

# What is a TURBT?

Transurethral Resection of Bladder Tumour





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WE ARE
HERE
to help you in
your FIGHT

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## ABOUT THIS DIGITAL BOOKLET

The Fight Bladder Cancer Patient Information Booklets are a range of free information materials covering the entire bladder cancer pathway and are tailored to each individual circumstance. They offer a wealth of information and real patient experience and stories.

#### **ENDORSED BY**

The British Association of Urological Surgeons

British Association of Urological Nurses

British Uro-Oncology Group

#### Other free support materials

In addition to our patient information booklets we offer a range of free materials to those affected by bladder cancer, including *Fight*Magazine, the only magazine of its type in the world, full of inspirational patient stories, medical research and clinical trial information. It is available in both print and digital editions.

We also have a **monthly newsletter** for patients that you can opt in to at:

fight bladder cancer. co.uk/contact-preferences

MORE KINDNESS
SUPPORTING EACH
OTHER AT WORK
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THE ONLY MARGENITY for people affected by 8 working and Based Caree

The ONLY magazine for people affected by 8 working and Based Caree

We hope you find this booklet, and the others in the series, useful. Please get in touch with us at **info@fightbladdercancer.co.uk** for more information about how we can support you.

### We're here to help!

MSD, Roche and the Merck-Pfizer Alliance have provided financial support to Fight Bladder Cancer to cover the costs associated with the production and dissemination of this information booklet. All editorial control has been retained by Fight Bladder Cancer.









Please remember, no part of this digital publication may be reproduced or used without the written permission of the publisher, Fight Bladder Cancer.

This series of booklets has been prepared by a team of patients and medical professionals working together to give the best guidance for patients.

The booklets have been produced in conjunction with the **British Association of Urological Nurses** (**BAUN**), the professional organisation for specialist urology nurses in the UK, and are endorsed by the **British Uro-Oncology Group** (**BUG**) and the **British Association of Urological Surgeons** (**BAUS**).

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Our patient tips come from real bladder cancer patients across the world!



Don't feel you need to read this booklet all in one go. It is designed in bitesized chunks so you can take it in at your own pace.

Fight Bladder Cancer is a patient-led charity in the UK that exists to:

- support anyone affected by bladder cancer
- raise awareness of the disease in order to improve early diagnosis
- campaign for and support research into this disease
- affect policy at the highest level to bring about change

Fight Bladder Cancer has a worldwide reputation and is supported by top international healthcare professionals.

### Hello

Are you – or is someone you know – being investigated for symptoms of bladder cancer? Or have you already undergone some initial tests and had your diagnosis confirmed?

Either way, you are likely to be experiencing a whirlwind of emotions. Whatever the outcome, it is important for you to remember that you are not alone. There are many people who can give you the support and information you need to get you through.

#### Finding out

This booklet is part of a patient information series written by people like you, who have been through the same tests, procedures and worries, and know that you are likely to be looking for accurate but accessible information and reassurance.

Another booklet, *Tests & investigations*, gives an explanation of the initial tests you are likely to have in order to determine whether you have bladder cancer. It explains:

urine tests, medical assessments and blood tests

- ultrasound scans
- cystoscopy
- CT and MRI scans

You may find it useful to read that booklet before embarking on this one.

This booklet explains the next investigation,

a Transurethral Resection of Bladder Tumour or TURBT

Remember that cancer is only one possibility so, however hard it may be, try not to jump to conclusions. Wait for your diagnosis.

Don't forget you can read our Tests & investigations booklet to find out more about confirming a bladder cancer diagnosis.

- what it is, why you are having it and what will happen next.

Tests & investigations A TURBT is a diagnostic procedure that should determine whether or not you have bladder cancer and, if so, what type. It may be the only procedure you need, or it may help the doctor decide what to do next.

#### The right information

You may be tempted to trawl the internet for information on your condition but take care. A diagnosis is as unique as you are and it is easy to find details that cause you unnecessary anxiety because they do not relate to your circumstances.

#### PATIENT TIP:

'Give Dr Google
a miss! We've all done
it, but trawling through
the internet can end up
making you feel
so worried and
confused.'

