



bladder
CANCER

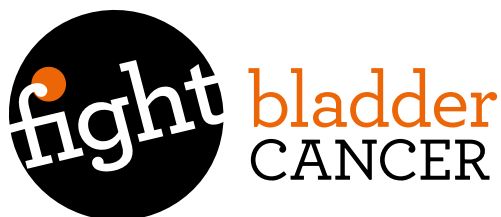
Patient Information Booklet

Surviving bladder cancer

& living every moment



A GUIDE FOR PATIENTS BY PATIENTS & PROFESSIONALS



YOU'RE NOT ALONE

Call us
01844 351621

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SUPPORT & MORE
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fightbladdercancer.co.uk

EMAIL US on info@fightbladdercancer.co.uk

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

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

**Bladder
Buddies**

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

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!

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)**.

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Paul Michaels | Susan Mullerworth | Jo Peacock | Ravi Ruparel | Michael Sloane**
for sharing their bladder cancer stories.

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First published 2020 by **Fight Bladder Cancer**
51 High Street, Chinnor, Oxfordshire OX39 4DJ

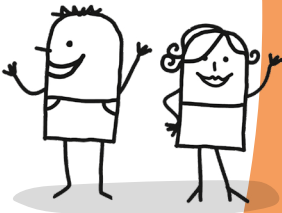
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Our **patient tips** come from **real bladder cancer patients** across the world!



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

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

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

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

Hello

As a bladder cancer patient, you're travelling on a journey that started the moment you heard those words none of us ever expects to hear:

'You have bladder cancer'

and from that moment, your life changed.

But if you have been through diagnosis, tests and treatments – and possibly emerged from all that – you will know that you are not alone. And as you face the challenges moving forward, remember that help and support will be there for you every step of the way. **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 the support you need to get you through.**

If you are anything like most people who are living with a bladder cancer diagnosis, you are likely to have gone through the whole gamut of emotions – and more than once. Even after successful treatments you will still need regular check-ups and possibly further treatments, which are important to try to make sure the cancer does not return. Try not to get too anxious when you are due for a check-up. If you can view it as a way of keeping clear of cancer, that may help.

This booklet has been written for and by bladder cancer survivors and the people who care about them and for them. (Look out for the useful patient tips.) No matter what path your bladder cancer journey takes, know that there are others here that will share the journey with you, in person, through support groups or via online support forums.

PATIENT TIP:

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

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.

Be positive and take control

Your future with bladder cancer is an unknown future – but then again, **life is always like that!** What is different for you is that you have experienced – or are now going through – a dramatic period of your life. From our own personal experiences, the best advice we can give is to face up to the challenge and remain as positive as you can. The way to do that is to embrace your cancer. Take control. Make sure you continue to do in life what you have always wanted to do. You will find that just about everything is still possible, even if the practicalities may be a bit more demanding.

Achieving this attitude is not an easy thing to do, so take small steps at first. Start by going to fightbladdercancer.co.uk and joining the private online forum (find out more on page 20). You will soon see how other people with bladder cancer are coping with life, indeed enjoying life, sometimes against all odds. Getting involved can also be a great tonic to help encourage a positive attitude to your future and get you back on track to a happy life.

But ... let's be honest about the negatives

Being positive may sound impossible right now because everything can feel so overwhelming. From the time of first diagnosis, dealing with the initial shock, the treatment and its aftermath encompass a whole range of physical, psychological, emotional, social and financial issues. It can be extremely tough. To survive all this you need to **focus on improving your quality of life**, whether that means dealing with physical issues like pain or emotional issues like anxiety or depression.

PATIENT TIP:

'Being busy helps distract my mind away from stress and worrying. My hobbies, art, knitting and crochet, can free my mind from worry.'



Don't let it be overwhelming

Because bladder cancer has such a high rate of recurrence, patients need to see their doctors and consultants regularly, even after successful treatment, to make sure the cancer has not returned. Even when there is no sign of a recurrence, these tests may cause emotional distress. **If you feel overwhelmed or have lost the pleasure in your life, your doctor can recommend someone to talk to.** For instance, some social workers and psychologists specialise in helping people manage ongoing chronic diseases like cancer.

Coping with the social impact

Bladder cancer and its treatment can also have an effect on your social life as well as your health. Troublesome urinary symptoms such as burning and irritation when weeing or incontinence issues after treatment are common side-effects. Many people also experience sexual problems. These side-effects can be very challenging and may require changes in work, hobbies and other social activities.

Sexual issues can also be difficult to talk about with your doctor, spouse or partner. But try to remember that your doctor will have seen these symptoms many times before and will not be embarrassed by them. In fact, they will have suggestions for ways to help you manage these side-effects effectively. They can refer you to sexual therapists, specialist cancer or stoma nurses, physical therapists and other specialists who can help. Talk to your clinical nurse specialist (CNS) about advice and support.

You can find more information about sex after bladder cancer on pages 8–11.

PATIENT TIP:

'I play online games, escaping into fantasy worlds is great! It just distracts my brain from "stuff" and then I am ready to face the world again.'

