MACMILLAN
CANCER SUPPORT

Understanding muscle-invasive and advanced bladder cancer

About this booklet

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

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

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

This booklet does not have information about non-muscle-invasive bladder cancer. We have another booklet about this called **Understanding non-muscle-invasive bladder cancer** (page 136).

How to use this booklet

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

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

On pages 142 to 155, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (page 156).

Quotes

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

For more information

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

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

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

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

Contents

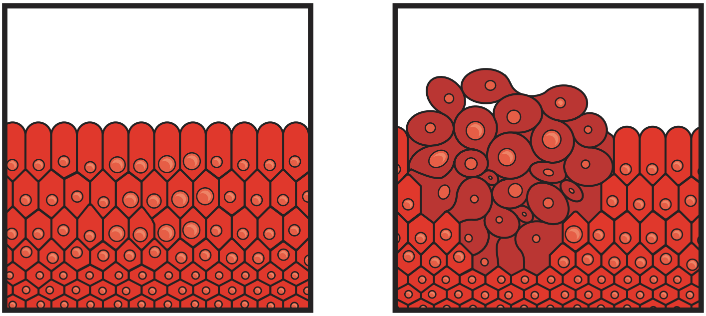
About bladder cancer

What is cancer?

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

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

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

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

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

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

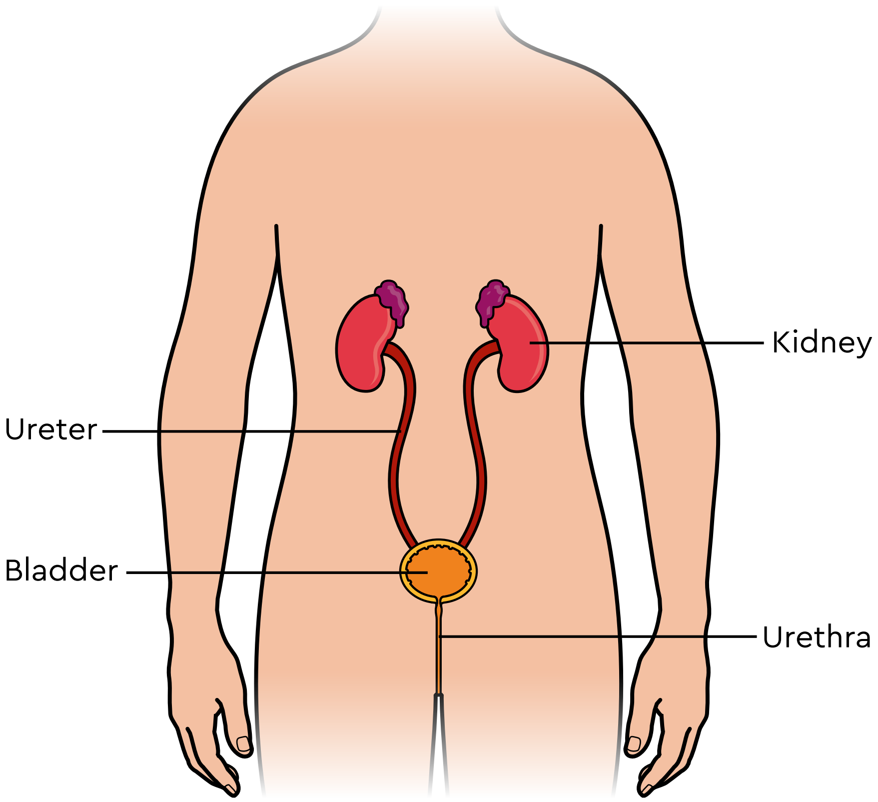
Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (page 12). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The bladder

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

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

The bladder in the body



What does the bladder do?

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

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

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

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

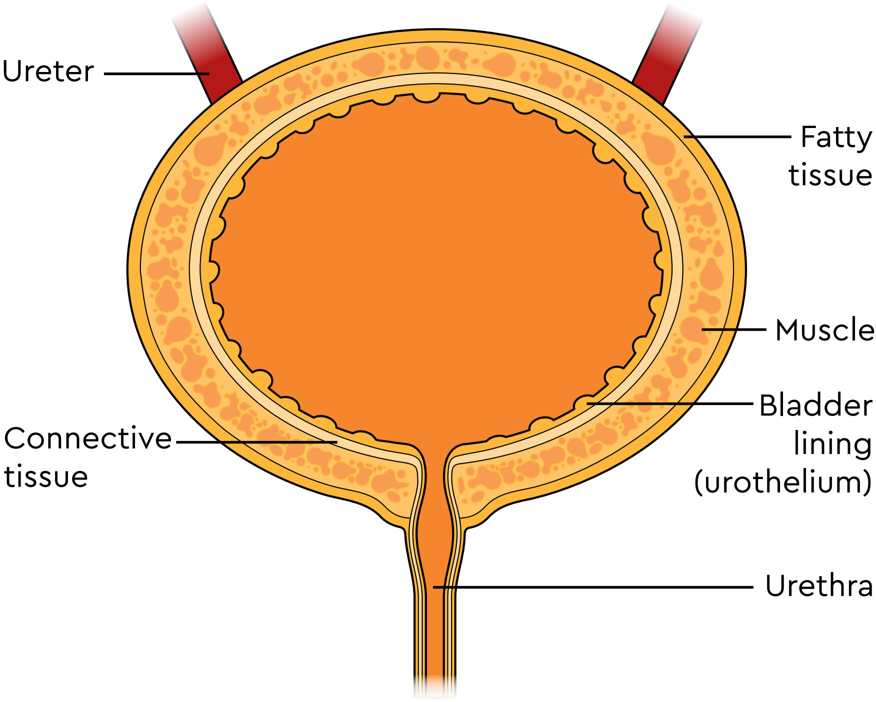
To empty your bladder, the pelvic floor muscles relax to open your urethral sphincter. At the same time, the bladder muscles tighten to push the pee out.

The layers of the bladder

The bladder wall is made of the following 4 layers:

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

The bladder



Bladder cancer

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

- Non-muscle-invasive bladder cancer – the cancer cells are in the inner lining or the connective tissue that surrounds the inner lining of the bladder. They have not spread into the muscle layer.
- Muscle-invasive bladder cancer – the cancer is in the muscle layer of the bladder or has spread through the muscle into the fat layer. It has not spread outside the bladder.
- Locally advanced bladder cancer – the cancer has spread outside the bladder into nearby tissues, the prostate, vagina, ovaries, womb or back passage (rectum). It may also be in lymph nodes in the pelvis, near the bladder (pages 12 to 13).
- Advanced bladder cancer – the cancer has spread to other parts of the body.

We have more information about non-muscle-invasive bladder cancer in our booklet **Understanding non-muscle-invasive bladder cancer** (page 136).

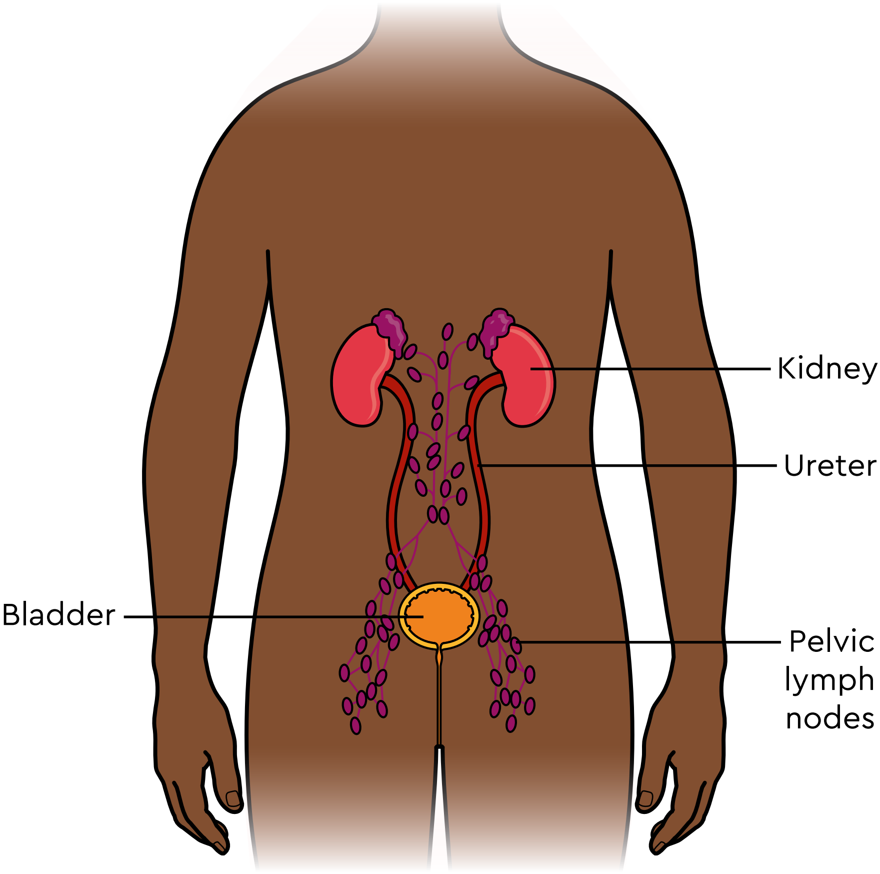
The lymphatic system

The lymphatic system helps protect us from infection and disease. It is part of the body's immune system. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body.

The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood. Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

Sometimes, cancer can spread through the lymphatic system. If bladder cancer spreads in this way, it is most likely to affect the lymph nodes near the bladder. These are called pelvic lymph nodes.

Pelvic lymph nodes



Causes and risk factors

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

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

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

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

Age

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

Smoking

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

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

Sex assigned at birth

Bladder cancer is more common in men than in women.

Exposure to chemicals at work

Exposure to certain chemicals can increase your risk of bladder cancer. These include chemicals previously used in dye factories and industries, such as:

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

Many of these chemicals are now banned and health and safety guidelines at work have improved. But it can take more than 30 years after exposure to them for bladder cancer to develop.

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

Urinary tract infections (UTIs)

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

Bladder schistosomiasis

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

Catheters

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

Previous treatment for cancer

People who have had radiotherapy to the pelvis have a higher risk of developing bladder cancer.