#### What is cancer?

First, a bit of background. Cancer is a genetic disease, the name given to a collection of related diseases, that can start almost anywhere in the human body, which is made up of trillions of cells. Cells are the components from which our bodies are built. They divide and grow while they are needed, then stop growing and die when they are not. If something goes wrong in a cell, it continues to divide, making more abnormal cells which eventually form a lump, or tumour.

A benign tumour will not spread beyond where it originally formed but a malignant tumour can grow into nearby tissue, and can travel around the body via the blood or the lymphatic system.

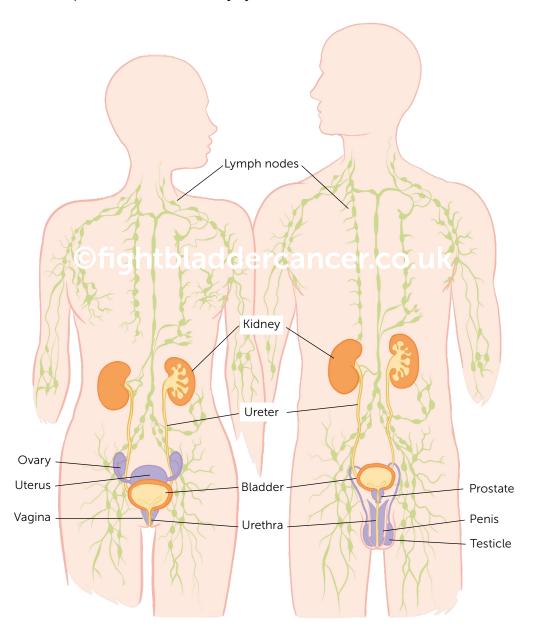
The lymphatic system is a network of organs and tissues that help the body to get rid of toxins, waste and other unwanted materials by circulating lymph, a fluid containing infection-fighting white blood cells.



Remember that every person is different – physically and mentally – so what is right for one person may not be right for another. Investigate, ask questions, talk to people and listen to their viewpoints, then make the best decisions for you.

#### The urinary system

Urine is formed in the kidneys, which filter the blood, removing waste products and water. Urine then travels to the bladder from the kidneys, via tubes called the ureters, leaving the body through another tube called the urethra. A tumour in the bladder, or anywhere in the urological system, can disrupt the rest of the urinary system.





## **STOP**SMOKING

Whatever your diagnosis, it is crucial that you think about your smoking habits — perhaps even more so if you have, or suspect you have, cancer. If you are a smoker, do please STOP. There will be a best way for you, so talk to your CNS or your GP and ask for support and advice.

The NHS has a dedicated online stop smoking service which offers all kinds of help and advice at

- nhs.uk/live-well/quit-smoking/
- wales.nhs.uk/healthtopics/lifestyles/smoking
- nhsinform.scot/healthy-living/stopping-smoking
- stopsmokingni.info

The personal quit plan is specifically targeted to give you the combination of ideas that is most likely to be successful for you.

It includes the reasons why you should give up – especially the risks of developing cancer, heart and lung disease and the fact that smoking increases the risk of the cancer returning. Most importantly, it also tells you about all the different methods you can use to help you stop; the support on offer; your local stop smoking services; Facebook,

Twitter and YouTube support; FAQs; and stop smoking aids, including patches.

Hatch a plan, get everyone on your side and STOP.

If you are not a smoker, or when you have given up, do try and keep away from smokers and smoky atmospheres.

#### Flexible cystoscopy

If you have already been diagnosed, you may have had a flexible cystoscopy as part of the diagnostic process, which is explained fully in another booklet in this series, *Tests & investigations*.

After a cystoscopy, the medical team will give you the results of the investigations. Sometimes, the problem will be obvious straight away and you will be given a diagnosis before you go home. Alternatively, it could be that you have to wait a few weeks for all the experts to review the results of your tests before they can let you know.

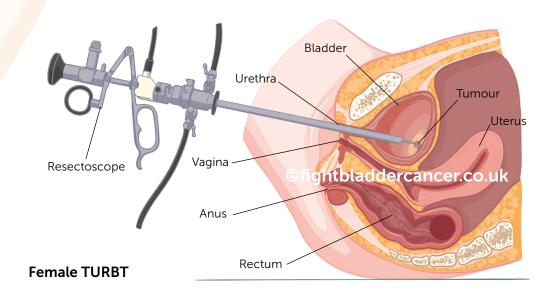
Whether you have to wait just half an hour or two weeks, it will seem like forever. Hang in there – this is all part of you getting the best treatment for your cancer as you move forward.

