

**Non-muscle invasive  
bladder cancer  
NMIBC**



**An introduction to NMIBC**

This guide has been written as a short introduction to non-muscle invasive bladder cancer – NMIBC (sometimes referred to as non-invasive bladder cancer, early or superficial bladder cancer). It is intended to give you more information following a suspected diagnosis and help you understand the basics of bladder cancer, how it is tested and graded, the main treatment options and where you can find more support.

If you have any questions during your treatment, make a note and take them to your appointment or contact your medical team. Throughout this leaflet we have suggested examples of things you might want to know.

There is a lot more information about bladder cancer and where to find support on our website, visit [www.actionbladdercanceruk.org](http://www.actionbladdercanceruk.org)

You can download this leaflet and other ABC UK bladder cancer leaflets and information sheets on our website [www.actionbladdercanceruk.org/resources](http://www.actionbladdercanceruk.org/resources)

You can also order print copies by using our online order form on our website or contact us on [info@actionbladdercanceruk.org](mailto:info@actionbladdercanceruk.org) or **0300 302 0085**.

## About bladder cancer

- Bladder cancer is not a rare cancer with around 20,500 people being diagnosed each year in the UK – around 4.5% of all new cancer cases\*
- Bladder cancer is one of the ten most common cancers in the UK for both males and females
- About 80% of people diagnosed will have non-muscle invasive bladder cancer
- Today, around 100,000 people are living with bladder cancer in the UK
- It is more common in males, but it tends to be diagnosed at a more advanced stage in females, which can affect the likelihood of successful treatment
- Although more common in older people, younger people can get bladder cancer too
- Smoking is known to be a contributory cause of bladder cancer in some cases. There has also been shown to be an association with dyes, industrial and agricultural chemicals in some cases. A cause may not be known in others.

## What is bladder cancer?

Your body has a huge number of cells, over 200 different types. They all work together to provide the structure of the body, its organs and tissues and a multitude of different functions. Cells regularly divide and make new cells, to enable the body to heal, repair and grow. Cancer starts when one cell becomes abnormal and starts to grow or multiply in an uncontrolled way. These abnormal cells form a lump or tumour and some of these tumours may be cancerous.

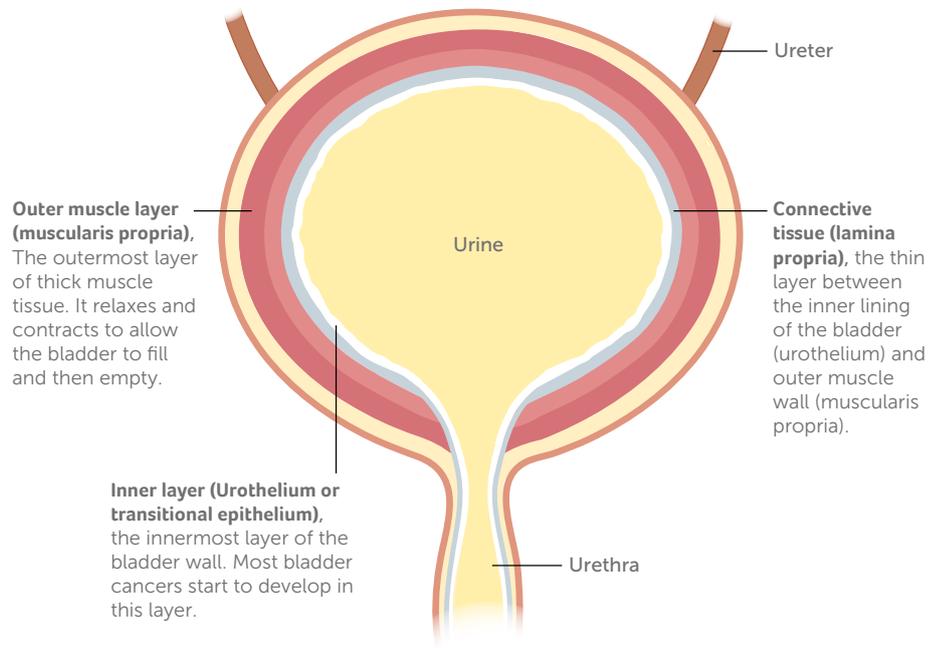
Bladder cancer is an abnormal tissue growth (tumour) that forms in the lining of the bladder. For some people, the tumour may grow further into the other layers of the bladder, it then becomes more advanced and harder to treat. A primary tumour is where the cancer starts, in this case in the bladder.

\*The 20,500 incidence figure includes the earliest stage cases of non-muscle invasive bladder cancer (those defined in histology with Ta or CIS)

## Anatomy of the bladder

The bladder is a hollow muscular organ that stores urine before it leaves the body. The kidneys filter the waste products from the body. Urine passes down two tubes (the ureters) into the bladder. It stays here until the person is ready to urinate, when the bladder's muscular layer contracts to expel the urine. The bladder can expand to store about 500 ml of urine.

The bladder has three main layers (shown opposite)



**Non-muscle invasive bladder cancer (NMIBC)** is when a cancerous tumour occurs in the inner layer of cells lining the bladder (the urothelium) and the thin middle layer (lamina propria), but has not grown into the deeper muscle layers of the bladder.

**Muscle-invasive bladder cancer (MIBC)** is when the cancer grows more deeply into the muscle walls of the bladder. These types of tumour are more difficult to treat and are more likely to spread.

