



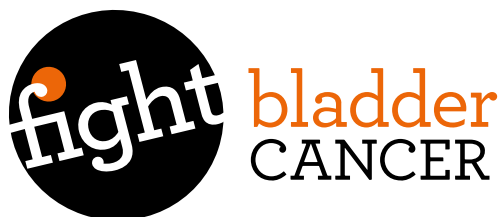
bladder
CANCER

Patient Information Booklet

HIGH-RISK
**Non-muscle-invasive
bladder cancer**
& your treatment choices



A GUIDE FOR PATIENTS BY PATIENTS & PROFESSIONALS



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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.

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:

fightbladdercancer.co.uk/contact-preferences

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!

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ENDORSED BY

The British Association of Urological Surgeons

British Association of Urological Nurses

British Uro-Oncology Group



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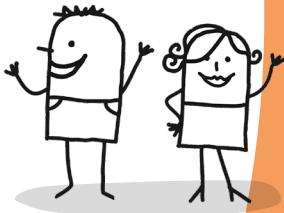
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Our **patient tips** come from **real bladder cancer patients** across the world!



Don't feel you need to read this booklet all in one go. It is designed in bite-sized 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

You have recently been given a diagnosis of high-risk bladder cancer, or perhaps you are the partner of the person affected.

Take a deep breath. If you are anything like most people who have recently been diagnosed with cancer, panic and fear are likely to be at the forefront of the emotions you are experiencing.

The words that none of us ever expects to hear:

'You have high-risk bladder cancer'

are likely to be ringing in your ears. Along with rising panic, you may be feeling overwhelmed, frightened and probably angry.

As a newly diagnosed bladder cancer patient, you are embarking on a journey. **Right now, as you begin this journey, the most important thing you should know is: you are not alone.**

There are thousands of others living with this disease, and there are people and resources to help you find the information you need so that you can make the best choices and enlist the support that will get you through.

This booklet has been written for and by bladder cancer patients and the people and professionals who care about and for them. No matter what path your bladder cancer journey takes, know that there are others here who will share the journey with you.

What is cancer?

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.

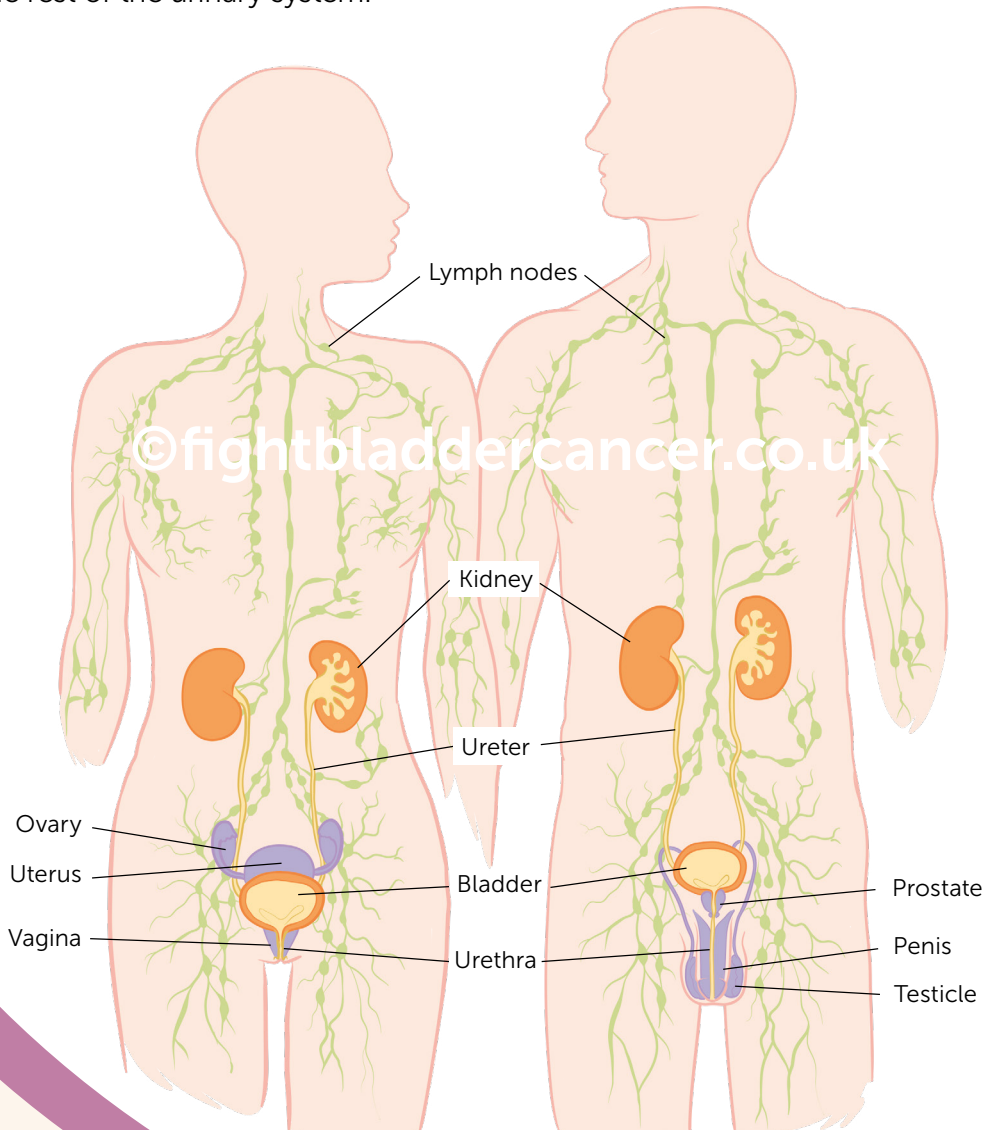
PATIENT TIP:

'Whatever your problem, there's always someone in the same boat. You're never alone.'