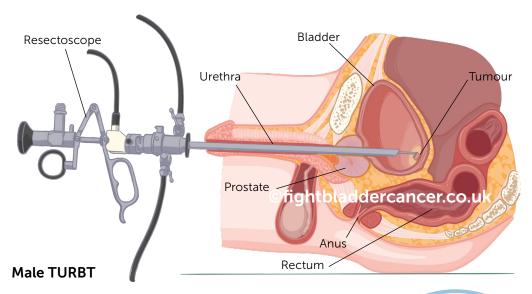
## A TURBT (Transurethral Resection of Bladder Tumour)

To investigate further when some abnormalities have been found and to make a full diagnosis, the urologist may suggest that the patient have a procedure to take a sample - a biopsy - of some of the abnormal cells, or even to remove any abnormal tissue or cancerous cells, if possible. This is known as a TURBT, which stands for Transurethral Resection of Bladder Tumour, and is performed in the same way as a cystoscopy. It is an 'incision-less' surgery, usually done as a day or overnight case in your local hospital under either a general anaesthetic or a spinal block.

The instrument used to take the sample or to remove the tumour during the TURBT is called a resectoscope and, like the cystoscope, it is introduced through the urethra into the bladder. Attached to this scope is a small, electrified loop of wire, which is moved back and forth through the tumour to cut away and remove the abnormal tissue. Electricity is used to seal off any bleeding vessels. This is sometimes called electrocauterisation or fulguration.

The advantage of this procedure is that it can be performed repeatedly at minimal risk to the patient and with excellent results.





There is a less than 10% risk of infection or injury to the bladder, and both are easily correctable if they do occur.

After surgery, a single dose of chemotherapy is often given directly into the bladder, using a catheter. The solution is kept in the bladder for an hour or two before being drained away.

#### PATIENT TIP:

'I found it much easier to understand medical diagrams by chatting them through with the nurse.'

#### Before the procedure

You will not be able to eat or drink anything for about six hours before your surgery. This is because you should not have food or drink in your stomach when you are given the anaesthetic. If you do, you are more likely to vomit while you are unconscious, which can lead to complications. The nursing staff will tell you when you will need to stop eating and drinking.

You will come into hospital either the afternoon before or the morning of your surgery and will generally be able to leave within 48 hours. The clinic will have supplied you in advance with information on what to do beforehand and where to go.

#### **Medication**

Make sure you take any prescription medication with you, and take it as usual on the day of your appointment, unless advised otherwise. However, if you are taking any medicines that thin the blood (for example, aspirin, warfarin, apixaban, dabigatran, edoxaban, fondaparinux, heparin, rivaroxaban or clopidogrel) you may need to stop taking them for a short period around the time of your surgery. Your consultant urologist will discuss this with you at your pre-operation assessment.

Please do not stop taking any medicine unless told to do so by your doctors.

If you are unsure, it is best to check in advance.

Do not take any valuables with you into hospital.

#### Just before the op

You will have your urine tested to ensure you don't have a urinary tract infection (UTI) at the time of the appointment and then be asked to get into a gown and some tight-fitting stockings, called antiembolism compression stockings. These help to prevent blood clots from forming in your legs. The consultant or clinical nurse specialist (CNS) will run through various checks with you and explain the procedure, including the risks and side-effects. This is an opportunity to ask any lastminute questions.

#### PATIENT TIP:

'I always plan for an overnight stay. I am often a day patient but it could be a longer stay.'

#### PATIENT TIP:

'Take a dressing gown in your overnight bag – much better than a hospital gown.' Some doctors may put a special dye, called hexvix, into the bladder, which makes the tumour appear a different colour to the rest of the inside of the bladder when using white light. Other doctors use a blue light to look inside the bladder, in which case the tumour stands out without the need for the dye.

You will then be taken to theatre by a member of the ward staff.

#### PATIENT TIP:

'Taking nail varnish off before your TURBT is easier done at home – you generally won't be able to wear it during surgery.'

## Having an anaesthetic

A TURBT is carried out either under a general or spinal anaesthetic. Your consultant will discuss the options with you before the operation so that you can decide which is best for you.

