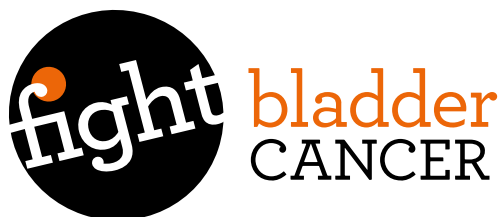


LOW-RISK &
INTERMEDIATE-RISK
**Non-muscle-invasive
bladder cancer**
& your treatment choices





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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.

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THE FIGHT BLADDER CANCER FORUM MEMBERS

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Sophie Maggs | Deborah Major | Paul Major | Dr Lydia Makaroff | Sue Williams**
and our late founder **Andrew Winterbottom**

MEDICAL PROFESSIONALS

With particular thanks to:

Hilary Baker, MSc, NMP, RN, Macmillan Lead CNS for Uro-oncology, University College London Hospitals; FBC Trustee

Dr Alison Birtle, FRCP FRCR MD, Consultant Clinical Oncologist, Rosemere Cancer Centre, Lancashire Teaching Hospitals; Honorary Senior Lecturer, University of Manchester, Secretary British Uro-Oncology Group; FBC Trustee

Professor Jim Catto, MB ChB PhD FRCS (Urol), NIHR Research Professor, Professor of Urology, University of Sheffield; Editor in Chief European Urology; FBC Trustee

Dr Bill Phillips, MBChB MSc FRCGP, GP, FBC Medical Adviser

Jane Brocksom, Lead Nurse for Urology, St James's Hospital, The Leeds Teaching Hospitals NHS Trust; BAUN President 2018–2020

Lucy Bowden, BSc, Urology CNS, Stockport

Heather James, RGN, BSc, Uro-Oncology CNS, Glan Clwyd

Morna Jones, BSc, Lead Urology CNS, East Kent

Laura Noble, BSc, Uro-Oncology CNS, Newcastle

EDITORIAL: Wendy Hobson DESIGN & PRODUCTION: Design Couch

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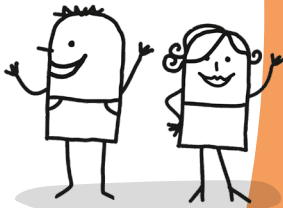
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Our **patient tips** come from **real bladder cancer patients** across the world!



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 low-risk or intermediate-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 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.

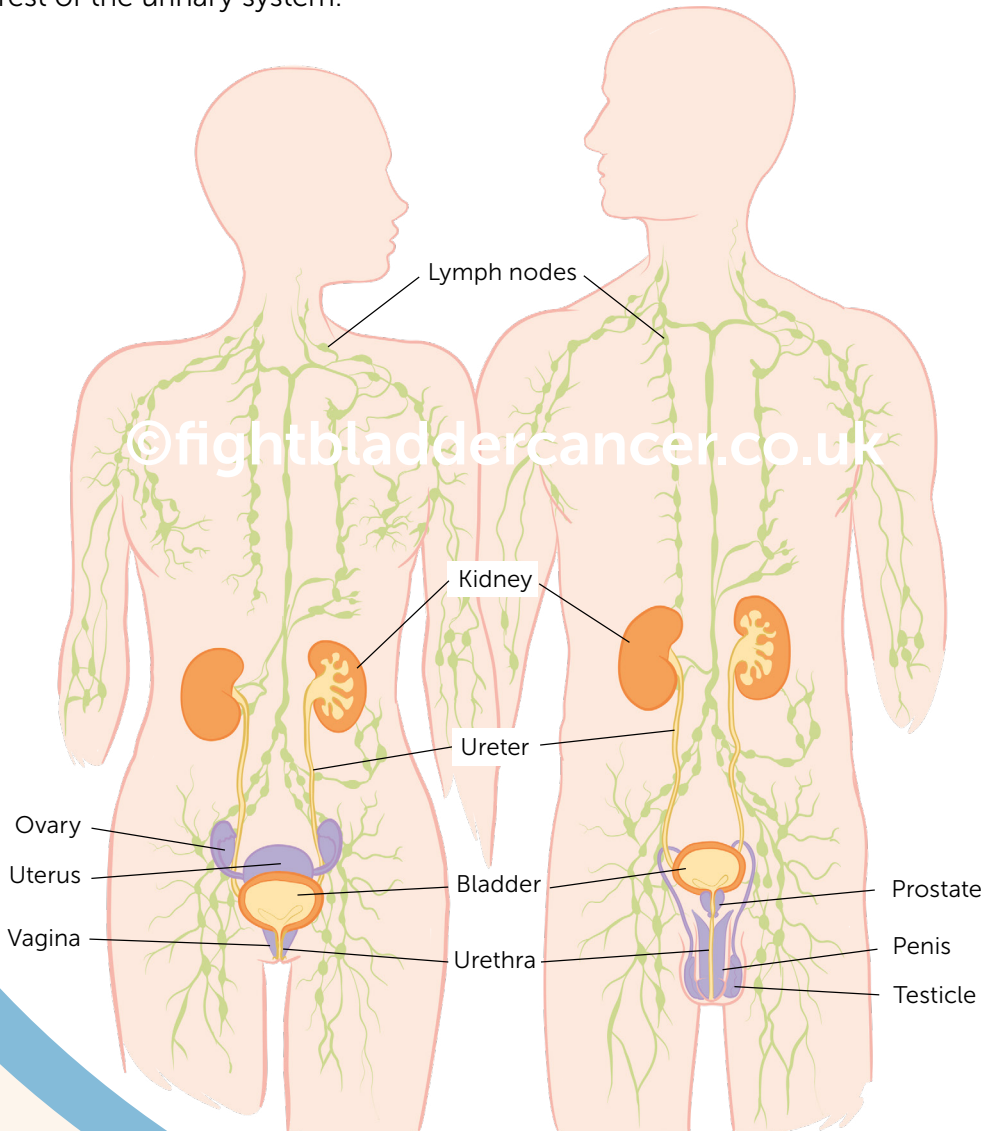
PATIENT TIP:

'Be ready for a heap of emotion but keep focused on the fact that it's treatable.'

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:

'Check out the Fight Bladder Cancer website. The information is much more reliable (and friendlier) than Dr Google.'

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.

Second thing, with low-risk or intermediate-risk non-muscle-invasive bladder cancer, there is every chance that you will be successfully treated. We understand that this may be little comfort at the beginning but it's true. Yes, people do die from bladder cancer but it very much depends on the type of bladder cancer and how aggressive it is.

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

Remember, with low-risk or intermediate-risk non-muscle-invasive bladder cancer, there is every chance that you will be successfully treated.

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. The booklet in this series called *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.

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

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.'

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

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 low-risk and intermediate 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:

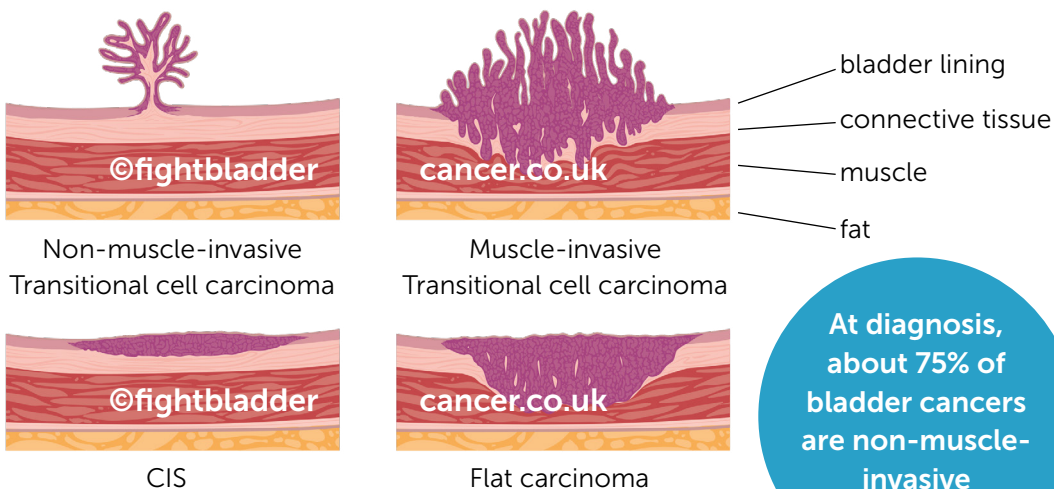
'I have found so many people on the FBC private forum who truly understand what I am going through and have a fountain of knowledge that I can call on.'

