



bladder
CANCER

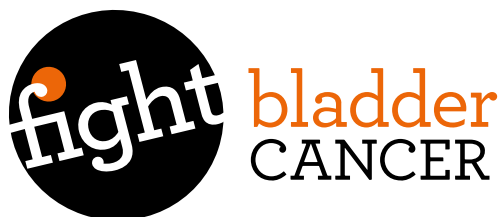
Patient Information Booklet

Advanced bladder cancer

& your treatment choices



A GUIDE FOR PATIENTS BY PATIENTS & PROFESSIONALS



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HERE**
to help you in
your **FIGHT**

Matching you with a patient
with a similar diagnosis – get
one-on-one support from our

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ABOUT THIS DIGITAL BOOKLET

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

Other free support materials

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

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

fightbladdercancer.co.uk/contact-preferences

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

We're here to help!

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ENDORSED BY


The British Association of Urological Surgeons

British Association of Urological Nurses

British Uro-Oncology Group



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

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

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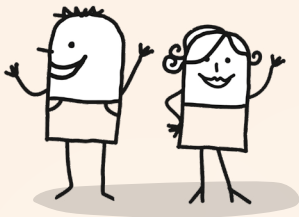
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Don't feel you need to read this booklet all in one go. It is designed in bite-sized chunks so you can take it in at your own pace.

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.

Hello

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 advanced bladder cancer'


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

Being given a diagnosis of having advanced bladder cancer is a huge shock and it can take a while to come to terms with what this means. But remember that 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 to make the best choices and find the support you need to get you through. This booklet has been written for and by bladder cancer patients and the people and professionals who care about them and for them.

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.

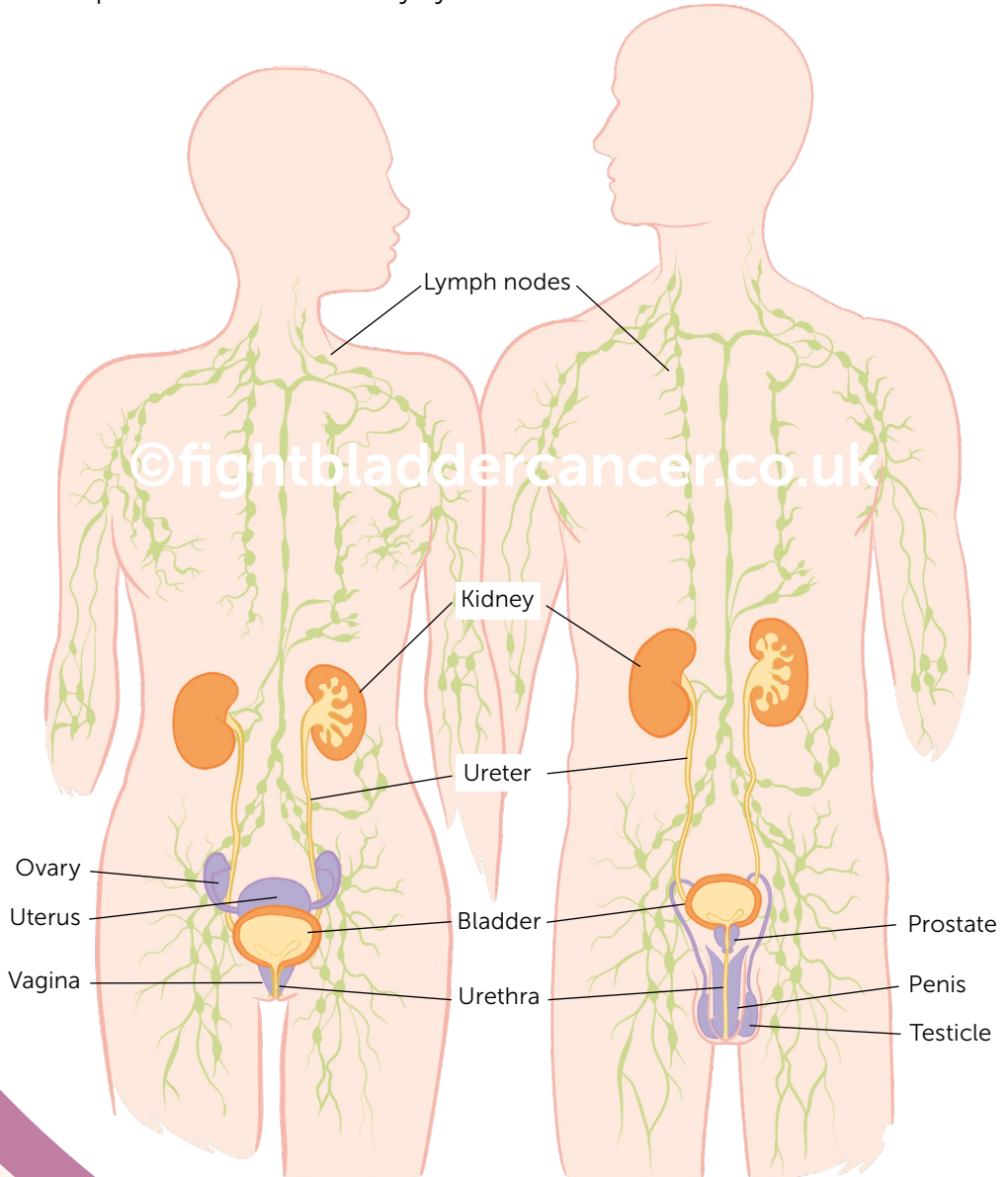
The lymphatic system is a network of organs and tissues that help the body to get rid of toxins, waste and other unwanted materials by circulating lymph, a fluid containing infection-fighting white blood cells.