**Advanced or metastatic bladder cancer** is when the cancer has spread outside the bladder to other parts of the body.

## Symptoms of bladder cancer

The most common symptoms are:

- Blood in the urine (even just once)
- Recurrent urinary infections
- Frequency, urgency or pain on passing urine when no infection has been found during urine tests
- Pain or aches in lower back or stomach (only some people will experience these)

**It is very important that you go to see your GP at the first sign of blood or other symptoms. Even if it goes away don't wait. It may not be bladder cancer but don't take that risk. The earlier that bladder cancer is diagnosed, the sooner it can be treated and the better the outcome.**

### Incidence rates

About 25% (1 in 4) of people with visible blood in their urine (haematuria) will have bladder cancer identified. This means that 75% (3 in 4) will not.

Sometimes you can't actually see the microscopic blood particles in urine (non-visible haematuria). In these cases, only around 5% of people will be confirmed with bladder cancer.



## Testing for possible bladder cancer

### At the GP

The first stage of testing will take place at your GP surgery. Your GP will usually discuss your general health, ask about symptoms and carry out a general examination. They may do a urine test at the surgery or send a sample to the lab. If appropriate, your GP will then refer you to the urology department at hospital.

There may be reasons other than bladder cancer for blood being found in your urine and it is vital that the cause is found and treated appropriately.

### At hospital

Once you've been referred by your GP, you may be given an appointment at a haematuria clinic (many hospitals now have these clinics) or to see a urologist or specialist nurse.

A doctor or nurse will ask you about your urinary symptoms, health and medical history, medications, family history, occupation and smoking history. You will have a physical examination which may include a rectal examination for males and a vaginal examination for females.

A mid-stream urine sample will be taken and sent to the lab to check for urinary infection. Urine may also be sent for cytology (checking for cancerous cells under a microscope). You will have blood tests to check the number of blood cells as well as liver and kidney function.

Further tests and scans will then be necessary to confirm (or exclude) bladder cancer.

### Questions

- What test(s) will I need and why?
- What does each test involve?
- How long will it take and do I need to take anyone with me?
- Can I drive afterwards?
- Will I need to stay in hospital?
- Will I feel unwell after the test?
- When will I get the results?
- What happens next?



## Confirming a diagnosis

When you are referred to hospital by your GP to see if you have bladder cancer, you will have various tests and/or scans. These tests may include:

Scans of your urinary tract to help the urologist detect any abnormal areas or growths and to assess the size and position of these areas.

The scan will be one of the following:

- **Ultrasound** – this is the most common scan which uses soundwaves to build up images
- **MRI** – magnetic resonance imaging is a type of scan that uses strong magnetic fields and radio waves to produce detailed images
- **CT** – computed tomography is an imaging procedure that uses special x-ray equipment to create detailed images

Some patients who have an ultrasound first may be referred for a CT scan, depending on ultrasound results.

### Note:

You might have an intravenous urogram (IVU) where dye is injected and the movement of the dye is viewed and assessed on an x-ray screen. However, in many centres, IVU has now been replaced by a CT Urogram which is often better quality than one produced with x-ray and also reduces exposure to radiation.

### Questions

- Will I need any scans?
- What will these scans show?
- Do I need to do anything to prepare for having a scan?
- Where will I have the scans?
- When will I get the results?



## Cystoscopy

This is the most important way of detecting abnormal areas or growths and the possible presence of bladder cancer. This involves examining the inside of the bladder with a very narrow fibre-optic tube with a camera and a light at the end (a cystoscope), inserted through the urethra (which is the tube that carries urine from the bladder to the body's exit). A **flexible cystoscopy** is done using local anaesthetic gel to make things more comfortable and only takes a few minutes. You may be asked to drink lots of fluid before and provide a urine sample. There's a small risk of urinary infection (happens in fewer than one person in 100), but any infection is treatable with antibiotics.

The results of flexible cystoscopy are instant, with the urologist or nurse being able to see anything unusual or any growths that require further investigation, and their size. You may be able to see this yourself on a screen. Sometimes a **rigid cystoscopy** is carried out under a general or spinal anaesthetic.

The urologist may also take tissue samples (biopsies) from the bladder and may, possibly, remove the growths. However, removal of any growth is more

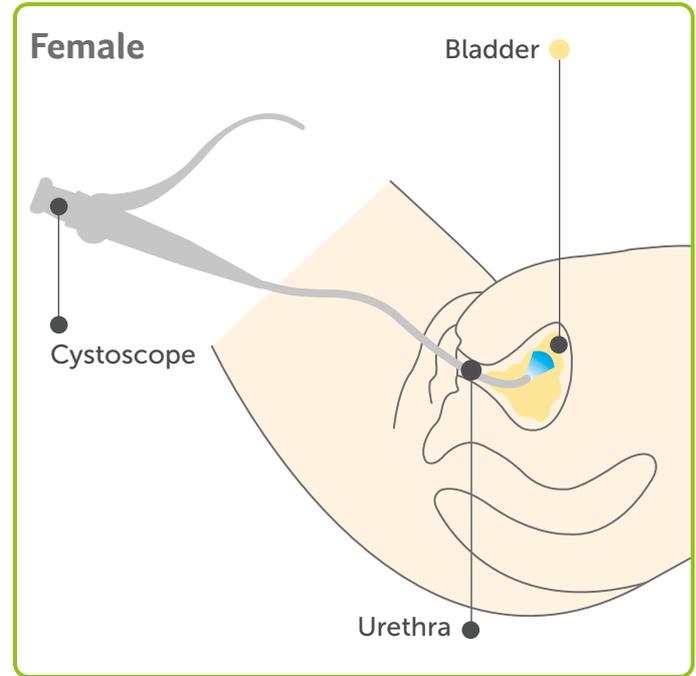
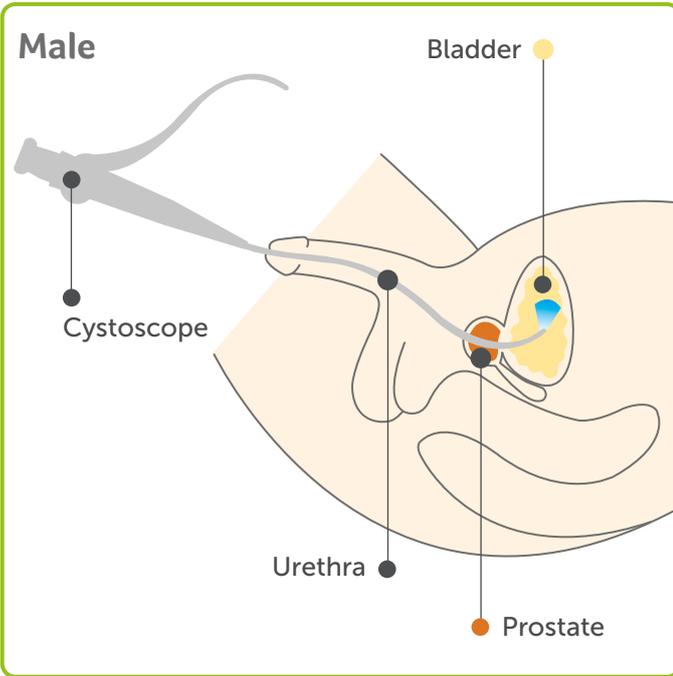
likely to be done, or completed, during a TURBT procedure (see following text). Any tissue samples are then checked to see whether they contain cancer cells and if so, what kind of cells they are.