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, high or intermediate risk and determine the type of treatment that 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).



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

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

This section deals with all kinds of bladder cancer, but remember that your doctor will be explaining everything that is relevant to *your* cancer, which is likely to be low or intermediate risk.

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

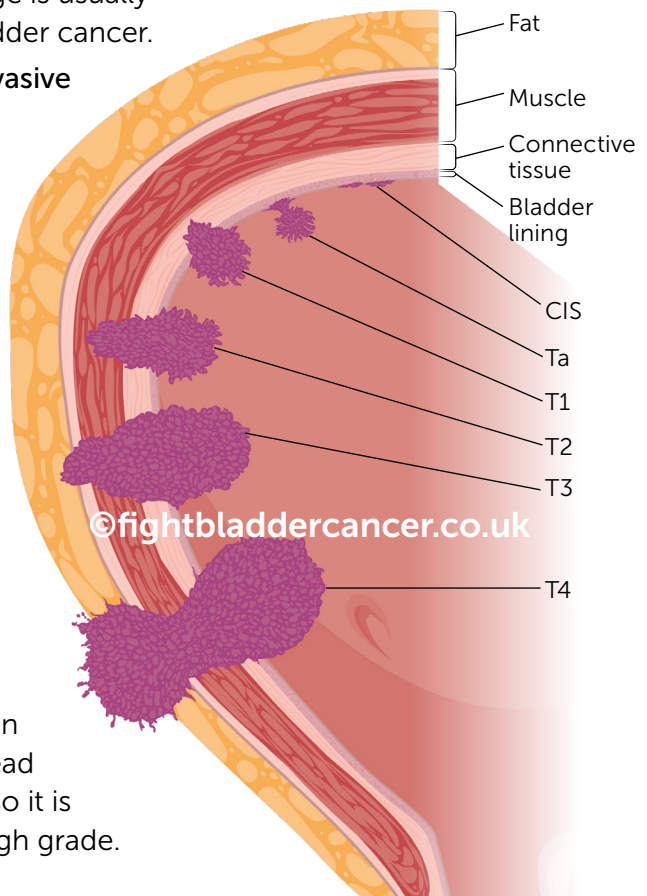
The T stages define how far the cancer has spread.

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.



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.

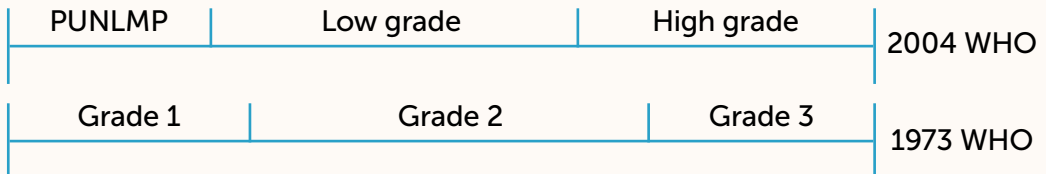
- **G1** / low grade
- **G2** / intermediate grade
- **G3** / high grade

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 is like comparing UK and European shoe sizes; a size 7 can be converted to a 40 or a 41.



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

PATIENT TIP:

'Ask your doctor or CNS to write down what type of cancer you have as it is easy to forget the details.'



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 low-risk bladder cancer are often cared for by a consultant, while those with intermediate-risk cancer are usually looked after 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 urinary tract conditions
- **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. 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 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 NICE², 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 clinical nurse specialist (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 your trust in them and an ability to communicate with them. Never hesitate to ask questions.

PATIENT TIP:

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

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 is the most likely first treatment?

If you have been diagnosed with non-muscle-invasive bladder cancer, your recommended treatment plan will depend on the risk of the cancer returning or spreading beyond the lining of your bladder. This will be discussed with your consultant or at the MDT meeting after the histology and CT scan have been reported.

This risk is calculated using a series of factors, including:

- the number of tumours that are present in your bladder
- whether the tumours are larger than 3 cm (1¼in) in diameter
- whether you have had bladder cancer before
- whether the tumours are limited to your bladder lining, or whether they've started spreading beyond the lining
- the grade of the cancer cells

Deciding what treatment is best for you can be difficult. Your medical team will make recommendations, but remember that the final decision is yours. On the next pages you will find more information about the treatment options for low-risk and intermediate-risk, non-muscle-invasive bladder cancer.