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.

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 system, can disrupt the rest of the urinary system.



You need the right knowledge

To add to the emotional storm whirling around you, is the fact that you need to take on board a whole raft of new information about your condition. To make the informed decisions that will be necessary, you will need to understand what your diagnosis means and what treatment options are open to you.

While your medical team will explain things to you, most people need time to reflect on all this new information, and look for more guidance from other sources. That can be valuable, but do remember:

- a bladder cancer diagnosis can mean many things and is as individual as you are
- always check that the source of the information you are looking at is a reliable one, such as a nationally respected research institute or organisation like Fight Bladder Cancer or Cancer Research UK
- discuss what you have found with your clinical nurse specialist (CNS) or medical team

This is personal

Cancer has one name but a vast number of subcategories. Bladder cancer alone subdivides into muscle-invasive and non-muscle-invasive, and different stages, grades and types. There is a big difference between muscle-invasive and non-muscle-invasive bladder cancer as far as the treatments and prognosis are concerned.



Doing blanket research before you understand your personal diagnosis may not only leave you with information overload but could also cause unnecessary worry.

PATIENT TIP:

'Despite my best intentions I did Google – and scared myself silly! Jumping on the FBC forum was a much better idea; the support and acceptance everyone showed me was amazing.'

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.

Where do you start?

First things first: it is normal to be scared. No matter what the doctors have said to you, your first reaction is likely to be fear. It happens to all of us when we are first diagnosed. It is also normal for your closest loved ones to be in the same state of shock and concern. Often their worries are even more intense than yours as they will feel totally helpless at the beginning.

The second thing is that – if you have high-risk, non-muscle-invasive bladder cancer or you have been told that an earlier treatment has not worked – the reality is that you do have a serious form of bladder cancer and it is important that you get the right treatment straight away. Yes, people do die from bladder cancer but the right treatment will give you the best chance of surviving it.

This is why you need to find out the details of your particular cancer.

With a serious form of bladder cancer it is even more important that you get the right treatment straight away. This will give you the best chance of a positive outcome.

You can find the most important questions to ask your CNS and urologist in this booklet and be assured that you have the right information that applies to the detail of your diagnosis and the treatment you are likely to be offered.



PATIENT TIP:

'If you have a decision to make on a procedure or treatment, the anxiety eases so much once you have made it. Feel happy with your decision and know it was the best choice for your needs.'

PATIENT TIP:

'It can be hard to concentrate after a diagnosis, but find out all you can about your procedure. Knowledge is power.'

How did we get here?

Let's just recap for a moment and clarify where we are in your cancer journey.

You may have found blood in your wee, or had other symptoms that caused you to go to your GP. Another booklet in this series, *Tests & Investigations*, outlines the procedures you will have gone through to determine whether or not you have bladder cancer.

Generally, after the initial diagnosis of a bladder tumour, the urologist will have suggested that the patient have a procedure in the hospital to examine the bladder more completely under anaesthesia (general or spinal) and to remove any tumours, if possible. The doctor may refer to this procedure as a TURBT (Transurethral Resection of Bladder Tumour). The TURBT may be followed by a chemotherapy bladder wash, filling the bladder with a chemotherapy solution – which can reduce the chance of the cancer recurring or spreading into the bladder muscle – then draining it off after an hour or two. Another booklet in this series, *What is a TURBT?*, gives full details of that procedure.

Urologists typically send a sample of the cancer tissue to a pathologist – a doctor who specialises in

PATIENT TIP:

'Write questions down as you think of them, make notes, put it on paper or on your phone. I don't want to come away from seeing the surgeon having forgotten things I wanted to ask.'

examining tissue – for review, known as a biopsy. The pathologist will confirm the type of bladder cancer and whether or not it has grown into the bladder wall.

The next consultation

The findings from the pathologist, along with results from imaging such as CT scans, will be sent to your urologist so that as much as possible is known about the cancer. A team of healthcare professionals, known as the multi-disciplinary team, will then decide if further treatment is necessary and what that treatment should be, using national and international guidelines, or whether you should

go on a programme of close monitoring of your bladder. They will explain all this to you at the next consultation.

Now you are beginning your cancer journey and, remember, we will be with you every step of the way.

Questions to help you understand your cancer

Keep in mind what we have already said: that everyone is different. Some people want to know every minute detail of what is likely to happen; others prefer just to stick to the basics. That's okay, but remember that the doctor or consultant cannot read your mind so they don't know how much detail you want to hear unless you tell them. It is up to you to ask the questions.



Take your time to evaluate what you are told as you are likely to be in shock for a while.

To begin with, these basic questions will help you understand your specific cancer.

- what do you mean by high-risk non-muscle-invasive, stages and grades?
- what are my treatment choices?
- which do you recommend for me and why?
- what are the expected benefits of each kind of treatment?
- what are the risks and possible side-effects of each treatment?
- who will be part of my medical team?
- how will treatment affect my normal activities?
- how will it affect my quality of life?
- how often do you treat patients in my situation?
- can I speak with a patient who has gone through this type of treatment?

When you are ready, sit down and make a list of all the questions you have. It doesn't matter if they sound silly; if the question has popped into your mind, then it needs an answer, so do not be embarrassed to ask it.

PATIENT TIP:

'The FBC forum is the place to ask questions. You can never ask too many questions.'

PATIENT TIP:

'I have found so many people on the FBC private forum who truly understand what I am going through and have a fountain of knowledge that I can call on.'

