment for a urine infection
- a urine test finds blood in your pee and you have urinary symptoms, but do not have a urine infection
- they are unsure what the problem is
- they think your symptoms could be caused by cancer.

At the hospital, you will see a urologist. This is a doctor who specialises in urinary, bladder and kidney problems. Or you may see a nurse called a urology nurse specialist.

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

If tests or symptoms suggest you could have bladder cancer, you should be seen by a specialist within 2 weeks.

At the hospital

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

Having tests to diagnose bladder cancer can take a few days. This can be frustrating, but it is important your doctor has all the information they need to make a diagnosis. You will usually have some of the following tests.

Blood tests

You have blood samples taken. These help your doctor check how well your kidneys and liver are working. You may have a blood test to show the number of blood cells in the blood. This is called a blood count.

Urine tests

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

You may have a test which looks for substances in the urine that are found in bladder cancer. This is called molecular testing.

Cystoscopy

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

Flexible cystoscopy

A flexible cystoscopy looks for changes inside the bladder. This is usually done under local anaesthetic. You are awake for the procedure. Before the cystoscopy, you are asked to give a sample of urine, which is checked for infection.

The doctor or nurse squeezes a numbing gel into the opening of your urethra (see the illustrations on pages 9 and 10). This is the local anaesthetic and makes the procedure less uncomfortable. The gel starts to work after a few minutes.

The doctor gently passes the cystoscope through the urethra and into the bladder. The light from the cystoscope helps them look closely at the lining of the bladder and urethra. The test takes a few minutes and you can go home after it. You may feel some discomfort during the procedure, but it should not be painful.

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 lots of fluids to help flush out your bladder.

> ‘The procedure is nothing to worry about. It’s slightly uncomfortable for just a few seconds as the camera goes in.’
>
> **Richard**

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

After the cystoscopy, the doctor can usually tell you if they have seen a bladder tumour. If they have, they will arrange for you to go back to the hospital to have a rigid cystoscopy (see below).

Narrow-band imaging (NBI)

Some people may have a type of flexible cystoscopy called narrow-band imaging (NBI). It filters the light from the cystoscopy into wavelengths of blue and green. Blood absorbs more blue and green light than white light. This makes it easier for your doctor to see any cancer cells or tumours.

This is not available at every hospital as it is a new procedure. Your doctor or specialist nurse can give you more information.

Rigid cystoscopy

During this test, the doctor passes surgical instruments through the cystoscope to either:

- remove the tumour
- take a small piece of tissue (biopsy).

You may have this done under a general anaesthetic or using a spinal anaesthetic. A spinal anaesthetic numbs the lower part of your body. You are awake during the test, but you do not feel anything.

We have more information about surgery to remove a bladder tumour (see pages 42 to 48).

Blue-light cystoscopy

During a rigid cystoscopy, the doctor sometimes uses a technique called blue-light cystoscopy. It is also called photodynamic diagnosis (PDD). This is a way of helping the doctor see small bladder tumours and tumours that are flat more easily. Tumours that are flat are called carcinoma in situ (CIS) – see pages 28 to 32.

Before the cystoscopy, a nurse passes a tube through the urethra and into the bladder. This tube is called a catheter. The doctor puts a light-sensitive drug into the bladder through the catheter. This drug is absorbed by any cancer cells.

During the cystoscopy, the doctor uses a special camera and a blue light to look at the bladder. Because the cancer cells have absorbed the drug, they look pink under the blue light. This means the doctor can see them more clearly.

Ultrasound scan

This scan can show anything unusual in the urinary system. It uses sound waves to create a picture of the inside of the body. You will be asked to drink plenty of fluids before the test. This means your bladder is full and can be seen easier. The hospital will give you instructions about this.

When you are lying comfortably on your back, the person doing the scan spreads a gel over your tummy (abdomen). A small device that makes sound waves is passed 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. Once the scan is over, you can empty your bladder.

CT (computerised tomography) urogram

A CT scan takes a series of x-rays, which builds up a three-dimensional picture of the inside of the body.

A CT urogram is a CT scan of the bladder, ureters and kidneys. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

You are usually given an injection of a dye (contrast) that helps your doctor see your bladder, ureters and kidneys more clearly. It may make you feel hot all over for a few minutes. Some people have a stronger reaction to the dye. Tell your doctor if you have asthma or an iodine allergy, as they increase the risk of a strong reaction. You should also tell your doctor if you have kidney problems or diabetes, particularly if you take a medication called metformin.