New techniques are also being used to improve visual detection of tumours and possible bladder cancer, both at diagnosis or at recurrence. These include:

**Photodynamic diagnosis (PDD) or Blue Light Cystoscopy** – a special dye is washed into the bladder before the operation. It is absorbed by cancer cells and glows bright pink under a blue light shone into the bladder during the surgery making areas of the cancer easier to see and remove.

**Narrow Band Imaging (NBI)** uses a narrow bandwidth of light for a similar purpose.

Further flexible or rigid cystoscopies will be necessary throughout your treatment and afterwards, if you do not have surgery to remove your bladder, to monitor the bladder.





## Questions

- How is a cystoscopy done?
- What is flexible cystoscopy and what is rigid cystoscopy?
- How long will it take?
- Will it be painful?
- Will I need an anaesthetic?
- How will I feel afterwards?



## Next steps after tests and scans

If a growth or abnormal area is seen on an ultrasound scan or flexible cystoscopy, this will be explained to you. A specialist nurse is usually available to offer support and information at this time. Arrangements will be made for you to go to hospital within a few weeks for a procedure under general anaesthetic to remove, or take a biopsy of, the growth or growths and to determine whether or not it is cancerous. That procedure is called a transurethral resection of a bladder tumour (often referred to by its initials as a **TURBT**).

The actual diagnosis of bladder cancer can only be confirmed following a TURBT, when the bladder samples removed during the TURBT have been examined in a lab.

### Questions

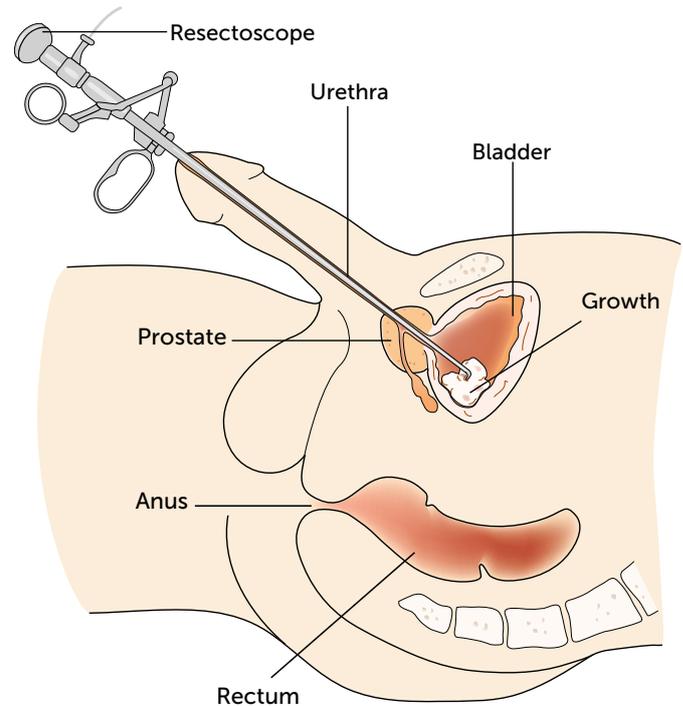
- Why do I need a TURBT?
- Can you explain the process?
- When and where can I have it?
- Should I do anything to prepare?
- How long will I be in hospital?
- How long will I need to recover?
- When will I be told the results and will they confirm whether I have bladder cancer?
- Will I need to have other treatment or an operation after having a TURBT?
- Will I be given Mitomycin C during the operation and will this stop my bladder cancer from coming back?
- Are there any side effects from this treatment?
- Will it affect my bladder function afterwards and if so, for how long?
- Will it affect my sex life?



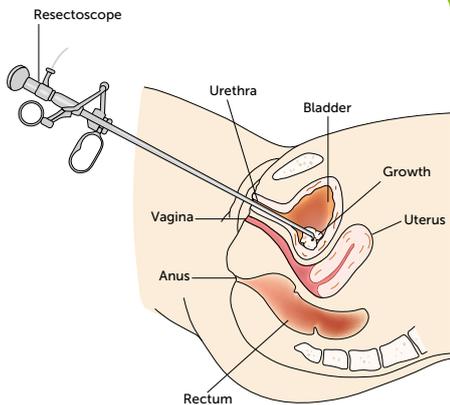
## TURBT (Transurethral resection of bladder tumour)

If an abnormal area or growth is seen, you will usually have a procedure called a TURBT – a transurethral resection of a bladder tumour. As well as being the process to get a confirmed diagnosis by investigating the type of growth in your bladder, a TURBT is also the first part of the treatment for NMIBC by actually removing the abnormal area or growth.