All about the types of bladder cancer

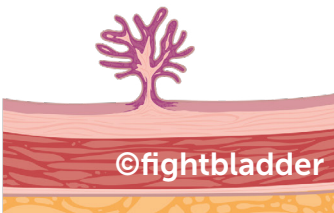
From the biopsy taken during the TURBT, the consultant will be able to ascertain what is known as the type, stage and grade of your cancer. This is what will define whether your cancer is low, intermediate or high risk and determine the type of treatment you will be offered. Both definitions and treatment options vary considerably, so it is important to take your time to discuss your situation with your doctor and make sure you understand your diagnosis and the treatment you are being offered.

TYPE

There are several different types of bladder cancer, the most common being **transitional cell carcinoma (TCC) or urothelial cancer**. TCC begins in the cells of the bladder lining and can be non-muscle-invasive or muscle-invasive. If your cancer is non-muscle-invasive – also called superficial or early-stage bladder cancer – it has only been found on the lining of your bladder and has not spread elsewhere. If your cancer is muscle-invasive, it has spread into or beyond the muscle wall (the detrusor muscle).

!
If you have ANY queries about your diagnosis or treatment options then ask your team until you are completely sure.

At diagnosis, about 75% of bladder cancers are non-muscle-invasive cancers.



Non-muscle-invasive
Transitional cell carcinoma



Muscle-invasive
Transitional cell carcinoma



CIS



Flat carcinoma

bladder lining
connective tissue
muscle
fat

Less common types of bladder cancer include *squamous cell cancer*, *adenocarcinoma*, *urachal* and *small cell bladder cancer*. These are usually muscle-invasive forms of cancer.¹

STAGE

The tumour will have begun on the inner surface of the bladder, and the stage indicates how far it has spread from that inner lining.

A system called the **TNM system** is used to define the stage of the cancer.

- 1 T** (tumour) – how far the tumour has grown into the bladder
- 2 N** (nodes) – whether the cancer has spread into nearby lymph nodes
- 3 M** (metastasis) – whether the cancer has spread into another part of the body, such as the lungs

1 The T stages

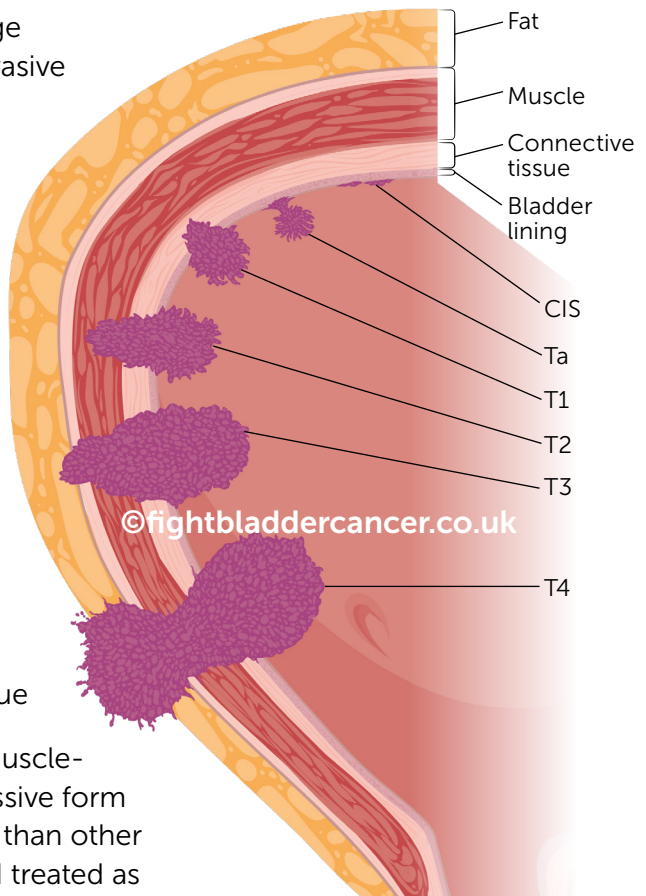
The T stages define how far the cancer has spread.

Bladder cancer up to the T1 stage is usually called non-muscle-invasive bladder cancer.

The T stages of non-muscle-invasive bladder cancer are:

- **T0:** no tumour
- **TIS (CIS):** carcinoma in situ, a flat, fast-growing tumour that spreads across the inner layer of the bladder
- **Ta:** papillary, mushroom-shaped, tumour that is only on the innermost layer of the bladder
- **T1:** tumour has started to grow into the connective tissue

Although CIS is a type of non-muscle-invasive cancer, it is of an aggressive form which may spread more quickly than other types, so it is always classed and treated as high grade. T1 cancer is also high grade.



If the tumour grows further than this, it's usually called muscle-invasive bladder cancer.

The T stages of muscle-invasive bladder cancer are:

- **T2:** tumour has grown through the connective tissue into the bladder muscle
- **T3:** tumour has grown through the layer of muscles into the surrounding fat layer

If the tumour grows further than the T3 stage, it's considered to be advanced bladder cancer.

The T stage of advanced bladder cancer is:

- **T4:** tumour has spread outside the bladder into other organs (such as prostate, uterus, vagina, pelvic wall)

2 The N stages

The N stages define the cancer in relation to its spread to the lymph nodes:

- **N0:** there are no cancerous cells in any of your lymph nodes
- **N1:** there are cancerous cells in one of the lymph nodes in your pelvis
- **N2:** there are cancerous cells in two or more of the lymph nodes in your pelvis
- **N3:** there are cancerous cells in one or more of the lymph nodes (known as common iliac nodes) deep in your pelvis

3 The M stages

There are only two definitions in the M system, relating to the further spread of the cancer:

- **M0:** the cancer has not spread to another part of the body
- **M1:** the cancer has spread to another part of the body, such as the bones, lungs or liver

PATIENT TIP:

'You get given so much technical information with a bladder cancer diagnosis it can be easy to feel overwhelmed. Take a breath and go through the information at your own pace.'