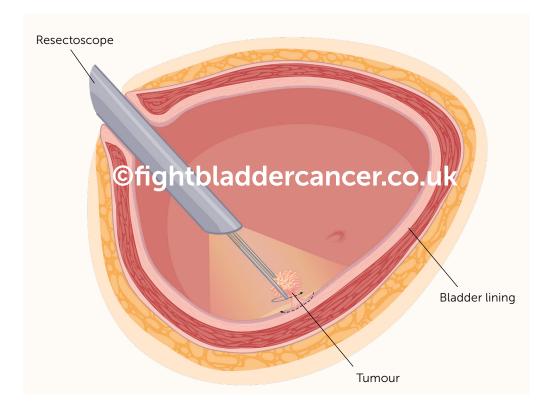
- a general anaesthetic is medicine that will make you unconscious (asleep) during your operation, so you will not be aware of the operation or feel any pain
- a spinal anaesthetic involves a special needle being inserted into your back so that the anaesthetic medication can be injected around the spinal nerves. This numbs the lower half of your body so you will be awake, but will not feel anything from your waist downwards. This can be combined with a sedative, which does not put you to sleep, but makes you feel drowsy and means you will not remember much about the operation

#### PATIENT TIP:

'For women who are staying in hospital after your TURBT, a nightie may be more convenient. I was still catheterised and it was much easier for me than pyjamas.'

#### **During the operation**

When you are anaesthetised, your doctor will place a slim, rigid fibre-optic telescope (resectoscope) up your urethra and into your bladder. This is a special tube that allows the doctor to see your bladder lining. The surgeon may take a biopsy of the tumour, in which case the abnormal cells will be sent to pathology for investigation. It is often possible to remove some or all of the tumours at the same time, in which case they will be cut away from the lining of your bladder wall using instruments inserted down the side channels of the resectoscope. This can cause some bleeding.



Once a tumour has been removed, any bleeding is stopped by using a mild electric current to cauterise (burn) the area where the tumour was situated. Most patients have a fine plastic tube (a catheter) inserted into the bladder to allow the bladder to empty and to remove any debris. Occasionally, the catheter needs to be kept in for several days if the bleeding is persistent or if there is a concern of bladder perforation. It will be removed before you leave hospital when your wee becomes rose-coloured or clear.

Once the operation is over, you will be taken to the recovery room to allow the anaesthetic to wear off. You will be taken back to your ward when you are fully awake, and the nurses will encourage you to drink plenty of water.

The tissue removed from your bladder will be sent to the pathology lab for microscopic examination.

PATIENT TIP:

'My dad's advice

after his TURBTs is

to drink and drink -

lots of water and

light fluids!'

Depending on the size of your tumour or tumours, the operation may take between 15 minutes and an hour.

#### **PATIENT TIP:**

'Be prepared for an overnight stay after your TURBT – although it may be longer or shorter – and make sure that you have someone to drive you back home afterwards.'

#### PATIENT TIP:

'After you've recovered, occupy your time because waiting for the results is the hard part.'

#### Chemotherapy bladder wash

As soon as possible after the TURBT operation, many patients are given a single dose of chemotherapy directly into the bladder. The use of this type of chemotherapy depends on the type of cancer you have and how the surgery went.

This type of treatment is called intravesical chemotherapy and involves placing a liquid solution of chemotherapy medication directly into your bladder using a catheter. The solution will be kept in your bladder for one or two hours before being drained away. It is not the same as chemotherapy given into the veins for much more advanced bladder cancer and does not affect your immune system.

Because the medication is put directly into the bladder, patients tend to avoid the sideeffects, such as nausea or hair loss, which they may experience with chemotherapy administered through a vein. With this type of chemotherapy, hardly any of the drug is absorbed into the blood, which means it rarely affects the rest of the body.

#### **PATIENT TIP:**

'Make your choices based on the information your surgeon and CNS give you. Talk to other patients, find out what everything entails ... then be confident that it is the right choice for you and go for it.'

Read Michael's
experience of a bladder
wash on page 18 or refer
to another booklet
in this series, Low-risk
& intermediate-risk
non-muscle-invasive
bladder cancer.

#### What are the risks?

Although serious complications are rare, every surgical procedure has risks. Your doctor or CNS will discuss the specific risks for this procedure with you in more detail before asking you to sign the consent form.