People who have had the chemotherapy drug cyclophosphamide also have an increased risk. But the benefits of cyclophosphamide treatment far outweigh the risk of developing bladder cancer.

Pioglitazone

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

Family history

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

Types of bladder cancer

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

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

Less common types of bladder cancer include:

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

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

Symptoms of bladder cancer

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

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

Blood in your pee (urine)

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

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

Urinary symptoms

You may:

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

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

Pain in the lower part of the tummy or back

Pain in the lower part of your tummy, below your belly button, is called pelvic pain. This type of pain, or pain in your lower back, are less common symptoms of bladder cancer. But it is important to get them checked by your GP.

> **"In hindsight I had some early symptoms of losing weight, pains in my abdomen and fatigue. Then one day I went to the toilet and right at the end of finishing my pee, blood passed through. This scared me. The next day I went to the doctor. They tested my urine and confirmed there was blood present and I would require further tests. „**

Steven, diagnosed with muscle-invasive
and advanced bladder cancer


Reception

Diagnosing bladder cancer

How bladder cancer is diagnosed

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

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

If your GP thinks you may have cancer or is not sure what is causing your symptoms, they will refer you to a urologist. This is a doctor who treats bladder and kidney problems. Or you may see a nurse called a urology nurse specialist. If tests or symptoms suggest you could have bladder cancer, your GP will refer you urgently. This means you should get a specialist appointment as soon as possible.

Most people see the nurse or doctor at a haematuria clinic or at a hospital urology department. The doctor or nurse may test your pee and give you an internal examination again. They will arrange for you to have further tests if they think you need them. You usually have most of the tests on the same day.

Cystoscopy

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

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

Flexible cystoscopy

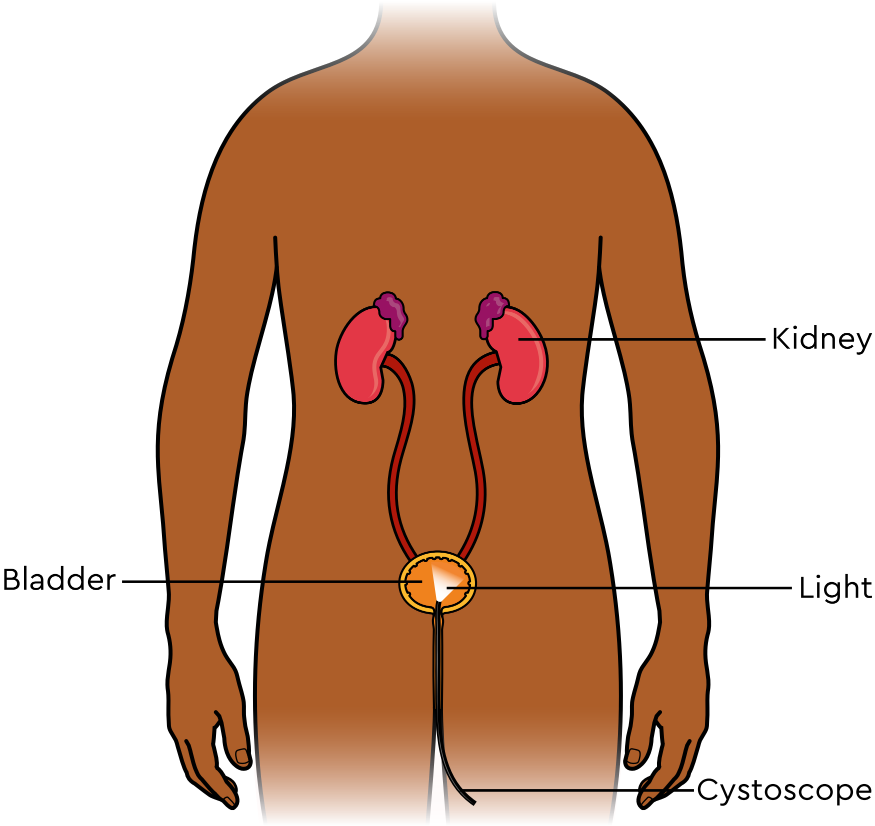
A flexible cystoscopy uses a cystoscope that can bend.

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

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

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

Cystoscopy



Rigid cystoscopy

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

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

You may have this done:

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

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

We have more information about having a TURBT on our website, and in our booklet **Understanding non-muscle-invasive bladder cancer** (page 136).

Cystoscopy side effects

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

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

Extra imaging techniques

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

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

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

Other tests

You may have blood tests to check how well your kidneys and liver are working and to show the number of blood cells in the blood.

A sample of your pee (urine) may be tested for cancer cells. It may also be tested for substances that are found in bladder cancer. This is called molecular testing.

You may have an ultrasound scan or a CT urogram to check for anything unusual in the urinary system. You may also have scans such as a CT, MRI or PET-CT to check areas near the bladder, or to look for signs of cancer in other areas of the body.

Ultrasound scan

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

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

CT urogram

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

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

The dye may make you feel hot all over for a few minutes. Some people have a stronger reaction to the dye. Tell your doctor if you have asthma or an iodine allergy, because you could have a stronger reaction to the injection.

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

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

You should be able to go home after the scan.

CT scan

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

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

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

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

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

Preparing for a CT scan

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

Ali, diagnosed with bladder cancer

MRI scan

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

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

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

During the scan, you need to lie still on a bed inside a long cylinder (tube). If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan. The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

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

PET-CT scan

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

Staging and grading

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

Bladder cancer staging describes:

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

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

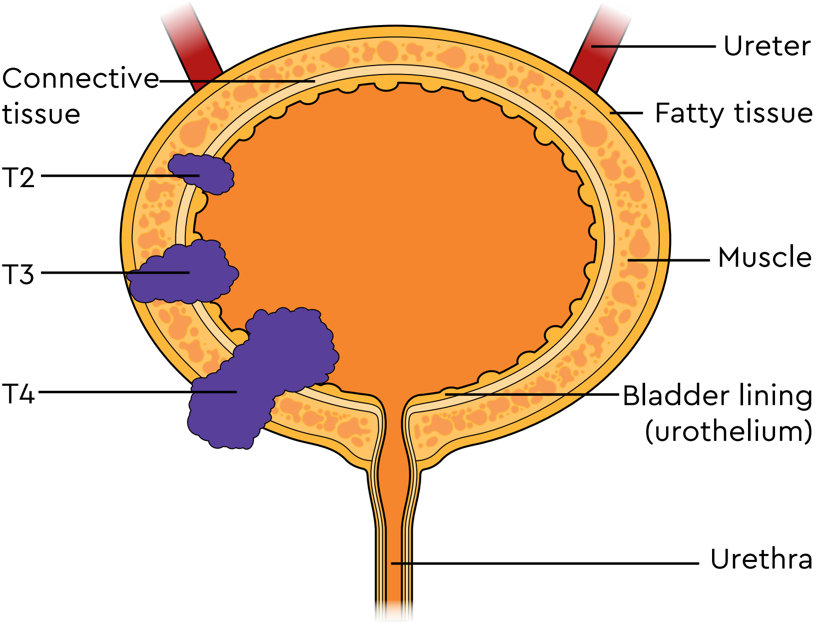
TNM staging

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

T stands for **t**umour – this explains how far the tumour has grown into the bladder, and how far it has spread into the surrounding tissue. Muscle-invasive and advanced bladder cancer is staged as T2 to T4:

- T2 means tumours have grown into the muscle of the bladder wall.
- T3 means tumours have grown through the muscle of the bladder and into the fatty tissue around the bladder.
- T4 means tumours have spread to other parts of the body near the bladder or in the pelvis.

Staging muscle-invasive and advanced bladder cancer



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

- N0 means there is no cancer in the lymph nodes.
- N1 means the cancer is in 1 of the lymph nodes in the pelvis, near the bladder.
- N2 means the cancer is in more than 1 lymph node in the pelvis.
- N3 means there is cancer in 1 or more of the lymph nodes further away from the bladder but in the tummy (abdomen).

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

- M0 means the cancer has not spread to other parts of the body.
- M1 means the cancer has spread to other parts of the body, such as the bones, lungs, liver, or lymph nodes outside the tummy.

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

Grading

Bladder cancer grading is about how the cancer cells look under a microscope compared with normal cells. With muscle-invasive or advanced bladder cancer, grading does not affect your treatment. Your doctor can tell you more about grading.

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected by a cancer registry (page 155).

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Radiotherapy machine

Treating bladder cancer

Treatment overview

Your cancer doctor or nurse will talk to you about the different treatment options and things to think about when making treatment decisions. Your treatment options will depend on the stage of the cancer (pages 34 to 36) and your general health. You may have some treatments as part of a clinical trial (pages 87 and 88).

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

Stop smoking

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

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

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

Treating muscle-invasive bladder cancer

Muscle-invasive means the cancer has spread into or through the muscle layer of the bladder wall. Treatment usually aims to cure the cancer with 1 of the following:

- Cystectomy (pages 53 to 60) – this is surgery to remove the bladder, and make a new way for you to pass urine (pee), called a urinary diversion. You may also have chemotherapy before or after the operation to reduce the risk of cancer coming back (pages 72 to 80).
- Radical radiotherapy – this is radiotherapy with other treatments (pages 61 to 71).

We have more information about choosing between these treatments on pages 48 and 49.

Some people with locally advanced bladder cancer may also be offered these treatments. Locally advanced means the cancer has spread outside the bladder into nearby areas.

If a cure is not possible, treatment can be given to control the cancer to help you live longer and reduce symptoms.

Treating advanced bladder cancer

Advanced bladder cancer means cancer that has spread from the bladder to other parts of the body. Sometimes this is called metastatic bladder cancer.

Unfortunately, it is not possible to cure advanced bladder cancer. Treatment aims to:

- shrink or control the cancer and help you live longer
- reduce your symptoms
- improve your quality of life.

Chemotherapy or immunotherapy drugs may help control the cancer and improve symptoms. Other treatments are given to help with a specific symptom caused by cancer. This is called supportive treatment or palliative treatment.