Whatever the stage of your cancer journey, right now, the most important thing you should know is: you are not alone.

The urinary system

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




Advanced bladder cancer

Advanced bladder cancer is when the cancer has spread from where it started in the bladder to another part of the body. Your cancer may be advanced when it is first diagnosed, or it may have progressed to the advanced stage some time after you were first treated. This is called recurrent cancer.

The cancer can spread into parts of the body close to the bladder, in which case it is called local spread. This would be in places like your ureters, urethra, prostate, vagina or into the pelvis.

Cancer that has spread to another part of the body is called a secondary cancer or metastasis. If bladder cancer does spread, it is most likely to spread to your lymph nodes, lungs, liver or bones.

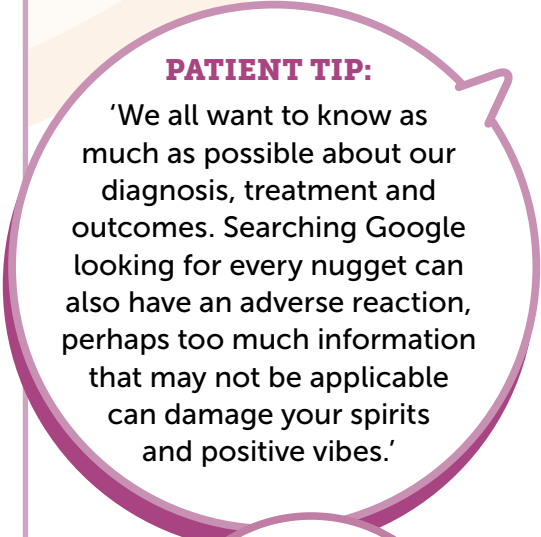


If you have ANY queries about your diagnosis or treatment options then ask your medical team until you are sure.


STAGE

Individual cancers are defined by stage and grade. A system called the TNM system is used to define the stage of the cancer, which indicates how far the tumour has spread from the inner lining of the bladder.

- 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



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.'



PATIENT TIP:
'No decision about me, without me.'

1 The T stages

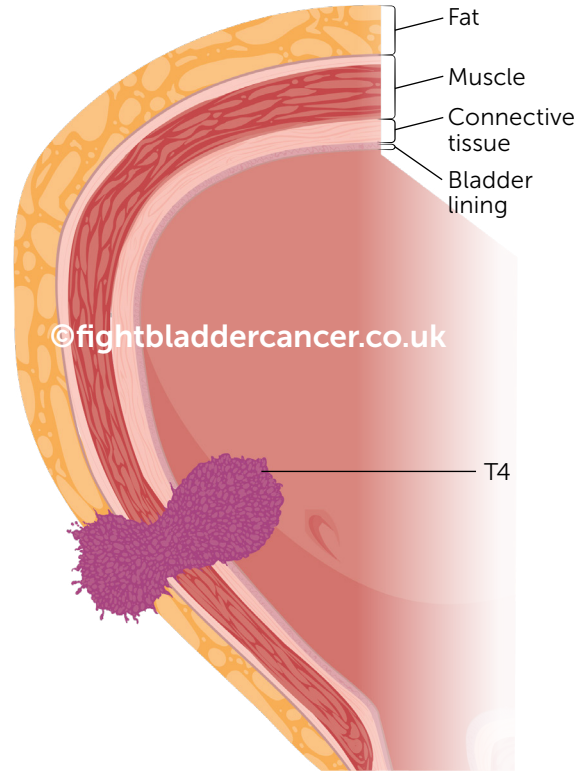
The T stages define how far the cancer has spread.

Bladder cancer up to the T1 stage is usually called non-muscle-invasive bladder cancer. Stages T2 and T3 are usually called muscle-invasive bladder cancer.

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

The T stage of advanced bladder cancer is:

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



2 The N stages

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

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

3 The M stages

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

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

GRADE

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

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

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

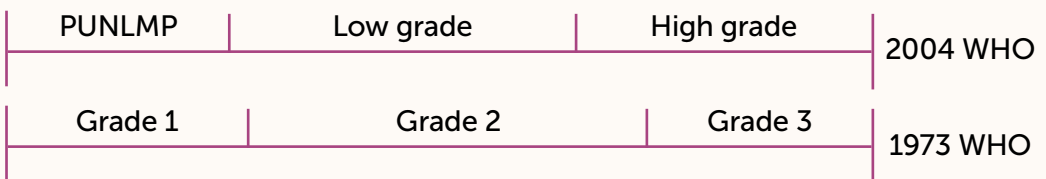
- **G1** / low grade
- **G2** / intermediate grade
- **G3** / high grade

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

In the 2004 system, the categories are:

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

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



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

!
Tumour grading can seem complex. Remember – your clinical nurse specialist (CNS) will talk you through everything in more detail.



