

# Muscle-invasive bladder cancer

## & your treatment choices



**A GUIDE  
FOR CARERS  
BY CARERS,  
PROFESSIONALS  
& PATIENTS**

Financial support provided by Merck, the  
Merck-Pfizer Alliance, MSD, and Roche.

*All editorial control has been retained by Fight Bladder Cancer.*



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# YOU'RE NOT ALONE

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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](http://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](mailto:info@fightbladdercancer.co.uk) for more information about how we can support you.

*We're here to help!*

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



### 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)**.

## WITH THANKS TO ALL THE CONTRIBUTORS

### THE FIGHT BLADDER CANCER FORUM MEMBERS

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Sophie Maggs | Deborah Major | Paul Major | Dr Lydia Makaroff | Sue Williams**  
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### MEDICAL PROFESSIONALS

#### With particular thanks to:

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

**Professor 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

**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: [designcouch.co.uk](http://designcouch.co.uk)**

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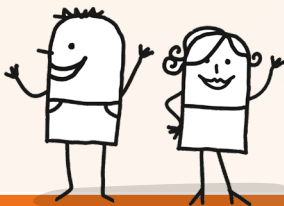
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Our **patient tips** come from **real bladder cancer patients** across the world!



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.

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.

# Hello

You may have recently received a diagnosis of muscle-invasive bladder cancer. It is also possible that you have been given this booklet because your BCG treatment for high-risk non-muscle-invasive bladder cancer has not been successful and your medical team is recommending a treatment more commonly used for muscle-invasive bladder cancer. You may be the patient, or perhaps the partner of the one 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 muscle-invasive 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 support.

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.

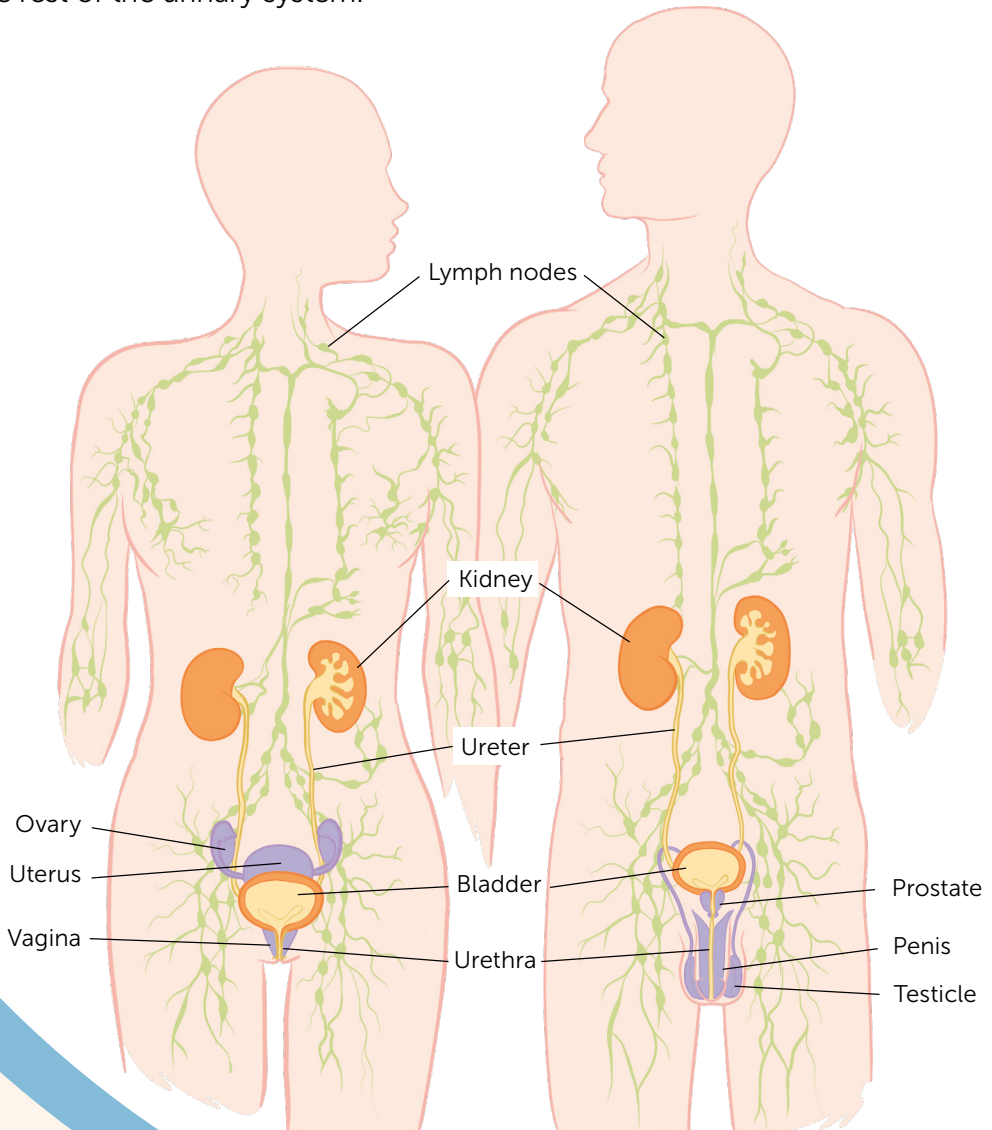
## What is cancer?

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.

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 very 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 are considerable differences 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:

'Definitely stay well away from Dr Google. You will completely freak yourself out, as I did!'

**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 muscle-invasive bladder cancer – 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 it very much depends on the type of bladder cancer and how aggressive it is, and 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.

Don't try to do everything at once – it will just be overwhelming. Pace yourself. Read this booklet a section at a time, for example.

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 the 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 – 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 for a biopsy – an examination of the tissue under a microscope. The pathologist, who specialises in examining tissue, will examine the sample under a microscope

### **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.'**

and confirm the type of bladder cancer and whether 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. 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 type of cancer do I have?
- what do you mean by 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?

As you get more confident and learn and understand more, you will begin to add your own questions to the list.

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:**

'Despite my best intentions, I did Google – and scared myself silly! Joining the forum was a much better idea; the acceptance and support was amazing.'

# 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. Keep asking questions until you understand fully.

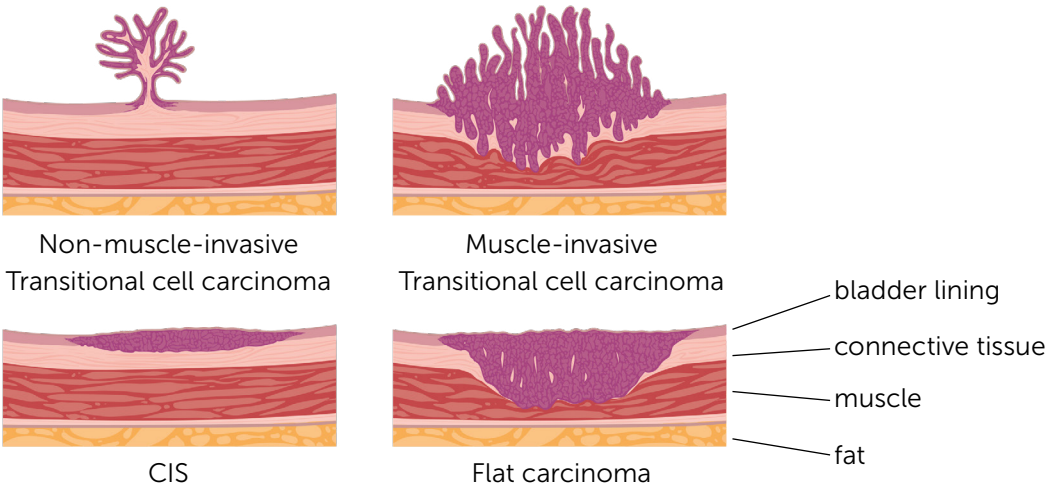


If you have ANY queries about your diagnosis or treatment options then ask your team until you are completely sure.