Before the scan, you need to have a blood test to check how well your kidneys are working. You should be able to go home as soon as the scan is over.

Other tests

You may need to have further tests after surgery to remove the bladder tumours.

MRI scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

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

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation (see pages 101 to 107) can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Staging and grading

Your cancer specialist needs certain information about the cancer to advise you on the best treatment for you. This includes the stage of the cancer and its grade. They get this information from the tests you have (see pages 20 to 26).

Your specialist doctor and nurse will talk with you about this. Knowing the stage and grade of the cancer helps you and your doctor decide on your treatment plan.

Staging

The stage of a cancer describes:

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

The test results give some information about the stage of the cancer. But your doctor will not know the exact stage until after the cancer has been removed by surgery (see pages 42 to 48).

The most commonly used staging system for bladder cancer is the TNM system.

TNM staging system

This staging system gives information about the tumour, if it has spread to any lymph nodes, or if it has spread to another part of the body (metastasis).

- **T** is how far the tumour has grown into the bladder.
- **N** is whether the tumour has spread to the nearby lymph nodes.
- **M** is whether the tumour has spread to another part of the body (secondary or metastatic cancer).

Non-muscle-invasive bladder cancers are N0 and M0. This is because the tumour has not spread outside the bladder.

Stages of non-muscle-invasive bladder cancer

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

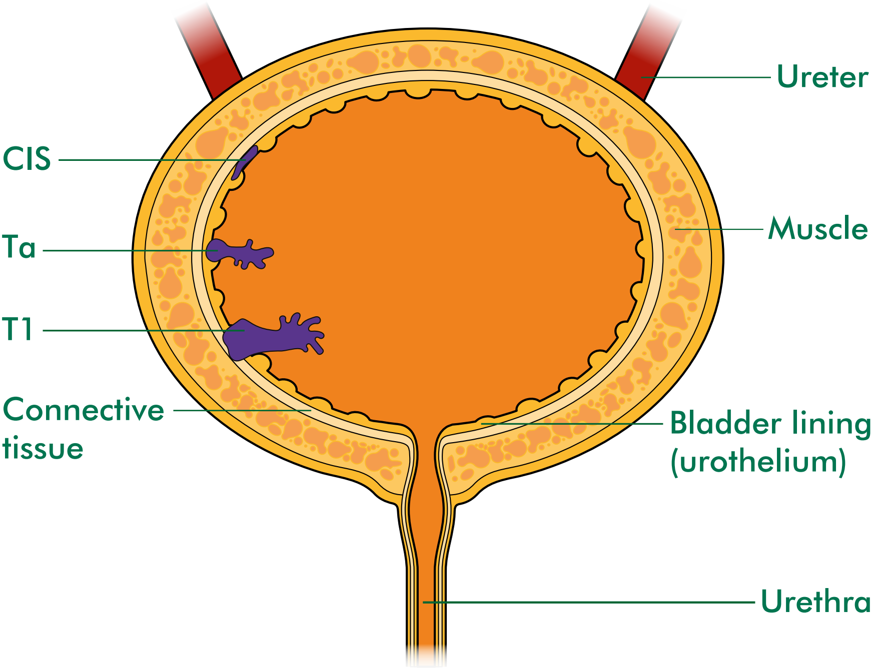
- **Carcinoma in situ (CIS)** – This is sometimes described as a flat tumour. The cancer cells are only in the inner layer of the bladder lining (urothelium).
- **Ta** – The tumour is a mushroom-like growth (papillary cancer). It is only in the inner layer of the bladder lining.
- **T1** – The tumour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

Invasive and advanced bladder cancer

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

We have more information in our booklet **Understanding muscle-invasive and advanced bladder cancer** (see page 96).

The stages of non-muscle-invasive bladder cancer



Grading

Grading is about how the cancer cells look under a microscope compared with normal cells. The grade helps your doctor plan your treatment. The grades for bladder cancer 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, which is a stage Ta tumour and a grade 1 tumour.

Doctors may also use another grading system for bladder cancer:

- **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.

Your doctor may combine the two grading systems.

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

Risk level

Your doctor looks at the risk of non-muscle-invasive bladder cancer spreading into the muscle of the bladder. They also look at the risk of it coming back. This helps them to advise you on the best treatment for your situation. Your doctor looks at different things to decide on the risk level of the cancer. This includes:

- 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 had non-muscle-invasive bladder cancer in the last year.