GRADE

The grade refers to what the cancer cells look like under the microscope compared to healthy tissue and indicates how aggressive the cancer is and how likely it is to spread. It is also affected by the number of tumours.

To classify bladder cancers, the World Health Organisation established one system in 1973, and then established a slightly different system in 2004.

In the 1973 grading system, grades are expressed as a number; the higher the number, the less the tumour resembles a normal cell and therefore the more aggressive it is.

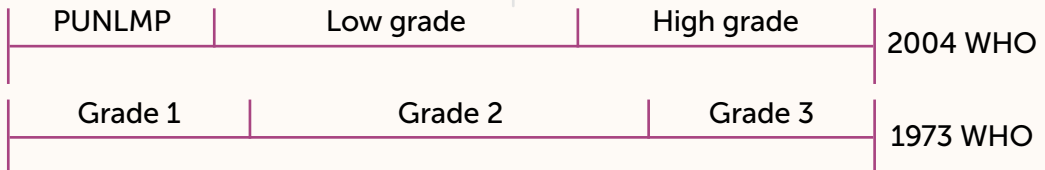
- **G1** / low grade
- **G2** / intermediate grade
- **G3** / high grade

Alternatively, your doctor may simply refer to the grade of your tumour as low, intermediate or high.

In the 2004 system, the categories are:

- **PUNLMP** (Papillary Urothelial Neoplasm of Low Malignant Potential)
- **low grade**
- **high grade**

You can see from the diagram below that the boundaries of the three sections are not the same. It's like comparing UK and European shoe sizes; a size 7 can be a 40 or a 41.



Stratification of tumours according to grade in the WHO 1973 and 2004 classifications

PATIENT TIP:

'If you have to make a choice between procedures, whatever choice you make, consider your doctor's recommendations, and maybe get a second opinion.'



Tumour grading can seem complex. Remember – your CNS will be able to talk you through everything in more detail.

You are part of a team

People with bladder cancer are cared for by a team of healthcare professionals, each with their own expertise. This is often known as a multi-disciplinary team (MDT). These specialists work together to make decisions about the best way to proceed with your treatment and are there to ensure you achieve the best quality of life during treatment and afterwards.

Who will be part of my medical team?

The members of your MDT may vary from one area to another and depending on your treatment programme but are likely to include:

- **urologist:** a doctor who specialises in treating conditions that affect the urinary tract
- **clinical and/or medical oncologist:** a specialist in the non-surgical treatment of cancer with drug treatments such as chemotherapy or immunotherapy or with radiotherapy (radiation treatment)
- **pathologist:** a specialist in interpreting biopsies and removed tissue
- **radiologist:** a specialist in interpreting x-rays and scans
- **GP:** your family doctor
- **clinical nurse specialist (CNS):** who will usually be your first point of contact with the rest of the team, also known as a key worker



Try to make sure you have a medical team you trust and can communicate easily with. Share information with them, and don't hesitate to ask questions.



In addition, you may see other practitioners, such as members of the community health services.

Get involved

Remember that you are the most important part of your healthcare team. To get the best out of them, you also need to be involved in your own treatment and care because a positive attitude will help to improve your quality of life and may even have a positive effect on the outcome.

Getting involved with your cancer begins by developing an understanding of your specific condition and what treatments you will be offered. You do this by talking to your CNS and other members of your team.

PATIENT TIP:

'Find out who your specialist nurse is, your CNS; this is the best point of contact for when you need information.'

Making decisions

With all the information that is now available, your medical team will be able to recommend the treatment that is best for you, considering both the details of your cancer and any other health issues you might have. They will take notice of the national guidelines for the treatment of bladder cancer that have been produced by NICE, as well as information from the British Association of Urological Surgeons and the European Association of Urology.

PATIENT TIP:

'Never feel pushed towards a certain treatment option without understanding what your options mean.'

A second opinion

Hopefully you will have developed a relationship of trust with your MDT and will feel the most important part of the decision-making process. However, if you feel that you want a second opinion you can ask your consultant or GP for a recommendation. Make sure that you provide the second doctor with all the relevant information so that an accurate assessment can be given.




Talk, talk, talk about it

At your first meetings with your consultant or CNS, when you are initially diagnosed, it is very common for you to feel overwhelmed, too dazed even to think of all the things you need to ask, let alone form those thoughts into sensible questions or understand and retain any of the answers. This is perfectly normal.

You will have the chance to ask those questions. Go home and think about what you have been told – or what you remember of it. This will throw up the questions you need to ask first. Write them down and take your notes with you to the next appointment.

Talk to your team about your concerns, share information with them, ask them about the things you don't understand. That way, you will develop a trust in them and an ability to communicate with them. Never hesitate to ask questions.



If your questions aren't answered completely or you don't understand, ask them again.

PATIENT TIP:

'It is hard to explain the emotions you go through when you are told you have cancer. To say I felt isolated is an understatement, and after many sleepless nights searching the Internet I found Fight Bladder Cancer, where there were people who felt just the same as me.'

Write it down

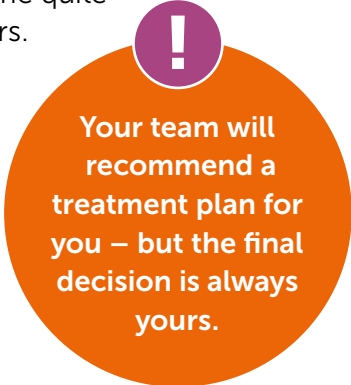
If possible, take a family member or friend to each appointment, so they can ask questions and hear the answers – often it takes more than one set of ears to get all the necessary information. Remember to write down your questions in advance, and take along extra paper to write down the answers.