## 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).



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.<sup>1</sup>



## 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

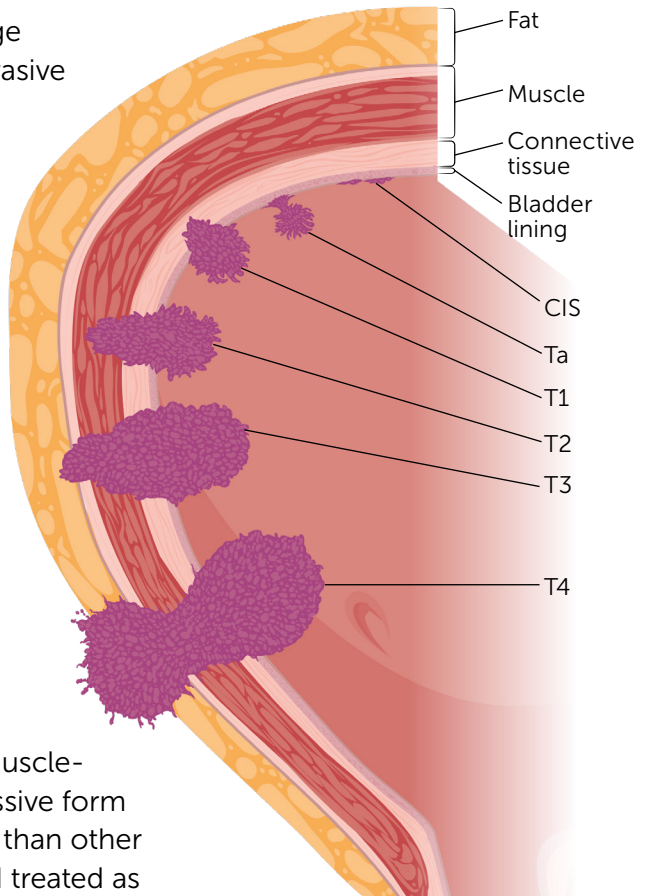
The T stages define how far the cancer has spread.

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 the prostate or uterus)

## 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.'

### PATIENT TIP:

'We all want to know as much as possible about our diagnosis, treatment and outcomes. Searching Google looking for every nugget can also have an adverse reaction, perhaps too much information that may not be applicable can damage your spirits and positive vibes.'

## 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. The number of tumours will also affect the grading.

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.

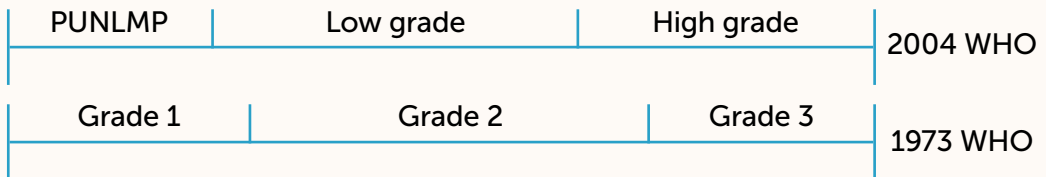
- **G1** / low grade
- **G2** / intermediate grade
- **G3** / high grade

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:

'When I was diagnosed I felt shocked, frightened, angry and so much more. I joined the FBC group with its happy, welcoming staff who always make time for you.'



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 and 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, 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.

### PATIENT TIP:

'My mantra is no decision about me, without me.'



# Choosing the most appropriate treatment

Essentially, the treatment choices for muscle-invasive bladder cancer are between the following three options or a combination of them:

- surgery: radical cystectomy (removal of the bladder) followed by the formation of a stoma or a neobladder
- radiotherapy
- chemotherapy

The choice is yours, depending on the MDT recommendations, although you may find that some doctors strongly recommend one over the other.

## PATIENT TIP:

'I spoke to Fight Bladder Cancer and they explained what the various procedures might entail. They also found me some great people to talk to who had already been where I had. It was such a relief to talk to people who understood.'

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

You will be able to speak with both a surgeon and an oncologist to get the best professional advice, and it is also a good idea to talk with your family and friends, and the other members of your medical team. You should also be able to talk to somebody who has been treated with surgery, someone who has had radiotherapy and someone who has had chemotherapy, so you can find out about their personal experiences, or you can contact Fight Bladder Cancer.



**Muscle-invasive bladder cancer is a high-risk disease because it can multiply quickly and spread to other organs. As part of your decision on which treatment to choose to combat your cancer, you will need to address the difficult question of risk assessment. Every procedure involves benefits and possible complications, and these need to be compared between the treatment options. Discuss this with your medical team.**

# SURGERY

## Radical cystectomy

A radical cystectomy, or RC, is surgery to remove your bladder as a treatment for muscle-invasive bladder cancer. It also involves removing the nearby lymph nodes, part of the urethra, the prostate (in men) and the cervix and womb (in women). It is a major operation, lasting at least six hours.

The team will assess your health and fitness and you will be encouraged to consider your diet, exercise, sleeping and mood to help prepare you for a life-changing operation. This will optimise the chances of a successful outcome. You will always be advised to stop smoking.

You will then be asked to sign a form consenting to the operation.

### Robotic surgery

Some RCs are carried out using robotic surgery. There are no differences in long-term quality of life, cancer recurrence or mortality compared to open surgery. However, robotic surgery may result in more days out of the hospital, fewer wound complications, reduced blood loss, and less pain.<sup>3</sup> This surgery is also useful for some people for whom traditional surgery would be dangerous due to other health issues.

### Why should you have a cystectomy?

The benefits of this operation will be discussed with you in more detail, but your doctor may be recommending this surgery for you for the following reasons:

- you have cancer in your bladder that would be best managed by completely removing the bladder
- your bladder may have developed a tumour after radiation treatment
- your bladder may be bleeding after radiotherapy
- your bladder may be damaged or bleeding uncontrollably from other causes or treatments



Before any procedure, the medical team should explain to you exactly what they are going to do, any risk factors and the likely outcome. You should be able to ask any questions you may have and keep asking until you have all the information you need.



## Risk assessment

### Surgical complications

In general, the bigger the operation, the more likely it is that there will be either general complications, associated with any surgery, or specific complications, relating to bladder surgery in particular. The likelihood of complications depends on how healthy you are and whether you have other health problems, like heart or respiratory disease, high blood pressure, kidney disease, fluid and electrolyte disorders, or combinations of these problems.

Being younger and in general good health will considerably reduce the chance of complications. About 30% of people experience complications, and complications are less likely to occur in people who had surgery in urban teaching hospitals.<sup>2</sup>

#### PATIENT TIP:

'Make sure you find out as much as possible. There is plenty of helpful info online, but be careful that you don't read things that aren't relevant to your situation. Stick with reputable bladder cancer sites.'

Being in good health before you have your surgery will reduce the likelihood of complications

#### PATIENT TIP:

'I was so worried about my RC and any problems, but the nurse explained everything very thoroughly.'