You may only need a TURBT once, or it may need to be repeated. It will usually mean a hospital inpatient admission (particularly for a first TURBT) but may occasionally only need you to come in for a day. You will have an anaesthetic and the inside of your bladder will be given a detailed telescopic examination through the urethra (no surgical incision is needed). During the TURBT, any abnormal areas or growths which can be seen will be removed, the tissue sealed and the bladder washed out. It is recommended in the NICE Guidelines that you are given a chemotherapy drug called Mitomycin directly into your bladder either at the same time or within 24 hours. This destroys any possible cancer cells that might still be present if you do have bladder cancer, and reduces the chances of recurrences.



**TURBT procedure male**



## TURBT procedure female



The abnormal area or growth is removed in pieces using a resectoscope

Samples of the removed abnormal area or growth will be analysed. If the abnormal area or growth is found to be cancerous, it will be classified according to how aggressive it appears as follows:

- How far it has grown into the bladder wall
- If it is present only in the inner lining or has penetrated into the muscle wall
- How likely it is to spread
- And, rarely, whether it has already spread to other parts of the body

If cancer is confirmed, your bladder cancer will then be described using letters and numbers – this is known as Staging and Grading.

## Cancer type

By looking at the pattern of cells under a microscope (called histology) and doing some tests, it's possible to tell the type of bladder cancer, which helps doctors predict how it will develop. Urothelial cancer is the most common type of bladder cancer, accounting for almost nine out of ten cases. This cancer develops from cells in the urothelium. Other rarer types include squamous cell carcinoma, adenocarcinoma, micropapillary carcinoma, small-cell neuroendocrine bladder cancer, sarcomatoid bladder cancer and lymphoepithelial-like bladder cancer.

Genetic profiling of the cancer can tell doctors which gene is faulty and has caused the cancer. This can be important for people having medical therapy, as some medications are effective only for people with certain genetic faults. Although these techniques are new, they're likely to become an important part of diagnosis in the future.



## What is NMIBC (non-muscle invasive bladder cancer)?

NMIBC is where the cancer is smaller and confined to the bladder lining layers and has not spread into the muscle wall of the bladder. About 75-80% of patients newly diagnosed with bladder cancer have non-muscle invasive tumours.

NMIBC is divided into three risk groups – low risk, intermediate (medium) risk and high risk – which indicate how likely it is that the cancer might spread further (progression) or come back after treatment (recurrence). The risk group depends on several things including the stage, grade and type of bladder cancer. As the name implies, High Risk NMIBC is a serious version of bladder cancer and can become life threatening if not treated successfully. The grading and staging section explains how non-muscle invasive bladder cancers are described. This information is essential when deciding the best treatment.

## Staging

Staging assesses how far the cancer has spread within the bladder and whether (more rarely) it has spread to the lymph nodes or elsewhere in the body.

The majority of non-muscle invasive bladder cancers fall into one of three stages:

**Ta** (or **0a**)

**CIS** (or **0is**)

**T1**

**T2/T3/T4** are used to refer to muscle-invasive bladder cancer.

<b>Ta</b>	Papillary bladder cancer. Confined to the bladder lining and looks like small growths which can be removed by surgery and may not come back.
<b>CIS</b>	Carcinoma in situ. High grade cancer cells, a flat, patch, tumour still in the innermost layer of the bladder lining. CIS is an aggressive form of bladder cancer and is more likely to come back.
<b>T1</b>	The cancer has grown from the bladder lining into the next layer of connective tissue. High grade T1 tumours can grow quickly and about 30-40% of T1 bladder cancers come back.
<b>T2 T3 T4</b>	These later stages refer to muscle-invasive bladder cancer where the cancer has grown into the bladder muscle or beyond into surrounding tissues e.g. pelvic wall, prostate, womb, vagina.

Sometimes a small letter p or c is written in front of the T (e.g. pTa) or it is written with an N or M instead of a T

<b>pT</b>	The stage has been found out by biopsy – pathological (microscope) findings.
<b>cT</b>	The stage has been based on clinical (often imaging) findings.
<b>N1 N2 N3</b>	The cancer has spread to lymph nodes. If lymph nodes are not involved it is staged <b>N0</b> .
<b>M1</b>	If the bladder cancer has spread to other parts of the body. The vast majority of bladder cancers have not spread and are staged <b>M0</b> .

## Stages of NMIBC

### Grading

Grading assess how aggressive the cancer is by looking at the cells under a microscope. Grades are scored from 1 to 3 and can be written as **G1**, **G2** or **G3**.