The risks of having a TURBT include:

- blood in your wee occurs in more than 3 in 10 people<sup>2</sup>
- burning sensation when you wee may last for a couple of days after your operation; you will be encouraged to drink plenty of water to keep hydrated and flush your system
- infection happens occasionally (in between 1 in 10 and 1 in 50 people);<sup>3</sup> you will be given antibiotics if this occurs
- or lots of less than 3 in 50 people)<sup>2</sup> and means that a small hole in your bladder wall has been created at the time of surgery. Most perforations are managed by leaving the temporary catheter in for longer (up to 10 days) and you will be able go home with the catheter in place. Very few people need an operation to repair the hole
- difficulty in weeing directly after the operation is rare,
   as most patients have a catheter for the first
   24 hours after surgery; it is most common
- deep vein thrombosis, or a blood clot, usually in the large leg veins, is also rare; the stockings you are given will help to prevent this, and you may also have an injection – the doctors will assess you and discuss whether it is necessary

in men with enlarged prostates

#### **PATIENT TIP:**

'If you are worried about blood loss, particularly if you have a temperature or lots of pain, then contact your team or GP for a quick test for an infection.'

#### PATIENT TIP:

'After a few weeks
don't be alarmed if you
pass a bit of blood and see
scabs; all part of the healing
process, just remember
to keep flushing
through with
water.'



#### What if I have problems at home?

You are likely to have a few aftereffects from the operation, but
each individual is different, so don't
be alarmed if you do experience
some problems – or if you don't.
Most people find it stings when
they wee, and can experience
bladder cramps and spasms. These
usually settle down after a few days.

It is likely that you may pass a few blood clots and tissue. These are scabs coming away from the healing areas and are nothing to worry about; in fact, it is a sign of healing that the scabs are being flushed out.

#### Seeking professional help

If you are concerned, or if you experience any of the following symptoms, contact your GP or go to your local A and E department:

- develop a temperature over 38°C (100.4°F)
- have pain and persistent burning when you wee
- are not able to wee for eight hours (unless you are asleep)
- pass large clots of blood that you are unable to pass easily
- have persistent bleeding

## When can I go back to normal activities?

Speak to your doctor about how much time you will need off work after your operation. This will depend on the type of work that you do, how quickly your body recovers and what happened during surgery. You will recover much more quickly from a small TURBT (for a biopsy or a small tumour) than a TURBT for larger tumours. Usually, you will need to take about two weeks off, but if your job involves lifting or heavy work, you may need to take three to four weeks off work.

#### **PATIENT TIP:**

'Be prepared for more nocturnal visits to the toilet when you are healing. I found it easier to have a bucket by my bed for a couple of weeks just in case.'

#### PATIENT TIP:

'Any wound needs to heal and bladders can be very sensitive to over-exertion. Don't rush back in to things too quickly, particularly if you have a manual job.'

#### **PATIENT TIP:**

'I came home from my op with a catheter for a couple of weeks. I could easily drive my car even with it in; there were no limitations. Not on the way home from surgery, though!'



#### **PATIENT TIP:**

'I took it easy to start with, but getting out and about helped enormously.'

#### Starting to exercise

You can start gentle exercises once any blood in your wee has gone or when your bladder symptoms are getting back to normal. This may be two or three days or a week after your surgery. Please don't start with anything too energetic, such as playing contact sports, for a month. If you see bleeding restart, then drink plenty of fluids and avoid exercise for another few days.

#### **Keep drinking**

If you are drinking a lot, it may be useful to buy a Radar key that gives you access to 9,000 accessible toilets throughout the UK.

You can buy the keys from disabilityrightsUK.org, where you can also access lists of toilet locations.

#### **Driving**

Don't drive until you feel safe and comfortable and, most importantly, are able to perform an emergency stop. Always check with your insurer before starting to drive again. Most patients are able to start driving safely two or three days after surgery.

#### PATIENT TIP:

'You can get a Radar key for the disabled toilets; you may want to go more urgently so these are very handy.'



#### The results

All the specimens from the TURBT will be sent to a pathologist for review. The pathologist will confirm whether you have bladder cancer, what type it is and how far it has invaded the bladder wall, if at all. These findings, along with results from imaging (such as CT scans) will determine if further treatment is necessary.