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

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

For example, a small TaG1 tumour is in a low-risk group. A tumour that is T1, grade 3 or CIS is in a high-risk group. Your doctor and 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. You can find more information at **macmillan.org.uk/cancerregistry**


← Consultin

TREATING NON-MUSCLE-INVASIVE BLADDER CANCER

Treatment overview

Treatments for non-muscle-invasive bladder cancer usually depend on what risk level the tumour is (see page 32). Your doctor and nurse will help you understand what the treatments involve and how they may affect your life. You and your doctor can then decide on the best treatment for your situation.

Surgery

Surgery is the main treatment for non-muscle-invasive bladder cancer. Tumours in the bladder can be removed using a cystoscope. This operation is called a transurethral resection of the bladder (TURBT) – see pages 42 to 47. You usually have chemotherapy into the bladder immediately after surgery (see pages 50 to 54). You may be in hospital for 1 to 3 days.

Further treatment

After surgery, you may need further treatment. Treatment is usually with chemotherapy (see pages 50 to 54) or an immunotherapy drug called BCG (see pages 55 to 59). Both are given directly into the bladder.

If you have a low-risk tumour, you will not need any treatment after surgery. If you have an intermediate or high-risk tumour, you usually need further treatment. High-risk bladder cancer is usually treated with BCG. See page 32 for more information about risk levels.

You may be offered other treatments as part of a clinical trial (see pages 60 to 63). Your doctor can give you more information.

Occasionally, your specialist may ask you to think about having surgery to remove the bladder. This may happen if you have a very high-risk cancer or a cancer that comes back after BCG treatment. The operation is called a cystectomy (see page 48).

Sometimes, non-muscle-invasive bladder cancer can come back in the lining of the bladder. This can still be treated with surgery and further treatment.

Advice on smoking

If you smoke, your doctor will usually advise you to stop smoking. Stopping smoking can:

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

Your specialist doctor or GP can offer different treatments to help you stop. But if you do not stop smoking, this should not affect the treatment plan your doctors offer you.

Your specialist doctor, nurse or GP can refer you to a stop-smoking service in your area. You can find contact details for stop-smoking services on page 106. We have more information about stopping smoking in our booklet **Giving up smoking** (see page 96).

Planning your treatment

In most hospitals, a team of specialists called a multidisciplinary team (MDT) will meet to discuss which treatment will be best for you. The MDT will usually include:

- **a urologist** – a surgeon who specialises in treating problems of the urinary system
- **an oncologist** – a specialist in cancer treatments, such as chemotherapy, radiotherapy and immunotherapy
- **a urology specialist nurse** – a nurse who gives information and support
- **a radiologist** – a doctor who helps to analyse x-rays and scans
- **a pathologist** – a doctor who advises on the type and extent of the cancer.

It may also include other healthcare professionals, such as a dietitian, physiotherapist, occupational therapist (OT), psychologist or counsellor.

The benefits and disadvantages of treatment

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

With high-risk, non-muscle-invasive bladder cancers, a specialist will talk with you about deciding between BCG treatment or an operation to remove the bladder.

This can be a difficult decision to make. Talking to your specialist 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.

Giving your consent

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

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

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

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

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

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

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Surgery

Surgery is the main treatment for non-muscle-invasive bladder cancer. The operation is called a transurethral resection of a bladder tumour (TURBT). Transurethral means through the urethra.

Transurethral resection of a bladder tumour (TURBT)

During this operation, the surgeon inserts a thin tube with a camera and light on the end (cystoscope) into the bladder through the urethra.

They remove the tumour (or tumours) using surgical instruments that are passed through the cystoscope. The surgeon may use a mild electrical current (cauterisation) to stop any bleeding.

Sometimes, blue-light cystoscopy (PDD) or narrow-band imaging are used during surgery to help your doctor remove the tumour (or tumours) – see page 24.

The surgeon sends the tumour (or tumours) they have removed to a laboratory to be looked at under a microscope. This tells your doctor more about the stage and grade of the cancer (see pages 28 to 32).

You may have another TURBT 2 to 6 weeks after the first one.

Your doctor may recommend this if:

- you have a high-risk, non-muscle-invasive bladder cancer – this is to make sure all of the tumour has been removed
- 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.

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

Before your operation

Before your operation, you will be seen at a pre-assessment clinic. You may have tests to check your general health.

These can include:

- blood tests
- a recording of your heart (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.

You will see a member of the surgical team and a specialist nurse who will talk to you about the operation. This is a good time to ask any questions, or to talk about any worries you may have.