Some examples of possible general complications after cystectomy are:

- digestive system complications (16%)
- disrupted/nonhealing wounds (4%)
- heart (cardiac) complications (4%)
- lung (respiratory) complications (4%)
- urinary complications (3%)

Some examples of possible specific complications after cystectomy are:

- blockage or leakage of the joins in the bowel
- blockage or leakage of the joins between the ureters and the bowel
- injury to the lowest part of the bowel (rectum)
- injury to the bowel (more likely after previous abdominal surgery or radiotherapy to the abdomen or pelvis)



The key worker throughout is your CNS, who will know all about the progress of your treatment.

### 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](http://baun.co.uk/publications/bladder-cancer-patient-held-record)

### Discovery of further cancer

When men have their bladder removed, around 30% are found to have unsuspected prostate cancer. In almost all of these men, the prostate cancer is confined to the prostate gland and, because that has been removed, together with the lymph glands around the bladder and prostate, no further treatment is needed.

### A stoma or a neobladder

If you have a radical cystectomy, your body will still need a way to get rid of your wee. As part of the same surgery as removing the bladder, the doctors will create an alternative way for this to happen and you will need to decide which option you prefer. There are two main ways this is done in the UK:

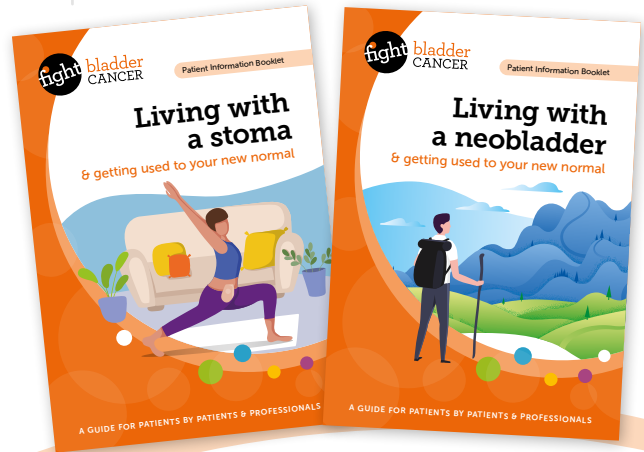
- **formation of a urinary stoma (or ileal conduit)**, where your wee is passed through a channel into a bag attached directly to your body
- **a bladder reconstruction, where a neobladder is made from part of the bowel**; this is emptied via the urethra in the usual way, or by using a catheter that is passed into the pouch

A less common method in the UK is a continent urinary diversion, by which the wee is diverted to the bowel.

It is not always possible to create a neobladder so, on rare occasions, a surgeon may have to decide during the course of the operation to create a stoma instead. It is worth discussing the likelihood of this before your operation.

It's important that you understand what is going to happen during the operation, so please ask questions if you are at all uncertain.

Read the other booklets in this series, *Living with a stoma* and *Living with a neobladder*, for full information on what is involved in each of these choices.



Rebecca  
(5 days post RC)



## How will the surgery affect me?

This is a major surgical operation, and you are likely to be in theatre for between eight and ten hours. There is a long recovery period before you can think of going back to work, but you can be home afterwards from as early as five or six days after stoma surgery or about two weeks for neobladder surgery.

To give an idea of the scale, a radical cystectomy is similar in many ways to a heart bypass so is a much more major procedure than a hip replacement, back surgery or a hysterectomy.

## Preparing for surgery

While you are making your decisions, keep asking questions and speak to as many people as you need to so that you understand your operation and the implications for your life after surgery. Remember that it is a good idea to write questions down before you go to see the surgeon, to help you remember and get the most out of your appointments.

In the days before your operation, your medical team will discuss the plan for your hospital stay with you in detail. They will also let you know what to eat and drink before your admission. Unless you have diabetes, they will often recommend that you have special high-carbohydrate drinks the night before surgery and early on the morning of the surgery. These help restore the function of your stomach and intestines after surgery. If these drinks are suitable for you, you will be given them at a clinic visit to keep at home for just before your surgery.

### PATIENT TIP:

'It is completely normal to feel extremely anxious and worried as you approach surgery day. Do talk to your loved ones about how you're feeling – it helps.'

### 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.'

You'll need to go to your hospital for a pre-assessment appointment, where some investigations and often a check for MRSA are done.

### You should let your medical team know if you have:

- an artificial heart valve
- a coronary artery stent
- a heart pacemaker or defibrillator
- an artificial joint
- an artificial blood vessel graft
- a neurosurgical shunt
- other implanted foreign bodies
- a prescription for an anticoagulant, such as warfarin, aspirin or Clopidogrel (Plavix)
- a previous or current MRSA infection

A CNS will see you, either before you come into hospital for surgery or on the day of your admission. If you are having a urinary stoma, they will mark the place where your stoma will be. If you are having a bladder reconstruction, they will still make a mark. On rare occasions, during surgery it becomes clear that a planned reconstruction is not possible. If this happens a stoma will need to be created for you, so they need to prepare for this.



Before the operation, you will be asked to put on a gown and some tight-fitting stockings, called anti-embolism compression stockings. These help to prevent blood clots from forming in your legs.


## During surgery

You will be given a general anaesthetic and an epidural to help with the pain after the operation. Special drips are placed into large veins and into an artery, so that you can be carefully monitored during and after surgery. You will be positioned very carefully on the operating table to minimise the effects of pressure on your skin. Your breathing is done for you with a machine called a ventilator.

Apart from your abdomen, you will be covered with operating drapes and a warming air blanket.

Throughout surgery, the anaesthetic team will check you very carefully, monitoring your temperature, heart rate, blood pressure and how the breathing machine is working. Blood tests are done during surgery to check on your body's response to the procedure.

You will be given fluid through the drips, to replace fluid that is lost, and a few patients are given a blood transfusion during surgery.



A radical cystectomy is a major operation and takes many hours.



The operating theatre team will check your body position carefully during surgery and move your arms gently from time to time, to help prevent them becoming stiff after surgery. Inflatable boots are used to squeeze your calves very gently at intervals during surgery, to reduce the risk of a blood clot in the veins.

If you are a woman, and have been through the menopause (change of life) and have not previously had surgery to remove your womb, the surgeons will usually remove:

- the bladder
- the womb
- both ovaries and fallopian tubes
- the top part of your vagina

Part of the vagina will be left in place, so that if you wish to be sexually active after the surgery, this should be possible.

### **PATIENT TIP:**

'One of the best tips I was given was to make sure my partner was busy while I was in surgery – rather than waiting at the hospital. It's a pretty long op and time can go very slowly while you are waiting for news, so doing something else is a good distraction.'

If you are a man, the surgeons will usually remove:

- the bladder
- the prostate
- the sperm sacs (seminal vesicles)
- in some cases, the urethra, if disease is present

If the position of your cancer permits, the surgeons may try to preserve the nerves that are involved in producing erections.

These run very close to the prostate, and they usually suffer some damage during the operation. This means that almost all men who have a cystectomy will not have spontaneous, usable erections after the operation. Do talk to your medical team about this in detail before you have surgery, as they will be able to explain the available treatments that may help. There is more information on page 47.

Following the removal of your bladder, your surgeon will either create a urinary stoma or perform a bladder reconstruction. See the booklets in this series, *Living with a stoma* and *Living with a neobladder*.

Find out  
about sex after  
RC surgery on  
page 46.

## Recovery in hospital

After surgery you are most likely to wake up in the recovery area of the operating theatre and be moved to the high-dependency unit for one or two days. The following day you will be moved to the urology ward.

Most patients who choose a stoma will spend from seven to ten days in hospital after their operation; for neobladder surgery, it is likely to be two to three weeks, during which time the staff will carefully monitor recovery.