There is more information about chemotherapy on pages 72 to 80. There is also more information about immunotherapy on pages 81 and 82. And you can find more information about supportive treatments on pages 84 to 86.

Finding out you have advanced cancer can be difficult to cope with. You may feel shocked and find it hard to understand. Or you may have questions about what to expect. Your doctor and specialist nurse are there to help. We have information that you may find helpful on our website and in our booklet **Coping with advanced cancer** (page 136).

Your cancer doctor or GP may refer you to a palliative care team. This is an expert team that helps manage symptoms, such as pain or nausea. There are palliative care teams based in hospitals hospices or in the community.

How treatment is planned

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT). The MDT look at national treatment guidelines or the latest evidence for bladder cancer.

If you have any treatment preferences, your doctor or nurse will share them with the MDT.

The MDT will usually include the following professionals:

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

The MDT may also include:

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

Talking about your treatment plan

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

Your specialist doctor should explain:

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

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

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

You may need more than 1 meeting with your doctor or nurse to talk about your treatment plan.

> “I needed my bladder removing urgently and was given a choice of a urostomy, neobladder or continent urinary diversion. I felt overwhelmed and sick making such a big and quick decision. In another room, a Macmillan nurse helped me make a more informed decision. I decided to have the urostomy.”

Steven, diagnosed with muscle-invasive and advanced bladder cancer

Making treatment decisions

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

Doctors sometimes ask you to choose between different treatments (pages 48 and 49). This is usually when 2 treatments work equally well.

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

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

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

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

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

Choosing between surgery or radical radiotherapy

The aim of both these treatments is to cure the cancer. They may both be effective. If you are asked to choose between them it may help to think about what each treatment involves and the different side effects.

Having the treatment

For a cystectomy, you will be in hospital for 4 to 14 days. You will have a general anaesthetic. You need to be well enough to cope with the operation. You will have tests on your heart and lungs before the operation. It may take 3 to 6 months to fully recover.

Radical radiotherapy is not usually as physically demanding as surgery. You will not have a general anaesthetic. You will travel to the hospital Monday to Friday, for 4 to 7 weeks for treatment. Often, radiotherapy is given with chemotherapy.

If the cancer comes back after radiotherapy, you may be able to have surgery to remove the bladder. But the effects of radiotherapy may make surgery more complicated. Your doctor can talk to you about this.

Effects on the bladder

A cystectomy removes the bladder. The surgeon makes a new way for you to pass urine (pee). This is called a urinary diversion. It takes time to get used to living with a urinary diversion (pages 92 to 105).

Radiotherapy means you keep your bladder and pass urine in the same way as before treatment. You are likely to have bladder irritation during treatment. Some people will have permanent bladder side effects such as needing to pass urine more often or blood in the urine.

Effects on the bowel

Surgery sometimes causes bowel complications. But these usually get better with time. Sometimes radiotherapy may cause permanent bowel symptoms such as ongoing loose stools (poo), diarrhoea or blood in the stools.

Effects on erections and sperm production

Both treatments can cause difficulties getting or keeping an erection. This is called erectile dysfunction or ED. But this is highly likely after a cystectomy. Both treatments can affect your ability to make someone pregnant. This is called your fertility.

Ask your cancer team to explain the risks of these side effects in your situation. It can depend on your age and the exact treatment you need.

Menopause and effects on the vagina

Both treatments can cause vaginal changes and may cause early menopause. Menopause means monthly periods will stop and it is no longer possible to get pregnant.

Vaginal changes can make penetrative sex or internal examinations more difficult. They may also change how sex feels.

Ask your cancer team to explain the risks in your situation. Sometimes your treatment can be given in a way that reduces the chance of these side effects.

We have more information about these effects on our website. You may also find our booklets **Cancer and fertility** and **Cancer and your sex life** helpful (page 136).

Decisions about advanced cancer

For advanced cancer, the aim of treatment is to control the cancer, help you live for longer and improve symptoms.

This can mean you have different treatments depending on when you need them. You may have long periods in between treatments when you feel well and can continue with daily life. You may have ongoing treatment to control the cancer. This is sometimes called maintenance treatment.

Your doctor can often give you an idea about how well a treatment will work. You may decide to have one treatment instead of another because:

- the side effects are different
- it means you will spend less time at the hospital.

We have more information about making treatment decisions on page 47 and in our booklet **Making treatment decisions** (page 136).

You may need to have a treatment for a while to see if it is helping. Doctors will try to avoid you having unnecessary side effects from a treatment that is not working well.

If it becomes difficult to control the cancer, you may decide not to have further treatment. Your doctor and nurse will support you and make sure your symptoms are managed.

You may find our booklet **Coping with advanced cancer** helpful (page 136).

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (page 45).

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

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

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

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

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

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

Cystectomy (bladder removal surgery)

A cystectomy is an operation to remove the bladder.

This is one of the main treatments for muscle-invasive or locally advanced bladder cancer. The aim is to cure the cancer. You may have chemotherapy before or after the operation (pages 72 to 80). These anti-cancer drugs help reduce the risk of cancer coming back.

Rarely, a cystectomy is used to help control symptoms of advanced bladder cancer. But it is not often likely to be the most useful treatment in this situation.

What does the operation involve?

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

Usually the surgeon removes the whole bladder. This is called a radical cystectomy. They may also remove nearby areas such as:

- the prostate gland or seminal vesicles – this is where semen is stored
- the womb, ovaries, cervix and part of the vagina
- part, or all, of the urethra
- lymph nodes linked to the bladder.

If the whole bladder is removed, the surgeon also makes a new way for you to pass urine (pee). This is called a urinary diversion (pages 92 to 105). There are different types of urinary diversion. You may have a urostomy, bladder reconstruction or continent urinary diversion.

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

Asking questions before your operation can help. Your nurse or an organisation such as The Urostomy Association may be able to arrange for you to meet someone who already has a urinary diversion (page 143). You can also visit our Online Community bladder cancer forum. You may be able to talk to someone who is living with a urinary diversion, or read about their experiences. Visit **community.macmillan.org.uk/cancer_types/bladder-cancer-forum**

Surgery may also have possible effects on your sexual well-being and fertility.

> **“I had surgery to have my bladder removed. I have regular CT or MRI scans, flexible cystoscopies and blood tests. I don't take medication, other than painkillers.”**
>
> Steven, diagnosed with muscle-invasive and advanced bladder cancer

Effects on erections and sperm production

A radical cystectomy usually removes the organs that make semen. The operation may also affect the nerves that help with erections.

After surgery, this means you will not be able to make someone pregnant without fertility treatments. If you are worried about this, talk to your doctor or specialist nurse before your surgery. You may be able to store sperm to use in the future with fertility treatments to start a pregnancy. But this has to be done before you have treatment or surgery for bladder cancer.

You may also have difficulties getting or keeping an erection. This is called erectile dysfunction or ED. Your doctor can tell you about treatments that may help improve ED.

Menopause

Surgery that removes the womb and ovaries will cause the menopause if you have not already been through it. This means monthly periods will stop and it is no longer possible to get pregnant.

If you are worried about this, talk to your doctor or specialist nurse before your surgery. Sometimes the surgeon can leave the ovaries in place to prevent early menopause. Your doctor or nurse can also give you information about managing menopausal symptoms and your options for possible fertility treatments to start a pregnancy in the future.

Vaginal changes

Removing part of the vagina during surgery makes it shorter. Going through the menopause can also cause vaginal dryness. Both these changes can affect how sex feels after a cystectomy. You may find penetrative sex uncomfortable or painful. Internal examinations can also be more difficult. A vaginal lubricant or moisturiser may help. Or try different sexual positions so you can control the depth of penetration. Sometimes using a vaginal dilator will help. Your cancer doctor or nurse can give advice about this.

Open or keyhole surgery

An open cystectomy means the surgeon makes one cut in your lower tummy (abdomen) to do the operation.

Keyhole or laparoscopic surgery means the surgeon makes several small cuts in the tummy. They pass a thin tube with a light and camera on the end called a laparoscope into the tummy through one of the cuts. They use surgical tools through the other cuts to remove the cancer.

Keyhole surgery may have less complications than open surgery, and wounds may heal faster. This may mean you recover more quickly.

Sometimes the surgeon uses a machine (robot) during keyhole surgery. This is called robotic-assisted surgery. The surgeon controls a robotic tool that holds the instruments. Your surgeon can explain more about the benefits and disadvantages of this type of surgery.

Your surgeon will talk to you about which type of surgery is likely to be best in your situation. Some types of surgery will not be available in all hospitals. You may need to be referred to another hospital to have it done.

Before the operation

Before the operation, you go to a pre-assessment clinic for tests to check you are well enough to cope with the operation. These can include:

- blood tests
- a blood pressure check
- a recording of your heart called an ECG.

Some people will have further tests.

You will meet a member of the surgical team to discuss the operation. This is a good time to ask questions or talk about any concerns you may have about the operation. If you think you will need help when you go home, tell them as soon as possible. They can help you with this.

Some hospitals follow an enhanced recovery programme. This aims to reduce the time you spend in hospital and speed up your recovery. It also involves you more in your own care. For example, you will be given information about diet and exercise before surgery. You may be given supplement drinks to take too.

Before the operation, you may have the following:

- Antibiotics – you may have antibiotics to prevent infection. You may have them as an injection or as tablets.
- An enema – because part of your bowel is used for a urinary diversion, you may need an empty bowel for the surgery. You may have fluid given into the back passage (rectum) to help empty the bowel. This is called an enema. You usually have it the evening before the operation.

After the operation

After the operation, nurses will look after you in a high-dependency or intensive care unit for 1 or 2 days. They will encourage you to start moving about as soon as possible after your operation.

At first, you have fluids through a drip (infusion) into a vein in your hand or arm. You may be given painkillers through your drip. Once you are eating and drinking again, the drip is removed.

Some people may have a tube that goes up the nose and down into the stomach. This is called a nasogastric tube. It is used to remove fluid from the stomach, so you do not feel sick. This is usually removed 1 or 2 days after surgery.

You may have a tube close to the operation wound to drain fluid away. A nurse will take this out after a few days, when fluid stops draining.

