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 for this type of cancer or has been diagnosed with it. This booklet may also be helpful for family members, friends or carers.

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

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

How to use this booklet

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

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

In this booklet, we have included quotes from people who have been affected by muscle-invasive and advanced bladder cancer. These are from people who have chosen to share their story with us. To share your story, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 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.

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

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

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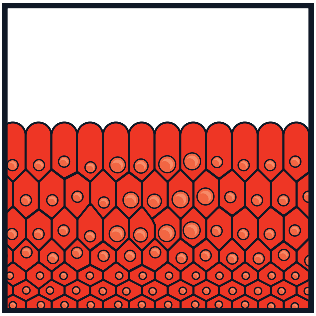
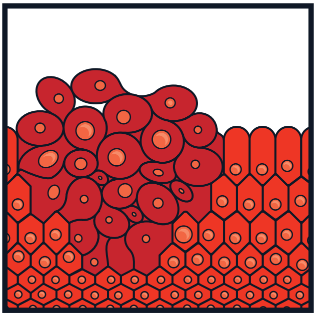
What is cancer?

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

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.


Normal cells


Cells forming a tumour

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

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system. When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

The bladder

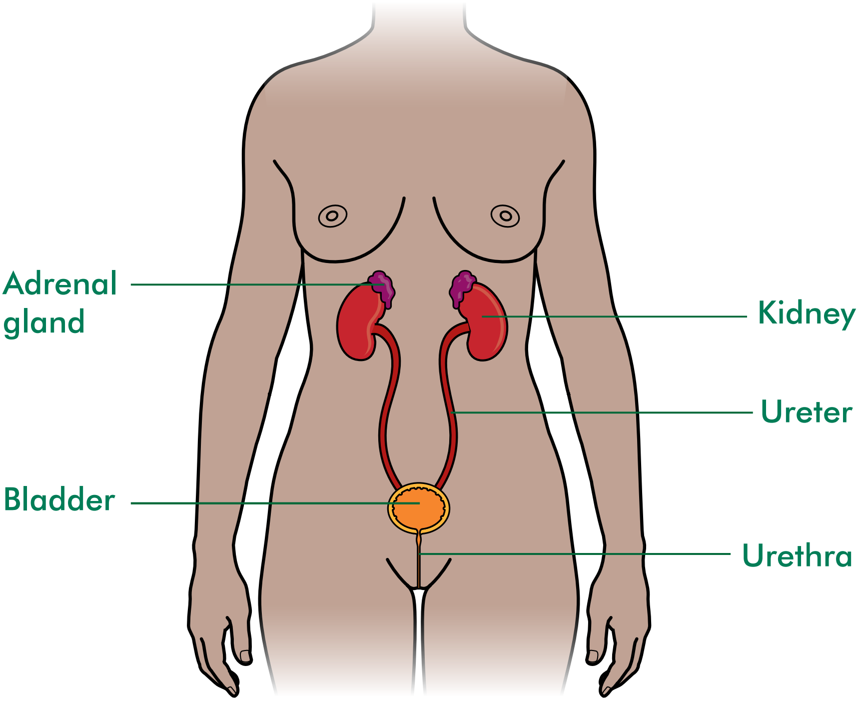
The bladder is a hollow and muscular organ that collects and stores urine (pee). It sits in the lower part of the tummy (abdomen), called the pelvis.

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

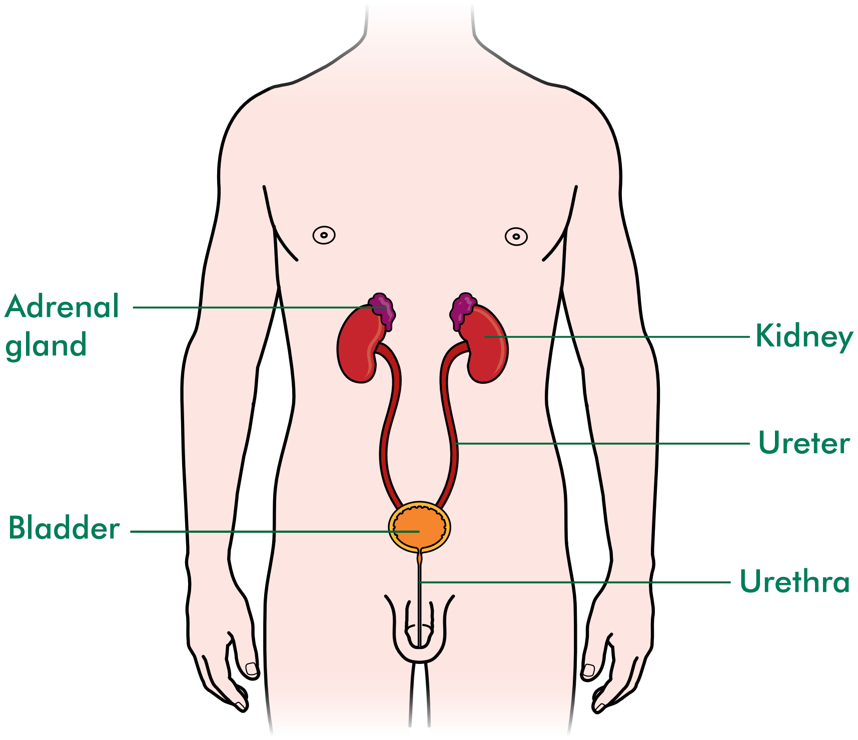
Urine is made of water and waste products. It is produced by the kidneys. Urine drains from your kidneys to your bladder through long tubes called **ureters.** As your bladder fills, it expands to store the urine. When it is full, it sends messages (nerve signals) to the brain. This makes you feel like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

The urethra has rings of muscle called the external and internal sphincter. These sphincters help to keep the urethra closed. This stops urine leaking out. The bladder is supported by a group of muscles that sit at the bottom of the pelvis (the area between the hips). They are called the pelvic floor muscles. In women, the urethra is a short tube that lies in front of the vagina (see the illustration opposite). In men, the urethra is longer and passes through the prostate gland to the end of the penis (see the illustration on page 10).

The bladder in women



The bladder in men



The lymphatic system

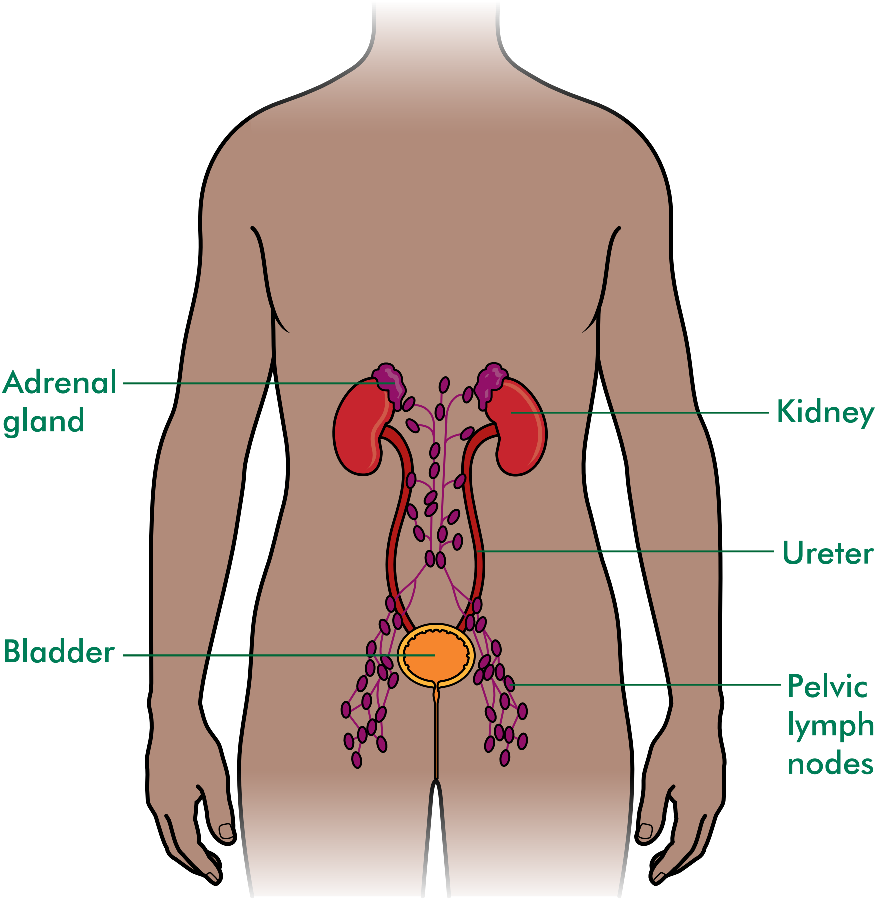
The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection.