#### (low)

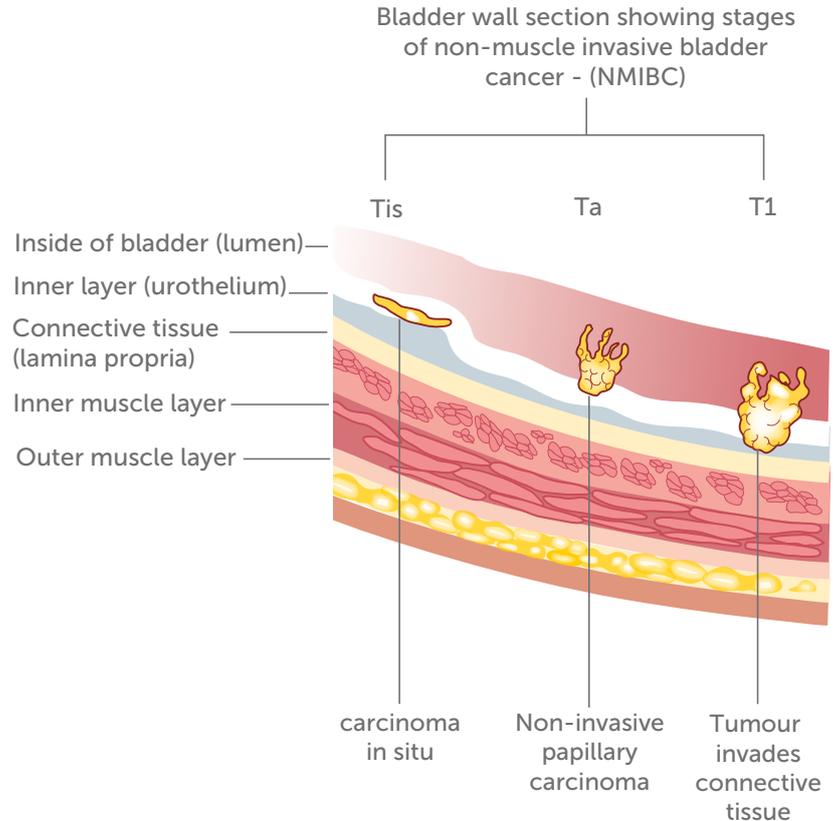
is the least aggressive, meaning that the tumour is less likely to spread and is slower growing.

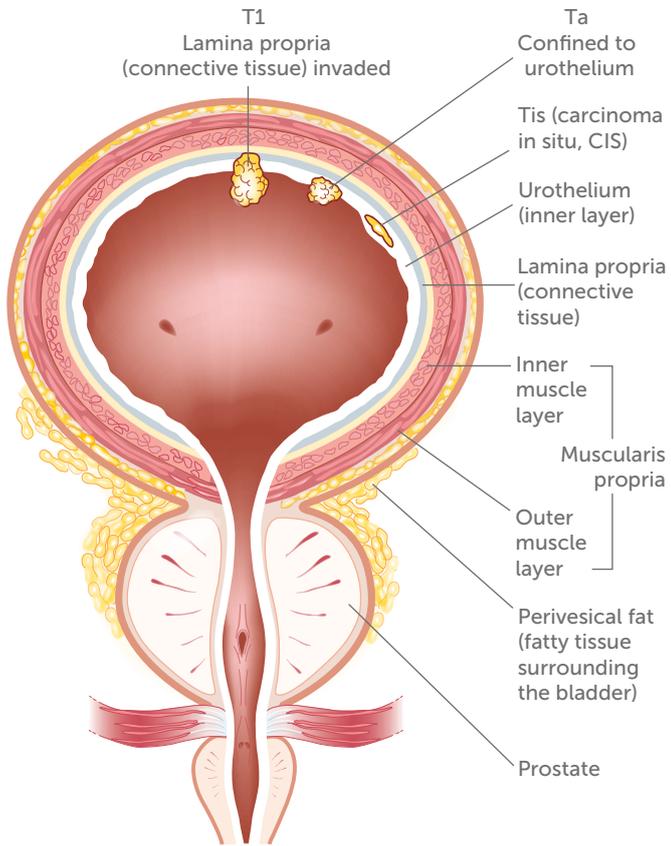
#### (moderate)

is moderately aggressive.

#### (high)

is the most aggressive, faster growing and most likely to grow and spread.





## NMIBC risk categories

Once graded and staged, the bladder cancer can be put into a **risk group**. This is based on how far it has grown into the wall of the bladder and how likely it is to spread or come back. There are three risk groups:

### Low risk

Small (under 3cm), single low grade 1 or 2 tumours that haven't grown beyond the inner layer of the bladder (papillary, shortened to pTa).

### Intermediate risk

Larger (over 3cm) or multiple low grade pTa bladder cancers. Also includes small, single low grade pT1 tumours if it shows the cancer has grown further into the bladder wall and low risk tumours which keep growing back.

### High risk

Grade 3 pTa or pT1 bladder cancers. All large (over 3cm) or multiple T1 tumours are also included. Carcinoma in Situ (CIS) is also in this category.

By assessing the severity and risk of your cancer, the doctor is then able to consider whether further treatment may be required and, if so, discuss possible treatment options with you.

## Treatment for different risk categories

### What is my individual risk?

The risk that your cancer will return depends on the stage of your cancer – the size, position and type of your tumour or tumours and how aggressive your cancer was found to be. Your doctor should explain this to you and talk to you about your choices and the benefits/risks of treatments, the grade and stage of your cancer and the likelihood of it spreading. They will also tell you about the effects and implications of treatments.

The majority of non-muscle invasive bladder cancers fall into either the low or intermediate risk category which, whilst rarely life threatening, can grow back - so you will require regular monitoring and repeat treatments may be required. Treatments for the low and intermediate risk categories are aimed at keeping and protecting your bladder.

Some or all of your cancer will have been removed during your first TURBT (transurethral resection of a bladder tumour). A second TURBT and/or a CT scan or MRI may have been needed to check that the cancer had been fully removed and to make sure it was non-invasive, meaning that it had not grown

into the muscle of the bladder wall. Some people may only need TURBT surgery to treat their cancer however, although your cancer was confirmed as non-invasive, this type of cancer can often return (recur) and you may be given further treatment after TURBT to help to reduce the likelihood of this happening.

### Low risk treatment

If the cancer is completely removed during the TURBT procedure, you may not need any ongoing active treatment. You will be monitored to check for any possible recurrences.

### Intermediate (moderate) risk treatment

After your TURBT, you will usually have a 6 week course of chemotherapy (Mitomycin C) directly into your bladder. You will also receive ongoing monitoring to check for any possible recurrences.