You will have tubes to help drain urine (pee) from your body. The tubes you have depend on the type of urinary diversion you have. Your doctor and nurse will give you more information.

You may have loose or runny stools (poo) after your surgery. This is because part of the bowel is used to make a urinary diversion. It usually gets better over time. Tell your doctor or specialist nurse if it continues.

Pain

You will need medicines to manage any pain for a few days. These can be given in different ways. You may have the following:

- Patient-controlled analgesia (PCA) – you press a hand control to get painkillers into a vein from an electronic pump.
- Epidural – an electronic pump gives you painkillers into the back, to numb the nerves in the area where you had surgery.
- Tubes around the wound – sometimes the surgeon puts small tubes into the area around the wound, which can be used to numb the nerves in the same way as an epidural.

If you are in pain, tell your nurse or doctor straight away. You will be given painkillers to take before you go home.

The wound

The surgeon uses stitches or staples to close the wounds during surgery. They will explain when these need to come out and will arrange for a nurse to do this. Wound infections can be a complication of the surgery. Signs the wound is infected include:

- heat
- redness
- swelling
- fluid or pus coming from the wound
- feeling unwell
- a fever or high temperature.

Tell your nurse or doctor if you have any of these symptoms, even after you go home. If you are unable talk to your hospital team, tell your GP or out-of-hours service.

Your urinary diversion

Getting used to a urinary diversion and learning to look after it takes time. Like anything new, it will get easier with time and practice. Your specialist nurse will give you lots of support before and after your operation. They will show you how to care for and manage the type of urinary diversion you have (pages 92 to 105).

Before you leave the hospital, the nurse will make sure you have the equipment you need. Depending on the type of urinary diversion, this may include urostomy bags or catheters. When you are at home, you can get your equipment directly from a supplier or your chemist. Your GP, district nurse or specialist nurse can tell you more about this. The Urostomy Association can also give you details of suppliers (page 143).

When you get home, you will still be able to speak to your specialist nurse for advice. They may also arrange for a district nurse or a community stoma nurse to visit you when you first leave the hospital. They can help you cope with any problems.

Going home

How long you are in hospital for will depend on the operation you have had and how quickly you recover. It can be anything from 5 to 14 days.

Your surgeon will tell you how soon you can get back to doing things such as work, driving, shopping, gardening or playing sport. This will depend on the operation you had and your recovery.

Before you leave hospital, you will be given an outpatient appointment for a follow-up visit a few weeks after your surgery (pages 108 and 109). It is a good time to discuss any concerns you may have after your operation. Your doctor will tell you if you need any further treatment.

Radical radiotherapy

Radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given while doing as little harm as possible to normal cells.

Radical radiotherapy uses high doses of this treatment to try to cure muscle-invasive or locally advanced bladder cancer. You may have it with one of the following treatments. This is to help the radiotherapy work better.

Chemotherapy

Chemotherapy given with radiotherapy is called chemoradiation. You may have chemotherapy every weekday in week 1 and week 4 of your radiotherapy. Weekdays are Monday to Friday. Or, you may have chemotherapy once a week during the radiotherapy course. Chemoradiation may cause more severe side effects, so you need to be well enough to have this.

Carbogen and nicotinamide

You may have a gas called carbogen that you breathe in for a few minutes before and during your radiotherapy. You also take nicotinamide tablets. Carbogen and nicotinamide help increase the amount of oxygen that the cancer cells get. They are more likely to be destroyed by radiotherapy if they have lots of oxygen. This treatment is not available in all hospitals. Your doctor will tell you if this is an option for you.

Before radical radiotherapy

Your cancer doctor or nurse will explain what your treatment involves and possible side effects. They will explain if you need other treatments before you have the radiotherapy, such as:

- a small operation to remove as much cancer as possible from inside the bladder – called a transurethral resection of a bladder tumour or TURBT (visit **macmillan.org.uk/turbt**)
- chemotherapy to shrink the cancer and reduce the risk of it coming back (pages 72 to 80).

Radiotherapy treatment may affect your fertility (page 71). Fertility is the ability to get pregnant or make someone pregnant. If you are worried about this, it is important to talk to your doctor before your treatment starts.

How radical radiotherapy is given

You have radiotherapy in the radiotherapy department at the hospital. Treatment is given as a series of short, daily treatments. It is usually given on weekdays.

You may have to travel to a hospital further away than your local hospital to have treatment.

Planning your radiotherapy treatment

Radiotherapy is always carefully planned by a team of experts. They will plan your treatment so it does as little harm as possible to normal cells. The radiotherapy will be aimed precisely at the cancer.

On your first visit to the radiotherapy department, you will usually have a CT scan of the area that is being treated (pages 30 and 31). The information from the scan is sent to a planning computer.

Using a radiotherapy planning computer

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the precise area to be treated.

During your scan, you lie still on a narrow bed. This is sometimes called a table. If you feel uncomfortable, tell the radiographers so they can help. It is important that you are comfortable, because you need to be able to lie in the same position for all your radiotherapy treatment.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They are made in the same way as a tattoo. The marks help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. If you are worried about them or already have a tattoo in the treatment area, tell your radiographer. They can discuss this with you.

The radiographer uses laser lights to position you for your radiotherapy treatment. These are not harmful to your skin.

Having radiotherapy treatment

You usually have radical radiotherapy for bladder cancer as an outpatient. Each treatment takes 10 to 15 minutes.

How often you have treatment may depend on your general fitness and other health conditions. The treatments are usually given once a day from Monday to Friday, with a rest at the weekend, for 4 to 7 weeks. If you are less fit, you may have 1 treatment a week for 6 weeks. Your radiotherapy team will explain how many treatments you will have and when you will have them.

At the beginning of each session of radiotherapy, the radiographer will make sure you are in the correct position and make sure you are comfortable.

When everything is ready, they leave the room and the treatment starts.

The radiographers can see and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to during your treatment.

Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Having radiotherapy

Side effects of radiotherapy to the bladder

Your doctor, nurse or radiographer will talk about side effects with you. Tell them about any side effects you have during or after treatment. There are often things that can help. Side effects may build up towards the end of your course of radiotherapy. After treatment finishes, side effects usually get better over a few weeks or months.

Radiotherapy to the bladder and nearby areas can cause the following side effects.

Bowel effects

These may include:

- loose stools (poo) or diarrhoea
- cramping pains in your tummy (abdomen) or back passage (rectum)
- feeling you need to go to the toilet although your bowel is empty (tenesmus)
- passing mucus or blood when you empty your bowels
- sore skin around the back passage.

Your specialist may give you anti-diarrhoea drugs to help. Your nurse or radiographer may suggest making changes to your diet, such as reducing how much fibre you eat. It is important to drink at least 2 litres (3½ pints) of fluids a day.

Bladder effects

These include:

- passing urine (peeing) more often than usual
- passing urine during the night
- a burning feeling when you pass urine (similar to a urine infection)
- a poor flow of urine
- a feeling that you are not able to wait when you need to pass urine
- leaking small amounts of urine (incontinence).
- blood in your urine.

Your doctor can give you medicines to help. They may also ask you for a urine sample to check if you have an infection. An infection is a common cause of symptoms and is easy to treat.

Drinking fluids will help. Try to drink around 2 litres (3½ pints) a day. Try to drink water instead of drinks that may irritate the bladder. These include:

- drinks containing caffeine, such as tea, coffee, drinking chocolate and cola
- alcohol
- fizzy drinks
- acidic drinks – for example, orange or grapefruit juice
- drinks with artificial sweeteners – for example, diet or 'light' drinks.

Effects on the skin

The skin in the area being treated may become red and sore or itchy. It may also become darker. Tell your radiotherapy team if you notice any skin changes. They can give you advice about looking after your skin.

Tiredness

Radiotherapy often makes people feel tired. Tiredness (fatigue) may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired. But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as short walks
- eat a healthy diet and drink plenty of fluids
- ask others for help with everyday jobs.

After treatment finishes, you may continue to feel tired for weeks or months. If it does not get better, tell your cancer doctor or specialist nurse.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 136. You can also listen to this booklet as an audiobook online. Visit **macmillan.org.uk/fatigueaudio**

Hair loss

Radiotherapy only affects hair in the area treated. You may lose some of your pubic hair. It usually grows back after treatment finishes. It may take several months to grow back, although it depends on the dose of radiotherapy you have. Sometimes, hair loss is permanent.

If you have chemotherapy with radiotherapy, the chemotherapy drugs may cause hair loss in other areas of the body, such as from your head. Your doctor or nurse will explain what is likely to happen. Some chemotherapy drugs cause all or most of your hair to fall out.

We have more information in our booklet **Coping with hair loss** (page 136).

> **"I was really into wearing brightly coloured wigs, but I get too hot, so now I just wear headscarves."**
>
> Anita, diagnosed with bladder cancer

Possible late effects of radiotherapy to the bladder

Some people may have side effects that do not improve, or side effects that happen months or years after treatment. These are called long-term or late effects. Your doctor or nurse will explain these to you.

Bowel or bladder changes

If your bowel is affected, you may have ongoing loose stools (poo) or diarrhoea. If your bladder is affected, it may not hold as much urine (pee) so you may need to pass urine more often.

The blood vessels in the bowel and bladder can become more fragile. If this happens, you may see blood in your urine or stools. If you notice blood, tell your doctor straight away. They will do tests and give you the right treatment.

Always tell your cancer doctor, nurse or GP about any bowel or bladder symptoms you have. They can give you advice and may do some tests. Often symptoms can be treated.

Vaginal changes

The vagina may become narrower and less stretchy after pelvic radiotherapy. This can make it more uncomfortable to have internal examinations. It can also make penetrative sex difficult or uncomfortable.

A vaginal lubricant or moisturiser may help. Sometimes using a vaginal dilator will help. Your cancer doctor or nurse can give advice about this.

Menopause

Radiotherapy is likely to cause menopause if you have not already been through it. This means monthly periods will stop and it is no longer possible to get pregnant.