Symptoms of advanced bladder cancer

The symptoms of advanced bladder cancer depend on which parts of the body are affected. Common symptoms can include:

- swollen legs
- pain in your bones
- pain in your abdomen
- ongoing fatigue
- difficulty in breathing or shortness of breath
- lumps in your abdomen or neck
- yellowing of the skin or whites of the eyes (jaundice)

Some people feel increasingly tired when their cancer has spread. But do remember that there are lots of reasons for feeling tired so it may not always be a symptom of the cancer. Remember that from time to time, you are likely to have aches and pains, and days when you don't feel very good, that may have nothing to do with your cancer, even if you worry that it does.

Check with your doctor or CNS about any symptom that is particularly worrying you. They will be able to discuss this with you and should be able to offer you solutions or help you deal with the problem.

PATIENT TIP:

'Some days I find myself thinking and worrying more than others. I'll do a crossword, jig around to some music in my living room – as long as I throw myself into something my mind will soon turn off.'

Always talk to your doctor or CNS about any problems you are having or any symptom that is causing you difficulty.

You are part of a team

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

Who will be part of my medical team?

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

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



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



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

Get involved

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

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

PATIENT TIP:

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

Making decisions

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

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.

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.



Questions to ask your doctor

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.

You are likely to have many questions to ask your doctor. Here are some of the most commonly asked.

- is there a specialist nurse I could see?
- what treatment do you recommend for bladder cancer that has spread?
- what is the aim of the treatment?
- what are the potential side-effects of the treatment?
- is there anything that can help mitigate side-effects?
- what happens if my cancer comes back again after this treatment?
- are there any clinical trials you would recommend for me?
- is there a counsellor I could talk things through with?
- what happens if I decide not to have treatment?



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

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

PATIENT TIP:

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

PATIENT TIP:

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



Coping emotionally

In this difficult situation, no one can make the decisions for you because every case is different and every person is different. Our best advice is to be open and talk to people about your cancer diagnosis as it can help you to weigh up the options and clarify the best decisions for you. If you find it difficult to talk with family or friends because it all becomes so emotional, then please do use the Fight Bladder Cancer online forum or our Bladder Buddy service, which will team you up with someone who has had a similar experience to your own.

PATIENT TIP:

'Mindfulness courses have been so useful. Plus ... talk to people, share things, it's so easy to become anxious.'

The way you choose to deal with a diagnosis of advanced bladder cancer is the right way for you. Remember that your decisions might change over time, depending on how you respond to treatment or other factors. You can change your mind if you want to. Liaising with your CNS has been reported to greatly enhance quality of life. They can signpost you to services such as counselling, benefits advice and community services, including palliative care and more.

Live your life the best way you can

There is no right or wrong way to deal with the emotional side of the diagnosis. But don't be afraid to ask for help or to accept offers when they are made, whether practical or emotional. If you want to create a bucket list and go off and climb mountains, then do so. If you want to simply spend time with your loved ones, then just do that. **Live your life the way you want to.**

Remember that Fight Bladder Cancer is here for you at any time, even if it is just for a chat.

Treatment options

The treatment options for advanced bladder cancer will depend on how much the cancer has spread, where it has spread to, what treatment you have already had and your age and general fitness.

Locally advanced cancer

For some people, the treatment aims to cure the cancer. If your cancer has grown through the bladder wall or has spread to the local lymph nodes but no further, it is called locally advanced bladder cancer. In this situation, having your bladder removed or undergoing radiotherapy can cure the cancer for some people. Recent advances in immunotherapy enable some individuals to keep their bladders.

PATIENT TIP:

'The pressure to make a life-changing decision quickly is so difficult. Find out as much as you can, ask questions, talk to someone who has been where you are now. Discuss your best options with your urology team and then decide on what feels right for you.'



You will need to understand what can be achieved with the treatment you are being offered so that your expectations are realistic.

Symptom control

If your cancer has spread to another organ in the body, then treatment is not likely to cure it, but may control it for some time and help to reduce symptoms. In this case, you will need to consider not only which treatment might be most helpful but whether to have treatment at all.

Fundamental to your decision will be how the treatment will affect your quality of life. This includes the possible side-effects as well as stresses such as travelling to and from the hospital.