## High risk treatment

High risk NMIBC is more difficult to treat and can progress to something more serious if not treated successfully. If your first TURBT operation shows you have high grade (Grade 3) bladder cancer, you will usually have a second TURBT, ideally within 6 weeks of the first, to check if any cancer remains and how far the cancer has grown.

### The main options after TURBT are:

**Immunotherapy with BCG**, which involves having the BCG vaccine delivered directly into your bladder over a course of treatments – it's not completely clear how this works, but it probably encourages your body's immune system to attack the cancer cells. BCG treatment is known to be successful in around 75% of High Risk NMIBC cases. If you (in discussion with your doctor) decide not to have BCG, or if BCG is considered not to be appropriate or doesn't work, the bladder may be removed to avoid the cancer spreading further in an operation called a primary cystectomy.

**Cystectomy**, which involves surgically removing your bladder completely (the operation is called a radical cystectomy)

About 1 in every 4 people who have immunotherapy or surveillance eventually have a cystectomy.

And in some (special) circumstances or as a matter of personal choice, another option is:

**Surveillance** (sometimes called watchful waiting or expectant management), which involves regular monitoring but no active treatment until a change is seen.

**There is more information about treatment decisions for high risk NMIBC in the ABC UK Patient Decision Aid leaflet.**

## Clinical trials

Clinical trials are vital to develop new and better treatments. They can also be a way of accessing a new treatment once it has been developed and tested in a laboratory but before it becomes generally available. Clinical trials might test a drug, procedure, device or another type of therapeutic intervention. As a bladder cancer patient, you might be asked by your doctor whether you wish to take part in a particular clinical trial or you may want to find out yourself what trials are available and which could be appropriate.

Not all patients will be suitable to take part in a clinical trial and some trials may only be available in certain hospitals. Speak to your doctor about any which might be appropriate for you.

You can search for current clinical trials at:

**[www.actionbladdercanceruk.org/find-a-clinical-trial](http://www.actionbladdercanceruk.org/find-a-clinical-trial)**

**[www.cancerresearchuk.org/about-cancer/  
find-a-clinical-trial](http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial)**

## Treatments and care plan

As well as your doctor, your care team, called a multidisciplinary team (or MDT), will be looking after you and will talk to you about the type of cancer you have, and how it could affect treatment decisions. They will discuss your treatment and care plan, what the treatment should achieve and the possible effects of treatment.

## Patient care plan

Every patient should have a care plan which should be worked out with the patient, their partner/family/carer and their hospital and care team. This plan will include a summary plus details of test results, treatment plans and progress. It should identify and address each patient's needs, empower the patient and improve their quality of life whilst living with cancer. Certain things should happen at key points in a treatment pathway and these should be shown on your care plan. A care plan should also include a HNA (holistic needs assessment) which looks at all a patient's needs. Other useful information it can show is details of any local bladder cancer support groups or well-being events.

## Questions

- How far has my cancer grown?
- How will this affect the treatments available?
- What is the time scale for treatment?
- What will happen next?



## Further information about treatments

### Intravesical therapy

You may need to have chemotherapy or immunotherapy treatment, both are sometimes called intravesical therapy. Intravesical means directly into your bladder rather than by mouth or an injection. As the drugs used in intravesical therapy are put directly into the bladder (as a liquid through a thin tube or catheter) rather than injected into the bloodstream, this helps target the correct area and destroy any cancer cells within the bladder itself.

There are two main intravesical treatments:

- **Chemotherapy** usually with a drug called Mitomycin C
- **Immunotherapy** with a drug called BCG

Their role and treatment effects are quite different and your doctor should provide you with full information so you can discuss and decide on the right treatment approach for your cancer. In general, these treatments are only recommended for patients whose cancer may be likely to recur or progress to a more advanced stage. Usually, intravesical therapy reduces your risk of recurrence and so is definitely worthwhile. Both treatments have been extensively used for many years and are generally safe.



### **Before having intravesical therapy**

You'll be given information about what to do before your treatment. Things you're likely to be advised to do include:

- Limiting the amount of fluid you have to drink before. It's more comfortable if your bladder isn't too full and it can also increase the concentration of the drug in your bladder.
- Not to take any other medications (such as diuretics) after treatment.

You won't be given treatment if you're not well or have an infection. You should always tell your doctor or nurse about any other medications you are taking or if you're not feeling well before a treatment appointment.

### **How intravesical therapy is given**

The nurse will put a catheter into your bladder whilst you are lying down and then put the drug (a liquid) through the catheter directly into your bladder.

The catheter is usually removed once the drug is in your bladder, although sometimes it is left in and clamped (but you can still walk around). You must not pass urine for about an hour in order to give the drug time to work. After that you'll be allowed to go to the toilet.

If you still have a catheter, the drug will be drained out before the catheter is removed.

Note: Radiotherapy and systemic chemotherapy (i.e. into the whole body) are not effective treatments for early or non-muscle invasive bladder cancer.

### **Intravesical chemotherapy or immunotherapy?**

- For an intermediate risk tumour, you will usually receive intravesical chemotherapy with Mitomycin C
- For a high risk tumour, you may receive intravesical immunotherapy with BCG

Immunotherapy with BCG can give better results but has more serious side effects. Chemotherapy with Mitomycin C can have fewer serious side effects but may not be as effective as BCG. It is now the recommended standard practice to put a single dose of intravesical chemotherapy (usually Mitomycin C) into the bladder at the end of a TURBT procedure which destroys any floating cancer cells.