If making notes is a problem, you might also want to consider recording meetings, then you can let family members and friends hear what was said if you want to. Do make sure you ask permission of those present as some people find this intrusive.

What are the possible treatments?

High-risk, non-muscle-invasive bladder cancer is a common type of bladder cancer. It is less serious than muscle-invasive cancer but can still be quite aggressive. The treatment options range between observation only (regular check cystoscopies to examine the bladder), BCG treatment into the bladder (regular instillations of BCG vaccine into the bladder) and bladder removal (cystectomy). While your chances of recovery are good for this cancer, it can require some quite aggressive treatment and observation for a few years.


Your medical team will make recommendations, but remember that the final decision is yours. The recommended treatments for this type of bladder cancer are quite precise so it is possible that the team will strongly recommend one type of treatment rather than a range that you can choose from.



Your team will recommend a treatment plan for you – but the final decision is always yours.

TURBT

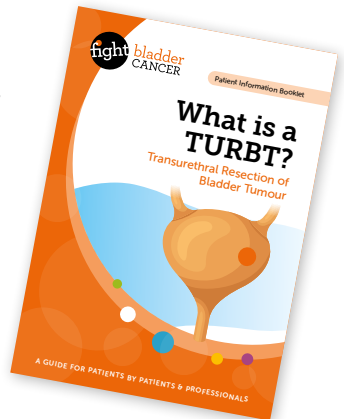
In cases of non-muscle-invasive bladder cancer, it is usually possible to remove the cancer cells while leaving the rest of the bladder intact. This is done using a surgical technique called Transurethral Resection of Bladder Tumour (TURBT).



PATIENT TIP:
'If something isn't right, make sure you speak up and fight to get the treatment you need as soon as possible.'

A full explanation of the procedure is given in another booklet in this series, *What is a TURBT?*. In the case of high-risk cancers, you can expect to have two or more TURBTs.

This may then be followed by BCG, or other intravesical treatment, in which a medication is introduced directly into the bladder (see page 16).



BCG treatment for a high-risk, non-muscle-invasive bladder cancer or CIS

The most common treatment for your high-risk bladder cancer will be BCG installed directly into the bladder. BCG stands for Bacillus Calmette-Guerin, which is a treatment that should reduce the risk of the cancer returning.

This type of treatment involves placing a liquid solution of 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 an immunotherapy treatment.

Advice on how to prepare for the treatment, how it is administered and the after-care will be provided before your first appointment. If you have any concerns, please contact your CNS.

The advantage of using this type of treatment is that because the medication is placed inside your bladder, rather than being injected into your blood, you are much less likely to experience the side-effects that are most commonly associated with some other treatments, such as nausea, fatigue and hair loss.

The BCG vaccine was originally used to prevent tuberculosis (TB), but it has proved to be a good treatment against bladder cancer. It works by stimulating the immune system to target and destroy any remaining cancer cells.

There are side-effects to be expected following treatment, however, and you will be advised of them before you start.

Most people need weekly treatments over a six-week period. Depending on your situation, maintenance therapy may also be recommended to prevent the cancer coming back. This involves further doses of the BCG, up to 27 times in total over three years, although most patients do not require this many sessions.

Before your BCG treatment

When your bladder has healed from your TURBT (so the BCG is less likely to enter your bloodstream), you will go into hospital as a day patient for your BCG treatment.

Depending on your urinary symptoms, which will be assessed pre-treatment, you may be advised not to drink for two to three hours before your treatment, or sometimes you may be asked for a urine sample before the treatment. The nurse will take a sample to check from the catheter she inserts to instil the BCG. If this sample shows signs of infection, you will not be treated with BCG until it clears up.

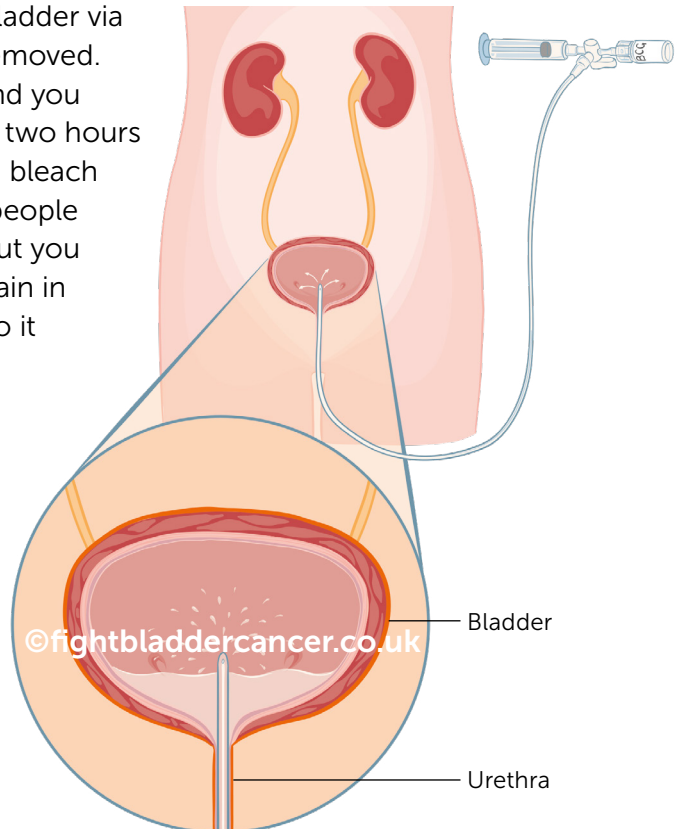
!
Take a friend to your appointments if you think it will help and make you feel more comfortable.

During treatment

The procedure only takes a few hours.