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

!
Low-risk patients are often only followed up for one year.

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 a Transurethral Resection of Bladder Tumour (TURBT). A full explanation of the procedure is given in another booklet in this series, *What is a TURBT?*



If you are low-risk

If your cancer was diagnosed as low-risk, non-muscle-invasive bladder cancer, you may not need further treatment as it is likely that your first TURBT will have removed the tumours.

If your medical team feels that not all the tumours were removed, they might suggest a second TURBT to make sure that none remains.

There is still a risk that the cancer might come back so you will be scheduled for a check-up after a few months when the doctor will examine the inside of your bladder to make sure that you are still clear. Check-ups are likely to continue at about three-monthly intervals for at least a year.

If the cancer does come back, they might repeat your original treatment or suggest trying something different.

Further treatment for intermediate-risk cancer

If your cancer was diagnosed as intermediate-risk, non-muscle-invasive bladder cancer, you may also have a second TURBT, usually followed by what is known as intravesical chemotherapy. The treatment you are offered will depend on what your medical team recommends and what hospital facilities are available. Trials may also be offered to some patients.

Intravesical chemotherapy

The most common option is to follow the TURBT with a course of chemotherapy installed directly into your bladder once a week for six weeks. 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.

PATIENT TIP:

'I still have brief periods of worry before scans, but it doesn't cripple me anymore. Time gave me perspective.'

Some residue of the chemotherapy medication may be left in your urine, so be careful not to splash yourself or the toilet seat with urine because it could irritate your skin. After you have had a wee, you can gently rinse the skin around your genitals.

The advantage of using this type of treatment is that, because the chemotherapy 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 chemotherapy, such as nausea, fatigue and hair loss.

PATIENT TIP:

'If I have any stinging after Mitomycin there are medications to help but with plenty of fluids the feeling does go away.'

Possible side-effects

The most common side-effect of intravesical chemotherapy is irritation and inflammation of the bladder lining. This can sometimes cause a frequent need to urinate and pain when urinating. Many men experience a rash on the skin of their groin and around the penis. These side-effects should pass within a few days. You should inform your medical team if the side-effects become particularly troublesome because additional treatments are available.

If you have sex, it is important that you use contraception while you are having intravesical chemotherapy because the medication that is used can temporarily affect the quality of a man's sperm and a woman's eggs. This increases the risk of birth defects.

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.'

What if my cancer comes back again or changes to be high risk?

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

It is possible that if your cancer comes back that it might be as a high-risk cancer rather than low-risk or intermediate-risk. If this happens it is likely that your medical team will suggest a change in treatment that has a better chance of preventing recurrence or the cancer spreading any further.

Should this happen to you, you will find appropriate information in another booklet in this series, *High-risk, non-muscle-invasive bladder cancer*. Ask your CNS for a copy or contact Fight Bladder Cancer.



If your cancer becomes high risk, then your team may recommend that you have your bladder removed, known as a radical cystectomy or RC. Full details are in *Muscle-invasive bladder cancer*.

PATIENT TIP:

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



Kelly



Gareth

Debs



Brian



Corrina



Ricky



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



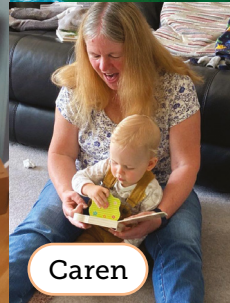
Brian



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.



PATIENT TIP:

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

Darren

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.

PATIENT TIP:

'Mindfulness meditation helps me to feel calmer.'



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 how to 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 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 Malcolm McNinch about his experience of bladder cancer.



What was it like at the start of your diagnosis and treatment?

January 2006 did not signal a happy new year for me. My marriage had recently failed, I had just come out as gay, and I was taken into hospital to have a polyp removed from my bladder. Not a good start; but it carried on going downhill.

I came round from the anaesthetic to find the polyp had turned out to be a transitional cell carcinoma or TCC – bladder cancer – so had been removed. The operation was followed by Mitomycin chemotherapy but at the time my head was just spinning so I didn't have much idea what was going on. Fight Bladder Cancer didn't exist back then and I had no-one to turn to who understood my position.