You usually go into hospital on the day of your operation. You usually have a general anaesthetic. But you may have the operation done under a spinal anaesthetic.

For a spinal anaesthetic, the doctor injects a drug through a 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. If you are having a spinal anaesthetic, you may also have another drug to help you relax.

You will see the doctor who gives you the anaesthetic (the anaesthetist) either at a pre-assessment clinic, or when you are admitted to hospital.

The nurse will talk to you about what you should do before the operation. This can include instructions about medications or eating and drinking.

After your operation

After your operation, the nurses will encourage you to start moving about as soon as possible. This helps to prevent problems such as chest infections or blood clots. They will encourage you to do regular leg movements and deep breathing exercises. A physiotherapist or nurse can explain these to you.

You will be given elastic stockings (TED stockings) to wear during the operation and for some time afterwards. This is to prevent blood clots in your legs.

Most people are given chemotherapy into the bladder straight after surgery (see pages 50 to 54).

You will usually have a tube (catheter) to drain urine from your bladder into a collecting bag.

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, large bags of fluid are connected to the catheter. This helps to flush out the bladder and stop blood clots forming.

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

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

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

These symptoms usually get better in 1 to 2 days. But they may continue for several weeks. Tell your doctor if they do not get better. Drinking at least 2 litres (3½ pints) of fluid every day can help to reduce these symptoms.

You can usually go home when you can pass urine without the catheter. This may be 1 to 3 days after the operation.

We have more information on looking after your bladder (see pages 67 to 75).

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.

Possible risks of surgery

Removing non-muscle-invasive bladder cancer is usually a safe procedure. However, there are some possible risks.

Urine infection

Some people may get a urine infection. This can happen in hospital or after you go home. Signs of an infection include:

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

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 10 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 severe tummy pain.

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

Damage to the bladder

There is a small risk of a hole (perforation) being made in the bladder during surgery. If this happens, the catheter is left in the bladder to allow the hole to heal. The catheter will be removed when the hole has healed. Rarely, you may have an operation to close the hole.

Going home

Everyone recovers from the operation in their own time. 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.

> ‘Recovery is an individual thing. You have to listen to your body and not overdo things.’
>
> **Christine**

Surgery to remove the bladder (cystectomy)

A cystectomy is an operation to remove the bladder. It is sometimes recommended if you have a high-risk, non-muscle-invasive bladder cancer, or if the cancer has come back (even with BCG treatment).

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.

Being advised to have your bladder removed when you have a non-muscle-invasive bladder cancer can be hard to accept. If you have any questions or concerns, talk to your doctor or nurse. They should be able to answer any questions you have.

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

Having your bladder removed is major surgery. But with help from family members, friends, health professionals and support organisations (see pages 101 to 107), people usually manage to cope well with a cystectomy.

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** (see page 96).

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs disrupt the way cancer cells grow and divide.

Having chemotherapy into the bladder

After your surgery, you usually have chemotherapy directly into your bladder. This is called **intravesical chemotherapy**. It reduces the risk of the cancer coming back in the bladder lining. Most people have 1 treatment of intravesical chemotherapy after surgery. If you have a low risk (see page 32) of the cancer coming back, you usually do not need chemotherapy after this.

If you have an intermediate risk (see page 32) 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.

The chemotherapy drug is in direct contact with the cancer cells in the bladder. Hardly any of the drug is absorbed into the blood, so it rarely affects the rest of the body. This means you do not get some side effects, such as feeling sick or hair loss.

How chemotherapy is given

When you have intravesical chemotherapy after your surgery, you will be in hospital with a tube (urinary catheter) going into your bladder.

The chemotherapy may be given 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 you have a lot of blood in your urine, or if there has been any injury to your bladder during surgery.

If you are having a course of intravesical chemotherapy, you have it 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 (stops you needing to pass urine (pee) too early)
- increase the concentration of the chemotherapy drug in your bladder.

People who take water tablets (diuretics) should take them after the treatment. Tell your doctor if you take any medications.

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

The chemotherapy drug used most often for non-muscle-invasive bladder cancer is mitomycin-C. Sometimes, other chemotherapy drugs may be used, such as gemcitabine or epirubicin. We have more information about these on our website (see page 96).

Before you have the chemotherapy, you are asked to lie down on a couch. A nurse passes a tube (catheter) through your urethra and into your bladder. The nurse then slowly puts the chemotherapy directly into your bladder through the catheter.