PATIENT TIP:

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

Treatments may include a combination or sequence of treatments, such as:

- chemotherapy into a vein
- immunotherapy into a vein
- radiotherapy
- unblocking the ureters or urethra, if necessary, possibly requiring the insertion of stents
- medication to strengthen your bones if the cancer has spread there

If treatments are not available in your local area, ask for a referral to a larger centre for a second opinion and further treatment options, including clinical trials (see page 42). Talk to your doctor, CNS or counsellor, and share your concerns with a close relative or friend, or someone from Fight Bladder Cancer. After you have had time to think about the options, you and your specialist will make the final decision together.

PATIENT TIP:

'I spoke to Fight Bladder Cancer and they explained what the various treatments 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.'

It is not an easy decision but remember that there are no right or wrong answers. It is your choice.



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 and possible outcomes. Discuss this with your medical team until you feel confident with your choice.



CHEMOTHERAPY

Chemotherapy can help to control advanced bladder cancer for some time but some types of chemotherapy can be quite intensive. In general, the same type of chemotherapy is used to treat advanced bladder cancer as to treat muscle-invasive bladder cancer, so it may be helpful to read *Muscle-invasive bladder cancer*, another booklet in this series. The less intensive types of chemotherapy can still work very well at shrinking the cancer and slowing its growth. You would need to discuss with your own doctor which type of chemotherapy is most suitable for you. Doctors often use a combination of two chemotherapy drugs called gemcitabine and cisplatin (GemCis®) or gemcitabine and carboplatin (GemCarbo®).

In particular, older people who are less fit may find the side-effects of some chemotherapy too severe. You can have less intensive types of chemotherapy if you have:

- other medical problems, such as heart, lung or liver problems
- poor kidney function
- cancer severely affecting your liver or lungs

If you had chemotherapy when you were first treated, your doctor will assess how well the chemotherapy worked for you. Then they can decide whether you are likely to respond in a similar way or if different chemotherapy drugs may work better for you.



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

How chemo is administered

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:

'Once you start chemo keep a diary of any side-effects so you can report them all and get some treatment for them.'

Potential side-effects

There are a number of potential side-effects:

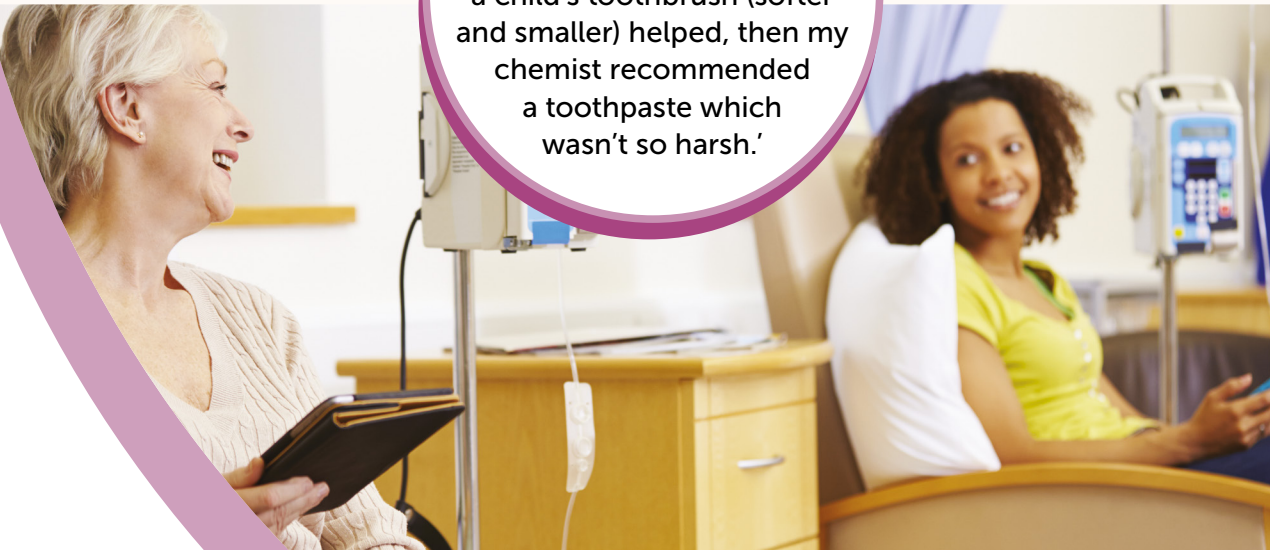
- risk of infection because the drugs reduce natural immunity
- infection could cause a high temperature and generally feeling unwell
- bruising or bleeding because of the effect of the drugs in reducing the bone marrow's capacity to make platelets
- anaemia because the bone marrow is not making sufficient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

PATIENT TIP:

'For a sore mouth and ulcers I sucked ice pops and ice cubes. Also, using a child's toothbrush (softer and smaller) helped, then my chemist recommended a toothpaste which wasn't so harsh.'

PATIENT TIP:

'Sleep whenever you need to.'



Coping with fatigue

Fatigue is a common problem with cancer treatments and you may need to find your own way to deal with exhaustion. If you are finding that you are completely lacking in energy and finding it hard to get through the day, speak to your doctor or CNS, who should be able to give you advice.