### Pain relief

If you are in pain, you will not mobilise and will struggle to do any deep breathing exercises. Everyone's pain threshold is different so an acute pain team will monitor your epidural to help ensure that you have very little or no pain, and you can move your legs normally. A few patients need a pump that allows them to give themselves doses of painkilling medication via a drip. The epidural will be left in place for a few days after surgery, and then replaced by other painkillers.



**If you do not have enough pain relief, ask for more.**



Lorraine



Alistair

### PATIENT TIP:

'When you wake up after your operation there will be a lot of tubes and machines attached to you – don't panic – these are completely normal and will be removed as you recover.'

### Nutrition

You should be offered at least three special nutritional drinks a day, in addition to a healthy balanced diet, to help combat the loss of weight and muscle that can follow surgery.

### Exercise

The nursing staff and physiotherapists will help you to get out of bed and start moving as soon as possible. This will reduce the risk of blood clots forming in your legs and lungs, and will also help to prevent chest infections and encourage your bowels to start working again.

Walking is an important activity following your operation, and you will be strongly encouraged to walk as much as and as soon as possible afterwards, with at least three walks a day, gradually increasing the distance each day as you recover from the surgery. The nurses and physiotherapists on the ward will help you become more independent, rather than lying in bed all day, even though this may seem daunting at first.

Being upright and mobile helps your body to get back to 'normal business' and helps to reverse some of the changes that happen following such a major surgery. Before you are ready to go home, you will be expected to be able to walk at least 100 metres and climb one flight of stairs. This means getting moving quickly after surgery. Many patients walk a good deal further than this.

This exercise will also require you to rest well in between, so a mixture of resting in bed and walking is a good combination.

### Blood circulation

You will continue to wear the compression stockings to encourage the blood to drain from the legs, and will have daily injections to make the blood less likely to clot. These injections should be continued for 28 days after surgery. Your team will teach you how to do this when you are on the ward, so that you can give yourself the injections after you go home. You should also wear surgical stockings for 28 days after surgery, so you'll need two pairs – one to wear while one is washing.



**Deep breathing exercises are important and should be done three times a day. While you are in bed, rotate your ankles three times in each direction and also slide your legs up and down the bed three times every hour.**

#### **PATIENT TIP:**

'Regular gentle walks really helped me during the time I was in hospital. Although initially I was exhausted after walking to the end of the ward – within a few days I was much improved.'



## Bowel function

Being more mobile will also encourage your bowel to start working, which normally takes a few days. During this period you will need to find a balance between eating and drinking enough to regain your strength, but not overfilling your stomach, which may make you feel sick.

One sign that the bowel is starting to work is that you break wind or start burping. Although it is not something that is generally discussed outside hospital, it is



a simple and helpful indication of how the gut is working, so you will need to get used to talking about this delicate matter after your operation!

It may take three to six months for the bowels to get back to normal after surgery<sup>4</sup>. Five to ten percent of people find that their bowel habits change permanently after surgery. If this does happen, typically the bowels will work once or twice more each day than before, and the stools may be a bit looser.

### PATIENT TIP:

'It can be tricky and sometimes uncomfortable when your bowel starts to function again post op. Beware farts too – as sometimes it's not just air trying to escape! Don't feel embarrassed if you do have an accident.'

## Managing your bladder substitute

While you are on the ward, the nurses will help you to get the hang of how to look after your stoma or neobladder. Although it will be very unfamiliar at first, you will quickly learn how to manage it. The specialist urology nurses and the urinary diversion or stoma nurses will help whilst you are on the ward and in the clinic afterwards. Read the other booklets in this series, *Living with a stoma* and *Living with a neobladder*, for more information.

## Recovery at home

When you leave hospital, it is usual to feel tired. Your body will continue to react to the surgery for several weeks. Also, in hospital, the ward staff will have been playing a big part in your care. Even small tasks at home, like going to get yourself a drink, will seem to be more of an effort than usual.

Your physical recovery will progress in the weeks that follow your surgery, although this may be in fits and starts rather than a steady improvement.

You may have bad days where it feels as if things are getting worse rather than better, but this is not usually a sign of a problem. It is important to try not to get downhearted. Your energy, appetite, how food and drink goes down, how your bowels work, how you sleep and your mood, will all get better over time.

When you get home, you will need to ensure that someone is able to accompany you out of the house every day, increasing your walking distance each time as much as you can manage, so that by two or three weeks after getting home you are walking at least half a mile each day, and preferably more. Many patients find that after their operation they are walking further than they have done for years, and feeling much better for doing so. Some patients come back to clinic a month after their surgery and are walking two or three miles each day.



After a quick start, it is normal for recovery to slow down and be more gradual.

### PATIENT TIP:

'I've started doing things to improve my health further, improving my diet and exercise. Being in the fresh air in the morning makes me feel so alive and ready to face anything.'

Keith



## Recovery milestones

The following are important recovery milestones:

- **heavy lifting:** for six weeks after surgery, avoid lifting anything heavier than a full kettle
- **recovering your energy:** your energy should be returning by six weeks
- **driving:** you should be able to gradually return to driving from six weeks – your wound will need to be checked first, and you should feel confident that you can make an emergency stop. We recommend that somebody accompanies you when you first return to driving

## After-effects of surgery

Any major surgery will mean changes for your body and can affect how you feel about yourself. This is completely normal, and we can help. Your CNS can also give you advice and answer questions.

Don't forget that there are hundreds of other patients on our **online forum** who have been through this surgery and can answer your queries, or we can put you in touch with someone through our **Bladder Buddy** service.

It will also be helpful to talk to your partner, a family member or a friend about the after-effects of surgery. As well as helping them to understand more about how you are feeling, it can also provide you with extra reassurance and give you more confidence as you prepare for your operation.

## Your new way of weeing

You will get plenty of help and support in order to familiarise yourself with dealing with a stoma or a neobladder. Other booklets in this series, *Living with a stoma* and *Living with a neobladder*, will give you all the basic information and a member of your medical team will show you all the procedures you need to know. As with anything, don't be afraid to ask questions. You may feel a little embarrassed at first but there is no need and you will soon get used to the new system as part of your normal routine.

**Full recovery after RC is likely to take from three to six months. If you had chemotherapy before your surgery, you can expect the recovery to be around six months. By this time most people will have returned to their normal activities without feeling more tired than usual.**

# RADIOTHERAPY

## What is radiotherapy treatment?

Radiotherapy can be an alternative treatment option for muscle-invasive bladder cancer and it is seen to be as effective as surgery for most people.<sup>5</sup>

It uses a type of external x-ray treatment that uses carefully measured doses of radiation to destroy cancerous cells and therefore shrink tumours in order to achieve a cure. It is given by a machine that beams the radiation at the tumour cells in the bladder. These abnormal cancer cells are more sensitive to radiotherapy than normal cells and will be destroyed.

Sessions of external radiotherapy for bladder cancer are usually given on a daily basis for five days a week, over the course of four to seven weeks, each session lasting for about 10 to 15 minutes, although the number and frequency of radiotherapy sessions will depend on the extent, size and type of the tumour. Radiotherapy is often preceded by chemotherapy into the veins to improve the overall results of treatment.

The likelihood of success with radiotherapy treatment is the same as cystectomy in terms of the chance



When radiotherapy is used to treat muscle-invasive bladder cancer it is very important that female patients tell their oncologist immediately if they suspect they may be pregnant.

to be cancer free. It tends to be preferred over surgery for patients who have other health problems or who are older and therefore the risks associated with surgery are greater. Many younger and fitter patients, especially those with good bladder function, choose radiotherapy both because the results are comparable with surgery, and the treatment is carried out as an outpatient and many patients carry on with their normal activities of life during the course of treatment.