Once the drug is in your bladder, the nurse usually takes the catheter out. They ask you not to pass urine for around 1 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. 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 drug drains from your bladder into a urine bag. Your nurse can then take the catheter out.

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 chemotherapy drug.

You will be asked to:

- sit down to pass urine – this avoids splashing urine on the toilet seat
- wash the skin in and around your genital area with soap and water after you pass urine – this cleans any drops of chemotherapy that may have splashed on to your skin
- wash your hands carefully after passing urine using soap and water.

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.

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

Side effects

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

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

Most side effects are caused by inflammation of the bladder lining. This is known as cystitis. This can take up to a week to get better.

Drinking fluids will help with the side effects. Try to drink 2 to 3 litres (3½ to 5 pints) each day. Taking mild painkillers can help. We have more information about looking after your bladder during and after treatment (see pages 67 to 75).

Some people may get a red rash on their skin. Tell your doctor or nurse straight away if you get a rash on any part of your body.

Tell your doctor straight away if:

- the side effects do not get better after 48 hours
- you feel cold, shivery, hot or sweaty
- your urine is smelly or cloudy.

These symptoms may mean you have a urine infection.

Rarely, a person may find it difficult to pass urine or have severe tummy pain. Some people may have pain around their penis. Tell your doctor or specialist nurse straight away if you have any of these symptoms.

Sex after treatment

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

BCG treatment

BCG is a type of immunotherapy drug used to treat some non-muscle-invasive bladder cancers. 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.

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.

When BCG is used

BCG helps prevent the cancer from coming back in the bladder lining. It also reduces the risk of the cancer becoming muscle-invasive. Doctors usually suggest this treatment if you have a high-risk bladder cancer, or sometimes if you have an intermediate-risk bladder cancer.

There is usually at least 2 weeks between the surgery to remove the cancer and the start of BCG treatment. This is to give your bladder enough time to heal from the surgery.

You usually have BCG treatment once a week for 6 weeks. This is sometimes called the induction course. You may be offered more BCG treatments. This is usually called maintenance treatment.

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

How BCG is given

If you are having a course of BCG directly into your bladder (intravesical BCG), you have it 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 (stops you needing to pass urine (pee) too early)
- increase the concentration of the BCG drug in your bladder.

People who take water tablets (diuretics) should take them after the treatment. Tell your doctor if you take any medications.

Before you have the BCG treatment, you are asked to lie down on a couch. A nurse passes a tube (catheter) through your urethra and into your bladder. The nurse then slowly puts the BCG directly into your bladder through the catheter.

Once the drug is in your 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 while waiting for the treatment to finish. Your bladder may feel full and a bit uncomfortable. 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 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 can then take the catheter out.

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:

- sit down to pass urine – this avoids splashing urine on the toilet seat
- wash the 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
- wash your hands carefully after passing urine with soap and water.

For about 2 days after each treatment, you will usually be asked to drink at least 2 litres (3½ 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.

Side effects

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 get better after this time. Taking painkillers can help.

Rare side effects include:

- a continuing high temperature (fever)
- pain in your joints
- a cough.

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 TB.

Sex after treatment

Men should use a condom during sex for the first week after each BCG treatment. If you are a woman having the treatment, your partner should use a condom during this time. This protects your partner from any BCG that may be present in semen or vaginal fluid. Your 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.

Other treatments

Other treatments are being tested for non-muscle-invasive bladder cancer. Because doctors need to find out more about these treatments, they are usually only available in clinical trials. This means they are only available at some hospitals. If your urologist thinks a clinical trial may be helpful for you, they can refer you to the hospital doing the trial (see pages 62 to 63).

Current research is looking at newer ways of treating non-muscle-invasive bladder cancer.

Heated intravesical chemotherapy

This treatment uses chemotherapy (see pages 50 to 54) and heat. A thin tube with a rounded end (a probe) applies microwave heat to the bladder lining. At the same time, chemotherapy is given into the bladder (intravesical).

Another type of this treatment uses a machine to heat the chemotherapy before it goes into the bladder. The chemotherapy is then given into the bladder through a tube (catheter).

Trials are trying to find out if using heat makes chemotherapy given into the bladder work better.

Electromotive intravesical chemotherapy

Electromotive intravesical chemotherapy uses chemotherapy and a small electrical current. This helps the cancer cells absorb more of the chemotherapy drug. This treatment is also called electromotive drug administration (EMDA).

Your nurse puts a catheter into your 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 your tummy. These are also attached to the small machine. The chemotherapy is put into your 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 your bladder (see pages 55 to 59). Your doctor or nurse can tell you more about this.