Your results should be available two to three weeks after your operation. You will have a follow-up appointment, where your consultant urologist and clinical nurse specialist (CNS) will review your results and discuss your future care. You will also be given contact details for your medical team if you do not already have them.

The results from your TURBT and discussions with your medical team will determine how much follow-up care you will need.

The TURBT may confirm that you had low-risk, non-muscle-invasive bladder cancer but the surgeon removed all the cancerous tissue

during the procedure. In this case, you are likely to have follow-up cystoscopies at about three-monthly intervals for at least a year, then be discharged into the care of your GP if you remain clear.

It is also possible that cancer was present and was removed during the TURBT procedure, but the size or spread of the tumour suggests a higher possibility of recurrence. In that case you may have another TURBT, then regular cystoscopies to check that the cancer has not returned. These will initially be at three-month intervals and then progressively less often if your bladder remains cancer-free.

If your cancer remains after the TURBT and is of a more serious nature, you will have further discussions with the consultant and will be introduced to a clinical nurse specialist (CNS), who will be the key professional in your ongoing journey. Your CNS will also be able to select the appropriate booklets from this series to give you.

#### Your medical team

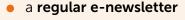
Some patients may only see a consultant at this stage, others may come under the care of a multi-disciplinary team (MDT). This will probably include a urologist, a clinical/medical oncologist, a pathologist, a radiologist, a clinical nurse specialist and your GP. There is more detail on the teams in subsequent booklets in this series.

#### How Fight Bladder Cancer can support YOU

Fight Bladder Cancer is a UK-based charity that was founded and is led by bladder cancer patients and their families, so we know exactly what you are going through. Depending on where you are in your cancer journey, you — and those closest to you — are likely to experience a range of emotions from panic and fear to confusion and anger — this is completely normal. The most important thing that you should know is **you are not alone**. We're here to support you and guide you to the people and resources you need.

Our four main principles are: offer support, raise awareness, campaign for research and affect policy. So as well as being involved internationally in the development of knowledge about bladder cancer and its treatment, we have a strong support network that includes:

- a dedicated website at fightbladdercancer.co.uk with a wealth of information about bladder cancer, its treatment and how people cope
- our private online Facebook forum at facebook.com/groups/ BladderCancerUK
- our free FIGHT magazine, which has articles on all aspects of bladder cancer and is available in print or digital editions
- Fight Club support groups in many locations throughout the UK
- a **Bladder Buddy service** which will team you up with a patient or carer who has gone through similar experiences



 a public Facebook page at facebook.com/ BladderCancerUK

a Twitter feed @BladderCancerUK

#### PATIENT TIP:

'I jump on to the support forum when I'm low. Chances are that someone else is feeling or has felt the same and so I never feel stupid or alone.'



#### What do patients say?

We chatted with cancer patient **Michael Sloane** about his experience of having a TURBT.





### What was it like to have a TURBT procedure?

After the shock of the initial diagnosis, the news that the tumour was to be removed by TURBT was met with a mixture of relief that I was not going to be cut open, but trepidation at the thought of a rigid cystoscopy. I had already had a flexible cystoscopy but a rigid one seemed another story. How was it possible to fit a tube containing a camera, surgical instruments

and cauterising loop through the narrow urethra without doing some damage? Fortunately, there was plenty of information on the FBC website, which eased some of my worries.

I've now had three TURBTs, two under general anaesthetic, but my first under a spinal anaesthetic. The thought of a spinal didn't appeal to me at all; fortunately it was not as bad as I thought it would be. I was awake during the operation, although I could not see what was going on. I had a catheter fitted during the procedure. At first, the wee collecting in the catheter bag was tinged red, but it gradually cleared to a normal colour during the day.

#### What was it like to have a bladder wash?

The bladder wash was carried out on the ward. The collecting bag was replaced by a bag containing the purple chemotherapy solution which was squeezed into the bladder and left there, by closing the catheter valve, for an hour or so, before being drained back into the bag. It did tingle a bit while the solution was in the bladder but it did not sting as I feared it might.

Finally, when the numbness had worn off and I was mobile, the catheter was removed. If you have a general anaesthetic, the nurses often do the procedure while you are still post op and not fully awake.