### Palliative radiotherapy

Radiotherapy can also be used to help control the symptoms in cases of incurable bladder cancer; this is known as palliative radiotherapy. This is given in between one and ten schedules and may be given either on a daily basis for one to two weeks or once a week.

## Planning radiotherapy treatment

Designing the radiotherapy treatment specifically for you is very important and ensures that the radiation can be applied as accurately as possible, resulting in the maximum benefit. It is similar to having a designer outfit or suit made – you would want the pattern and finished product to fit you uniquely, and that is what happens with the planning scan, which is usually a CT scan done in the radiotherapy department. This is completely different from the other scans you will have had to diagnose the extent of the cancer, so please do not think this is a duplication.

CT scanners and simulators are used to help define the exact area to treat and x-rays are taken as a permanent record of treatment.

During the procedure, the radiographers may draw some marks onto your skin. The radiographer will ask your permission to make some of these marks permanent – using a small needle. These tiny permanent marks, together with the measurements taken, will ensure

the pinpoint accuracy of your treatment.

The planning scan appointment usually takes between 20 and 60 minutes. When you are being given the permanent marks you may feel a slight scratch but otherwise the process is painless. It is important that you lie as still as you can throughout the procedure.

At the end of this appointment you will receive the date and time of your first radiotherapy session. You will be given the rest of your dates and times when you attend that session. Your treatment should start as soon as possible, but some treatments require detailed planning and take longer to prepare.

### PATIENT TIP:

'I found planning for my first session of radiation therapy the most anxious time. It was so new and unfamiliar. Now I am in the swing of treatment it is all matter of fact and I'm not at all worried.'

## What happens during radiotherapy treatment?

On your first day, the radiographers will explain what is going to happen when they take you into the treatment room. The treatment machines are quite big, and you may feel anxious, but remember, the treatment is painless.

You may be asked to do what is called bowel prep before radiotherapy. This usually consists of gentle laxatives given by mouth or as a preparation up the bottom to help empty the bowel better before treatment. You will probably also be asked to empty your bladder as much as possible.

The radiographers will help you onto the treatment couch and into the correct position using the measurements and marks from the planning appointment. It may be necessary to remove some clothing to see the treatment area and permanent marks.

It is important to remain very still throughout your treatment, but be sure to breathe normally. The radiographers operate the machine from outside the room, so you will be left alone during this time. Most machines make a noise when they are operating, so you will know when they are switched on.

Radiographers monitor you on a CCTV system. If you need the radiographers during this time, raise your hand.

Treatment times are usually very quick, about two minutes, but each session is about half an hour getting you in the right position for treatment. You will only be alone in the treatment room for a few minutes.

### PATIENT TIP:

'I found it very helpful to deal with my sessions by going into a kind of meditative state.'

### What happens when the treatment finishes?

Before you finish treatment, you will receive some personalised advice on how to manage any side-effects following treatment. You will also be given a contact number should you experience any difficulty or are worried for any reason following your course of radiotherapy.



**PATIENT TIP:**

'Take warm things – woolly socks and a hat, because it can be very cold in the treatment rooms.'

## Possible side-effects of radiotherapy

Normal cells can be damaged along with the cancer cells, which is why there are potential side-effects, as with any treatment.

Side-effects can occur during and after radiotherapy (early reactions), which usually occur during the second half of a course of treatment, and can last for some time after the treatment is finished. Several months later, late reactions can occur which may or may not be permanent.

- **early reactions include:** fatigue, sore skin, bladder problems, bowel problems
- **late reactions include:** fatigue, bladder and bowel problems, sexual issues, dietary issues

Everyone will react differently to radiotherapy, so please ask the radiographers if you are unsure about anything. You should be given a booklet with specific side-effects common to your treatment area, and how to manage them.



Always make sure you let the radiographers know exactly how you feel and whether you experience any side-effects.

Find out more about the most common side effects from radiotherapy on pages 32–34.



### PATIENT TIP:

'Pace your activities throughout the day and plan frequent rest periods to minimise the fatigue.'

### Fatigue

As radiotherapy can damage normal tissues close to or in the treated area, your body will use a great deal of energy to repair these damaged cells. This means that tiredness is a very common side-effect of radiotherapy. If you feel fit enough, gentle exercise can help. Do not force yourself to do things you do not have the energy to do.

### Sore, red skin (erythema)

Radiotherapy can make the skin in the treated area itchy, red and sore, especially early on. It is usually a good idea to use a moisturiser such as Aveeno and to let the team know if your skin starts to become uncomfortable in the treated area. Never use a cream without checking it is safe to use with radiotherapy.

### Infertility

One permanent side-effect of radiotherapy is infertility so if you still want to have children, discuss possible treatment options with your medical team before your treatment begins.

For example, men can have their sperm frozen and women can have their eggs frozen for use in future artificial insemination treatments or IVF. This will not be possible for women who have a radical cystectomy because their womb will be removed.

External radiotherapy is painless and will not make you radioactive, nor will you pose any danger to other people, including children and pregnant women.

### Second malignancies

Compared with someone who has never had radiotherapy to the pelvis, you stand a small increased risk of developing another cancer, caused by the radiation, in the years to come.



## Bladder symptoms

You may experience changes in the flow of your wee, a need to wee more often or more urgently, a burning sensation when you wee and/or a small amount of blood in your wee. Your consultant may be able to prescribe you something to help with these symptoms.

Drink plenty of water-based fluids such as cordial, at least eight mugs a day. Tea and coffee can make the symptoms worse so try decaffeinated. Some people find cranberry juice helpful.

## Bowel symptoms

**Please do not modify your diet or take any medication for your bowels without discussing it with a radiographer or consultant.**

Radiotherapy treatment may irritate your bowel and make you go to the toilet more often. You may develop *tenesmus*, which is an urge to open your bowels without passing anything. This can feel like constipation.

You may also notice an increase in the amount of wind you pass.

The doctor may recommend medication such as Fybogel, to regulate your bowel movements. The doctor should also explain the importance of dietary fibre.

### PATIENT TIP:

'I drank peppermint tea to ease my abdominal pain. Short walks helped ease my symptoms too.'

- **foods containing soluble fibre soften the stools and absorb water as they move through the body.** Examples are fruits, vegetables, pulses and oats, which you should include in your diet
- **foods containing insoluble fibre increase the speed at which food moves through the body.** Examples are wholegrain cereals and wholemeal bread. Avoid these foods whilst you are experiencing diarrhoea

If opening your bowels becomes painful or you notice some spotting of blood, let your medical team know. These side-effects are not uncommon so do not be alarmed.

If you are having problems with excessive wind and bloating, you might find it helpful to cut down on peas, beans, lentils and cabbage. You should avoid carbonated drinks.

### Dietary issues

It is important to eat well and maintain your weight whilst undergoing radiotherapy. There are a number of dietary tips that can help.

- try to eat small frequent meals and snacks
- maintain a good fluid intake. It may be helpful to limit hot drinks and include more cold drinks, but avoid alcohol
- choose foods which you enjoy and find easy to swallow
- don't worry too much about having foods that are low in fat and sugar for the time being (unless you have another medical condition)
- some people find that including live yoghurt in their diet can help with diarrhoea
- check with a dietician or chemotherapy nurse if you are also having chemotherapy

Especially if you experience nausea when eating, try to eat small amounts, little and often. Some people find that food and drink containing ginger helps with nausea.

You may also find another booklet in this series, *Diet and nutrition for bladder cancer patients*, of interest.