The lymphatic system and bladder cancer

Sometimes, cancer can spread through the lymphatic system. If bladder cancer cells spread outside the bladder, they can go to the lymph nodes near the bladder. These are called pelvic lymph nodes (see the illustration opposite). You usually have tests (see pages 24 to 33) to check if there are any signs the cancer may have spread to the lymph nodes.

The lymphatic system



Causes and risk factors

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

There are certain things that can affect the chances of developing bladder cancer. These are called risk factors. Having a risk factor does not mean a person will get bladder cancer. People with no risk factors can also develop bladder cancer.

Age

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

Smoking

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

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

There is more information in our booklet **Giving up smoking** (see page 136).

Gender

Bladder cancer is more common in men than in women.

Exposure to chemicals at work

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

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

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

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

Infection

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

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

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

Previous treatment for cancer

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

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

Diabetes

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

Family history

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

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

Types of bladder cancer

Urothelial bladder cancer

This is the most common type of bladder cancer. It is also called transitional cell carcinoma (TCC). It starts in cells in the bladder lining (see page 8). These cells are called urothelial or transitional cells. Bladder cancer may be non-muscle-invasive, muscle-invasive or advanced. In non-muscle-invasive bladder cancer, the cancer cells are only in the inner lining of the bladder.

This information is about muscle-invasive bladder cancer and advanced bladder cancer.

Muscle-invasive bladder cancer is when the cancer has spread (invaded) into or through the muscle layer of the bladder (see pages 35 to 38).

Advanced bladder cancer is when the cancer has spread to other parts of the body (see pages 35 to 38).

Less common types of bladder cancer

Less common types of bladder cancer include:

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

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

For more information about these types of bladder cancer, you can call the Macmillan Support Line on **0808 808 00 00**.


Consulting Rooms

Symptoms

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

Blood in the pee (haematuria)

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

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

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

Urinary symptoms

Some people may:

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

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

Pain in the lower part of the tummy or back

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

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How bladder cancer is diagnosed

Most people are diagnosed after going to see their GP when they notice symptoms (see pages 20 to 21). Your GP will ask you about your symptoms. They will arrange for you to have your pee (urine) tested. They can do a quick test to find out if there is any blood in your pee. Blood in the pee is known as haematuria.

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

Your GP will usually refer you to a specialist if:

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

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

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

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

At the hospital

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

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

Blood tests

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

Urine tests

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

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

Cystoscopy

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

Flexible cystoscopy

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

The doctor or nurse squeezes a numbing gel into the opening of your urethra (see the illustrations on pages 9 to 13). This is the local anaesthetic and makes the procedure less uncomfortable. The gel starts to work after a few minutes.

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

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

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

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

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

Rigid cystoscopy

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

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

You may have this done under a general anaesthetic or using a spinal anaesthetic. A spinal anaesthetic numbs the lower part of your body. You are awake during the test, but you do not feel anything. There is more information about surgery to remove a bladder tumour on pages 54 to 66.

Blue-light cystoscopy

During a rigid cystoscopy, the doctor sometimes uses a technique called blue-light cystoscopy. It is also called photodynamic diagnosis (PDD). This is a way of helping the doctor see small bladder tumours and tumours that are flat more easily.

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

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

Ultrasound scan

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

When you are lying comfortably on your back, the person doing the scan spreads a gel over your tummy (abdomen). A small device that makes sound waves is passed over the area. The sound waves are then turned into a picture by a computer. The scan is painless and takes about 15 to 20 minutes. Once the scan is over, you can empty your bladder.

CT scan

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

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

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

Having a CT scan

MRI scan

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

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

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

A CT and MRI scan checks lymph nodes near to the bladder and further away from the bladder. They also check other organs in the body, such as the lungs and liver. This helps your doctor to see if the cancer has spread from the bladder.

Having an MRI scan

Other tests

PET/CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

Bone scan

A bone scan can show any abnormal areas of bone. It may be done to find out if the cancer has spread to the bones. A small amount of radioactive liquid is injected into a vein, usually in the arm. The level of radioactivity used does not cause any harm. Abnormal bone absorbs more of the radioactive substance than normal bone. Your doctor can see these areas on the scan. They are known as hot spots.

After having the injection, you have to wait for up to 3 hours before you have a scan of your whole body. This gives time for the bone to absorb the radioactive substance. You may want to bring something with you to do during this time, such as a book or magazine to read.

A bone scan can show conditions other than cancer, such as arthritis. If this happens, you may need to have further tests, such as an x-ray of the abnormal area.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation can also provide support – see pages 141 to 147. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Staging and grading

Your cancer specialist needs certain information about the cancer to advise you on the best treatment for you. This includes the stage of the cancer and its grade. They get this information from the tests you have (see pages 24 to 33).

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

Staging

The stage of a cancer describes:

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

The test results give some information about the stage of the cancer. But your doctor will not know the exact stage until after the cancer has been removed by surgery (see pages 54 to 66).

The most commonly used staging system for bladder cancer is the TNM system. We explain it over the next few pages.

TNM staging system

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

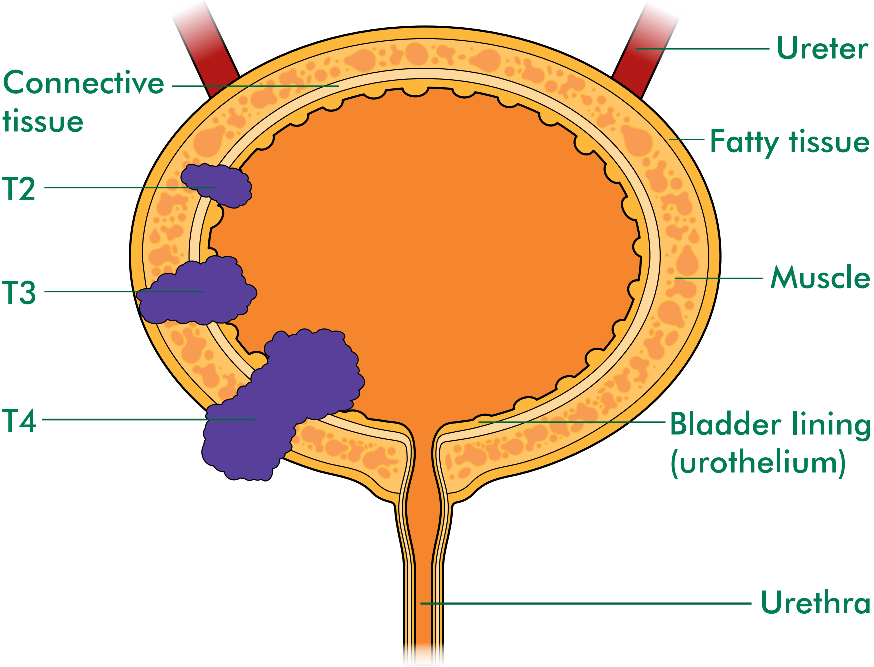
- **T** is how far the tumour has grown into the bladder, and how far it has spread into the surrounding tissues.
- **N** is whether the tumour has spread to the nearby lymph nodes.
- **M** is whether the tumour has spread to another part of the body (secondary or metastatic cancer).

T Tumour

Muscle-invasive and advanced bladder cancer is staged as T2 to T4. Your doctor or specialist nurse can tell you more about the stage of the bladder cancer you have. We also show them in the illustration opposite.

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

The stages of muscle-invasive and advanced bladder cancer



N Nodes

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

M Metastasis

- **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.

Doctors may use other terms to describe bladder cancer:

- **Muscle invasive** – The cancer is in the muscle layer of the bladder or has spread into the fat layer. But it has not spread outside the bladder.
- **Locally advanced** – This is when the cancer has spread outside the bladder into nearby tissues, the prostate, vagina, ovaries, womb or back passage (rectum). It may also be in one of the lymph nodes in the pelvis, near to the bladder.
- **Advanced** – This is when the cancer has spread to other parts of the body, such as the liver, lungs or bones, or to the lymph nodes.

Grading

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

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**

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Treatment overview

There are different treatments for muscle-invasive and advanced bladder cancer. Your doctor and nurse will help you understand what the treatments involve and how they may affect your life.

Your doctor will look at the stage of the cancer (see pages 35 to 38) and your general health to help plan the best treatment for you.

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

Treatment to cure the cancer

People with muscle-invasive bladder cancer, and some people with locally advanced bladder cancer, usually have treatment that aims to cure the cancer. Your cancer doctor or nurse will talk to you about the different treatment options and things to think about when making treatment decisions. You can then decide together what treatment is best for you. We have more information in our section on treatment decisions (see pages 47 to 52).

Most people have either surgery or radiotherapy. Your doctor may ask you to choose between these treatments.

If you are having radiotherapy, you may have chemotherapy at the same time to make this work better. This is called chemoradiation.