Your doctor or nurse can also give you information about managing menopausal symptoms and your options for possible fertility treatments to start a pregnancy in the future. We have more information on our website. Visit **macmillan.org.uk/menopausal-symptoms**

Erection problems (erectile dysfunction)

Radiotherapy can cause problems getting or keeping an erection. There are treatments that can help with erection problems. We have more information on our website. Visit **macmillan.org.uk/male-pelvic-side-effects**

Fertility problems

Radiotherapy to the pelvic area can affect your ability to get pregnant or make someone pregnant and may cause permanent infertility. If you are worried about this, it is important to talk to your doctor before you start radiotherapy.

We have more information in our booklets **Managing the bowel late effects of pelvic radiotherapy** and **Managing the bladder late effects of pelvic radiotherapy**. You may also find in our booklet **Understanding pelvic radiotherapy** helpful.

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

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. How this treatment is used to treat bladder cancer depends on the stage of the cancer.

Chemotherapy into a vein is called intravenous. It can be used for muscle-invasive or locally advanced bladder cancer. You may have chemotherapy into a vein:

- before surgery (pages 53 to 60) or radiotherapy (pages 61 to 71), to shrink the cancer and reduce the risk of it coming back – this is called neo-adjuvant chemotherapy
- with radiotherapy, to make treatment work better – this is called chemoradiation
- after surgery, if there is a high risk of the cancer coming back – this is called adjuvant chemotherapy.

For advanced bladder cancer, you may have chemotherapy on its own as your main treatment to help to shrink and control the cancer and improve your symptoms. It may help you live for longer.

Chemotherapy drugs for bladder cancer

Most people have a combination of drugs. Some common combinations are:

- gemcitabine and cisplatin (GemCis)
- methotrexate, vinblastine, doxorubicin and cisplatin (MVAC)
- mitomycin and fluorouracil (5-FU) – usually given at the same time as radiotherapy (chemoradiation)
- gemcitabine – usually given at the same time as radiotherapy (chemoradiation)
- paclitaxel and carboplatin
- gemcitabine and carboplatin (GemCarbo).

Other chemotherapy drugs may also be used, or you may have one of these drugs on its own. We have information about individual chemotherapy drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs**

How chemotherapy is given

Your cancer doctor or nurse will explain your treatment plan and what to expect. You usually have treatment as an outpatient in the chemotherapy day unit. You can usually go home afterwards. Sometimes, you may need to stay in hospital for 1 to 2 days.

Chemotherapy is usually given as a session of treatment. Each session takes a few hours. After the session, you have a rest period of a few weeks. Together, the chemotherapy and the rest period are called a cycle of treatment. The length of a cycle depends on the treatment you are having. Your doctor or specialist nurse will tell you how many cycles you will have.

The nurse gives you chemotherapy drugs into a vein by injection or as a drip (infusion). It can be given through:

- a short, thin tube the nurse puts into a vein in your arm or hand called a cannula
- a fine tube that goes under the skin of your chest and into a vein close by called a central line
- a fine tube that is put into a vein in your arm and goes up into a vein in your chest called a PICC line.

Fluorouracil (5-FU) is usually given through a small pump, which is connected to your central or PICC line. You can wear this on your belt or carry it in a bag. It gives the drug slowly over 4 to 5 days.

We have more information on cannulas, central lines, PICC lines and chemotherapy drugs on our website (page 136).

Contraception

Your doctor or nurse will give you advice about using contraception during and after your treatment. This may include information about the following:

- Contraception to prevent pregnancy – chemotherapy can be harmful to an unborn baby. During your treatment, and for a time after, it is important to use contraception if you or a partner could become pregnant.
- Contraception to protect partners – small amounts of chemotherapy can get into your body fluids. This includes fluid made in the vagina and the fluid that contains sperm. To protect any partners, your cancer doctor may advise that for a few days after treatment you use a condom for vaginal or anal sex, and a condom (or a latex barrier such as a dental dam) for oral sex.

Fertility

Some cancer drugs can affect whether you can get pregnant or make someone pregnant. If you are worried about this, it is important to talk with your doctor before you start treatment.

Side effects of chemotherapy

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well-controlled with medicines. Side effects usually go away once treatment has finished. Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect from your treatment.

The main side effects are described here as well as some ways to reduce or control them.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

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

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

You may be given a drug called G-CSF. This encourages the body to make more white blood cells. You have it as a small injection under the skin.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily.

You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Having a blood test

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Sometimes doctors prescribe a drug called erythropoietin or darbepoetin. This helps the body to make more red blood cells. It is given as an injection under the skin. But it is more common to have a blood transfusion for anaemia. Some people have both.

Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids.

If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

Sore mouth and throat

Chemotherapy may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

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

Sucking ice chips may sometimes help relieve mouth or throat pain.

Hair loss

Some chemotherapy drugs may cause hair loss. It depends on the drugs you are having. Some people may have complete hair loss including eyelashes and eyebrows. Others may only experience partial hair loss or thinning. Your doctor or nurse can explain what to expect and tell you more about ways to cope with hair loss.

Hair loss is almost always temporary. Your hair will usually grow back after treatment finishes.

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

If you feel sleepy, do not drive or use machinery.

Changes to periods

If you have a period, these may become irregular or stop while you are having chemotherapy. This may be temporary, but it can sometimes be permanent. Your menopause may start sooner than it would have done. Your doctor or nurse can give you more information.

Effects on the kidneys and liver

Some chemotherapy drugs can affect your kidneys or liver. You will have regular blood tests to check how well your kidneys and liver are working.

We have more information about these chemotherapy side effects on our website. Visit **macmillan.org.uk/chemotherapy**

Immunotherapy

The immune system protects the body against illness and infection. Immunotherapies are treatments that use the immune system to find and attack cancer cells. A type of immunotherapy called a checkpoint inhibitor may be used to treat bladder cancer that has spread.

Checkpoint inhibitors are usually only used if:

- cisplatin chemotherapy is not suitable
- cisplatin chemotherapy is not working well
- the cancer comes back after chemotherapy.

Sometimes, they are given after chemotherapy to keep the cancer under control. This is called maintenance treatment.

Your cancer doctor will explain if a checkpoint inhibitor is a suitable treatment for you. Some drugs may only be available as part of a clinical trial (pages 87 to 88). Checkpoint inhibitors that are used to treat bladder cancer include:

- atezolizumab
- pembrolizumab
- avelumab
- nivolumab
- ipilimumab
- durvalumab
- tremelimumab.

Your cancer doctor will tell you if they think any of these drugs, or a drug not listed, is suitable for you. We have more information about immunotherapy on our website. Visit **macmillan.org.uk/immunotherapy**

How checkpoint inhibitors are given

You have the immunotherapy drug as a drip into a vein (intravenously). You usually have treatment in the chemotherapy day unit and go home afterwards.

Your cancer doctor or nurse will explain your treatment plan and what to expect. After the treatment, you have a rest period of a few weeks. Together, the immunotherapy and the rest period are called a cycle of treatment. The length of a cycle depends on the treatment you are having.

Possible side effects

Common side effects of checkpoint inhibitor drugs include:

- feeling tired
- skin changes
- diarrhoea
- feeling short of breath
- hormone problems.

Side effects may be mild, but sometimes they can become serious very quickly if they are not treated. Side effects can start weeks, months, or sometimes more than a year after you finish treatment.

Your cancer doctor or nurse will give you information about managing side effects. It is important to tell them about any side effects you have, even after you have stopped having treatment.

Your doctor, nurse or pharmacist will also give you a card with information about your treatment on it. It is important to always have the card with you during treatment and after treatment finishes. You should show it to any doctor or healthcare professional you need to see.

Supportive treatments

Symptoms of advanced bladder cancer can often be relieved by treatments that control the cancer. For example, if you have chemotherapy or immunotherapy drugs, any symptoms you have may improve.

At times, you may also need treatments that only aim to control symptoms. These are called supportive treatments.

You can find more detailed information about each of the following treatments on our website (page 136). We also have more information on our website about managing other symptoms such as breathlessness, feeling sick or tiredness.

Always tell your doctor or specialist nurse if you have new symptoms, or if your symptoms get worse.

Ureteric stent

You may need ureteric stents if cancer blocks 1 or both ureters. The ureters are the tubes that carry urine from each kidney to the bladder.

When a ureter is blocked, urine cannot flow from the kidney to the bladder. If the blockage is not treated quickly it can make you feel very unwell. You may:

- have pain or discomfort in your back or side
- have a high temperature (fever)
- feel sick.

Your doctor may suggest an operation to put a stent into 1 or both ureters. A stent is a thin, flexible tube that holds the ureter open.

Having a stent

Ureteric stents can be put in in the following ways:

- Retrograde stenting – the stents are put in while you are under a general anaesthetic, using a cystoscopy inside the bladder.
- Antegrade stenting – the stents are put through the back of the body, below the ribs. You have injections to numb the area first. Sometimes, people have a sedative.

Your doctor will explain what to expect during and after the operation. They should also explain when the stent should be changed or removed. Ureteric stents can usually stay in for a number of months. Some can be left in for longer if needed.

Nephrostomy

Your doctor may suggest an operation to insert a nephrostomy if it is not possible to put in a ureteric stent.

A nephrostomy is a tube that lets urine drain from the kidney through an opening in the skin on your back. The tube is attached to a drainage bag outside the body. You may need 1 or 2 nephrostomy tubes, depending on whether 1 or both ureters are blocked.

Having a nephrostomy

You usually have a local anaesthetic for a nephrostomy insertion. Most people only stay in hospital for a short time. A doctor usually does the procedure in the x-ray (radiology) department. The doctor, called a radiologist, uses x-rays and ultrasound scans to help them place the nephrostomy tube in the kidney.

Your doctor will explain what to expect during and after the operation. They will tell you when the nephrostomy is likely to be removed or replaced. Before you go home, the nurse will show you how to look after your nephrostomy. They can arrange any support you need to do this at home.

Radiotherapy to treat symptoms

Radiotherapy uses high-energy rays to treat cancer cells. When it is used to improve symptoms, it is sometimes called palliative radiotherapy. Your cancer doctor or nurse will explain what your treatment involves and possible side effects.

For bladder symptoms, such as pain or bleeding, you usually have 3 to 5 treatments over a week. Sometimes, you will have 1 treatment. Each treatment takes around 10 to 15 minutes.