Fortunately, there was plenty of information on the FBC website, which eased some of my worries.

Finally, when the numbness had worn off and I was mobile, the catheter was removed. It would be fair to say that putting a catheter in is easier than getting it out – but the discomfort is over quickly!

#### The first post-op wee

Then came the first post-op wee. This was done in a designated toilet so that any residue of Mitomycin C would not get onto other patients. Bleach was put into the toilet before it was flushed. It did sting a lot initially and it was difficult to let go as a result, but it gradually became easier. There was also a fair amount of blood in the wee, which was expected but a bit disconcerting.

I was kept overnight for the first two TURBTs but went home the same day the third time. I continued to get some blood in my wee for nearly three weeks, then, after about four weeks, I passed the blood clot from the operation, with the strange sensation of something being squeezed along a tube, which I suppose is what it was.

#### PATIENT TIP:

'Each time I went to the toilet after my TURBT, the stinging feeling got less.'

#### PATIENT TIP:

'Hot water bottles are amazing at relaxing my abdomen after a TURBT. You can also get wheat bags that heat up in the microwave. Makes such a difference for me.'

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#### Fight Bladder Cancer Support - our private forum

On our private online members-only forum, patients, carers, families and professionals can discuss any worries or issues 24/7, find out about treatment options, or raise any other questions. Everyone is welcome.



#### PATIENT TIP:

'The great thing about the private forum is being able to post questions, no matter how silly or trivial they may seem, and get immediate answers from others in the same position.'

Join our private online forum at: facebook.com/groups/BladderCancerUK

## Can **you** help us in the fight against bladder cancer?

Supporting bladder cancer patients and their families is our primary objective. We are facing a growing demand for our services and urgently need more funds, so we rely on the generosity of friends like Michael to support our work.

#### Listen to what Michael said about FBC:

'The information on the FBC website explaining the procedure, together with accounts from others who had gone through it, eased some of my worries, which was a great help. Plus my initial fears about pain, injury and incontinence proved to be unfounded and I'm very grateful to the skill and dedication of the surgeons, doctors and nurses for the fact that I'm still here and still have a bladder. Supporting FBC is my way of saying thank you.'

#### Your donations matter

A donation from you would ensure that we can be here when it matters most, to help improve the lives of people affected by bladder cancer.

Ways that your donations can help:

- providing support and information to everyone who calls and emails
- setting up and running patient support groups (Fight Clubs) around the UK
- connecting patients through our Bladder Buddy scheme
- spreading awareness of bladder cancer and campaigning to improve early diagnosis

We rely on voluntary donations and with your support can make a difference to the lives of thousands of people every year. Whatever you choose to do – whether you want to make a one-off donation or set up a monthly gift, do some fundraising, volunteer or raise awareness – we **thank you** – from the bottom of our hearts.

## Fundraising with transparency & credibility

- we are open, honest and transparent
- we will always comply with the law as it applies to charities and fundraising – we will be respectful of your rights and your privacy
- we will be fair and reasonable

   treating all supporters and the public fairly showing sensitivity and being adaptable
- we will be accountable and responsible – managing our resources wisely

We are committed to ensuring that we meet the requirements of the Fundraising Regulator and follow the Code of Fundraising Practice to ensure we meet the highest standards, so you can donate and fundraise for us with confidence and trust. You can read our fundraising promise at fightbladdercancer.co.uk

#### This is how you can make a donation to Fight Bladder Cancer ...

Online: The easiest way to donate is via the donation button on our website fightbladdercancer.co.uk/make-a-donation where we offer a secure platform to make donations.

**By post:** If you prefer, you can send a cheque (payable to Fight Bladder Cancer) to our office at **Fight Bladder Cancer**, **51 High Street**, **Chinnor**, **Oxon OX39 4DJ**.

**Call the office:** If you'd rather speak to someone in the team about donating, fundraising or volunteering – then call us on **01844 351621**. We would really love to chat with you.





Research is vital to increase our knowledge base, to help with prevention of disease and to develop new and better forms of diagnosis, treatment and after-care. A clinical trial can be offered at any stage in the bladder cancer journey and usually compares new with standard treatments. Each one will have its own eligibility criteria and you should discuss your suitability with your medical team. You can apply for trials outside your area if you are prepared to travel.