Surgery

Surgery (see pages 54 to 66) usually involves removing the whole bladder (cystectomy) and making a new way for you to pass urine (urinary diversion).

Radiotherapy

Radiotherapy (see pages 67 to 76) uses high-energy rays to destroy cancer cells.

Chemotherapy

Chemotherapy (see pages 77 to 84) uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is often used to shrink the tumour before surgery or radiotherapy. This is called neo-adjuvant chemotherapy. Some people have chemotherapy after surgery. This is called adjuvant chemotherapy. Chemotherapy can also reduce the risk of cancer coming back.

Treatment to control the cancer

If the cancer has spread to other parts of the body, it is called advanced cancer or metastatic cancer. You can usually have treatment to help shrink and control the cancer, and to reduce symptoms. Your doctor will explain the different treatment options and how they may affect you. This is called supportive treatment or palliative treatment – see pages 88 to 89.

Chemotherapy can help to control the cancer, but you need to feel well enough to be able to have it. Your cancer doctor can tell you if it is an option for you. They will talk to you about the possible risks and benefits of having chemotherapy.

If your doctor does not think that chemotherapy is suitable for you, they may recommend an immunotherapy drug (see pages 86 to 87). Immunotherapy drugs (sometimes called targeted therapy) are newer drugs that are sometimes used to control advanced bladder cancer.

Radiotherapy can be used to treat symptoms such as bleeding and pain from a tumour in the bladder. It may also be used to relieve bone pain if cancer has spread to the bones.

Advice on smoking

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

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

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

Your hospital doctor, nurse or GP can refer you to a stop-smoking service in your area. We also have a booklet called **Giving up smoking** – see page 136.

Planning your treatment

In most hospitals, a team of specialists called a multidisciplinary team (MDT) will meet to plan your treatment. The MDT will look at the following things when discussing your treatment plan:

- your general health
- the type and size of the tumour
- whether the tumour has started to spread.

The MDT usually includes:

- a **urologist** – a surgeon who specialises in treating problems of the urinary system
- an **oncologist** – a specialist in cancer treatments, such as chemotherapy, radiotherapy and immunotherapy
- a **urology specialist nurse** – a nurse who gives information and support
- a **radiologist** – a doctor who helps to analyse x-rays and scans
- a **pathologist** – a doctor who advises on the type and extent of the cancer
- a **specialist stoma nurse** – a nurse who supports people with stomas (see pages 58 to 61).
- a **palliative care specialist** – a doctor or nurse who specialises in symptom control.

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

Talking about your treatment

After the MDT meeting, your specialist doctor and nurse will talk with you about your treatment options. Before this, you might find it useful to write down a list of questions. You could use the space on page 148. It is a good idea to have a partner, family member or friend with you at the appointment. They can help you remember what was said and talk it over with you afterwards.

Your doctor will explain your treatment options and its aims. This should include the:

- benefits and disadvantages (risks and side effects) of different treatments
- other treatments that may be available
- what is likely to happen if you do not have treatment.

They will explain different side effects and how they can be managed. They will help you make decisions about your treatment. Treatment can be given for different reasons. The possible benefits will depend on your individual situation.

If there is anything you do not understand, ask your specialist doctor or nurse to explain it again. Cancer treatments can be difficult to understand. It is also hard to take things in when you are feeling anxious. You can ask to have more than one meeting with your doctor about your treatment. Some people will have a specialist nurse that they can call to ask any questions.

Making treatment decisions

You and your doctor can decide on the right treatment plan for you. It is important to remember that your doctor is an expert in bladder cancer and its treatments, but you know your own situation and preferences best.

Your doctor may ask you to choose between surgery or radiotherapy as your main treatment (see pages 49 to 52). These treatments may both be effective. Make sure you understand what each treatment involves and its advantages and disadvantages.

Here are some things you may want to ask your doctor when making treatment decisions:

- How will the different treatments and side effects affect my day-to-day life?
- Will any other medical condition(s) I have affect how I can cope with treatments?
- What treatment options do I have if the cancer comes back?

We have included some tables over the next few pages that show the main differences between surgery and radiotherapy. You may find it helps to look at this table again after you have read about surgery and radiotherapy.

If the cancer is advanced and has spread to other parts of the body, treatment may help to control the cancer and help you live for longer. Treatment can also help to improve symptoms and quality of life. But sometimes, the treatment may have no effect on the cancer but you still have the side effects to deal with.

Making treatment decisions in this situation can be difficult. You may want to talk about it with your cancer doctor, nurse or people close to you. If you decide not to have treatment, your doctor can give you medicines to control any symptoms. This is sometimes called supportive or palliative care (see pages 88 to 89).

Giving your consent

Before you have any treatment, your doctor or nurse will ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent. Make sure you fully understand what is involved before you give consent.

Sometimes people choose not to have treatment even though their doctor advises them to. Always tell your doctor or nurse about any worries about treatment so they can give you the best advice.

Second opinion

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

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

Choosing between treatments

	Surgery	Radiotherapy
During and after treatment	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.	You will travel to the hospital each day (not on weekends), for 4 to 7 weeks for treatment. You will not have a general anaesthetic. Radiotherapy is not usually as physically demanding as surgery. 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.

	Surgery	Radiotherapy
Effects on bladder function	You will need surgery to make a new way for you to pass urine. This is called a urinary diversion (see pages 58 to 61). This will take time to get used to.	You pass urine in the same way as before treatment. Bladder irritation is a common side effect during treatment (see page 71). Sometimes the bladder may be permanently affected by the late effects of radiotherapy (see pages 74 to 75). For example, you may find your bladder reduces in size. This means you need to pass urine more often.

	Surgery	Radiotherapy
Effects on the bowel	Bowel complications may sometimes happen after surgery. But these usually get better with time.	Sometimes the bowel is permanently affected by the late effects of radiotherapy (see pages 74 to 75). This means you may have bowel movements (poo) more often and have diarrhoea.

	Surgery	Radiotherapy
Effects on the sex life	Men have a high risk of not being able to get or keep an erection after surgery. This is called erectile dysfunction, or ED (see pages 106 to 107). Women may have a shorter vagina due to surgery (see page 107). This can make vaginal penetrative sex more difficult or cause changes in sensation.	Some men may find radiotherapy makes it more difficult to get an erection. Some women may find radiotherapy narrows their vagina. This can make sex more difficult or uncomfortable (see page 107).

> ‘Everyone goes down different routes for different reasons. Ask your consultants questions, listen to what they say, and then make your own decision.’
>
> **Ann**


BTOG
BTOG
BTOG

Surgery

Surgery that involves removing the whole bladder (a cystectomy) is one of the main treatments for muscle-invasive or locally advanced bladder cancer. Your doctor will explain if surgery is a possible treatment for you. This will depend on the stage of the cancer (see pages 35 to 38) and your general health. Removing the bladder is major surgery, so you need to be well enough to cope with it. You may need tests to make sure you are well enough for the operation.

Having a cystectomy is not available in all hospitals. This is because it is a specialised operation. You may have to travel to a hospital further away from your local hospital to have it.

When your whole bladder is removed, the surgeon will make a new way for you to pass urine (pee). This is called a urinary diversion (see pages 58 to 61). It is done at the same time as the operation to remove your bladder. There are different types of operation to make a urinary diversion. Some people may have an operation to make a new bladder. This is called a bladder reconstruction (see page 60). Passing urine in a new way can take time to get used to. But with practice, most people cope well.

Some people with rarer types of bladder cancer may be able to have only part of their bladder removed. This is called a partial cystectomy. Your surgeon will explain if any of these operations are suitable for you.

Surgery to remove the bladder (cystectomy)

Your operation will usually involve removing some areas close to the bladder, as well as the whole bladder.

Your surgeon or specialist nurse will talk to you about what the surgery involves and the effects this may have on your life. This includes possible effects on your sex life and fertility (see pages 105 to 109).

Your doctor or specialist nurse will talk to you about this before surgery.

Men

In men, the surgeon removes the bladder, prostate gland, seminal vesicles (where semen is stored) and sometimes part, or all, of the urethra. They also remove the lymph nodes (glands) close to the bladder.

After a cystectomy, you may have difficulties getting or keeping an erection. This is called erectile dysfunction or ED (see pages 106 to 107). This is because the prostate gland is removed and surrounding nerves may be damaged. Your doctor can tell you about treatments that may help improve ED.

After the operation, you will not be able to produce semen. This means you will not be able to make someone pregnant. If you are worried about this, talk to your doctor or specialist nurse before treatment starts. You may be able to store sperm to help preserve your fertility.

Women

In women, the surgeon removes the bladder, nearby lymph nodes and the urethra. You can see these organs in the illustrations on pages 9 and 13. They usually also remove the womb, ovaries, cervix and part of the vagina. If you have not been through the menopause, your doctor may talk to you about leaving your ovaries in place.