Radiotherapy can also be used to treat pain if the cancer has spread to the bones. You may only need 1 treatment or up to 5 treatments.

Bone-strengthening drugs

You may have a type of drug called a bisphosphonate or a drug called denosumab if bladder cancer has spread to the bones. These drugs help strengthen the bones and may reduce bone pain.

We have more information about denosumab and different bisphosphonate drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs**

Clinical trials – research

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

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

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

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

Taking part in a clinical trial

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

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

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

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part – page 51. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

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

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

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

If the cancer comes back

If the cancer comes back, you can usually have more treatment. The type of treatment you have will depend on:

- where it has come back
- the treatment you had before.

If the cancer comes back after radiotherapy, some people may be able to have surgery to remove their bladder (pages 53 to 60). If you have had your bladder removed, other treatments can be used. Your doctor will talk to you about the treatment that is best for your situation and ask about your preferences.

Finding out that cancer has come back can be a shock. Everyone has their own way of coping with this. Our cancer support specialists can also give you information and emotional support. Call them on **0808 808 00 00**.

Living with a urinary diversion

Urinary diversions

If your treatment involves surgery to remove the bladder, you will have a new way to pass urine after the operation. This is called a urinary diversion. The different types of urinary diversion are:

- urostomy
- bladder reconstruction
- continent urinary diversion.

You can read about these on the following pages.

Getting used to a urinary diversion and learning to look after it takes time. Like anything new, it will get easier with time and practice.

Your specialist nurse will give you lots of support before and after your operation. They will show you how to care for and manage the type of urinary diversion you have.

Before you leave the hospital, the nurse will make sure you have the equipment you need. Depending on the type of urinary diversion, this may include urostomy bags or catheters. When you are at home, you can get your equipment directly from a supplier or your chemist. Your GP, district nurse or specialist nurse can tell you more about this. The Urostomy Association can also give you details of suppliers (page 143).

When you get home, you will still be able to speak to your specialist nurse for advice. They may also arrange for a district nurse or a community stoma nurse to visit you when you first leave the hospital. They can help you cope with any problems.

Any type of urinary diversion is a big change to your body. If you feel anxious about your body or about going out in public, it may help to talk to others in a similar situation. Our Online Community has a stoma support forum where you can share your experience and find out how other people have coped. Visit **community.macmillan.org.uk/cancer_experiences/ileostomy-and-colostomy-discussions-forum**

You may also want to find out more about coping with body changes and body image after cancer. We have information on our website and in our booklet **Body image and cancer** (page 136). Or you may want to read our tips for using public toilets when you are out and about (pages 116 and 117).

> **"I have had a cry once in a while. But then I think I don't want to spend time worrying about what I look like. It's not all about looks – I'm really happy with who I am."**
>
> Anita, diagnosed with bladder cancer

Urostomy (ileal conduit)

A urostomy is an opening on your tummy (abdomen) made during surgery. It lets urine drain out of the body from the kidneys into a flat, watertight bag. The bag has a sticky back which can stay in place for several days without needing to be changed. It also has a small tap or valve at the lower end so you can empty the bag into a toilet when needed. This bag is called a urostomy bag or urostomy pouch.

A urostomy is sometimes called an ileal conduit because it is made using part of the bowel called the ileum. The surgeon removes this section of bowel. They use it to connect the 2 tubes called ureters from your kidneys to a small opening in the skin of the tummy. The opening is called a stoma.

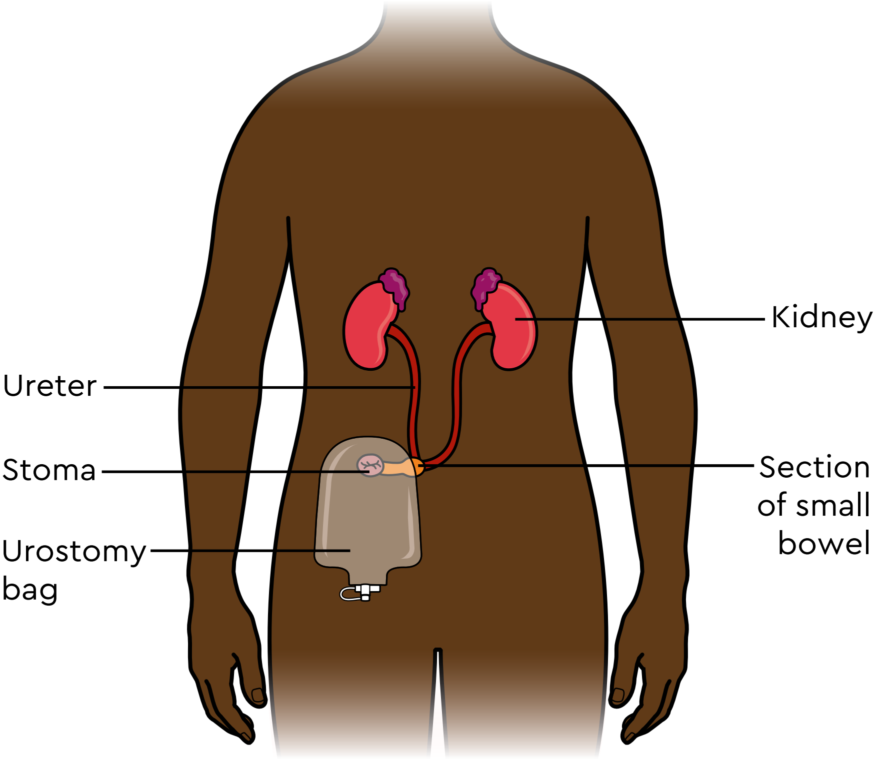
Before the operation, the surgeon or stoma nurse will talk to you about the best position for your stoma. The stoma should be easy for you to reach to empty or change the bag.

The stoma

The urostomy stoma will be bruised and swollen at first. But it will shrink to its final size within a few weeks.

At first, it is not unusual for the stoma to bleed slightly when cleaned. Your nurse will tell you more about this. The stoma will also produce mucus. This is a thick, white liquid. It might appear as pale threads in the urine.

A urostomy (ileal conduit)



Emptying or changing a urostomy bag

For the first few days after your operation, your nurse will look after your urostomy for you.

As soon as you feel ready, they will show you how to do the following:

- Empty the urostomy bag – most people get into their own routine of when and how often the bag fills up and needs to be emptied. At night, you can attach a larger bag to the tap at the bottom of your urostomy bag so you do not need to empty it until the morning.
- Care for the stoma – some urostomy bags are made to stay on for several days, but it can vary. When you change the bag it is important to clean the stoma and nearby skin carefully.
- Fit the new bag – the bag should fit closely around the stoma to keep urine away from your skin and prevent soreness. Tell your stoma nurse if you find the type of urostomy bag you have difficult to use. They can give you advice or may suggest another type of bag.

You may want to have a family member or friend with you while you are taught how to care for your stoma. This means they will know how to help you at home, if needed.

Living with a urostomy

Urostomy bags are flat. This means they will not be easily noticed under your clothes. How noticeable the bag is through your clothes depends on the size of the stoma and where the stoma is on your tummy.

Many people with a urostomy can wear their tightest clothes without anyone knowing they have a stoma bag. You may be very aware of your urostomy. But people will not usually notice it unless you choose to tell them.

Having a urostomy will not usually affect the activities you can do. Many people are able to do go back to work and can do hobbies, including swimming. If you are worried about your life after surgery, you can talk to your stoma nurse.

> **"As my body was changing post-surgery, the bags did not fit correctly. This led to accidents, until the stoma nurses helped me with different fitting bags. As time progressed it became easier. I can call and see a stoma nurse as and when required."**
>
> Steven, diagnosed with muscle-invasive and advanced bladder cancer

Bladder reconstruction (neobladder)

A bladder reconstruction or neobladder is a new bladder made from a section of your bowel during surgery.

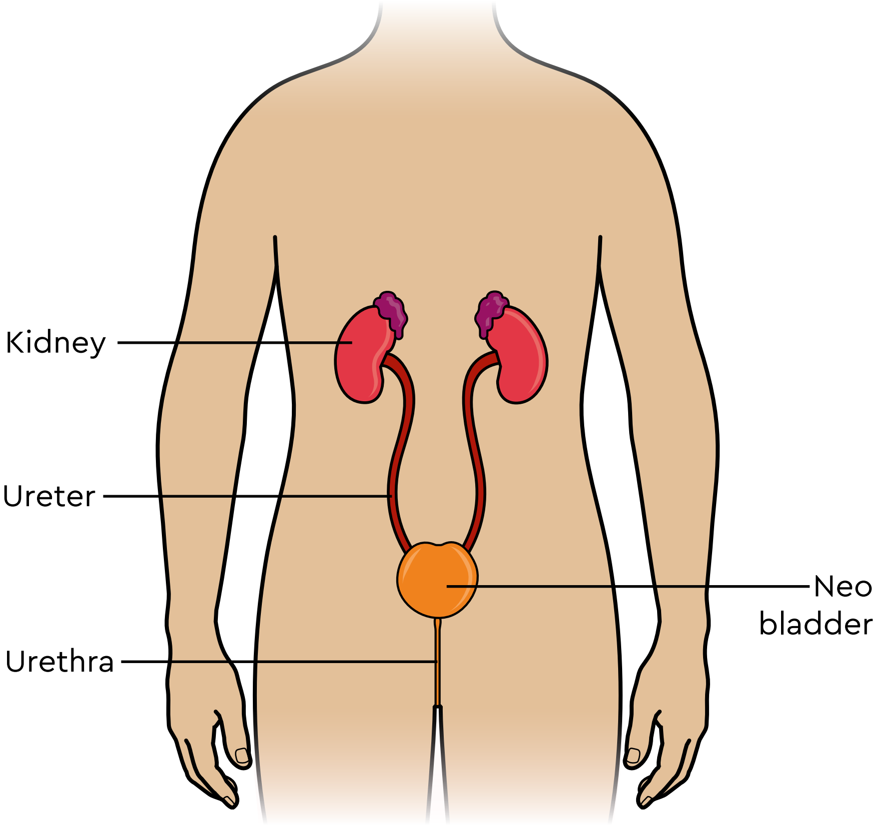
The surgeon connects 1 end of the new bladder to the 2 tubes called ureters from the kidneys. They connect the other end to the tube that carries urine out of the body. This is called the urethra.