## **Intravesical chemotherapy with Mitomycin C**

This is the standard treatment for intermediate risk NMIBC. If you require a further course of intravesical chemotherapy, in addition to the single dose given after your TURBT procedure, you will usually have this treatment once a week for 6 weeks as an outpatient. You will be able to go straight home after each treatment session. You may require a further course of this treatment in the future. As the chemotherapy drug for this treatment goes directly into the bladder, you won't usually get side effects such as nausea or hair loss, which can happen with chemotherapy which goes into the bloodstream.

### **Hyperthermic Mitomycin C**

In some areas of the country, you may have treatment where Mitomycin C is put into your bladder whilst your bladder wall is heated using a small microwave probe. This is called Hyperthermic Mitomycin C (or sometimes intravesical microwave hyperthermia chemotherapy or Synergo). Doctors think that the heat makes the cancer cells more sensitive to the chemotherapy, making it work better.

## Intravesical immunotherapy with BCG

Intravesical immunotherapy is given at least two weeks after surgery – BCG vaccine is injected into the bladder.

- Treatments are usually given once a week for 6 weeks (the induction course)
- Each hospital treatment takes between 2 to 3 hours in the outpatient department and you can usually go home straight after, with a short period of recovery needed at home.
- You will then have a shorter maintenance course of BCG treatments, usually once a week for 3 weeks. This course will start around 6 weeks after the induction course. This maintenance may be needed for up to 3 years.
- You will need regular cystoscopy examinations throughout your treatment programme to check your bladder, usually 6 weeks after each course of treatments.
- Follow-up tests and scans are needed several times a year for at least 5 years.

- You may have some side effects from immunotherapy BCG treatment. These can vary for individuals and may be minor and settle after each session or be more serious. The dosage or length of the course may be altered if you get more severe effects. Always talk to your medical team about any side effects that you experience.

## New developments

Treatments for bladder cancer are changing and new possibilities are emerging. The options offered to you may reflect local decisions about the best approach. In some areas of the country, you may be offered the following as well as, or in place of, some of the other options:

- Hyperthermic mitomycin, which involves delivering mitomycin C (a chemotherapy drug used to treat different types of cancer) to your bladder
- Radiotherapy, which uses ionising radiation to stop cancer growing. Whilst radiotherapy would not be considered first line treatment for NMIBC, in some instances it may be considered.
- Some hospitals are also using shorter schedules of BCG treatment.

## After having intravesical therapy

You will need to take some precautions for about 6-7 hours after having treatment to protect yourself and others which your nurse will explain. These include:

- Taking care not to splash when you pass urine (men should sit down)
- Adding bleach to the toilet bowl after passing urine
- Washing your hands carefully
- Washing around your genitals each time you pass urine
- Drinking 2-3 litres of fluid daily for around 48 hours to flush out your bladder.

You may experience some effects from the treatment such as a stinging feeling when passing urine or needing to pass urine more often. There can also be some blood in your urine. These effects should get better in a couple of days. Drinking a lot of fluid or taking normal painkillers may help. If you have any other effects such as a temperature, rash or cloudy urine you should tell your nurse or doctor immediately.

## Questions

- Will I have intravesical chemotherapy with Mitomycin C, hyperthermic chemotherapy with Mitomycin C or intravesical immunotherapy with BCG?
- Why am I being given this particular treatment rather than the other options?
- How long is the course of treatment and where will I have it?
- How often does it happen and how many times?
- What are the names of the drugs?
- What will the treatment do?
- Will I have any side effects from the treatment?
- Who should I contact if I feel unwell during treatment?
- Will I have any other tests during the treatment?
- How will I be followed up?
- Are there any clinical trials I can be involved with?
- What happens if I can't tolerate the side effects of treatment or it isn't effective?

## Cystectomy

Cystectomy is an operation to remove your bladder and replace it with either a bag outside your body filled through a stoma in your abdomen wall, or a reconstructed bladder made from a section of bowel.

If you have been diagnosed with high risk NMIBC, the risks of your cancer recurring and/or progressing are high and your medical team should discuss the possible option of primary cystectomy alongside that of BCG treatment. They will provide a full explanation regarding the risks and benefits of both treatments prior to you making a decision regarding which treatment option to take. Cystectomy may be specifically recommended when other treatments are not considered appropriate or are not working effectively. Whilst offering long term control and a high level of 5 year survival, removing the bladder has significant implications and requires careful consideration.

Other ABC UK information leaflets which may be relevant:

- **ABC UK Patient Decision Aid**
- **ABC UK Cystectomy Information Sheet and sheets on bladder replacement.**

## Follow up and monitoring

Regular surveillance is very important for the management of NMIBC even if you are having no further active treatment. It is also essential during any course of chemotherapy or immunotherapy to ensure treatment is being effective and to react quickly to any recurrence. If NMIBC is confirmed, it is likely that you will need follow up cystoscopies both during and after any treatment to monitor that everything is OK and to look out for problems within the bladder or any recurrence. You should be told what to look out for (ask if you're not sure) and always contact your medical team with any concerns or questions.

The current recommendations from NICE (which are based on limited evidence) for follow up and monitoring of the different risk categories are as follows (what you are offered by your own hospital may vary):

- **Low risk NMIBC** - you will be discharged to primary care if there is no recurrence of bladder cancer within 12 months.
- **Intermediate risk NMIBC** – you should be offered follow up cystoscopies initially at 3, 9 and 18 months and once a year after that.

- **High risk NMIBC or CIS** – you should have a cystoscopy at 3-4 months. If negative it should be repeated every 3-4 months for 2 years, then every 6 months for 5 years. After this time an annual cystoscopy is recommended.

### Questions

- Will I have further follow up tests?
- What will happen at my follow up appointments and how often will they be?
- What symptoms should I watch out for?
- Who do I contact if I'm worried?
- Should I make any lifestyle changes?
- Will I need further treatment in the future?
- What happens if the cancer returns?