After surgery, women may find their sexual sensation is very different. Removing part of the vagina makes it shorter, which may make it uncomfortable or more difficult to have penetrative sex. You may be advised to use a vaginal dilator to try to help with this (see page 107). Your specialist nurse can give you more advice.

> ‘I had my bladder removed and reconstruction surgery. It’s a major operation and requires some time to fully recover. However, I had no complications and am now managing fine.’
>
> **Tess**

Open or laparoscopic (keyhole) surgery

Your operation may be done as open surgery or as laparoscopic (keyhole) surgery. Your surgeon will talk to you about which type of surgery is likely to be best in your situation.

Open surgery means the surgeon makes one large cut (incision) in your abdomen (tummy).

In laparoscopic (keyhole) surgery, the surgeon makes several small cuts in the tummy rather than one big cut. They pass a thin tube with a light and camera on the end (a laparoscope) into your tummy through one of the cuts. They pass specially-designed surgical tools through the other cuts to remove the cancer.

Keyhole surgery may have less complications than open surgery, and your wounds may heal faster. Keyhole surgery is not suitable for everyone. It is not available in all hospitals. You may need to be referred to another hospital to have it done.

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

Types of urinary diversion operation

When your bladder is removed, your surgeon makes a new way for you to pass urine. This is called a urinary diversion.

There are different types of urinary diversion operation:

- urostomy (ileal conduit)
- bladder reconstruction (neobladder)
- continent urinary diversion.

Your surgeon and nurse can advise you on which type of urinary diversion is most suitable for you. These operations are only done by specialist surgeons. You may need to travel to a different hospital to have the operation.

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 (see pages 97 to 103).

The thought of urinary diversion surgery may seem overwhelming. Asking questions before your operation can help. Your nurse may be able to arrange for you to meet someone who already has a urinary diversion. With time and practice, living with your urinary diversion will get easier.

Urostomy (ileal conduit)

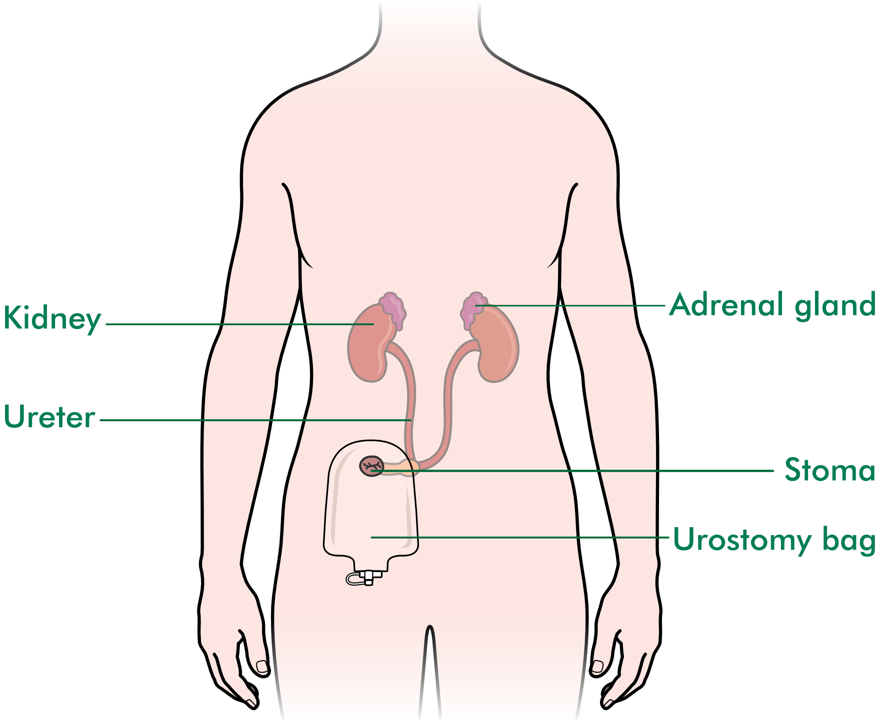
Having this operation means your urine is collected in a bag outside your body. You stick the bag onto your tummy (abdomen). The operation is sometimes called an ileal conduit.

During the operation, the surgeon removes part of your small bowel (ileum) and joins the two ureters to one end of it. They bring the other open end of your bowel out through a small opening in the skin of your tummy. The opening is called a stoma.

The ureters carry urine from your kidneys to the piece of bowel. The piece of bowel acts as a channel (conduit), taking the urine to the surface of your tummy.

You place a flat, watertight bag over the stoma to collect your urine. The bag has a sticky back which keeps it in place. This fills with urine, and you will need to empty it regularly.

A urostomy (ileal conduit)



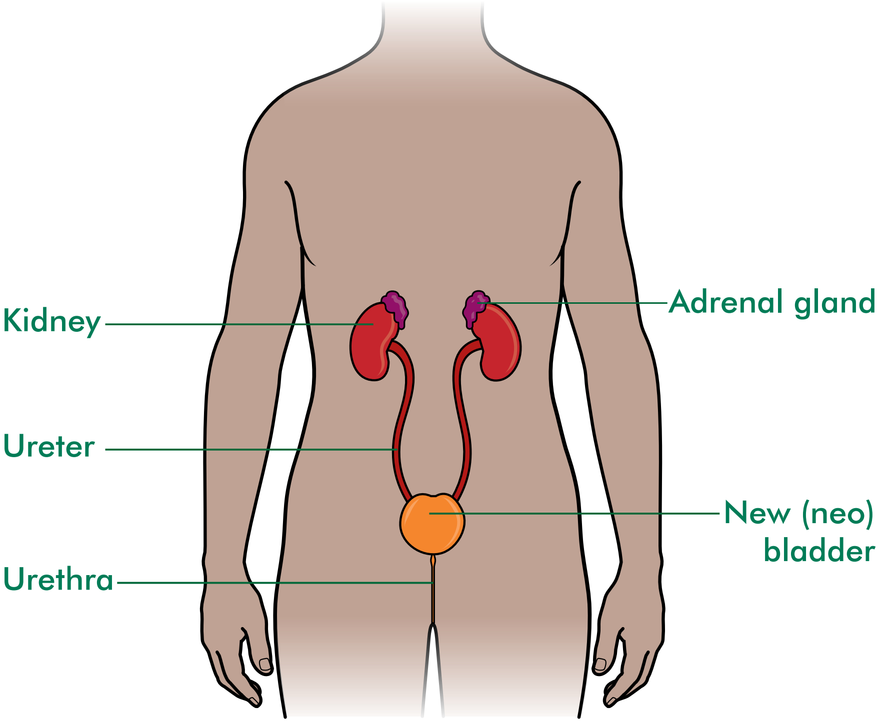
Bladder reconstruction (neobladder)

The surgeon makes a new (neo) bladder using a piece of your bowel which they connect to your urethra. This new bladder is attached to your ureters and holds urine. 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.

Some people may need to pass a tube (catheter) into their 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. Your surgeon will talk with you about the risk of this before surgery.

A bladder reconstruction (neobladder)

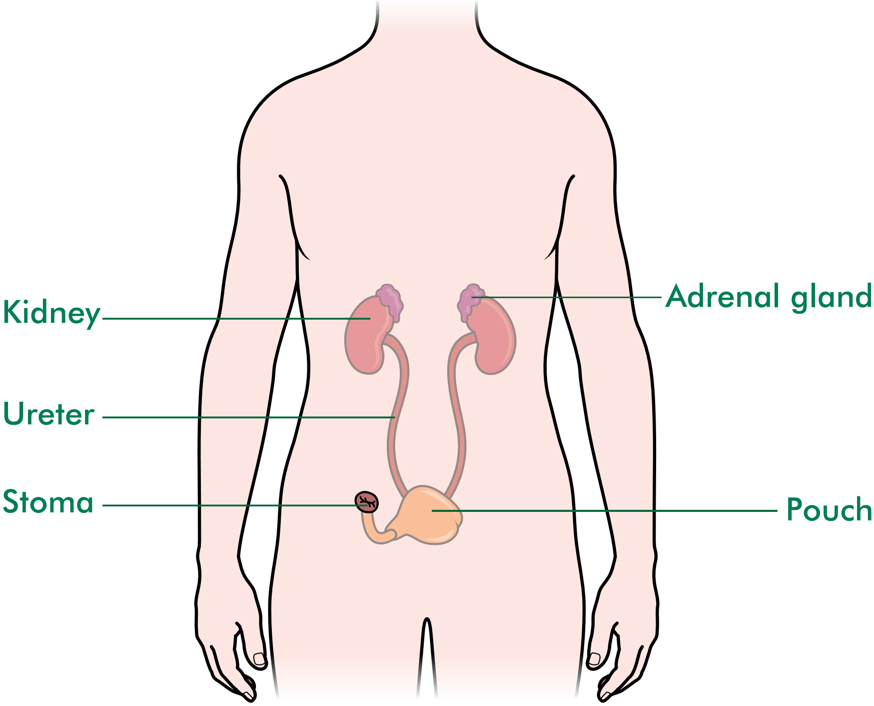


Continent urinary diversion

This is like a urostomy, but you do not need a bag to collect your urine. From a piece of your bowel, your surgeon makes a pouch that holds urine. They attach your ureters to the pouch so that urine from your kidneys drains into the pouch. The surgeon uses another piece of tissue (such as your appendix) to make a tube to connect the pouch to your tummy wall. They make a small opening (stoma) from the tube on to the tummy wall. This type of stoma lies flat against the skin.