**Avoid smoking** which can prevent your body from repairing itself.

**Avoid drinking alcohol**, especially spirits, which can irritate your mouth and make it sore.

**Avoid food that is very hot, spicy, acidic, hard or crunchy.**

It may be necessary to move to a softer, more liquid diet in some cases.

#### PATIENT TIP:

'Avoid fatty, spicy or fried foods as well as rich sauces. Plainer food like mashed potato was my go to.'

#### PATIENT TIP:

'I was careful with food preparation and didn't eat raw or undercooked food while on my treatment.'

Try and maintain a healthy, balanced diet as you go through treatment and maintain your weight

# CHEMOTHERAPY

## Types of chemotherapy treatment

This section is about chemotherapy treatment injected into the bloodstream. These treatments, which can also be called systemic chemotherapy, reach all areas in the body that have a blood supply.

The doctor may be able to give you information on the improvements expected from each treatment in your individual case. Remember when you are quoted statistics that they apply to a group of patients, some of whom may do much better than the average, and some who will do not quite as well.

### Neoadjuvant

Chemotherapy is often given before radiation therapy for muscle-invasive bladder cancer and also before radical cystectomy. This is called neoadjuvant treatment, meaning before the main treatment. Neoadjuvant chemotherapy in suitable patients has been shown to improve survival<sup>6</sup>.



You are an individual patient so there are no hard-and-fast guarantees.

### Concurrent

Concurrent chemotherapy is given alongside radiotherapy to make the cancer cells more sensitive to the radiotherapy. This can include giving it alongside treatments 1 to 5 and 16 to 20 of radiotherapy, usually using a combination of drugs given through a special drip called a PICC line so the drugs drip into the system 24 hours a day for five days. All this can be done while you are going about life as normal and you do not need to be in hospital.

Doctors can use a treatment called BCON. This involves taking nicotinamide vitamin tablets before radiotherapy and breathing carbogen (high-dose oxygen) throughout the treatment, which makes the cancer cells more sensitive to radiotherapy. Your doctor will give you more information about this if you are suitable.

### Adjuvant

This form of chemotherapy is additional to the main treatment, such as an RC, to try to reduce the chance of the cancer returning. This is not usually given if you have had neoadjuvant treatment.

Your oncologist should give you a detailed patient information sheet. Read it carefully and share the information with family members, friends or a Bladder Buddy to make sure you have understood everything correctly. Write down any questions that you have to ask the medical team.

It is also worth buying a thermometer and practising so that you can take your own temperature accurately. You will then be able to monitor your temperature during any chemotherapy treatment if you feel unwell in any way as a raised temperature can indicate an infection.



#### **PATIENT TIP:**

'The chemo nurses were always there at the end of the phone line with help and reassurance 24 hours a day.'

### Palliative

This means that your medical team cannot cure the cancer but can give you treatment to improve symptoms and extend life – hopefully of good quality. It does not mean that you are terminal. Doctors use the phrase terminal to mean someone for whom there is no treatment available that targets the cancer.

## What happens during chemotherapy treatment?

Chemotherapy is usually given in blocks of treatments with a rest in between cycles to allow the body to recuperate. The number of treatments and the timing of the gaps will vary for different people.

The treatment is usually given at a day care chemotherapy unit. For your first few treatments you may prefer to ask for a side room, if that is available, but sometimes people find that the camaraderie you establish with the other patients is positive.

The chemotherapy drugs will be administered by injection or an intravenous drip, or sometimes by tablet.

You will be able to take someone with you to the sessions and you should make sure someone can drive you there and back.

### PATIENT TIP:

'Take water and strong-flavoured sweets to your chemo session, plenty of reading material, crosswords, music and something to wrap up in if it's cold, layers if it's warm.'

### PATIENT TIP:

'I always found the chemo chair comfy, but the chair for your partner may not be as comfortable, so if possible take a cushion with you.'

### PATIENT TIP:

'Take a small blanket or a fleece as your temperature may change during treatment.'

### PATIENT TIP:

'Have a couple of glasses of water before you go for chemo, and keep your hands warm on the way there. You could lay a hot water bottle or a wheatybag on your arm if it's cold weather as it makes it easier for the nurse to find a "way in".'

## Possible side-effects of chemotherapy

There are a number of potential side-effects of chemotherapy:

- **risk of infection** because the drugs reduce natural immunity
- **infection** could cause a high temperature and generally feeling unwell
- **bruising or bleeding** because of the effect of the drugs in reducing the bone marrow's capacity to make platelets
- **anaemia** because the bone marrow is not making sufficient red blood cells
- **nausea and vomiting**
- **sore mouth and gum infections**
- **hair loss**, depending on the drugs administered
- **fatigue**



**Talk to your chemotherapy team about how best to deal with possible side-effects.**

**Our private online forum members came up with their best tips for coping with chemotherapy side-effects:**

'Download some boxsets or settle down with Netflix. Put your feet up and just chill.'

'I tolerated room temperature food much better than hot during treatment.'

'During chemo, I liked sweet or sharp food; things with more flavour helped mask the metallic taste in my mouth.'

'My anticipation and worry were worse than the actual treatments. Try not to let your mind run wild with disastrous scenarios. Thinking positively changed my experience.'

'Because of my sore mouth and metallic aftertaste I found water was more tolerable with a small squeeze of lemon.'

'Soups are all easy to digest but full of goodness and calories.'

'I did get very tired and had rather a foggy brain. Get plenty of rest, take it one day at a time – you will get through it.'

'Jigsaws are a really good distraction – you can dip in and out of them, they aren't too taxing but give you a sense of doing something.'

'We all worry about the future at times. Don't let things get out of hand; never be afraid to ask your GP for help with depression.'

'Chemo can make you really sensitive to everyday smells so you may find smells you usually love become unbearable. Buy unscented toiletries until after treatment.'

'During long chemo sessions I take lots of little snacks. I need bits for the first half of treatment but don't want anything by the end of it, so definitely eat while you can.'

'When you go to your chemo session take a good book and a good sense of humour.'

'If you still feel sick despite your anti nausea meds then talk to your team – sometimes a switch to a different drug is all you need to get rid of the nausea.'

'A small amount of exercise every day helped limit my side-effects and made me feel more positive throughout treatment.'

'For a sore mouth and ulcers I sucked ice cubes and ice pops. Also using a child's toothbrush which was softer and smaller helped.'

'Sleep when you need to, have "nana naps" throughout the day, and don't be afraid to tell friends you're too tired for visits.'



# Telling people you have cancer

Breaking the news that you have just been diagnosed with muscle-invasive 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:

'The forum is a great source of comfort in what is the most distressing chapter of my life.'

### PATIENT TIP:

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

## 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
- 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!

## Controlling anxiety

You are struggling with a serious health condition so you are bound to feel all kinds of emotions, which are likely to vary from day to day. Going back for regular check-ups in itself can be stressful so allow yourself some leeway to come to terms with your emotions.

Most people find it helpful to understand what is going on, so keep asking questions, and talk to people in our private online forum who know what you are experiencing. Also take someone with you when you go for your check-ups. This not only gives some support but it is very hard to remember everything that is said at a consultation and a second person can make some notes or may remember some useful details that you had not grasped.

### PATIENT TIP:

'Please don't just survive, but live your life to the fullest. Do whatever you want to when you can.'

You can also talk with your companion beforehand about any questions you want to ask and they can help you remember the answers afterwards.

There is no right or wrong way to deal with anxiety – find your own coping mechanisms.

Everyone will have both good and bad days when coping with cancer. For the most part, talking about how you feel, indulging in something you enjoy, having a massage or a treat can help to get you back on an even keel.