- make sure you are getting enough sleep, and add a regular sleep during the day if you need to
- alternate short periods of light activity and resting
- don't undertake too much activity – keep exercise regular and low key
- make sure you are eating a good balanced diet
- drink plenty of water
- avoid stress as much as possible
- avoid caffeine and alcohol
- try some relaxing complementary therapies such as acupuncture, massage, aromatherapy or meditation
- listen to soothing music

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

PATIENT TIP:

'You'll probably be very tired. People may offer to help; take them up on it when you need to.'

PATIENT TIP:

'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.'

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.'

Discuss with your CNS how you can mitigate any problems.

PATIENT TIP:

'Have "nana naps" throughout the day, don't be afraid to tell friends that you are too tired for visits.'

PATIENT TIP:

'You can buy covers to keep your PICC line dry when you are washing. I used to wrap my arm in cling film, and tried to keep it out of the water.'

PATIENT TIP:

'I used lengths of Tubifast during the day to keep my PICC line tidy and stop the dangly bits catching on things. The important thing is to keep it clean and dry.'

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".'

PATIENT TIP:

'I'm washing in the bath for now. I find it a lot easier than trying to keep my PICC line dry in the shower.'

RADIOTHERAPY

Your specialist may suggest radiotherapy if advanced bladder cancer is causing symptoms, for example, pain from cancer that has spread to a bone. Radiotherapy can work very well in this situation. Sometimes the treatment is given in one session and sometimes in several treatment sessions. The radiotherapy will not cure your cancer but it can improve the quality of your life. It can help to keep the cancer under control in the area of the body that has been treated.

If you had radiotherapy to your bladder and pelvis when you were first treated, then you will probably not be able to have any more to that area. This is because there is a limit to the amount of radiation any part of the body can tolerate. But you can have radiotherapy to another part of the body, if necessary.



PATIENT TIP:

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

PATIENT TIP:

'I found getting ready for my first session of radiation therapy the most anxious time. It was new and unfamiliar and not like my previous treatments. I've had several sessions to treat symptoms of my advanced cancer. It really has helped and now I feel very matter of fact about it and I'm not at all worried.'



Possible side-effects of radiotherapy

Side-effects from radiotherapy depend on which part of the body is treated so it can be misleading to give general information. However, they may include diarrhoea and the need to wee frequently if the pelvis has been treated. Most areas treated with radiotherapy will experience skin reactions and pain for around two weeks until the swelling resolves.

Patients react in different ways to radiotherapy and the targeted doses are designed to minimise any side-effects. Some patients find that it makes them feel very tired, and that this is cumulative so can last longer than the tiredness associated with chemotherapy.



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

PATIENT TIP:

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

SURGERY

If you still have cancer inside your bladder, or if it has grown back, it can make it painful or difficult to pass urine because of the pressure of the tumour growing inside the bladder. The cancer may also sometimes bleed. Your specialist may suggest removing most of the cancer to stop the bleeding and slow down the spread of the cancer, or surgery may be used to debulk the tumour. Debulking is when surgery removes as much of a tumour as possible. As well as relieving symptoms, this may improve the chance of chemotherapy or radiotherapy killing the tumour cells.

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

Unblocking the ureters or kidneys

Sometimes the cancer can block your ureters or kidneys, which can make urine build up in the kidneys and stop them from working properly. As well as relieving symptoms, clearing the blockage can help the kidneys to work normally again and the improvement in your kidney function may mean that you are able to have chemotherapy.

Your doctor may suggest an operation to bypass the blockage caused by the cancer. In one type of operation, the doctor puts a small tube (a stent) inside the ureter

to allow the wee to drain. Usually, your doctor may put a tube (called a nephrostomy tube) through the skin and into the blocked kidney to drain the urine into a bag outside the body. Then, later on, it may be possible to pass a stent into the ureter so that wee can drain from the kidney into the bladder.

Your doctor will do these procedures to try to relieve your symptoms. It is important to establish that the benefit of these procedures will be greater than the drawbacks of having an operation, so you and your doctor will need to talk this through beforehand.

PATIENT TIP:

'It took me a while to get my energy levels back to normal. Just small walks and building up each day and you will realise that you have got your oomph back.'

Secondary bone cancer

In some cases, advanced bladder cancer spreads to the bones. Symptoms include:

- bone pain
- weak bones, sometimes resulting in fractures
- raised calcium levels, indicated by nausea, thirst, fatigue and sometimes confusion

If you experience any of these symptoms and the doctor suspects that your cancer has spread to your bones, you will be given tests, including a bone scan, to find out whether and how far it has spread.

Your MDT will then suggest treatment options designed to manage and control the symptoms.

- hormonal therapy is given as tablets or injection
- chemotherapy uses anti-cancer drugs to destroy the cancer cells
- various types of medication can be used to strengthen the bones and reduce the likelihood of fractures
- surgery may be used to remove a secondary tumour, relieve pressure on the spine or strengthen a weak bone

PATIENT TIP:

'After a while I stopped thinking every ache and pain was an indication of something sinister.'

What happens after treatment?