You empty urine from the pouch through the stoma by using a tube (catheter). This is called self-catheterisation. You need to do it about 5 or 6 times a day.

A continent urinary diversion



Having a blood test

Before your operation

Before your operation, you will 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 (ECG).

Some people will have further tests. The anaesthetist will also see you to explain about the anaesthetic. Before the operation, you may have antibiotics to prevent infection. You may have them as an injection or as tablets.

You will meet a member of the surgical team to discuss the operation. A specialist nurse will talk to you about managing your urinary diversion before you have surgery. They will also arrange to visit you after your surgery. This is a good time to ask questions or talk about any concerns you may have about the operation. If you need help when you go home, tell your nurse as soon as possible. They can help you with this.

Before your operation, the nurse or doctor will carefully plan the position of the stoma. They do this even with a bladder reconstruction. This is in case they need to make a urostomy. They make a mark on your tummy, so the surgeon knows the best place for the stoma.

A stoma is often placed on the right side of your belly button (navel). But if you are left-handed, it can be positioned on your left side. It is usually placed to suit your needs.

If you are having a continent urinary diversion, the stoma is placed where you can see it and put a catheter into it.

Because part of your bowel is used for a urinary diversion, you may need an empty bowel for the surgery. Some people have a fluid given into the back passage (rectum) to help empty the bowel. This is called an enema. It is usually given the evening before the operation.

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

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.

After your operation

After the operation, you will be looked after in a high-dependency or intensive care unit for 1 or 2 days.

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

You may have loose bowel movements 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.

We have more information about managing your urinary diversion after surgery and at home on pages 97 to 103.

Drips and drains

At first, a nurse gives you 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, it is removed.

Some people may have a tube that goes up the nose and down into the stomach (nasogastric tube). It is used to remove fluid from the stomach, so you do not feel sick. This is usually removed 1 to 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 from your body. The tubes you have will depend on the type of urinary diversion you have. Your doctor and nurse will explain more about this to you.

Pain

After your operation, you will need painkilling drugs for a few days.

To begin with, you may be given painkillers into a vein using an electronic pump. You control the pump using a hand control that you can press when you need more of the painkiller. This is called patient-controlled analgesia (PCA). It is fine to press the hand control whenever you have pain. The nurse sets the pump so you cannot have too much painkiller.

Some people are given painkillers into their back. This is called an epidural. The drugs numb the nerves in the area where you had the operation to control your pain. You usually have them through a drip (infusion) attached to an electronic pump.

Sometimes during the operation, the surgeon puts small tubes into the area around the wound. After the operation, your doctor or nurse uses these tubes to give you painkillers. This helps 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.

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 from 4 to 14 days.

Your doctor 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 a few weeks after your surgery. 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.

Our booklet **Going home from hospital** has more information – see page 136 for details of how to order.

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is given using equipment similar to a large x-ray machine.

You may be given radiotherapy to try to cure bladder cancer (radical radiotherapy) or to help symptoms (palliative radiotherapy).

Positioning the radiotherapy machine

Radiotherapy to cure the cancer

You may have high-dose (radical) radiotherapy if the cancer has not spread outside the pelvis. The aim is to try to cure the cancer.

Having other treatment with radiotherapy

You may have other treatment with radiotherapy to help make it work better. You may have radiotherapy either with chemotherapy or with a gas called carbogen.

Chemotherapy given with radiotherapy is called **chemoradiation**. You may have chemotherapy either:

- every day (Monday to Friday) in the first and fourth week of your radiotherapy
- once a week during the radiotherapy course.

Your doctor or nurse will tell you when you will have chemotherapy. Chemoradiation may cause more severe side effects, so you need to be well enough to have this.

Some people 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. You take them before radiotherapy. Cancer cells 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.

How radiotherapy is given

Radiotherapy is given in the radiotherapy department at the hospital as a series of short, daily treatments. You may have to travel to a hospital further away than your local hospital to have this treatment. You can usually have it as an outpatient. Each treatment takes 10 to 15 minutes.

The treatments are usually given once a day from Monday to Friday, with a rest at the weekend. For bladder cancer, it usually takes 4 to 7 weeks to have a course of radiotherapy. Your doctor or nurse will tell you what to expect, and talk to you about possible side effects.

There are different ways of giving radiotherapy to treat bladder cancer:

- **Image guided radiotherapy (IGRT)** uses the pictures from scans taken before, and sometimes during, each treatment. These pictures show the size, shape and where the tumour is in the bladder. IGRT means the radiographers can use the pictures to adjust the treatment area before each treatment. This makes the radiotherapy very precise.
- **Intensity modulated radiotherapy (IMRT)** shapes the radiotherapy beams. It allows different strengths of radiotherapy to be given to different parts of the bladder. It may be used if you have large bladder tumours or if the cancer has spread to the lymph nodes in the pelvis.
- **Conformal radiotherapy** uses a device inside the radiotherapy machine to shape the radiation beams to match the shape of the cancer. This reduces the radiation received by surrounding, healthy cells.

Your radiotherapy team can tell you more about these types of radiotherapy.

Planning your treatment

Radiotherapy has to be carefully planned to make sure that it is aimed precisely at the cancer. This means it causes the least possible damage to the surrounding tissue.

On your first visit to the radiotherapy department, you will usually have a CT scan of the area that is being treated (see pages 28 to 29). This helps plan the precise area for your radiotherapy. The information from the scan is sent to a planning computer. Your radiotherapy team use it to work out the dose and area of your treatment. During your scan, you need to lie still on a hard couch (sometimes called a table). Your head, arms and legs may be supported with moulded plastic, foam or rubber cushions. If you feel uncomfortable, tell the radiographers. They can help you feel more comfortable. This is important as you need to be able to lie in the same position for your radiotherapy treatment.

You may need some small marks made on your skin. The marks help the radiographer put you in the right position and show where the rays will be directed. Usually, permanent markings (tattoos) are made. They are very small and are only done with your permission. These marks must stay visible throughout your treatment. It may be a little uncomfortable while they are done. The radiographer may use laser lights to position you for your radiotherapy treatment. These are not harmful to your skin.

Treatment sessions

At the beginning of each session, the radiographer will position you carefully on the couch and make sure you are comfortable – see the photo on page 67. During your treatment you will be alone in the room, but you can talk to the radiographer who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Side effects of radiotherapy

Your doctor, nurse or radiographer will talk to you about side effects. Tell them about any side effects you have during or after treatment. There are often things they can do to help. After treatment ends, side effects usually get better over a few weeks or months.

We have more information about managing side effects of pelvic radiotherapy during treatment (see page 136).

Bowel effects

You may have diarrhoea and sore skin around the back passage (rectum). 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 (3 ½ pints) of fluids a day.

Bladder effects

You may need to pass urine (pee) more often. You may also have a burning feeling when you pass urine. Tell your radiographer if you have these side effects. They will ask your doctor to give you medicines to help.

Drinking fluids will help. Try to drink around 2 litres (3 ½ pints) a day. Some fluids can irritate the bladder and make symptoms worse. These include:

- drinks with caffeine, such as tea, coffee, cola and hot chocolate
- fizzy drinks
- drinks with artificial sweeteners
- diet or light drinks
- alcohol.

These effects usually start to get better a few weeks after treatment finishes.

Effects on the skin

Some people may find that the skin in the area being treated becomes red and sore or itchy. It may also become darker. The radiographer will give you advice on looking after your skin.

Tiredness

Radiotherapy can cause tiredness, especially towards the end of treatment. Tiredness can continue for weeks or sometimes longer after your treatment has finished. If you do feel tired, try to get plenty of rest. But try to balance this with doing some regular, physical activity, such as going for short walks. This will help give you more energy.

There is more information in our booklet **Coping with fatigue** (see page 136).

Hair loss

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. Your doctor or radiographer can tell you more about this.

‘After treatment finished, the fatigue kicked in. A wave came over me and drained all my energy. I had to lie down on the sofa until it passed.’