# Where can I find support?

It is likely that you will need some additional support as you cope with your diagnosis, undergo treatment and learn to live with bladder cancer. This may take different forms such as helpful information to read, finding another patient to talk to, attending a support group or advice on where to find help.

## Bladder cancer patient support groups

From your first diagnosis and throughout your treatment journey, getting the right kind of support can make a big difference.

Many bladder cancer patients and their families/friends find it helpful to attend a bladder cancer support group. It can give you an opportunity to talk, ask questions and listen to other people who have gone (or are going through) the same thing as you are. You can search on the ABC UK website for a group near you at [www.actionbladdercanceruk.org/patient-support](http://www.actionbladdercanceruk.org/patient-support)

Not every region of the UK has an active group which is why ABC UK is working to help set up new groups. If there isn't a group within easy travelling distance of where you live and you

would like to see one set up, please get in touch with us at [info@actionbladdercanceruk.org](mailto:info@actionbladdercanceruk.org)

Your CNS (Clinical Nurse Specialist) can also contact us to ask for advice and assistance in setting up a new group at their hospital.

## Questions

- What support is available if I want to alter my diet, stop smoking or take more exercise?
- What other kind of support is available?
- Is my GP going to be involved?
- Who can I talk to if I have questions or I am worried?
- What support is there for family or carers?
- What are they entitled to or who can they talk to?
- Is there a Patient Support Group for bladder cancer patients at my hospital or close by? If not, why not?



# How can Action Bladder Cancer UK help you?

You can always ask Action Bladder Cancer UK for help.

- **There is a lot of information about bladder cancer on our website.**
- **ABC UK Information leaflets** – about aspects of bladder cancer and treatment or Living with Bladder Cancer - either as downloads from our website or you can ask us for free printed copies of all our materials.
- We can help you find your nearest support group – we also run online groups which you may be able to join.
- **One to one support** – if you would like to speak (or email) one of our Patient Advisors contact us on:

 [info@actionbladdercanceruk.org](mailto:info@actionbladdercanceruk.org)

 **0300 302 0085**

## Living with bladder cancer

Adjusting to life with, and beyond bladder cancer, can sometimes be difficult and often something of an emotional rollercoaster. During this time, many people find that there can be all sorts of practical issues that they need help or advice on.

Action Bladder Cancer UK has a range of resources on living with bladder cancer – you can find them on our website, order print copies online at [www.actionbladdercanceruk.org/resources](http://www.actionbladdercanceruk.org/resources) or ask us to send them to you.

There is a list of organisations who offer advice on various issues on our website

[www.actionbladdercanceruk.org/living-with-bladder-cancer](http://www.actionbladdercanceruk.org/living-with-bladder-cancer)

## Other useful websites

Cancer Research UK [www.cancerresearchuk.org](http://www.cancerresearchuk.org)

Macmillan [www.macmillan.org.uk](http://www.macmillan.org.uk)

NHS Living with Cancer  
[www.nhs.uk/Livewell/Cancer/Pages/Cancerhome](http://www.nhs.uk/Livewell/Cancer/Pages/Cancerhome)

My Cancer Treatment  
(For information on hospitals and urology services)  
[www.mycancertreatment.nhs.uk](http://www.mycancertreatment.nhs.uk)

## Key people

The following are some key people you might meet during your treatment:

### **Care Team:**

The team of healthcare professionals who will manage your care (also see MDT)

### **CNS (Clinical Nurse Specialist):**

A nurse who is an expert within a certain field e.g. cancer, urology, bladder cancer, palliative care. A key person during bladder cancer treatment and often your main contact for information and support.

### **Continence Nurse or Advisor:**

A nurse with special training in bladder and bowel issues who can help and advise those who have incontinence.

### **Key Worker:**

Your designated point of contact from your care team.

### **MDT (Multidisciplinary Team):**

A specialist team with different skills and experience. The team might include urologists, oncologists, radiologists, pathologists and specialist nurses.

### **Oncologist:**

A doctor who specialises in treating cancer with drugs or radiotherapy.

### **Pathologist:**

A doctor who specialises in examining tissue samples for example to study the nature and causes of a disease.

### **Radiologist:**

A doctor who specialises in carrying out and examining scans of the body.

### **Specialist Urology Multidisciplinary Team:**

A specialist team with different skills and experience who manage more complicated types of bladder cancer.

### **Urologist:**

A doctor who specialises in diagnosing and treating problems in the male and female urinary tract and male reproductive organs.

**Urology Multidisciplinary Team:** A specialist team with different skills and experience who specialise in problems in the urinary tract.



## Action Bladder Cancer UK (ABC UK)

ABC UK is a national charity. We work to support bladder cancer patients and their families, improve diagnosis and outcomes for bladder cancer patients and encourage and fund research into bladder cancer.

ABC UK has been working since 2009 to get bladder cancer recognised as a common cancer with the awareness, new treatments and research investment it merits and those with bladder cancer deserve. We want bladder cancer patients to have a voice and the support they and their families need. Our trustees are drawn from the UK's leading medical and research specialists and bladder cancer patients.

There is a lot more information about bladder cancer, ABC UK information materials, support groups and our work on our website.

**W:** [www.actionbladdercanceruk.org](http://www.actionbladdercanceruk.org)

Or contact us:

**E:** [info@actionbladdercanceruk.org](mailto:info@actionbladdercanceruk.org)

**T:** 0300 302 0085

Registered charity no: 1164374



Content for this publication has been written by Action Bladder Cancer UK, bladder cancer patients and medical specialists.

The print costs of this publication were supported by an educational grant from medac Pharma. medac Pharma has had no influence over the content of this publication.