Regular cystoscopies and frequent trips into hospital were the order of the day. A year after being diagnosed I went through a six-week course of Mitomycin treatments. It was fine at first but eventually I became very tired and had to take time off work. It gave me five years clear though. However, the cancer did come back, and I went through further treatment, but I'm now almost six years clear and things have looked up for me.

What has it felt like to live with bladder cancer?

Lonely. Invisible. Sometimes very, very low. I always felt I had a lower-league cancer and was therefore embarrassed to even say I had bladder cancer. I didn't know anyone like me. I worked out my own methodology and psychology of dealing with things. I would face my tests each year then, if I was clear, lock it away. I never felt I had the right to feel awful or moan, because everyone else seemed to have a rougher deal than me. So, I became invisible just like my cancer seemed to be. I didn't know Fight Bladder Cancer was there – thank goodness I have found it now!



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](https://twitter.com/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 services and urgently need more funds, so we rely on the generosity of friends like Malcolm to support our work.

Listen to what Malcolm said about FBC:

'When I found FBC, it was the first time I could tell my story. That was so important because it stopped me from feeling invisible and enabled me to say to others, "It's okay to feel angry, hopeless and desperate, but it won't last for ever. It hasn't harmed my career; it hasn't taken my life." Fight Bladder Cancer has given me an outlet and helped me get to a better place. I don't want anyone else to walk the lonely road I did. No one should have to feel they are alone. Fight Bladder Cancer has made me feel like I have a story to tell and that story is worth listening to.'



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.



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.

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



There are trials in progress to assess advanced immunotherapy drugs. Talk to your consultant to see whether any might be suitable for you.

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 about any new treatments that are becoming available, or any clinical trials that may be 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

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

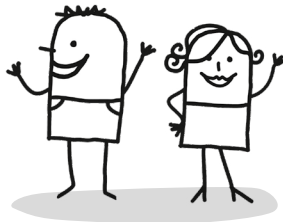
fightbladdercancer.co.uk

via our online forum at

[facebook.com/groups/BladderCancerUK](https://www.facebook.com/groups/BladderCancerUK)

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

by phone on **01844 351621**



References:

- 1 Vecchia, C.L. (2004). Mediterranean diet and cancer. *Public health nutrition*, 7 7, 965–8
- 2 National Institute for Health and Care Excellence (25 February 2015). Bladder cancer: diagnosis and management NICE guideline [NG2] Retrieved from <https://www.nice.org.uk/guidance/ng2/ifp/chapter/Treating-non-muscle-invasive-bladder-cancer>

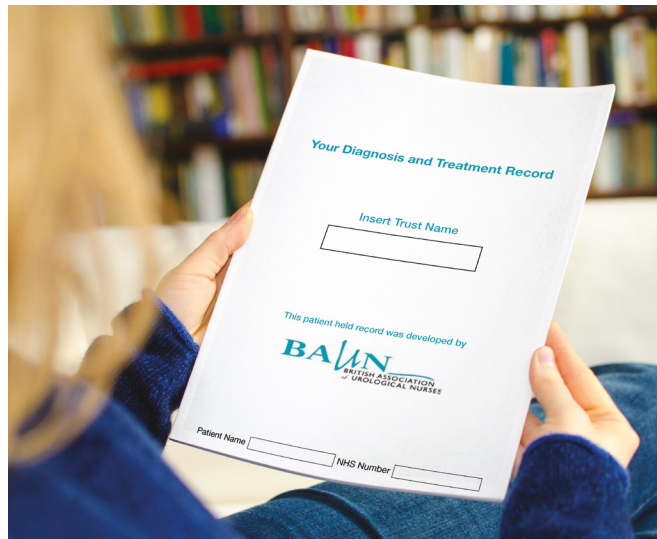
PATIENT TIP:

'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

My useful information

Hospital number _____

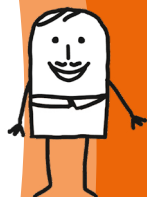
NHS number _____

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

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

Fight Bladder Cancer

51 High Street | Chinnor
Oxfordshire | OX39 4DJ

+44 (0)1844 351621

info@fightbladdercancer.co.uk

fightbladdercancer.co.uk

 [facebook.com/BladderCancerUK](https://www.facebook.com/BladderCancerUK)

 [@BladderCancerUK](https://twitter.com/BladderCancerUK)

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CANCER