The liquid drug is fed into your bladder via a catheter, then the catheter is removed. Most hospitals ask you to stay, and you need to hold the liquid for about two hours before voiding it into a toilet with bleach in it. It can be difficult for some people to hold the liquid for that long, but you must allow the treatment to remain in the bladder as long as possible so it can work effectively.

Since the bladder is like a bag and the aim is to coat the whole lining of the bladder with the solution as thoroughly as possible, you may be advised to walk around, or to lie down and turn over every fifteen minutes or so. You might want to take music, podcasts or audio books to distract you during the two-hour holding period.



Possible side-effects

BCG treatment is not an easy treatment for everyone. It can be uncomfortable and sometimes painful. Some people are lucky and sail through the treatment, whilst others have quite a difficult time during the process.

It will help if you drink plenty of water, and make sure you look after yourself, eating a good, balanced diet and taking gentle exercise and avoiding stress as much as possible.



BCG treatment can cause uncomfortable and sometimes painful symptoms in some people.

PATIENT TIP:

'If my husband feels a bit uncomfortable when the treatment is in his bladder he walks about to distract himself, then he thinks less about it. Afterwards he has been well enough to do normal things, just taking it a bit easy.'

PATIENT TIP:

'BCG treatment affects people in all different ways from people who have "no problems at all" to others who say, "it was hell and I needed every painkiller available.'"

Important– It is important to use a condom during sex if either you or your partner is having BCG treatment. Do talk to your CNS to get advice on this.

The common side-effects of BCG treatment include:

- a frequent need to wee
- pain when weeing
- blood in your wee
- joint or back pain
- tiredness
- flu-like symptoms:
- urinary tract infections (raised temperature, cloudy or unpleasant-smelling wee, lower back pain or feeling tired or shaky)
- many men experience a rash in the groin and around the penis

If you experience any of these symptoms and they persist or are troublesome, contact your medical team.

Pain relief

Pain with BCG treatment is quite common but most people get all the relief they need with over-the-counter painkillers. If these don't work, talk to your consultant or CNS and they can help you choose other painkillers that might work better for you.

PATIENT TIP:

'You may want to avoid caffeine and alcohol – both tend to irritate my bladder. I drink decaf all the time now and it really helps.'

Radical cystectomy

A radical cystectomy (or RC) is surgery to remove your bladder. It is most usually appropriate in cases of muscle-invasive bladder cancer. It may also involve removing the nearby lymph nodes, part of the urethra, the prostate (in men) and the cervix and womb (in women). If your medical team feel this is appropriate for you they will discuss all the details with you. You can also ask your CNS for another booklet in this series, *Muscle-invasive bladder cancer*, which looks at the procedure in detail.

What if my cancer comes back again or changes to be muscle-invasive?

Bladder cancer has a high recurrence rate, so you will have to continue to come for regular check-ups and possibly further investigations and treatment, even if your first round of treatment is successful.

There is also a possibility that you find that the BCG doesn't work for you or the side-effects are just too toxic. In these cases, your medical team will be able to offer other treatment options. Your clinical nurse specialist will be able to advise you and to give you further appropriate booklets in this series.



If your cancer recurs there is a possibility that it could return as a higher grade which would require different treatment options.

PATIENT TIP:

'I worried a lot about recurrences at first. Take your time, it will get easier.'



Liz



Keith



Kelly



Gareth



Brian



Ricky



Debs



Corrina



Dylan

Looking after yourself

It is important to look after yourself while you are undergoing treatment so that you have the best chance of a positive outcome and of coping well with your treatment.

- stick to a healthy balanced diet (take a look at our *Diet & nutrition for bladder cancer patients* booklet)
- get plenty of sleep
- take gentle exercise when you can
- keep up with as many of your usual hobbies and activities as possible
- don't overdo it!

PATIENT TIP:

'Whatever you do, don't lose your sense of humour – laughter is like the best medicine.'

PATIENT TIP:

'Waiting between check-ups can create some nerves. Keep your mind active on other things, something not too difficult but that keeps you concentrating.'

PATIENT TIP:

'I'm now on a yearly cystoscopy. It can seem a long time between checks, but I find it reassuring to think of it as having a yearly MOT!'

Remember that many other bladder cancer patients have been successfully treated and are living life to the full!



Lorraine



Brian



Kelly



Susan



Caren



Teri



Alan

STOP SMOKING



It is crucial that you think about your smoking habits. 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 help and advice at

- [nhs.uk/live-well/quit-smoking/](https://www.nhs.uk/live-well/quit-smoking/)
- [wales.nhs.uk/healthtopics/lifestyles/smoking](https://www.wales.nhs.uk/healthtopics/lifestyles/smoking)
- [nhsinform.scot/healthy-living/stopping-smoking](https://www.nhsinform.scot/healthy-living/stopping-smoking)
- [stopsmokingni.info](https://www.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.² 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.

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

PATIENT TIP:

'Look at this month's calendar right now. Circle a date and make that the day you will stop smoking.'

PATIENT TIP:

'If I had known how strong the link was between bladder cancer and smoking I would have quit years ago. Stop as soon as you can!'

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

Alternative and complementary therapies

There is no scientific evidence that alternative treatments using diet, herbs or homeopathic remedies, can be successful. If you are considering including any such remedies in your treatment programme, do discuss it with your consultant before taking any action.

Many complementary therapies – such as yoga, meditation, acupuncture, aromatherapy, reflexology, mindfulness and massage – can help you to combat stress and help you feel more relaxed and able to cope with your ongoing fight against bladder cancer.



Darren

PATIENT TIP:

'Homeopathy doesn't work on cancer. Don't waste your time or money.'

PATIENT TIP:

'Mindfulness meditation helps me to feel calmer.'