After your main treatment, you will need to have regular check-ups, including cystoscopies (if you still have your bladder), x-rays, CT scans, urine tests and blood tests. You might not have all these tests at every visit to your specialist but your doctor will almost certainly examine you and ask questions in order to determine your current symptoms and how you are coping. If you are worried, or notice any new symptoms between appointments you must let your doctor or specialist nurse know straight away. You do not have to wait for your next appointment.

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. You can also talk with your companion beforehand about any questions

PATIENT TIP:

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

you want to ask and they can help you remember the answers afterwards. 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.

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.

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

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 so that worry is seriously affecting your life, you may need more help. It is quite common for people to have counselling during or 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/
- wales.nhs.uk/healthtopics/lifestyles/smoking
- nhsinform.scot/healthy-living/stopping-smoking
- stopsmokingni.info

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

It includes 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.



Darren

PATIENT TIP:

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

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, especially for women. 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:

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

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:

'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.'

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 partner¹

Women

Women's sexual problems tend to 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.

Living life to the full

A bladder cancer diagnosis can mean many things in terms of how it impacts your life physically, mentally and in terms of life expectancy. The overall five-year survival rate is 70%, which means you may have plenty of time to enjoy a long and fulfilling life, doing the things you wanted to. With advanced cancer, when the disease has spread to nearby lymph nodes or organs, the five-year survival rate is 36%. That means your time may be limited.

That is almost impossible to comprehend. Those who get the most out of their remaining years are the people who are able to focus on the present, grasp the pleasure in the small things and live in the moment.

Mindfulness

You may like to investigate mindfulness; there are many books on the subject as well as courses, YouTube videos and individual tutors.

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, but will help you live your life to the full.



PATIENT TIP:

'Life is precious and we all have so little time here, we really need to try to enjoy the moments we have. Value the small moments, the moments that we might easily dismiss as unimportant: your husband leaving a drink on your bedside table with paracetamol, in case you wake up in the night; laughing so much with your best friend that your sides ache and you forget about the cancer. Don't waste a single one of those precious times.'

Telling people you have cancer

Breaking the news that you have just been diagnosed with advanced 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.'



Coming to terms with a terminal diagnosis

Sadly, the reality is that many people do die from bladder cancer. While medical teams strive to find ways to help people to win their bladder cancer fight, many will lose.

If you are reading this section, it is likely that you or a loved one are faced with this situation, or perhaps are getting closer to losing their fight if the current treatment doesn't work. Phrases like 'this is not looking good' and 'we are going to have to find another treatment' can just be the sign of a blip in your medical treatment and your medical team will try to get it sorted and you will be back on track. Sometimes, however, this really will mean that things are not looking good and you might have to start preparing for something you hoped would not be happening now.

Overwhelming emotion

When you hear the words

'There's not a lot we can do now ...'

it's a bit like a kick in the stomach. It can feel as though your whole world has been turned upside-down. Perhaps you had never thought it would come to this. Perhaps that horrible thought had been nagging at the back of your mind ever since you were first diagnosed.

Most people who have been diagnosed with cancer have asked themselves more than once, 'Will I die?' You may have even asked your medical team that precise question. Now you have the answer and it is the one you hoped never to hear – that your bladder cancer can't be cured.

The initial shock of hearing that your medical team can't cure your cancer and that they think that your time is now limited will hurl you into

a whirlwind of emotions. Shock. Disbelief. Anger. Fear. Tears. This is just not fair! Why me?



PATIENT TIP:

'We all worry about the future at times. Don't let things get out of hand, and never be afraid to ask for help if you are struggling.'

Do you give up? Do you fight like you've never fought before? Is there nothing they can do? What do you tell people? What do you tell your children? What do you tell your parents? Your friends?

With all these questions swirling around your head, it is likely that you will experience a rollercoaster of emotions. You may be constantly tearful, feel overwhelming anger, or feel deeply depressed and be unsure about how you will cope. As you come to terms with the news, things will settle down and your distress will ease a little. Many people even eventually reach a stage of acceptance and calmness. Talking helps, so rely on those who will listen and share your feelings. Your specialist nurse and community palliative care nurses are there to support you. Lean on others; do not be alone.



How long?

Your consultant will not have a precise answer to this question. All they will be able to give you is their best guess based on research outcomes and clinical experience and knowledge. Whatever you are told, bear in mind that you might live longer or you may have less time than they predict. This

uncertainty can make you feel even worse. 'Why can't they just tell me how long I have so I can decide what I have to do next?' These fears and emotions are very normal.

PATIENT TIP:
'Try and live in the moment and grab each day.'

But somehow you have to work out a way to move on without an answer; because there is no answer to that question. Talking to other people in a similar situation can really help you to keep your perspective and perhaps even come to terms with what is happening. While that is your priority, try to do as many things as possible that make you happy. While you are able, get outdoors or meet up with friends. If you find things too exhausting, watch some TV of places you want to visit; listen to audiobooks instead of reading books if you find reading tiresome. At such times, small things can bring you moments of joy.