Tumour ablation

This treatment uses a laser (infra-red light) to burn any areas of cancer away. The surgeon inserts a cystoscope into your bladder. A cystoscope is a thin tube with a camera and light on the end. The surgeon then passes a laser fibre through the cystoscope, which burns the tumours away.

Sometimes, blue-light cystoscopy (PDD) is used during tumour ablation (see page 24). 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

Immunotherapy drugs encourage the body's immune system to fight cancer cells. There are some clinical trials looking at immunotherapy drugs to treat non-muscle-invasive bladder cancer. Your doctor may talk with you about this if it is suitable for you.

Research – clinical trials

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

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

Taking part in a clinical trial

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

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

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

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials) –** see page 96.

Blood and tumour samples

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

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

Follow-up

The most important test for follow-up is a cystoscopy (see pages 21 to 24). You may also have your urine checked for cancer cells.

After your treatment has finished, you will have regular cystoscopies. These are done to:

- monitor how well treatment has worked
- check that no new cancers are growing in the bladder.

You have the cystoscopy in the outpatient department or at a specialist clinic.

How often you have a cystoscopy depends on the risk of the cancer coming back (see page 32). High-risk and intermediate-risk tumours need to be monitored more often than low-risk tumours. At first, follow-up will usually be every 3 to 6 months. Your doctor or specialist nurse will tell you how often you will have a cystoscopy. Most people have cystoscopy follow-up for several months or years after treatment finishes.

It is important to tell your doctor straight away if you notice any new symptoms, or symptoms that come back, between your appointments. Your doctor will check what may be causing your symptoms.

Many people find they get anxious before their follow-up appointments. This is natural. It may help to get support from a partner, family member or friend. If you feel you have no one to talk to, you can call our cancer support specialists on **0808 808 00 00**.

If the cancer comes back

It is not uncommon for bladder cancer to come back in the lining of the bladder. Non-muscle-invasive bladder cancer that comes back in the bladder can usually be cured or controlled for a long time. It can usually be treated with surgery to remove it again. Some people may also have chemotherapy or BCG into the bladder.

In some situations, a urologist may advise 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).

A cystectomy aims to treat the cancer before it goes into or spreads further in the muscle of the bladder.

It can be hard to hear you need to have your bladder removed. Urologists will always consider the different treatments available to try to keep your bladder. With help from family members, friends, health professionals and support organisations (see pages 101 to 107), people usually manage to cope well with a cystectomy.

> ‘If you are worried about any ache or pain, see your GP. It may be nothing, but it’s always good to get it checked rather than live with the worry.’
>
> **Christine**

> ‘The yearly checks are always a nervous moment. But I have had excellent care from my doctor and any worries I have are taken seriously.’
>
> **Alex**

COPING DURING AND AFTER TREATMENT

Coping during and after your treatment

Understanding the cancer and its treatment helps many people to cope. It can help to talk about plans for treatment, tests and check-ups with your doctors and nurses. This means you can be involved in the decisions that are made. This can help you feel more confident and can help you get back control of your life.

Bladder health

During your treatment, you may have symptoms such as:

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

For most people, these symptoms last for a few days after treatment. Your urologist or specialist 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 (see pages 21 to 24). 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 (see page 101).

What you can do to help

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.

Some fluids 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
- diet or light drinks
- alcohol.

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. The chemicals in cigarette smoke irritate and damage the lining of the bladder. They can also make your symptoms worse. There is lots of support available to help you stop (see page 106). Our booklet **Giving up smoking** has more information (see page 96).

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

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

Well-being and recovery

Most people with non-muscle-invasive bladder cancer will be cured or have their cancer controlled for many years. You may find that the cancer does not affect your life very much after the treatment has finished.

Even if you already follow a healthy lifestyle, you may choose to focus more on your general health after treatment is over. Certain lifestyle changes can help improve your long-term health and well-being. It can also make you feel more in control of your situation.

Living a healthy lifestyle can help your body recover after treatment. It can also help to reduce the risk of other illnesses, such as heart disease, diabetes and strokes.

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.

> ‘Since my treatment, I work out regularly and eat more healthily. I can safely say having bladder cancer is my “why” for leading a healthier lifestyle.’
>
> **Alex**

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, and 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 a healthy diet will give you more energy and help you to recover. Try to eat lots of fresh fruit and vegetables (5 portions a day), and less red meat. Follow any advice you have been given by a dietitian or specialist nurse. Our booklet **Healthy eating and cancer** has more information (see page 96).