Richard

Possible late effects of radiotherapy

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. There are different ways late effects of pelvic radiotherapy can be managed. We have more information about the late effects of pelvic radiotherapy in men and women, including information about how treatments can affect your sex life. See page 136 to order.

Effects on the bowel or bladder

Sometimes, the bowel or bladder may be permanently affected by radiotherapy.

If your bowel is affected, you may need to pass bowel movements (poo) more often and have diarrhoea.

Your bladder may become smaller. This means it cannot hold as much urine, 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 (poo). If you notice blood in your urine or stools, tell your doctor straight away. They will do tests and give you the right treatment.

Let them know about any bowel or bladder symptoms you have. They can give you advice and may do some tests.

Women

In women, radiotherapy to the pelvis can make the vagina narrower. This can make it more uncomfortable to have internal examinations. It can also make sex difficult or uncomfortable.

You may be advised to use a vaginal dilator to try to stretch the vagina. This can make sex and internal examinations more comfortable. Your specialist nurse or radiographer will give you more advice and explain how to use them. There are other treatments that can also help (see page 107). Your doctor can give these to you.

Men

In men, radiotherapy to the pelvis may make it more difficult to get an erection. This is called erectile dysfunction or ED. There are treatments that can help with this (see pages 106 to 107).

Infertility

Radiotherapy to the pelvic area can cause infertility in men and women. If you are worried about your fertility, talk to your doctor before your treatment starts.

We have more information about fertility in men and women (see page 136).

Radiotherapy to treat symptoms

You may have radiotherapy to help with symptoms of the cancer. Usually, 1 to 5 radiotherapy treatments are given in a week. If you have any side effects, they are often mild.

Bladder symptoms

Radiotherapy can be used to help bladder symptoms, such as pain or bleeding. It may be given as 3 treatments over a week. This is usually given every other day. For example, you may have the radiotherapy on Monday, Wednesday and Friday.

Each treatment takes around 10 to 15 minutes. Sometimes, you will only have 1 treatment.

Bone symptoms

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

It can take a few weeks to feel the benefits, so you will need to keep taking painkillers during this time.

We can send you our booklet **Understanding secondary bone cancer** (see page 136).

Chemotherapy

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

The type of chemotherapy you have will depend on:

- the stage of the bladder cancer (see pages 35 to 38)
- how side effects are likely to affect you (see pages 81 to 84).

Your cancer doctor and specialist nurse will talk to you about the aims of your treatment.

If the cancer has not spread outside the bladder or it is locally advanced, you usually have chemotherapy along with other treatments. You may have chemotherapy on its own if the cancer has spread to parts of the body such as the liver or lungs.

Chemotherapy can be given:

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

Our booklet **Understanding chemotherapy** has more information (see page 136).

Chemotherapy for advanced cancer

If the cancer has spread to other parts of the body, you may have chemotherapy as your main treatment. Chemotherapy may help to shrink and control the cancer and improve your symptoms. It may help you live for longer.

You may have a combination of chemotherapy drugs or one drug on its own. You can talk to your doctor or specialist nurse about the possible benefits and disadvantages of chemotherapy for you – see page 46. Talking to your family and close friends may also help.

If you decide not to have chemotherapy, there are other ways to help treat symptoms such as pain, urinary symptoms or blood in the urine (haematuria). Your doctor or nurse will explain this to you.

The chemotherapy drugs used

Most people have a combination of drugs to treat bladder cancer. Some commonly used combinations are:

- gemcitabine and cisplatin
- 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 (called 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. Your doctor or nurse will give you more information. We have more information about chemotherapy drugs on our website – **macmillan.org.uk**

How chemotherapy is given

You usually have treatment in the chemotherapy day unit and go home afterwards. Sometimes, you may need to stay in hospital for a couple of days.

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 (cannula)
- a fine tube that goes under the skin of your chest and into a vein close by (central line)
- a fine tube that is put into a vein in your arm and goes up into a vein in your chest (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.

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.

If you are having chemoradiation, your doctor or nurse will tell you when you will have the chemotherapy.

Having chemotherapy

Side effects of chemotherapy

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

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

Risk of infection

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

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

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

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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

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

Bruising and bleeding

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

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

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

Anaemia

This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

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

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

Sore mouth

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

If your mouth is sore:

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

Hair loss

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

If you do experience hair loss your hair should start to grow back within about 3–6 months of the end of treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Our booklet **Coping with hair loss** has more information – see page 136 to order.

Tiredness

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

Our booklet **Coping with fatigue** has more information (see page 136).

Early menopause

Younger women may find that chemotherapy causes an early menopause. This can cause symptoms of the menopause like hot flushes and sweats. Your doctor can give you hormone replacement therapy (HRT). Talk to your cancer doctor or specialist nurse about this.

Contraception

Your doctor will advise you not to become pregnant or make someone pregnant during treatment. This is because the drugs may harm a developing baby. It is important to use effective contraception during, and for a few months after, chemotherapy. You can talk to your doctor or nurse about this.

Protecting your partner

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

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.

Immunotherapy drugs

Immunotherapy drugs encourage the immune system to recognise and help destroy cancer cells. These drugs can be used when the cancer is locally advanced or advanced. They are usually only used if cisplatin chemotherapy is not suitable, is not working well, or the cancer comes back after chemotherapy.

These drugs may not be widely available on the NHS. Some are only available as part of a clinical trial (see pages 90 to 91).

If a drug is not available, there may be different ways you are still able to have it. Your doctor can give you advice about this.

Your specialist will tell you if they think one of the following immunotherapy drugs, or a type we have not mentioned, is suitable for you.

Atezolizumab

Atezolizumab is a type of immunotherapy drug called a checkpoint inhibitor. It works by targeting a protein (receptor) called PD-L1. When the PD-L1 receptor is blocked, it stimulates the immune system to fight the cancer cells. This can help to shrink the tumour or slow the growth of the tumour.

Pembrolizumab

Pembrolizumab is also a checkpoint inhibitor drug. It targets a protein (receptor) called PD-1 found on the surface of T-cells. T-cells are part of our immune system. When the PD-1 receptor is blocked, it stimulates the immune system to fight the cancer cells. This can help to shrink the tumour or slow the growth of the tumour.

For more information about this drug, visit **macmillan.org.uk**

How the drugs are given

Atezolizumab and pembrolizumab are both given as a drip into a vein (intravenously), every 3 weeks. The nurse will give you this at the clinic and you can go home on the same day.

Possible side effects

Common side effects include:

- feeling tired
- skin changes
- feeling sick
- diarrhoea
- feeling short of breath.

Because of the way immunotherapy drugs work, they can cause the immune system to attack other parts of the body. This is not common, but it can cause serious side effects in the lungs, other organs or glands that make certain hormones. Sometimes, the treatment needs to be stopped. It is important to tell your doctor or nurse about any side effects you have, even after you have stopped having treatment.

Supportive treatments

The symptoms of advanced bladder cancer can often be relieved by different treatments to control the cancer. Radiotherapy can treat symptoms such as pain. Sometimes this works quickly, and you may notice an improvement within a few days. But sometimes it may take a few weeks before you feel the benefit. Sometimes, drugs called bisphosphonates are used to help control bone pain.

But there are also other ways to relieve and control symptoms. We have more information about how symptoms such as pain, breathlessness, feeling sick or tiredness can be relieved.

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

Many hospitals have doctors and nurses who are experts in treating pain and other symptoms. They are sometimes called palliative care experts.

Treating a blockage in a ureter or kidney

Sometimes, bladder tumours can block urine (pee) draining from the kidneys to the bladder through the ureters (see the illustrations on pages 9 and 10). If this happens, you may have:

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

Tell your doctor or specialist nurse if you have any of these symptoms.

If a ureter is blocked, your doctor may suggest an operation to put a tube (stent) into one or both ureters. This allows urine to drain from the kidney into the bladder. Your doctor will tell you if this is a possible treatment for you. This will depend on your general health, as it is done under general anaesthetic using a cystoscope (see pages 25 to 27).

During the surgery, the doctor passes the cystoscope through your urethra and into your bladder. They put the stent (or stents) into the ureters using a thin wire that they pass through the cystoscope.

If it is not possible to put in a stent, you may have a tube put into your kidney (or kidneys). This is called a nephrostomy. This allows urine to drain out through the tube. The doctor puts the tube into the kidney through the skin on your back. The doctor (a radiologist) uses an x-ray or ultrasound scan to find the best place in the kidney to put the tube.

The doctor numbs your back with a local anaesthetic and inserts a fine guide wire into the kidney. The guide wire helps the doctor put the nephrostomy tube in the right place. They use stitches or dressings to hold the tube securely in place. The tube is connected to a bag, which is worn under your clothing. Your nurses will give you advice and support on looking after your nephrostomy.