Urine drains from the kidneys into the new bladder.

With time and practice, most people learn to empty their new bladder in the same way as before the operation by passing urine into the toilet. Some people may need to pass a tube called a catheter into the urethra to empty their new bladder. This is called self-catheterisation.

Sometimes the surgeon may not be able to make the new bladder during surgery. If this happens, they make a urostomy instead (pages 94 to 97). After the operation urine drains out of the body from the stoma into a bag. Your surgeon will talk with you about the risk of this before surgery.

A bladder reconstruction (neobladder)



After surgery

After your surgery, you may have a tube that goes through the tummy wall into the new bladder. This drains urine and will help if there are any problems where the new bladder joins the urethra. Your nurse will explain when this can be removed.

You will also have a tube called a catheter in the urethra to drain the urine from your new bladder. This stays in place for a few weeks while you recover from the operation. Your nurse will explain how to look after the catheter and your new bladder before you go home.

A few weeks after surgery, you will return to the hospital. Some people may have an x-ray called a cystogram to check how the new bladder is working. If there are no signs of leaks or other problems, your nurse or doctor will remove the catheter. You may have to stay in hospital for 1 or 2 days after this. This is to make sure your bladder is emptying fully.

Emptying your new bladder

To empty your new bladder, you tighten your tummy muscles by holding your breath and pushing down into your tummy. You need to do this regularly, because you do not have the nerves that tell you when your bladder is full.

At first, you will have to empty your bladder every 2 to 3 hours. The feeling of needing to pass urine can be different. You might find it helpful to set an alarm to remind yourself to pass urine. Over time, your new bladder will stretch and be able to hold more urine. But you may still have to empty it every 4 to 6 hours.

You may also need to pass a catheter into your urethra a few times. This is called intermittent self-catheterisation. It helps to make sure the new bladder is completely empty. If you need to do this, your specialist nurse will show you how.

Leaking urine

To start with, you might leak urine, especially at night. But this usually gets better after a few months. Your specialist nurse or surgeon can suggest things to help. They may refer you to a continence adviser. Before your surgery, your nurse will show you how to do pelvic floor exercises. It is important to keep doing these as they can help you have more control over leaking urine.

You may feel anxious about going out in public and worry about finding a toilet in time. Planning ahead so that you are prepared can help you feel more confident. There are tips on pages 116 and 117.

Looking after your new bladder

As well as emptying your new bladder regularly, you may have to wash it out. The bowel tissue used to make the new bladder continues to make mucus. This can cause an infection if it is not washed out. To do this, you put fluid through a catheter that is put into the new bladder through the urethra. Your nurse will show you how to do this.

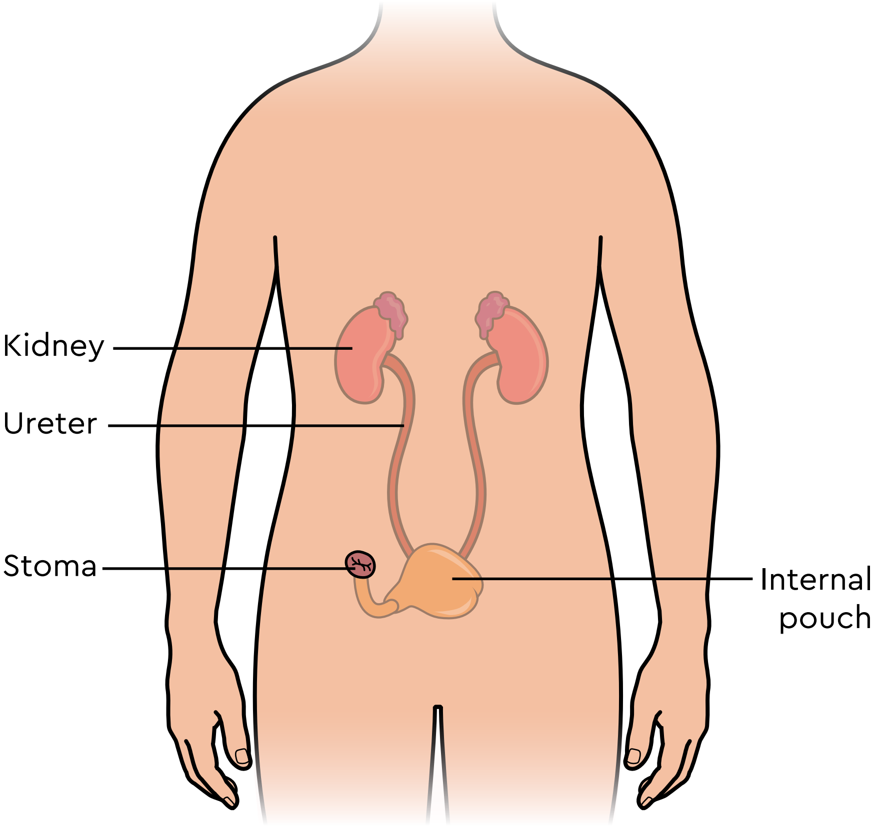
Continent urinary diversion

A continent urinary diversion lets you drain urine through an opening called a stoma on the tummy (abdomen). You put a tube called a catheter through the stoma when you want to do this.

The surgeon makes a pouch that holds urine from a section of the bowel. They attach the 2 tubes from your kidneys called ureters to the pouch so that urine from the kidneys drains into the pouch.

The surgeon uses another small section of bowel to make a tube to connect the pouch to the stoma on the tummy wall. This type of stoma lies flat against the skin.

A continent urinary diversion



After surgery

After surgery, you will have 2 catheters in place. One goes into the pouch through your tummy and the other goes through the stoma. These stay in place for a few weeks while you recover from the operation.

Once the pouch has healed you will go back to the hospital. It usually takes about 6 weeks after surgery for the pouch to heal.

You will usually stay in hospital for 1 or 2 days for the catheters to be removed.

You will also learn how to empty the pouch and wash it out. Your specialist nurse will teach you how to do this.

Emptying your pouch

To empty your pouch, you put a tube called a catheter through the stoma into the pouch. Your specialist nurse will show you how to do this.

At first, you do it every 1 to 2 hours, until your pouch stretches.

Eventually, you may be able to leave the pouch for up to 6 hours without emptying it. You may find it helpful to set an alarm to remind yourself to empty the pouch.

Washing out your pouch

As well as emptying your pouch, you need to wash it out.

The bowel tissue used to make the pouch continues to make mucus. This is a thick, white liquid. It might appear as pale threads in the urine. If it is not washed out, it can cause an infection.

You need to wash out your pouch several times a day. To do this, you put fluid through the catheter that you use to drain your pouch. Your specialist nurse will teach you how to do this.

After treatment

Follow-up

After treatment for bladder cancer, you will have regular follow-up appointments with your cancer doctor or nurse. These are usually every few months to start with. If you have any problems or notice new symptoms between appointments, let your doctor or nurse know as soon as possible.

After surgery or radical radiotherapy

You may have scans to check for any sign of the cancer coming back. Your doctor or nurse will explain what type of scans and how often you need these.

After surgery to remove the bladder, you will also have regular scans and blood tests to check your kidneys are working well.

If your urethra was not removed during surgery, there is a small risk that the cancer could come back there. You will have tests every year to check the urethra. These are called urethroscopies. This usually continues for 5 years.

If you had radiotherapy, you will have regular cystoscopies. These are important because if cancer comes back, you may be able to have surgery to treat it again. The cystoscopies will be every 3 months at first, but less often over time. You will have them for at least 5 years after treatment finishes.

If you have advanced bladder cancer

You will have regular appointments with your doctor or nurse to check how you are. They will also help manage any symptoms caused by the cancer. You may have tests and scans to monitor the cancer.

You may also have appointments with a palliative care team. This is an expert team that helps manage symptoms, such as pain or nausea.

There are palliative care teams based in hospitals, hospices or in the community. Your cancer doctor or nurse can give you more information.

You may find our booklet **Coping with advanced cancer** helpful.

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

Sex and fertility

Sex after bladder cancer treatment

Cancer and cancer treatment may have a direct effect on your sex life or affect your sexual well-being. For example, you may be coping with bladder or bowel changes after treatment, or a change to your body such as a stoma. These can affect how you feel about your body or make you less interested in sex.

Surgery or radical radiotherapy can also cause the following effects:

- vaginal changes that may make penetrative sex uncomfortable or painful (pages 56 and 70)
- menopausal symptoms such as hot flushes, vaginal dryness and loss of interest in sex (pages 55 and 71)
- difficulties getting or keeping an erection (pages 55 and 71).

There are treatments that can help with these problems if they are affecting your sexual well-being. Help and support is available, and there are usually things that can help you cope. But it can be difficult to start a conversation about sex with your healthcare team. Some people feel embarrassed or uncomfortable talking about something so personal. Remember that healthcare professionals are used to talking about these issues. It is important to talk to your cancer doctor, nurse or GP so they can help you get the right advice and treatments.

We have information on our website about coping with side effects that affect sexual well-being. This includes things that might help and information about where to get support. You can:

- find out more at **macmillan.org.uk/information-and-support/coping/relationships/your-sex-life-and-sexuality**
- call us on **0808 808 00 00**.

We have more information in our booklets **Cancer and your sex life** and **Body image and cancer**. Sexual well-being and relationships may also be affected by things other than just physical changes. You can find more information in our booklets **How are you feeling? The emotional effects of cancer** and **Cancer and relationships – support for partners, families and friends**.

Fertility after bladder cancer treatment

If treatment for bladder cancer is likely to cause fertility problems, your cancer doctor or nurse should talk to you about this before treatment starts. But you can ask for more information at any stage before, during or after your treatment has finished. We have more information about fertility and cancer in our booklet **Cancer and fertility**.

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

Living well

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

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

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

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

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

Stop smoking

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

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

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

Keep to a healthy weight

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

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

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

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

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

Eat a healthy diet

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

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

If you have had radiotherapy, you may have been advised to make changes to your diet to help with any bowel effects. Follow any advice you have been given by a dietitian or specialist nurse. We have more information in our booklet **Healthy eating and cancer** (page 136).