Be physically active

Being physically active helps to keep you to a healthy weight. It can reduce stress and tiredness. Physical activity also reduces the risk of other health conditions. Some hospitals can refer you to local exercise or fitness groups, which are for all abilities. Our booklet **Physical activity and cancer treatment** has more information (see page 96).

Stick to sensible drinking guidelines

The current guidelines say that if you drink alcohol:

- do 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.

We have more information about ways to reduce stress, including a booklet on **Cancer and complementary therapies** (see page 96).

> ‘I am very careful about my stress levels. I am actually healthier and happier than I have ever been, with more zest for life.’
>
> **Alex**

Using public toilets

The side effects from treatment may mean you need to go to the toilet more often, or that you sometimes need to use the toilet urgently. Because of this, some people can feel anxious about going out in public. It may help to do the following things.

Plan ahead

Think about where you can find a toilet when you are not at home:

- Many areas have lists or maps of the local public toilets. Try typing ‘public toilets’ and the name of the place you are visiting into a search engine such as Google.
- Visit the website **toiletmap.org.uk** to see a map with details of public toilets.
- Download a phone app that can help you find a public toilet.

Get a toilet card

You can show this 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.

We have a free toilet card you can use. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00** to order one. The Bladder and Bowel Community also offer a free Just Can’t Wait toilet card and phone app (see page 101).

Use disabled toilets

These 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 from Disability Rights UK (see page 106). You can also order a guide that tells you where the toilets are.

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 can visit patients and their families at home if needed.

The **hospital social worker** can talk to you about social services and other benefits you may be able to claim, such as:

- meals on wheels
- a home helper
- hospital fares
- child care during and after treatment.

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

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

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

Shock and disbelief

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

Fear and anxiety

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

It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

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

Avoidance

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

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

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

Anger

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

Guilt and blame

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

Feeling alone

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

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists.

Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups**

You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

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

If you need more help

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

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

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

> ‘About 3 months after treatment was the first time I slowed down and really took in what had happened.’
>
> **Alex**

Relationships

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

Your partner

Some couples become closer through a cancer experience. But cancer can put a lot of strain on a relationship. Problems sometimes develop, even between couples who have a very strong relationship. If a relationship was already difficult, the stress of a major illness may make things worse.

Even couples that are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help avoid misunderstandings and find ways to cope with problems.

Treatment for bladder cancer may affect your sex life. You may have pain or discomfort in your bladder or urethra. This can make having sex uncomfortable. Following the bladder health advice can help (see pages 67 to 75).

If you have any worries about sex, talk to your urologist or specialist nurse. They can help with advice and support.

Our booklets **Cancer, you and your partner, Sexuality and cancer – information for men** and **Sexuality and cancer – information for women** have more information (see page 96).

Family and friends

Your family and friends may not always understand if you are not feeling positive about getting on with things. They may not know how treatment is affecting your day-to-day life.

Talking about how you feel will help them give you the support you need. Our booklet **Talking about cancer** has more useful tips (see page 96).

If you are a relative or friend

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

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

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

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer.

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

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

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

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

Teenagers

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

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

Our booklet **Talking to children and teenagers when an adult has cancer** has more information (see page 96).

There is also a video that may help at **macmillan.org.uk/talkingtochildren**

FINANCIAL SUPPORT AND WORK

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

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

Benefits

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

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

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

Personal Independence Payment

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

Attendance Allowance

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

Special rules

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

Help for carers

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

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

Macmillan Grants

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

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

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

Insurance

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

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

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 96.

Our Online Community forum **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

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

You can also get information about benefits and other types of financial help from Citizens Advice – see page 105.

Our booklet **Help with the cost of cancer** has lots more information – see page 96.

Work

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

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

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful – see page 96.

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

Employment rights

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

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

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

Our booklet **Your rights at work when you are affected by cancer** has more information – see page 96.

FURTHER INFORMATION

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**
If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 9am to 5pm).

Other useful organisations

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

Bladder cancer support organisations

Action on Bladder Cancer UK

Tel 0300 302 0085
Email info@actionbladdercanceruk.org
www.actionbladdercanceruk.org
Works with healthcare professionals, patients, carers and the general public to help improve the care of people with bladder cancer.

Bladder and Bowel Community

Tel 0192 635 7220
Email help@bladderandbowel.org
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
Email info@fightbladdercancer.co.uk
www.fightbladdercancer.co.uk
A national charity providing information, support and advice to all people affected by bladder cancer. Also supports research into causes, treatments and better patient aftercare.