We have more information about having a nephrostomy on our website – **macmillan.org.uk**

Research – clinical trials

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

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

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, immunotherapy, radiotherapy or other treatment is better than what is already available.

Taking part in a clinical trial

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

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

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

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)** (see page 136).

Blood and tumour samples

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

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

After treatment

Follow-up

After treatment, you will have regular follow-up appointments. You will also have scans to check for any sign of the cancer coming back.

If you have had a urinary diversion or a bladder reconstruction (see pages 58 to 61), you will have regular scans to check your kidneys are working well. You will also have blood tests.

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 (urethroscopies). This usually continues for 5 years.

If you have had radiotherapy, you will have regular cystoscopies (see pages 25 to 26). These will be every 3 months at first, but you will have fewer cystoscopies over time. You will have them for at least 5 years after treatment finishes.

Tell your doctor straight away if you notice any new symptoms or symptoms that come back between your appointments.

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

If the cancer comes back

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 and the treatment you had before. Your doctor will talk to you about the possible options.

If the cancer comes back after radiotherapy, some people may be able to have surgery to remove their bladder. 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.

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> ‘I have had no issues with getting supplies of bags and other items. My supplier provides everything I need. I can also contact a stoma nurse when I need to.’
>
> **Steve**

Managing 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. When you get home, you will still be able to speak to your specialist nurse for advice. You may also have contact with a community stoma nurse. They can help you cope with any problems.

Before you leave the hospital, the nurse will make sure you have a supply of the equipment you need. This can include urostomy bags or catheters. When you are at home, you can get your equipment directly from a supplier or your chemist. Your stoma nurse will tell you more about this. The Urostomy Association can also give you details of suppliers (see page 141).

The hospital staff will arrange for a district nurse or a community stoma nurse to visit you when you first leave the hospital. The nurse can help you if you have any problems with your urinary diversion.

Urostomy

Having a urostomy (see pages 58 to 59) is a big change to your body. It can take time to get used to. You may find it helpful to talk to someone who is used to living with a urostomy. Your stoma nurse may be able to arrange this for you. This can be very helpful, especially in the first few months after your operation.

A stoma nurse will show you how to look after your urostomy and can help you cope with any problems.

Most people who have a urostomy get back to a normal life. Many 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.

The stoma

For the first few days after your operation, your nurse will look after your urostomy for you. They will make sure that the bag is emptied and changed when needed.

The 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.

As soon as you feel ready, your nurse will show you how to clean your stoma and change the 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.

Before you change or empty your bag, make sure that you have plenty of bags and cleaning materials with you. It is a good idea to keep everything you need in one place, so that you do not have to search for things at the last minute. Give yourself plenty of time, so you can work at your own pace without any interruptions.

There are different types of bags available. Your nurse will help you choose one that suits you best.

Appearance

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.

> ‘Getting used to managing my stoma was very alien at first. But as time went on, it became easier.’
>
> **Steve**

Bladder reconstruction

After your surgery, you will go home with a tube (catheter) to drain the urine from your new bladder (neobladder – see page 60).

Your nurse will explain how to look after it before you go home. The bowel tissue used to make the new bladder continues to make mucus. This is a thick, white liquid. It might appear as pale threads in the urine. To stop this blocking the catheter, you need to flush it several times every day using fluid and a syringe. Your nurse will show you how to do this, or they can refer you to a district nurse who will help.

After a few weeks, you will return to the hospital. Some people may have an x-ray called a cystogram. A 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

At first, you will have to empty your bladder every 2 to 3 hours. The feeling of needing to pass urine (pee) 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. This is called 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.

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.

As well as emptying your new bladder, 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

When you go home, you will have two catheters. One goes into the pouch through your tummy and the other goes through the stoma (see page 61).

Once the pouch has healed (usually about 6 weeks after your surgery), you will go back to the hospital. 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 (catheter) through the stoma into the pouch. Your specialist nurse will show you how to do this. At first, you do it every couple of 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.

Different surgeons may give slightly different instructions on how you should empty and flush out your pouch, and the equipment you should use. Follow the advice you are given. If you need more support, talk to your specialist nurse or doctor.

Using public toilets

You may feel anxious about going out in public. You might worry about needing to use a toilet to empty a urine bag, use a catheter or empty your neobladder. It may help to do the following things.

Plan ahead

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

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

Get a toilet card

You can show this quickly and easily to staff in shops, pubs and other places. It explains that you have a medical condition and need urgent access to a toilet.

We have a free toilet card you can use. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00** to order one. The Bladder and Bowel Community also offers a free Just Can't Wait toilet card and phone app. Visit **bladderandbowel.org/help-information/just-cant-wait-card**

Use disabled toilets

These often have more privacy and space. The National Key Scheme (NKS) offers access to over 9,000 locked disabled toilets in the UK. You can buy a key from Disability Rights UK (see page 146). You can also order a guide that tells you where the toilets are.

Body image changes

You may be worried about adapting to changes in the way your body looks and works. This can affect your body image. Body image is the picture you have in your mind of how you look, and how you think and feel about your body. This is a normal reaction and it can take time to adjust. It is important to talk to your nurse or doctor if this does not improve.

Many people find they feel reassured once they have spoken to someone about their worries. Talking also gives other people the chance to understand how you are feeling. You could talk to a partner or someone close to you about it. Or you can talk to our cancer support specialists on **0808 808 00 00**. Our **Body image and cancer** booklet also has more information (see page 136).

Sex and relationships

Treatments for bladder cancer may have a direct effect on your sex life. If you have a scar or stoma, you may feel self-conscious and have concerns about your body image. This may affect your desire to have sex. Side effects of treatment or symptoms, such as tiredness, can also make you feel less interested in having sex.

Your doctor or nurse will explain the possible effects of treatments on your sex life. If cancer and its treatments affect your sex life, it can feel like a serious loss. You do not need to be in a relationship to feel this. We have more information about how cancer treatment can affect your sex life, and ways to cope. See page 136 to order.

Talking about sex

You may find it difficult to talk about sex with your doctor or nurse. But doctors and nurses who treat people with bladder cancer are used to talking about these issues. They can advise you and answer your questions. If you need more specialised advice, they can refer you to an erectile dysfunction (ED) clinic or to a sex therapist.

If you identify as gay, bisexual, transgender or LGBT+, you may worry about being treated insensitively by your healthcare team. Many sexual difficulties caused by bladder cancer are similar whatever your sexuality. But you may have some specific questions. Having your sexual or gender identity acknowledged may also help you feel more supported. It also means your healthcare team can give you the right information and advice.

If you feel unable to talk to your healthcare team about your sexuality, the LGBT Foundation has a helpline that can give you confidential advice and support. Call **0345 3 30 30 30**.

Effects of treatment on your sex life

Erectile dysfunction (ED)

Surgery and radiotherapy can damage the nerves of sexual organs. If this happens, you may not be able to have or maintain an erection. This is known as erectile dysfunction (ED). ED is more common after surgery, but it can also happen after radiotherapy.

There are practical ways to help overcome sexual difficulties. Your doctor or nurse will give you information about these.

Most treatments aim to increase the blood supply to the penis. At first, you may need to try a treatment a few times.

Talk to your doctor or specialist nurse about what might be best for you. They will be able to explain about the different treatments in more detail. Your specialist doctor may suggest using a combination of tablets and a vacuum pump soon after treatment.

Tablets

Treatment may involve tablets such as:

- sildenafil (Viagra®)
- vardenafil (Levitra®)
- tadalafil (Cialis®).

These tablets help to produce an erection if the nerves are not damaged. If you have heart problems, these may not be recommended for you.

Pellets and injections

Pellets can be put into the tip of the urethra. Or drugs can be injected into the penis with a small needle. These can help to produce an erection.

Pumps

Vacuum pumps can also be used to produce an erection. They may be called vacuum erection devices (VEDs). The pump is a hollow tube that you put your penis into. It makes the penis fill with blood by creating a vacuum. You put a stretchy ring around the base of the penis to hold the erection. It can be maintained for up to 30 minutes.

Vaginal changes

Surgery and radiotherapy can cause changes to the vagina. Surgery usually shortens the vagina. Radiotherapy can make the vagina narrower and less stretchy.

These changes can make having penetrative vaginal sex difficult or uncomfortable. It can also make it uncomfortable to have an internal examination.

It is important to try to prevent the vagina narrowing. When you feel ready, having vaginal penetrative sex regularly and gently can help gradually stretch the vagina. This can make having sex easier and more enjoyable.

Your hospital team may recommend that you use vaginal dilators. Vaginal dilators help stop the vagina narrowing. Dilators are tampon-shaped plastic tubes of different sizes that you use with a lubricant. Although they are commonly used, there is no strong evidence to say how well they work. Your specialist nurse or doctor will explain the best way to use them in your situation.