Be active

Keeping active helps you:

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

Some hospitals can refer you to local exercise or fitness groups, of all abilities. You may find our booklet **Physical activity and cancer** helpful (page 136).

Stick to sensible drinking guidelines

NHS guidelines suggest that you should:

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

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits. There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

Reduce stress

Think about ways to reduce the stress in your life. You could make time to do things that you enjoy or that make you laugh. Some people find it relaxing to meditate. Other people start a new hobby or evening class.

You may find our booklets **Cancer and complementary therapies** and **Life after cancer treatment** helpful (page 136).

Using public toilets

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

Toilet card

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

> **"Macmillan helped me to access a toilet card. Now I'm confident to go shopping as I know there'll be somewhere to go nearby."**
>
> Ali, diagnosed with bladder cancer

You can order our Macmillan toilet card to carry and use when you are out in public (page 136). It also comes with a fob version that can be attached to a key ring. We cannot guarantee that it will work everywhere. But we hope it helps you get access to a toilet without any awkward questions.

The Bladder and Bowel Community also offer a free Just Can't Wait toilet card and toilet card app (page 142).

Plan ahead and find a public toilet

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

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

Use disabled toilets

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

Coping with your emotions

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You will have good and bad days, but if you are overwhelmed by these feelings, tell your doctor or nurse. It may be that you have depression. This is treatable, so they should be able to help.

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family or friends, going on holiday or starting a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a healthier diet, getting fitter or starting a complementary therapy.

You may find the following booklets helpful (page 136):

- **How are you feeling? The emotional effects of cancer**
- **Healthy eating and cancer**
- **Physical activity and cancer**
- **Cancer and complementary therapies**

> “For me, the most lonely time was after treatment ended – when hospital appointments have longer gaps between them. With the help of my specialist cancer nurse and a Macmillan nurse from the well-being course, I started a cancer support group.„

Steven, diagnosed with muscle-invasive and advanced bladder cancer

> “Macmillan have been invaluable, I have a wonderful nurse and counsellor. It's really nice to speak to them and know that how I'm reacting to things or dealing with things is normal.”

Anita, diagnosed with bladder cancer

Who can help?

Many people are available to help you and your family.

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

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

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. But many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you are at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There is also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

Your feelings and relationships

Your feelings

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

We have more information about emotions on our website and in our booklet **How are you feeling? The emotional effects of cancer** (page 136).

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

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

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

There is more information on pages 138 to 141 about other ways we can help you.

“I'm a lot more understanding of other people. I've been more focused on friends and family, I don't take anything for granted. I used to get upset with small things but now I'm much more calm.„

Anita, diagnosed with bladder cancer

Relationships

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

We have more information about relationships online and in our booklets **Talking about cancer** and **Cancer and relationships – support for partners, families and friends**.

If you are a family member or friend

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

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

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

Talking to children and teenagers

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

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

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

Work and financial support

Help with money and benefits

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

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

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

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

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (pages 148 and 149).

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

Grants

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

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit **macmillan.org.uk/insurance-cancer**

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

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

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

Work

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

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

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

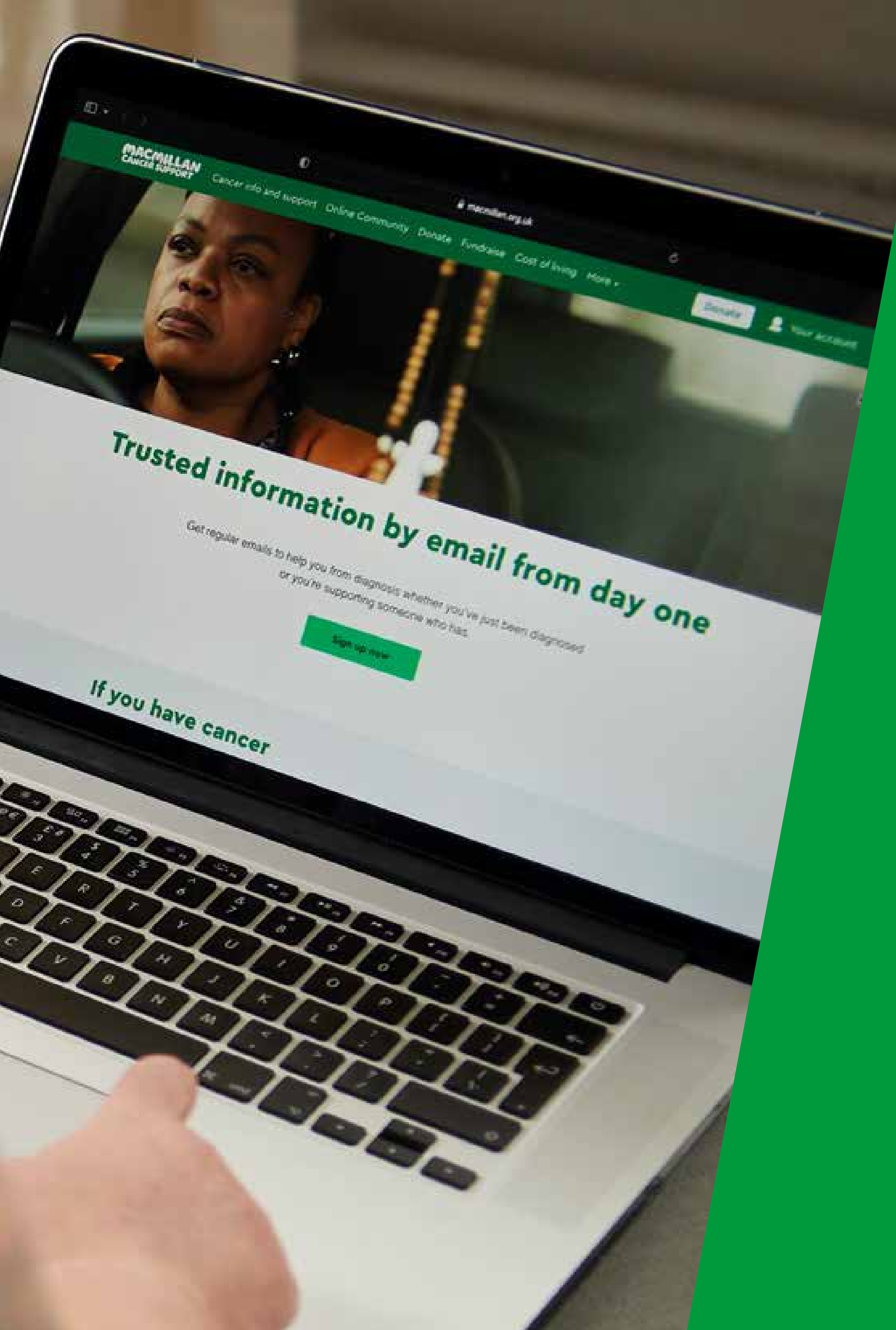
Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer**.

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

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

“My work put me on sick leave and kept in touch. But I decided to hand my notice in because it was a stressful job and I didn't want to go back to that. At the moment I'm taking a break to process everything. „

Katherine, diagnosed with bladder cancer



Trusted information by email from day one

Get regular emails to help you from diagnosis whether you've just been diagnosed or you're supporting someone who has.

If you have cancer

Further information

About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

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

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

Online information

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

Other formats

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

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

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

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

The language we use

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

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

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

To find out more about how we produce our information, visit **macmillan.org.uk/ourinfo**

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

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

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

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

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial advice

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

Help accessing benefits

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

Help with work and cancer

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

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Bladder cancer support organisations

Action Bladder Cancer UK

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

Bladder and Bowel Community

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

Fight Bladder Cancer

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

Urostomy Association

Tel **0138 643 0140**
www.urostomyassociation.org.uk
Supports people who are about to have or have had a urinary diversion, and their carers.

Help with sexual well-being

College of Sexual and Relationship Therapists

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

Institute of Psychosexual Medicine

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

Sexual Advice Association

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

General cancer support organisations

Cancer Black Care

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

Cancer Focus Northern Ireland

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

Cancer Research UK

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

Macmillan Cancer Voices

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

Maggie's

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

Penny Brohn UK

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

Tenovus

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

General health information

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS 111 Wales

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

NHS Inform

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

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

UK Council for Psychotherapy (UKCP)

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

Emotional and mental health support

Mind

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

Samaritans

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

Financial support or legal advice and information

Advice NI

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

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

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

Citizens Advice

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

England

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

Scotland

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

Wales

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

Disability and Carers Service

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

GOV.UK

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

Jobs and Benefits Office Enquiry Line Northern Ireland

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

Law Centres Network

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

Local councils (England, Scotland and Wales)

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

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

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

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

NiDirect

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

Northern Ireland Housing Executive

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

StepChange Debt Charity

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

Unbiased.co.uk

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

Support for older people

Age UK

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

LGBT-specific support

LGBT Foundation

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

OUTpatients

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

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

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

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

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

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

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

Northern Ireland – Northern Ireland Cancer Registry (NICR)

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

Your notes and questions

Disclaimer

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, Clinical Nurse Specialist; Mr Ben Ayres, Consultant Urological Surgeon; Kathryn Chatterton, Clinical Nurse Specialist; Charlotte Etheridge, Clinical Nurse Specialist; Mr Jonathan Makanjuola, Consultant Urological Surgeon; Professor Duncan McLaren, Professor and Consultant Clinical Oncologist; Vinod Nargund, Consultant Urological Surgeon; Santhanam Sundar, Consultant Clinical 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 **informationproductionteam@macmillan.org.uk**

Sources

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

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

Witjes JA, Bruins HM, Cathomas R, et al. Muscle-invasive and metastatic bladder cancer. European Association of Urology [Internet], 2021, Available from uroweb.org/guideline/bladder-cancer-muscle-invasive-and-metastatic/ [accessed September 2021].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

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

Card number
☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Valid from
☐☐ ☐☐

Expiry date
☐☐ ☐☐

Issue no
☐☐☐

Security number
☐☐☐

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

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

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

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

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

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

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

Trusted Information Creator
Patient Information Forum