Help with sexual difficulties

College of Sexual and Relationship Therapists

Tel 0208 543 2707
Email info@cosrt.org.uk
www.cosrt.org.uk
A national specialist charity for sex and relationship therapy. Provides information about sexual and relationship issues.

The Institute of Psychosexual Medicine

Tel 0207 580 0631
Email admin@ipm.org.uk
www.ipm.org.uk

Provides a list of accredited doctors who accept psychosexual referrals. The list gives details of doctors and clinics, both private and NHS run, throughout the UK.
Find a specialist at **www.ipm.org.uk/25/find-a-doctor**

The 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 with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email nurseline@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email info@cancersupportscotland.org
www.cancersupportscotland.org

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

Maggie's Centres

Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org

Has a network of centres in many locations in the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Tenovus

Helpline 0808 808 1010 (Daily, 8am to 8pm)
Email info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk

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

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

NHS UK

www.nhs.uk

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88 (Mon to Fri, 8am to 10pm, and Sat and Sun, 9am to 5pm)
www.nhsinform.scot

NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300
Email bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

UK Council for Psychotherapy (UKCP)

Tel 0207 014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline 0300 123 3393
(Mon to Fri, 9am to 6pm)
Text 86463
Email info@mind.org.uk
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

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 or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674
(Mon, Tue, Wed and Fri,
9am to 5pm, and Thu,
10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits

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

Carer's Allowance Unit

Tel 0800 731 0297
Textphone 0800 731 0317
(Mon to Fri, 8am to 6pm)
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 in the phone book or by contacting:

England

Helpline 0344 411 1444
www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Wales

Helpline 0344 477 2020
www.citizensadvice.org.uk/wales

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

GOV.UK

www.gov.uk

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

Equipment and advice on living with a disability

British Red Cross

Tel 0344 871 1111
Textphone 0207 562 2050
Email
contactus@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disabled Living Foundation (DLF)

Helpline 0300 999 0004
(Mon to Fri, 10am to 4pm)
Email info@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Disability Rights UK

Tel 0330 995 0400
Email
enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK.

Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Stop-smoking services

Smokefree (England)

Tel 0300 123 1044
(Mon to Fri, 9am to 8pm,
Sat and Sun, 11am to 4pm).
www.nhs.uk/smokefree

Smokeline (Scotland)

Tel 0800 848 484
(Mon to Fri, 8am to 10pm,
Sat and Sun, 9am to 5pm).
www.canstopsmoking.com

Stop Smoking Wales

Tel 0808 252 8216
Text 'HMQ' to 80818
www.helpmequit.wales

Want2stop (Northern Ireland)

www.want2stop.info
Text 'QUIT' to 70004

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

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

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
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, and Wales)
0808 808 7777
(Mon and Tue, 10am to 4pm)
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 support groups for carers in their area.

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.

With thanks to: Paula Allchorne, Urology Lead Nurse; Mr Ben Ayres, Consultant Urological Surgeon; Dr Alison Birtle, Consultant Oncologist; Charlotte Etheridge, Clinical Nurse Specialist; Mr Jonathan Makanjuola, Consultant Urological Surgeon; Dr Hugh Mostafid, Consultant Urologist; Mr Vinod Nargund, Consultant Urological Surgeon; Dr Santhanam Sundar, Consultant Oncologist; Miss Kay Thomas, Consultant Urological Surgeon; and Deborah Victor, Clinical Nurse Specialist.

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

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

Sources

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

European Association of Urology (EAU). Non-muscle-invasive bladder cancer guidelines. 2017.
National Institute for Health and Care Excellence (NICE). Bladder cancer: diagnosis and management. NG2. 2015.
National Institute for Health and Care Excellence (NICE). Suspected cancer: recognition and referral. NG12. 2015 (updated July 2017).

Can you do something to help?

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

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

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

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

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

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

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

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

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

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

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

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

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

FR Registered with FUNDRAISING REGULATOR

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

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

27530

This booklet is about non-muscle-invasive bladder cancer. It is for anyone who is having tests for non-muscle-invasive bladder cancer or has been diagnosed with it. It may also be helpful for family members, friends or carers.

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

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

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

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

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

MAC14220_E06_N. Next planned review 2021. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Printed using sustainable material. Please recycle.

The Information Standard
Certified member

This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

What's this logo? Visit **macmillan.org.uk/ourinformation**