Some people are given gels or creams that contain the female hormone oestrogen. These can help with any discomfort in the vagina. Your doctor will let you know whether these are suitable for you.

Relationships

Talking openly with a partner can help you feel closer. It can also help you make changes to your sex life together. Explaining the sexual difficulties you are having may help reassure them. There are different ways you can show your partner you care about them. This can include spending time together and showing affection through touching, holding hands or putting an arm around their shoulder. You may also find new ways to share sexual pleasure.

Ask your partner to come to appointments with you. This can help them understand the issues you are dealing with. They can learn how to use any treatments for sexual difficulties before you try them at home.

If you are not in a relationship, it is natural to worry about meeting a new partner or your sex life. You may need some time to come to terms with what has happened.

Some people find it helps to talk to a counsellor or sex therapist. The College of Sexual and Relationship Therapists (COSRT) has a list of nationwide counsellors and therapists who can offer advice and support. See page 142 for COSRT's contact details.

Fertility after treatment for bladder cancer

Having a cystectomy will cause infertility in men. It will also cause infertility in women if you have not been through the menopause and your womb and ovaries are removed.

Radiotherapy to the pelvic area may also cause infertility in men and women.

It can be difficult to hear that you may become infertile due to cancer treatment. Before treatment starts, talk to your doctor or nurse if you are worried about the effect of treatment on your fertility. Women may be able to freeze embryos or eggs and men may be able to freeze sperm. Your doctor or nurse can refer you to a fertility clinic for advice about this.

We have more information about sex and fertility after cancer treatment. See page 136 to order.

YOUR FEELINGS AND RELATIONSHIPS

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What you can do

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'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

Find ways to cope

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 with your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up 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 more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

Make positive lifestyle choices

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

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

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

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

> ‘I went to a well-being course at the Macmillan centre to help with exercise. I also attended a course to deal with the emotional effects. Both were an enormous help.’
>
> **Steve**

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. The chemicals in cigarette smoke irritate and damage the lining of the bladder. They can also make your symptoms worse. There is lots of support available to help you stop (see page 44).

Some studies suggest that stopping smoking may decrease the risk of bladder cancer coming back, if you have not had your bladder removed.

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

See page 146 for organisations that can help you stop smoking. Our booklet **Giving up smoking** also has more information (see page 136).

Keep to a healthy weight

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

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

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

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

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

Eat a healthy diet

Eating a healthy diet will give you more energy and help you to recover. Try to eat lots of fresh fruit and vegetables (5 portions a day), and less red meat. If you have had radiotherapy, you may have been advised to make changes to your diet to help with any bowel effects. Follow any advice you have been given by a dietitian or specialist nurse. Our booklet **Healthy eating and cancer** also has more information (see page 136).

Be physically active

Being physically active helps to keep you to a healthy weight. It can reduce stress and tiredness. Physical activity also reduces the risk of other health conditions. Some hospitals can refer you to local exercise or fitness groups, which are for all abilities. Our booklet **Physical activity and cancer** also has more information (see page 136).

Stick to sensible drinking guidelines

The current guidelines say that if you drink alcohol:

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

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

Reduce stress

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

Our booklet **Cancer and complementary therapies** has more information about ways to reduce stress (see page 136).

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. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're 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's 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

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

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

Shock and disbelief

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

Fear and anxiety

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

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

Avoidance

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

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

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

Anger

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

Guilt and blame

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

> 'The loneliest time for people with cancer is usually after treatment. To help with this, I started a cancer support group in my town. It now has over 100 members!'
>
> **Steve**

Feeling alone

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

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

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

If you need more help

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

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

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them. See page 136 to order.

Relationships

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

Your partner

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

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

Family and friends

Your family and friends may not always understand if you are not feeling positive about getting on with things. They may not know how treatment is affecting your day-to-day life. Talking about how you feel will help them give you the support you need.

Our booklet **Talking about cancer** has more useful tips (see page 136).

If you are a relative or friend

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

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

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

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer (see page 136).

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information. See page 136 to order. We also have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

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

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

Teenagers

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

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

We have a booklet with more information called **Talking to children and teenagers when an adult has cancer**. See page 136 for details of how to order. There is also a video that may help at **macmillan.org.uk/talkingtochildren**


TOSHIBA

FINANCIAL SUPPORT AND WORK

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Financial help and benefits

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

Statutory Sick Pay

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

Benefits

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

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

Employment and Support Allowance (ESA)

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

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

Personal Independence Payment

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

Attendance Allowance

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

Special rules

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

Help for carers

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

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

Macmillan Grants

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

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

How much you get will depend on your situation and needs. The average grant is around £380, but this may change from time to time. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

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

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

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 136 to order. Our Online Community forum **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

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

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

Our booklet **Help with the cost of cancer** has lots more information – see page 136 to order.

Work

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

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

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more useful information – see page 136 to order. There is also lots more information at **macmillan.org.uk/work**

Employment rights

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

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

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

Our booklet **Your rights at work when you are affected by cancer** has more information – see page 136 to order.


BE.MACMILLAN
WANT TO MAKE OR ORDER SOMETHING?

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About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:
- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

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

Help with work and cancer

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

Work support

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

Other useful organisations

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

Bladder cancer support organisations

Action on Bladder Cancer UK

Tel 0300 302 0085
Email info@actionbladdercanceruk.org
www.actionbladdercanceruk.org

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

Fight Bladder Cancer

Tel 01844 351 621
Email info@fightbladdercancer.co.uk
www.fightbladdercancer.co.uk

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

Help with bladder problems

Bladder and Bowel Community

Tel 01926 357 220
Email help@bladderandbowel.org
www.bladderandbowel.org

Provides information, advice and support for a range of symptoms and conditions related to the bladder and bowel.

Urostomy Association

Tel 01386 430 140
Email info@urostomyassociation.org.uk
www.urostomyassociation.org.uk

Supports people who are about to have or have had a urinary diversion, and their carers.

Help with sexual difficulties

College of Sexual and Relationship Therapists (COSRT)

Tel 020 8543 2707
Email info@cosrt.org.uk
www.cosrt.org.uk
A national specialist charity for sex and relationship therapy. Provides information about sexual and relationship issues.

The Institute of Psychosexual Medicine

Tel 020 7580 0631
Email admin@ipm.org.uk
www.ipm.org.uk
Provides a list of accredited doctors who accept psychosexual referrals. The list gives details of doctors and clinics, both private and NHS run, throughout the UK.

The Sexual Advice Association

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

General cancer support organisations

Cancer Black Care

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

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Support Scotland

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

Maggie's Centres

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

Has a network of centres in many locations 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.

Tenovus

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

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

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

NHS

www.nhs.uk

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

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

NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

UK Council for Psychotherapy (UKCP)

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

Emotional and mental health support

Mind

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

Samaritans

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

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 022 2450
(Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make a Call helpline on 0800 232 1271 to check if you are getting all the benefits you are eligible for.

Carer's Allowance Unit

Tel 0800 731 0297
Textphone 0800 731 0371
(Mon to Thu, 8.30am to 5pm, Fri, 8.30am to 4.30pm)
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Wales

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

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

GOV.UK

Tel 0141 572 0237
www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Equipment and advice on living with a disability

British Red Cross

Tel 0344 871 11 11
Textphone 020 7562 2050
Email information@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel 0207 250 8181
(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)

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

Stop-smoking services

Smokefree (England)

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

Smokeline (Scotland)

Tel 0800 84 84 84
(Mon to Fri, 8am to 10pm,
Sat and Sun, 9am to 5pm)
www.canstopsmoking.com

Stop Smoking Wales

Tel 0808 252 8216
(Mon to Thu, 8am to 8pm,
Fri, 8am to 5pm,
Sat, 9am to 4pm).
Text ‘HMQ’ to 80818
www.stopsmokingwales.com

Want2stop (Northern Ireland)

Text ‘QUIT’ to 70004
www.want2stop.info

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk

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

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, Sat, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org

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

Carers UK

Helpline (England, Scotland, Wales) 0808 808 7777
(Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

YOUR NOTES AND QUESTIONS

Disclaimer

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

Thanks

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

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

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

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

Sources

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

European Association of Urology (EAU). Muscle-invasive and metastatic bladder cancer guidelines. 2017.
National Institute for Health and Care Excellence (NICE). Bladder cancer: diagnosis and management. NG2. February 2015.
National Institute for Health and Care Excellence (NICE). Suspected cancer: recognition and referral. NG12. Published June 2015 (Updated July 2017).

Can you do something to help?

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

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

5 WAYS YOU CAN HELP SOMEONE WITH CANCER

Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

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

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

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

27530

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

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

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

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

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

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