You will find a list of current UK trials in our *Fight* magazine or at **fightbladdercancer.co.uk/research** 

#### New treatments for bladder cancer

A great deal of research is underway to develop knowledge in the fight against bladder cancer; new studies are being established, and new treatments are being offered. There are quite a few exciting scientific discussions and new clinical trials of immunotherapy and targeted therapy drugs, although these are particularly targeted at advanced bladder cancer.

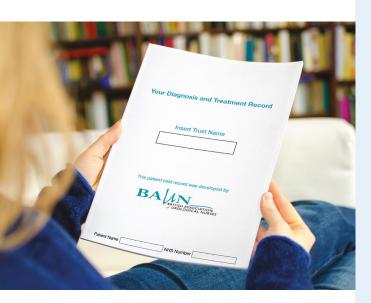
Visit fightbladdercancer.co.uk/newdevelopments to keep abreast of the new treatments.

#### Patient-held records

In 2016, NICE approved the use of patient-held records (PHRs) – researched and developed by FBC and BAUN – for bladder cancer patients.

Already used successfully in obstetrics and diabetes care, they are designed to inform and involve patients in their care and facilitate communication between the different groups of people caring for them. They also provide a useful source of data on cancer care.

They can be used in digital or printed format and filled in by the patient with their CNS at each consultation. Both patient and hospital keep a copy. The PHR contains all the information relevant to the patient and their diagnosis and treatment. The documents are currently available for any CNS to personalise and download from baun.co.uk/publications/bladder-cancer-patient-held-record



#### National Cancer Registry & Analysis Service (NCRAS)

Information on cancer incidence, diagnosis and treatment is recorded by the UK government in order to assess and improve the quality of service, treatment and research.

Information recorded includes the name, address, age, sex and date of birth of patients; data about the type of cancer and how advanced it is; and the treatment received. It is derived from medical records from GPs and various hospital departments, including independent hospital and screening services.

The NCRAS has the legal authority to collect this data without requesting consent and treats that privilege with the utmost respect. The data can only be released for specific medical purposes. To view your own data, or to opt out you can write to the Director NCRAS, Public Health England, Wellington House, London SE1 8UG. More information can be found at ncin.org.uk



### Finally ...

The aim of these patient information booklets is to provide comprehensive but straightforward information to support you in your fight against bladder cancer.

We understand what you are going through and we know you will have other questions.

We are here to help.

## REMEMBER, YOU CAN CONTACT US AT ANY TIME FOR SUPPORT

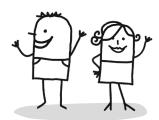
or to engage with us in fighting bladder cancer

via our website at **fightbladdercancer.co.uk** 

via our online forum at facebook.com/groups/BladderCancerUK

by email at info@fightbladdercancer.co.uk

by phone on **01844 351621** 





Hospital number
NHS number
GP
Consultant
CNS
Other MDT members



If you come across terms you don't understand, you will find a comprehensive glossary in our *FIGHT* magazines or online at

fightbladdercancer.co.uk/glossary

Everyone associated with the preparation and production of these booklets has made every effort to ensure that the information was correct at the time of going to press. However, the booklets are not intended as a substitute for professional medical advice. Anyone affected by bladder cancer, or any other medical problem, must seek the care and guidance of a suitably qualified doctor or medical team. Neither the publisher, nor contributors, nor anyone associated with them will take responsibility for any actions, medical or otherwise, taken as a result of information in this book, or for any errors or omissions.

This booklet is part of a series that covers all aspects of bladder cancer. The booklets are available free in print or digital format. You can order them via your clinical nurse specialist or direct from Fight Bladder Cancer at **fightbladdercancer.co.uk** 

#### THE SERIES INCLUDES:

- Tests & investigations
- What is a TURBT?
- Low-risk & intermediate-risk, non-muscle-invasive bladder cancer
- High-risk, non-muscle-invasive bladder cancer
- Muscle-invasive bladder cancer
- Living with a stoma
- Living with a neobladder
- Advanced bladder cancer
- Surviving bladder cancer
- Diet & nutrition

#### **ENDORSED BY**

The British Association of Urological Surgeons

British Association of Urological Nurses

**British Uro-Oncology Group** 

#### Fight Bladder Cancer

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facebook.com/BladderCancerUK

**■** @BladderCancerUK











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