CBD

Cannabidiol (CBD) is a cannabinoid found in marijuana and hemp.

Research is under way to establish whether it could aid cancer treatment by reducing tumour growth; enhancing uptake of certain medications; and easing treatment side-effects such as pain, nausea, anxiety and poor appetite.

There is currently no scientific evidence that CBD might help cancer patients and since it can interfere with the uptake of certain medicines, as well as having its own side-effects – such as appetite and weight changes, diarrhoea and fatigue – you should consult your medical team before considering its use.



There is currently no scientific evidence that CBD might help cancer patients.

Telling people you have cancer

Breaking the news that you have just been diagnosed with bladder cancer will not be easy. You may feel concerned about upsetting your family and friends, and worried about how they might react. Even after you have shared the news, you may find that at times it is difficult to communicate openly. Sometimes it's uncomfortable to ask for help, answer questions about how you're doing, or tell well-meaning relatives and friends that you need help or some time and space to yourself.

Here are a few tips to help break down that communication barrier with those closest to you:

- you are the one who guides the conversation and decides how much information to share
- target the content and tone to the person you are speaking to; you may not want to tell everyone everything
- if you have a partner, involve them in medical appointments when possible; they will gain a first-hand understanding of your diagnosis and treatment options and be better prepared to understand how you're feeling
- be clear about what you need; don't assume other people know what you most need at any given time if you don't tell them
- delegate when you can't face doing things and pick them up again when you can; be prepared to change your mind as you will not feel the same way all the time
- try to remember that your partner and family are worried about you but they have their own cares and concerns too
- accept that different people have different ways of coping
- be sensitive to possible changes in your sexual relationship with your partner – talk about it honestly and openly



Always try to use direct, simple language when telling people you have cancer.

PATIENT TIP:

'Don't expect everyone to understand what you have been through or to want to hear you talk about cancer. Going to a support group made me feel so much better, just seeing others who understood meant such a lot.'

Talking to children

Here are a few tips on targeting how you speak with children about your cancer:

- plan the conversation in advance so that you know what you're going to say
- use direct, simple language and don't go into too much detail at the beginning
- you will be able to go into more detail with an older child but younger children will just need basic honesty within their understanding
- use the word 'cancer' where you can
- you might explain where the cancer is and that you will be taking some strong medicines
- make absolutely sure they know that it is not their fault in any way
- let their teachers or carers know what is going on
- make sure children keep up with their school and social activities
- older children may be embarrassed or angry – try not to let them see if their reactions upset you and allow them to cope in their own way
- ask for help from professionals in your team if you need it
- anticipate questions about the future – try to be honest without being dramatic

PATIENT TIP:

'Give your kids lots of hugs, especially after tough talks.'



Remember ...

that asking for help is a strength. Tell people exactly what you need from them. Your GP, your CNS and all of us here at Fight Bladder Cancer are here for you. **You are not alone.**

What do patients say?

We chatted to cancer patient Mary Lovett about her experience of bladder cancer.



“ Just as my husband’s bowel cancer journey thankfully ended, I was diagnosed with bladder cancer.

I’d had blood in my wee for at least a couple of years and was constantly prescribed antibiotics by my GP, who said it was probably due to the fact that I self-catheterise. However, after a particularly heavy bleed that went on all evening and overnight, I went to A&E, and the young doctor referred me to a urologist. Despite both the urologist and GP saying it was nothing to worry about, I knew something was wrong and argued for a flexible cystoscopy, during which, the urologist identified red patches! Once again I was told this was due to self-catheterising. This rang alarm bells in my head – but not his! What he hadn’t counted on was my determination to get to the bottom of it. I insisted on a further investigation so the urologist agreed to do a TURBT and a biopsy.

The first time cancer was mentioned was when I signed the consent forms for the op and the registrar pointed out that I might need a chemo flush as there was a 95% chance it was bladder cancer. Just what you want to hear before surgery! But I managed to remain calm.

At the first post-op consultation, the consultant was faffing about and as he disappeared to find a colleague, I jokingly said, ‘He’s gone to get a Macmillan nurse!’ Then he returned with a Macmillan nurse! I had to take the initiative and I asked him to get straight to the point and that was when he confirmed it was cancer and the tumour was an aggressive T1, Grade 3 and CIS, which had spread to the connective tissue beneath the bladder lining and had a high risk of progression to muscle-invasive disease. Two days later I started a six-week course of Mitomycin (at the time there was a BCG shortage). I was sure six weeks would do the trick, but another flexible cystoscopy later showed another recurrence. The consultant said he wanted to completely remove my bladder as well as nearby tissues and organs. By this time I had started reading up on treatments and asked for BCG. He was totally against it, but I was adamant that I was not having a radical cystectomy when there were other options to explore. He reluctantly agreed and in total over a period of time I completed the full course of 27 BCGs, which I feel was the right decision for me. I’m happy I made the right choice for me and am currently on watch and wait!

What was your experience of BCG?

BCG is harsh, and has caused many side-effects: bladder spasms, joint pain, flu-like symptoms, tiredness and the much increased frequency of needing the loo, especially through the night, which disrupts sleep. It's not easy for some and can cause many complications, which can have a cumulative effect over the years, as I have found. Yet I still don't regret it.

I think people's perception of bladder cancer is that they don't realise the seriousness of it. I have actually had people say to me that I don't look like I have cancer! Is that why – apart from my husband and daughter, who have been absolutely brilliant – I have never been offered any physical help, not even by close friends or other family members?

I may appear to have a flippant attitude to it all, but that's just how I deal with it. I'm coping reasonably well, but I do get fed up with being told how brave I am. I'm not brave, I'm just not afraid.

I get annoyed when consultants don't acknowledge these side-effects and say the treatments only cause mild symptoms.