Things you can do to help include:

- talk to friends, online support or professional counsellors
- join a Fight Club or other support group
- post on the FBC forum
- follow whatever spiritual direction helps you, be that humanist, religious or spirituality in another form
- take up offers of practical support to reduce your physical workload
- research more information about your condition and the options open to you
- eat well
- get plenty of sleep and rest regularly during the day
- socialise as much as possible – but don't wear yourself out!
- slow down
- keep up with hobbies such as drawing, dancing or sport
- accept that you may have to make changes in your life
- keep a diary and focus on all the positive things every day
- learn relaxation techniques

**PATIENT TIP:**

'To help relax, there are some great apps you can download on your phone that help you practise your breathing any time you need'

**PATIENT TIP:**

'Being busy helps distract my mind away from stress and worrying. My hobbies – painting or learning to play an instrument – can free my mind from worry.'

**If it becomes overwhelming**

If you are still feeling overwhelmed, unable to cope, are not sleeping, eating, or just feel like you cannot carry on and worry is seriously affecting your life, you may need more help. It is quite common for people to have counselling after cancer treatment. This is a way of exploring more deeply what is worrying you and helping you come to terms with it. Talk to your doctor if you would like this help.



Talk to friends, call your CNS, your GP, or get in touch with our private online forum and be guided to find the help you need.

# STOP SMOKING



If you did not know before, you have almost certainly been made aware that smoking has probably contributed to your cancer and may adversely affect any future treatment. Especially if you reach for a cigarette at times of stress, giving up will not be easy. However, it is the best course of action so please talk with your CNS or your GP, discuss your specific smoking habits and hatch a plan to give up, or at least to cut down your smoking.

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 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:**

'Your quality of life is important and giving up will really contribute to a healthier lifestyle.'

## **PATIENT TIP:**

'This could be a challenge for you, but giving up smoking will give you the best chance of a better outcome.'

**Get everyone  
onside to help  
you.**



## 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

### PATIENT TIP:

'Mindfulness and meditation helps me 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.





## Let's talk about sex

Whatever treatment you have had, and especially for those who have had a radical cystectomy, the procedures will almost certainly affect your sex life and it is important that you are aware of this and understand that there are plenty of things you can do to re-establish your sexual relationship.

The most likely things you may experience are:

- loss of libido
- men: inability to achieve or sustain an erection
- women: vaginal dryness, shortening of the vagina

First and foremost, don't be embarrassed to ask for help. Your GP, CNS and consultants are dealing with it all the time and will be happy to help you to deal with the issue.

## Self-image and loss of libido

Whatever physical issues you may encounter, having major bladder surgery will almost certainly affect the way you feel about your body and it can have a dramatic effect on your emotions. This starts with the loss of dignity accompanying many of the investigations and treatments but try to view them as necessary and a means of restoring your health. Take photos when you are feeling good to remind yourself when you feel down that it's not all bad.



**Don't be embarrassed to ask your medical team for help. A good sex life is important and there are many treatments to help if you are having problems after bladder cancer treatment.**

Not feeling good about yourself very often leads to a lack of interest in sex. Don't ignore it. Try to talk with your partner openly about how you feel and make time for some tender moments that start to re-establish your connection. Sex is not the only way to communicate your love for someone.

Counselling is available via your GP or consultant so seek help and find an expert to discuss your problems with and that will be the first step towards normalising your sexual relationship.

**PATIENT TIP:**

'Don't be put off by any of the treatments offered. Try them all until you find the one that is right for you.'

**PATIENT TIP:**

'I wondered if I was ever going to be a "man" again. How wrong I was. Life is different but with additional treatment for ED I am enjoying every day.'

**PATIENT TIP:**

'Our first step after treatment was being intimate with each other – after that everything fell into place.'

## Men

On the physical side, erectile dysfunction can be a consequence of any bladder cancer treatment, but it is easy to diagnose and there are many remedies, one of which is likely to be suitable for you. Your doctor will advise which is the best option to try first, but don't be discouraged if you have to try more than one option before resolving the issue.

The main options are:

- **PDE5 inhibitors in the form of tablets**, such as Viagra® and Cialis® are available over the counter in the UK, although you should always discuss any medication with your GP or consultant
- tablets used successfully in combination with **vacuum devices**, although in some areas these devices are no longer available
- **treatment through injection** or a pellet gently inserted into the tip of the penis, or a cream called alprostadil are other often-successful treatments
- if none of these works for you, there is the option of a **penile implant**. It involves major surgery but results in 86% satisfaction rates for both the patient and their partner<sup>7</sup>

**PATIENT TIP:**

'Yes, things have changed but our first simple solution was more cuddles and holding hands.'

**PATIENT TIP:**

'Don't be put off by the sound of some treatments. I needed to inject my treatment into my penis – but it was fine and I didn't feel a thing.'

Although your specialist may make recommendations, for many men it takes trying a few different types of Erectile Dysfunction treatments to find the best option for you.

## Penile implants

Discuss the options with your medical team so that you have all the information you need. Procedures are performed in hospital under a general anaesthetic, with its associated risks.

The first option is malleable implants: two semi-rigid rods which are inserted into the penis. There are no additional components and therefore the risk of device malfunction is low, but some patients do not like the idea of a penis remaining rigid all the time.

The most commonly used implant is an inflatable penis prosthesis as it is concealed when not in use and mimics a natural erection. It consists of two inflatable silicone cylinders and a pump, which is placed in the testicles. When inflated, fluid moves from the reservoir into the cylinders, then returns when deflated.

**PATIENT TIP:**

'After my implant surgery my penis was enormous, inflated and swaddled in a heap of bandages. By my three-week check up, the nurse watched me inflate my penis – a bit strange but looking good, given that it had reduced from its Frankenstein proportions. Op day plus ten weeks – I am smiling! Now I know why this procedure has such a high satisfaction rate. It just felt normal!'

## Women

Women's sexual problems may be emotionally charged and counselling is sometimes needed. Physical issues may take less time to solve than the restoration of your sexual desire, as this is often so bound up with self-image.

Chemotherapy, radiotherapy and particularly surgery will have effects on your sex life, in particular:

- any treatment can lead to loss of libido and vaginal dryness
- surgery is likely to lead to a shortening of the vagina, making penetrative sex painful or difficult
- damage to the nerves and muscles during surgery can make the genital area less responsive, especially if the blood supply to the area is compromised
- having your ovaries removed will bring on menopause if you haven't already reached menopause

### PATIENT TIP:

'Pelvic floor exercises and relaxation helped me in achieving better stimulation and sensation.'

### PATIENT TIP:

'I found that if I was feeling anxious due to my cancer, I found it impossible to feel sexually aroused. Counselling really helped me get through it.'

The main treatments are:

- **hormonal cream** to increase moisture
- **using a vaginal dilator**, a plastic, cone-shaped device designed to gently stretch your vagina and make it more supple; you use it for a five to ten-minute session every day, gradually increasing the size
- **pelvic floor exercises** to improve blood flow, which in turn improves the moisture levels in the vagina
- **sexual activity** is also helpful, although make sure you take it at your own pace and use suitable lubricants



It can take time to come to terms with the change to your sex life. Be patient and give yourself time.



# Life after treatment

Remember, many other patients have gone through treatment and are now living full and happy lives. You can chat to other patients and ask questions on our private online forum.



**Remember ...**  
asking for help is a sign of strength. Don't pass up offers of help and do try to tell people what you would like them to do.