PATIENT TIP:

'Dream big, stop being busy, take a moment to remember what's really important. Then go out there and LIVE.'

Making plans

Prioritise what is most important, plan it and do it. If you have always harboured a dream to see Venice, book a trip for next week or next month, not next year. Now could be the time to plan that holiday of a lifetime. Perhaps sort out all those old photos and make a memory book. Visit old friends. Write a journal full of notes to leave to your family. If it's your thing, why not organise a party?

What to expect

When you are ready, talk to your medical team about how they think things will progress. What things should you look out for? What symptoms are you likely to experience and what will they mean? What can you do about the new symptoms? What about pain relief?



Whatever you want to do, why not do it if you feel strong enough?

Practical issues

You will also need to decide on some key practical issues including where you want to die and who you will want with you. Find out the options available to you: at home, in hospital, in a hospice.

Sorting out your estate

Everyone should have a Will, so if you don't have one, do it now. Don't assume that you don't need a Will if your affairs are straightforward; having a proper legal document will make arrangements much simpler and quicker for your loved ones. You can use a solicitor, which is the most expensive option but advisable if your affairs are complex, or a Will-writing service, which usually charges a fixed price. Alternatively you can simply write your own Will but do sign and date it in front of two independent witnesses, who should also add their names, signatures, occupations and addresses to the Will. Keep it safe and make sure someone knows where it is.

There will be many additional everyday and financial things to sort out. If you wish, you can give someone Power of Attorney over your affairs, which means that they can act on your behalf; if so, visit gov.uk/power-of-attorney to find out more and to apply.

What arrangements do you need to put in place so that the plans will go smoothly when the time comes?

With all such arrangements, make sure the right people know where to find the details.

You might also want to clear up any arguments or grievances with family or friends.

Make sure your loved ones know how you feel about organ donation.

You may have taken out a funeral plan or have specific ideas about what you would like to happen at your funeral. Write it down and let people know.

PATIENT TIP:

'There wasn't a big fanfare at the end of treatment or a bell to ring – I felt in limbo. Apparently it's quite normal. I had a great chat with another patient who felt just the same and it made me feel so much better.'

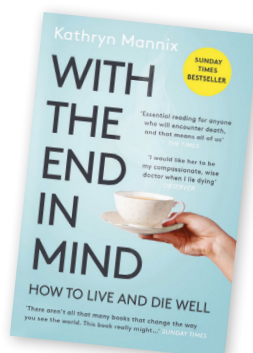
Knowing the end is coming

There will come a time when you will reach this last stage of life. This may now be a time of peace and acceptance for you, but if it's not, do tell the people around you so you get the help you need. Make sure you get any necessary pain relief and consider how you want to spend your last few days. Make sure that you can get the physical care that you need. Perhaps a hospice will be right for you. Perhaps you will want to be at home. Have the loved ones you want with you when the time comes to say your last goodbyes.

If you need somewhere to talk in confidence about end of life issues and worries, the members of the FBC online forum are there and ready to talk to you. We have people of all ages affected by bladder cancer and at all stages of their fight.

You might also like to read a book by Kathryn Mannix that our late founder, Andrew Winterbottom, described as 'compassionate and insightful'. In an open letter, he thanked Dr Mannix for writing a book that had given him 'a significant amount of peace for my last months'.²

The final moments are very peaceful for most people.



Remember ...

a diagnosis of advanced bladder cancer may mean you have a serious and life-threatening condition but many patients go on to live happily for many years. Your ultimate goal is to travel in hope, making each day the best it can be.

How Fight Bladder Cancer can support YOU

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

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

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

PATIENT TIP:

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



What do patients say?

We chatted with cancer patient **Anita Brown** about what it was like to be diagnosed with advanced bladder cancer.



How did you feel when you received your diagnosis?

It was hard enough to be diagnosed with bladder cancer let alone then to be told that it had spread and was far more advanced than was first thought. My initial reaction was bewilderment followed by 'Am I going to die?' We spent the first few months in a total whirlwind – one minute it all felt surreal, like it wasn't happening to me, then the next it was overwhelming, a nightmare that we couldn't escape from.

The first few seconds of the morning were always good ones ... until it hits you again and you had to ride those waves of emotions for another time, almost like being diagnosed daily.

The tears came and it didn't matter where you were – the supermarket, cleaning the loo – it was all you could think about, holding your breath and hoping it was some kind of mistake. This can't be happening to me, can it? Then berating ourselves for not being more insistent with the GPs. Wondering more than once what the oncologist's words actually meant and – bewildered with all the terminology – why he couldn't just talk in plain English.

My initial reaction was bewilderment followed by 'Am I going to die?'

You live in a whirlwind of emotions, a bubble; you live and breathe your diagnosis and wonder how you will ever come to terms with it.

Eventually you do, but not without a lot of help and support from friends, family and Facebook forums. It helps to know that there are others out there experiencing the same emotions as you, and that you can find a listening ear when you don't always know what's going on in your head. Mostly it helped just to know that everything you feel is totally normal.