What's your advice to people who have problems such as blood in their wee?

- if anyone notices symptoms that could be bladder cancer, act on it straight away
- stand your ground if you feel you are not being listened to and insist on further testing
- if you are diagnosed, join an online support group such as the Fight Bladder Cancer private forum, where you'll meet people who understand exactly how you feel
- it's your cancer, your body, don't let anyone try to persuade you to have surgery or treatments you are not happy with

Where did you find the best sources of support?

I'm so very grateful to the NHS for the treatment I've been given. However, I do feel GPs and other medical staff need more training and should be more proactive when a patient presents their symptoms, and perhaps a little more empathetic when a patient reports symptoms that are not listed in the textbooks.

The support and information I received from Fight Bladder Cancer has been amazing.



My appointments

Date & Time	Location	Questions to ask

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 **regular e-newsletter**
- 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.'



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](https://www.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 service and urgently need more funds, so we rely on the generosity of friends like Mary to support our work.

Listen to what Mary said about FBC:

‘Before I was diagnosed, I knew nothing about bladder cancer. We need much more awareness in the media and among medical professionals so people who are diagnosed can be directed to the best sources of information and advice. I’ve learned so much from FBC – both practical advice and emotional support for myself and my family, because it’s so important that loved ones are not overlooked. I remain positive. Cancer picked the wrong person to fight with when it picked me!’



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.



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

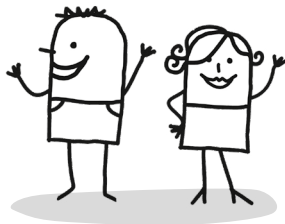
fightbladdercancer.co.uk

via our online forum at

facebook.com/groups/BladderCancerUK

by email at **info@fightbladdercancer.co.uk**

by phone on **01844 351621**



References:

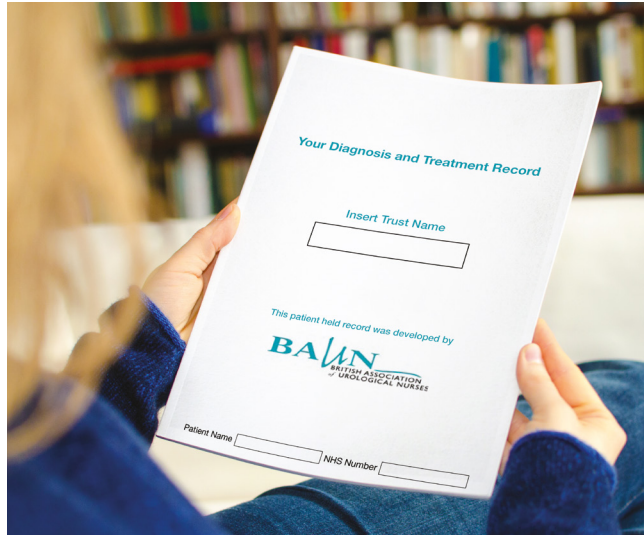
- ¹ Mahon, J., Faraday, M., & McVary, K. (2019). 204 Patient and Partner Satisfaction Rates after Penile Prosthesis Surgery: A Systematic Review. *The Journal of Sexual Medicine*, 16(4), S100-S101
- ² [sciencedirect.com/science/article/abs/pii/S0302283811007470](https://www.sciencedirect.com/science/article/abs/pii/S0302283811007470)

PATIENT TIP:

'I'm on my own but I keep busy. I volunteer at a local garden centre and joined the University of the Third Age. It's hard to tell people but if they are real friends they'll know you are reaching out for support.'

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

Clinical trials

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. Your doctor may be able to recommend a clinical trial that may help your condition.

A clinical trial can be offered at any stage in the bladder cancer journey, from initial diagnosis, through investigations and different treatments to later follow-ups or even the end of life.

Clinical trials in bladder cancer usually compare new treatments with the current standard treatment. Different trials are available in different hospitals, and each one has its own specific eligibility criteria. You can still apply to studies that are not in your area if you meet those criteria and are prepared to travel.

You should always discuss your suitability for a trial with your doctor or medical team, and make sure they are kept fully informed of the progress of the trial.

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



If you have advanced cancer, talk to your doctor and ask them if immunotherapy is available and suitable for your type of cancer.



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.

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 for advanced cancer.

Immunotherapy drugs are synthetic antibodies that effectively 'alert' our immune system to cancer. Some examples of immunotherapy drugs that are currently authorised or in clinical trials for advanced bladder cancer include: atezolizumab (Tecentriq®), pembrolizumab (Keytruda®), nivolumab (Opdivo®), durvalumab (Imfinzi®), and avelumab (Bavencio®). Some of these drugs are authorised by the European Medicines Agency and

funded by the NHS, and some are not.

Targeted therapies are drugs that block the growth of cancers by acting on specific proteins in cancer cells. Some examples of targeted therapies include erdafitinib (Balversa®), enfortumab vedotin and rogaratinib.

Talk to your doctor and ask them if targeted or immunotherapies are available, or offered in clinical trials, and are suitable for your type of cancer.

In order to keep you up to date with the latest developments, we have created a designated page on our website where we post the latest information on advances in treatment. Visit: fightbladdercancer.co.uk/newdevelopments

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. If you wish to view your own data, or to opt out of registration, you can write to the Director NCRAS, Public Health England, Wellington House, London SE1 8UG. More information can be found at ncin.org.uk

My useful information

Hospital number _____

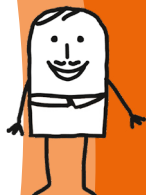
NHS number _____

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

The photos in this booklet are all of patients who have successfully undergone bladder cancer treatment.

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

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British Association of
Urological Nurses

British Uro-Oncology Group



MSD



Roche



MERCK

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