# 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 whether you are a carer or a patient and where you are on the cancer journey, 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](https://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](https://facebook.com/groups/BladderCancerUK)
- our **Fight magazine** – sign up for your free digital or print copies at [fightbladdercancer.co.uk/contact-preferences](https://fightbladdercancer.co.uk/contact-preferences)
- download back issues of *Fight* from [fightbladdercancer.co.uk/downloads](https://fightbladdercancer.co.uk/downloads)
- **Support groups** in many locations throughout the UK and online
- a **Bladder Buddy service** which will team you up with a carer or patient who has gone through similar experiences
- a **regular e-newsletter**
- a **public Facebook page** at [facebook.com/BladderCancerUK](https://facebook.com/BladderCancerUK)
- a **Twitter feed** [@BladderCancerUK](https://twitter.com/BladderCancerUK) and **Instagram** [@BladderCancerUK](https://www.instagram.com/BladderCancerUK)
- a **LinkedIn company page** [linkedin.com/company/fight-bladder-cancer](https://linkedin.com/company/fight-bladder-cancer)





## What do patients say?

We chatted to cancer patient *Dorothy Markham* who told us about her experience of muscle-invasive bladder cancer.



### What was it like to find out you had muscle-invasive bladder cancer?

I started seeing blood in my urine but I didn't think too much of it and even told the GP I had cystitis although a test showed no sign of that or any other infection and three courses of antibiotics made no difference.

It sounds a bit gory, but within six weeks my urine looked like cranberry juice and I was getting very worried. I was finally referred to a consultant, but I had a six-week wait for the appointment – that seemed a very long time.

An exploratory operation then found a stone in the bladder wall and fortunately the surgeon took some biopsies which, to everyone's surprise, confirmed I had aggressive bladder cancer. The only realistic option was to have my bladder removed because alternative treatment would have increased the chances of the cancer recurring. Three months later I was living with a stoma instead of a bladder.

**The only realistic option was to have my bladder removed because alternative treatment would have increased the chances of the cancer recurring.**

When an infection saw me back at my local hospital they lost me on their system and for three days I didn't see a consultant. Apart from that, no one seemed to know anything about bladder cancer or even how to change a stoma bag, and that seems so common. Even in the main cancer hospitals there was no literature about bladder cancer. It's like it's a forgotten disease.

And I was just like nearly everyone else – I had never heard of bladder cancer. Women, in particular, are used to bladder infections and bleeding,

so perhaps that masks the symptoms and makes it harder to diagnose, leading to late diagnosis with reduced chances of survival and limited intervention options. What people need to realise is that bladder cancer is not rare; in fact, it is common. People are constantly asking me what the symptoms are. Blood in your wee, I tell them, and the frequent urge to go to the toilet as well as urinary infections that don't go away.

### **Where does Fight Bladder Cancer come into your story?**

After the operation, I asked my consultant what I could do to help others. He gave me the contact number for Andrew Winterbottom, who called me and enthusiastically introduced me to Fight Bladder Cancer, the charity he had set up when he was diagnosed. This was the beginning of a new chapter in my life. Sadly Andrew is no longer with us, but his influence always will be.

**So far so good. I just feel lucky that I am one of the ones still here. I'll always fight it, but it is such a nasty disease.**



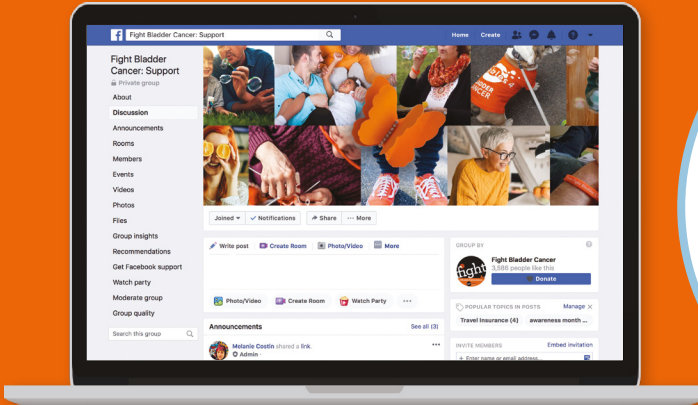
I think Andrew was inspirational and that the small Fight Bladder Cancer team of staff and volunteers are doing an amazing job with very few resources. I think that with an army of us patients behind them, Fight Bladder Cancer will be able to raise awareness so more people know about the disease; and they will be able to make sure more patients and carers get the right help.

I'm now on six-monthly checks and an annual scan. So far so good. They say 20,000 people in the UK get a diagnosis every year. I'll always fight it, but it is such a nasty disease.



## 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 Dorothy to support our work.

### Listen to what Dorothy said about FBC:

*'I make a monthly donation to the charity and I volunteer as a Bladder Buddy and am often asked to speak to women who have been recently diagnosed to give advice and just chat. I'm also helping the charity develop their plans for a Scottish office, and I'm seriously passionate about getting more politicians to understand the need for more funding for bladder cancer. I'll definitely be making a noise in Scotland every May for Bladder Cancer Awareness Month!'*



## 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](http://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](http://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, High Street, Chinnor, Oxon.**

**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 open trials in our *Fight* magazine or at [fightbladdercancer.co.uk/research](http://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](https://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](https://ncin.org.uk)



# Mindfulness

Whatever the future holds for us, it benefits us all to live every moment and try to remain positive. Looking after ourselves – physically and mentally – and doing our best to see the good things in life and appreciate them will help you to get through the tough times ahead.

Mindfulness is a way of helping you to do that. Basically, it just means trying to 'live in the moment'. You can find out more about it online, through YouTube videos, books or group or individual tutors. There is no shortage of helpful guidance so you are bound to find something that suits you.

You achieve mindfulness through meditation. You can learn to focus solely on the present, giving you the ability to really appreciate those minute things that pass most of us by: a drop of rain on a rose blossom, the sound of children playing, the smell of baking bread. This will make those moments even more poignant, and will help you live your life to the full.

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- <sup>7</sup> Mahon, J., Faraday, M., & McVary, K. (2019). 204 Patient and Partner Satisfaction Rates after Penile Prosthesis Surgery. *The Journal of Sexual Medicine*, 16(4), S100–S101

# 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

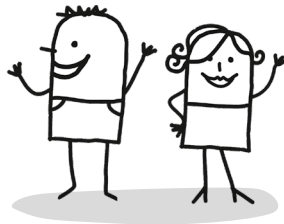
**[fightbladdercancer.co.uk](http://fightbladdercancer.co.uk)**

via our online forum at

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

by email at **[info@fightbladdercancer.co.uk](mailto:info@fightbladdercancer.co.uk)**

by phone on **01844 351621**





## My useful information

Hospital number \_\_\_\_\_

NHS number \_\_\_\_\_

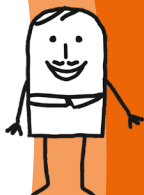
GP \_\_\_\_\_

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/get-help/glossary](http://fightbladdercancer.co.uk/get-help/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 download direct from Fight Bladder Cancer at [fightbladdercancer.co.uk/downloads](http://fightbladdercancer.co.uk/downloads)

### 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
- Carers' A to Z guide
- New developments in treatment for bladder cancer

### Fight Bladder Cancer

High Street  
Chinnor | Oxfordshire

+44 (0)1844 351621

[info@fightbladdercancer.co.uk](mailto:info@fightbladdercancer.co.uk)

[fightbladdercancer.co.uk](http://fightbladdercancer.co.uk)

   BladderCancerUK



### ENDORSED BY

The British Association of  
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British Association of  
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British Uro-Oncology Group

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