We each deal with our diagnosis in a unique way and that's why it is vital to have forums like Fight Bladder Cancer, so you can speak freely about how you really feel and how you are coping. You don't have to explain the 'why' to anyone because you know they understand, and you don't have to cope with the fear of upsetting those closest to you and putting too much on them.

As time goes by, you learn to live with your diagnosis. You learn to come to terms and you will find that sometimes, you may forget for a few minutes, or even hours, that you are ill, but it is always there in the back of your subconscious, the elephant in the room, the black cloud of cancer, hanging over you.

Every occasion is tinged with 'is this going to be the last time we do this? My last Christmas? My last birthday?' Somehow you learn to be able to live your life daily.

How has Fight Bladder Cancer helped you?

Through the online forum, I have made so many friends – others going through similar experiences have helped to support me in the darkest moments and also given me that chance to help and support others. Knowing that there is someone on the end of a phone if I have a question that I can't find the answer to, there is always someone who is happy to find out, is a great relief. With the forum having a mixture of patients and healthcare professionals, it really is a wonderful place to find the answers to whatever questions you have, as well as getting support.

Why do you support FBC?

Having a charity that deals solely with our cancer is so vital. BC is so underplayed by many of the healthcare professionals that I have come into contact with, and we are left feeling that our cancer doesn't matter, but FBC is a pillar of support, understanding and listening. Everything that they do is in the interest of the patients.

FBC has been helping to research treatments, supporting patients, and helping to spread the awareness of this evil disease. They encourage us to help them spread the word, too, and we feel a wonderful sense of mutual support. We feel included; we feel recognised. The staff have knowledge and a great level of understanding. We feel that we belong somewhere. After all, 'Wee are family'.



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 Anita to support our work.

Listen to what Anita said about FBC:

'I support Fight Bladder Cancer because we need a cancer charity that focuses solely on the bladder. It is vital they exist because without them bladder cancer has no voice and will carry on being forgotten. I have got such a wonderful sense of mutual support from the team at FBC and fundraising and awareness-raising with them has really helped me feel I'm making a difference.'



Your donations matter

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

Ways that your donations can help:

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

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

Fundraising with transparency & credibility

- we are open, honest and transparent
- we will always comply with the law as it applies to charities and fundraising – we will be respectful of your rights and your privacy
- we will be fair and reasonable – treating all supporters and the public fairly – showing sensitivity and being adaptable
- we will be accountable and responsible – managing our resources wisely

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

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

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

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

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



Clinical trials

Research is vital to increase our knowledge base, to help with prevention of disease and to develop new and better forms of diagnosis, treatment and after-care. Your doctor may be able to recommend a clinical trial that may help your condition.

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

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

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

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



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



National Cancer Registry & Analysis Service (NCRAS)

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

New treatments for bladder cancer

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

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

funded by the NHS, and some are not.

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

If you have advanced cancer, ask your doctor if targeted or immunotherapies are available, or offered in clinical trials, and are suitable for your type of cancer.

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

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

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

Finally ...

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

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

We are here to help.

REMEMBER, YOU CAN CONTACT US AT ANY TIME FOR SUPPORT

or to engage with us in fighting bladder cancer

via our website at

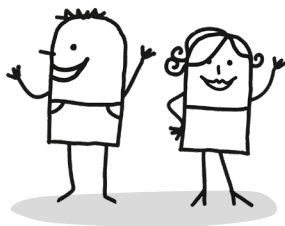
fightbladdercancer.co.uk

via our online forum at

facebook.com/groups/BladderCancerUK

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

by phone on **01844 351621**



My useful information

Hospital number _____

NHS number _____

GP _____

Consultant _____

CNS _____

References:

- 1 Mahon, J., Faraday, M., & McVary, K. (2019). 204 Patient and Partner Satisfaction Rates after Penile Prosthesis Surgery: A Systematic Review. *The Journal of Sexual Medicine*, 16(4), S100-S101
- 2 Mannix, Kathryn, *With the end in mind*



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

fightbladdercancer.co.uk/glossary

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

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



THE SERIES INCLUDES:

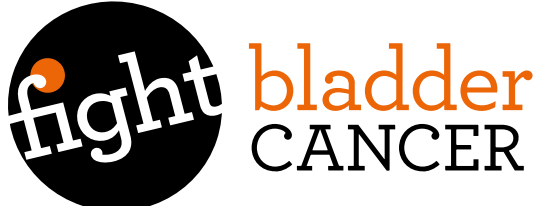
- Tests & investigations
- What is a TURBT?
- Low-risk & intermediate-risk, non-muscle-invasive bladder cancer
- High-risk, non-muscle-invasive bladder cancer
- Muscle-invasive bladder cancer
- Living with a stoma
- Living with a neobladder
- Advanced bladder cancer
- Surviving bladder cancer
- Diet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

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ENDORSED BY

The British Association of Urological Surgeons

British Association of Urological Nurses

British Uro-Oncology Group



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