PATIENT TIP:

'I got very depressed and anxious after my surgery. Everyone has to seek help at times; I had antidepressants and talking therapy and am now going from strength to strength.'

Quality of life

Bladder cancer is the most expensive cancer for the NHS to treat and monitor per patient.¹ This is because the high likelihood of it recurring demands frequent monitoring and sometimes repeat treatments, or even a completely new treatment regime if the cancer returns.

This can mean that the doctor's first priority may not always be your quality of life. As you come to terms with life after your initial treatment or surgery, you will find that doctors do not always raise quality-of-life issues. And they won't know that there is a problem unless you bring it up. We strongly encourage you to talk with a doctor, nurse or other healthcare provider about any concerns you may have during or after your treatment. **They are there to help you live a full, happy life after a bladder cancer diagnosis.** It is up to you to take the responsibility of telling them how you feel.



Consider making a list of what you want to discuss. For example, is there a new symptom that you want to ask the doctor about?

Do you have a concern about how a treatment is affecting your daily life? If you have more than a few issues to discuss, put them in order and ask about the most important ones first.

Bring up the things that are really on your mind early in your appointment rather than leaving them to the end.

!
It may be helpful to take a family member or friend to your appointments.

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.'

I'm a survivor!

Once you are through treatment, you will transition from being a patient to being a survivor. How we deal with becoming a cancer survivor is as individual as we are. While one person may go from being a couch potato to running marathons, another may feel lost and hopeless. There is no right or wrong way to deal with surviving cancer.

Many of us have experienced a feeling of deflation once treatment has finished and we move on to regular check-ups. This is because, while in treatment, you feel you are actively doing something about your cancer, but once treatment ends you have time to deal with the emotional impact of your diagnosis and what it means to your life.

You may have questions about what lifestyle changes you should undertake to give yourself the best future life possible.

- should I stay at work, reduce my hours or change my job?
- how much exercise should I do and what type?
- can I carry on with the social activities I enjoy?
- is my diet nutritious?
- am I getting enough sleep?

A measure
is, if it feels
good,
do it.

Everyone is different, so you'll need to work out the details of how you plan your lifestyle. You may have things you know you definitely want to do, or others that are just possibilities but they are all worth investigating. If you have always wanted to do a skydive, find out where you could go, whether you would be able to do it and the logistical details. If you want to try it, go for it. Always wanted to try ballroom dancing? Don't let anything stop you.

PATIENT TIP:

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

If you can't get your head round what you need to do, talk to family or friends, raise your questions in the **Fight Bladder Cancer private online forum** or speak with your doctor or CNS and they will help you.



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.'

Les



Brian

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.'

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.


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 resolve 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 look at when you are feeling down and remind yourself that it's not all bad.

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.



Not feeling good about yourself very often leads to a lack of interest in sex. Don't ignore it.

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 thing to try first, but don't be discouraged if you have to try more than one option before resolving the issue.**

Try different options to find something right for you.

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 have been used successfully in combination with **vacuum devices**, although vacuum devices are no longer available in some areas
- **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**; this tends to be a last resort as it does involve major surgery but results in about 86% satisfaction rates for both the patient and their partner²

PATIENT TIP:

'I remember how I felt the first time the doctor told me I would need to inject the drug into my penis to get an erection – I was so scared! But the truth is I don't feel a thing and it has given me such confidence – and my wife and me, a return to a wonderful sex life.'

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. You can read more about the different types of implant over the page.

PATIENT TIP:

'I really wondered if it was worth carrying on, was I ever going to be a "man" again? How wrong I was, life is different but really good.'

PATIENT TIP:

'Op day plus one: I felt okay but my penis was enormous, inflated and swaddled in a heap of bandages. Hello robocock! By my three-week check-up, the nurse watched me inflate my penis – a bit strange but looking good, given that it has 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. I had sex and it just felt normal!'

Implant options

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.

Instead, 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:

'Yes, things have changed but our simple solution to changing everything was having more cuddles and holding hands.'



Tim, Sherlock and Anita

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

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



If you're having sexual difficulties, do not suffer in silence. Talk about it with your GP or CNS.

PATIENT TIP:

'My only advice would be to talk to your CNS now about any sexual problems as a result of your treatment. Don't wait.'

We have all felt this way sometimes

Never think that you are the only person who has experienced emotional problems – you are not alone and there are people who understand and can help.

Depression and anxiety

While for many a feeling of anger and sadness can linger after treatment, for some it can develop further into clinical depression or anxiety. If that happens to you, it is important that you talk to your GP as soon as possible about getting help to overcome your depressive feelings. They may be able to offer counselling, or medication may be appropriate in the short term.

PATIENT TIP:

'I just go with however I feel and cry, shout, argue, laugh – everyone finds their own way.'

PATIENT TIP:

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

Fear of recurrence

This is very common – every ordinary ache and pain can make you fear the cancer has returned. Time will help this fear lessen, but it may never completely go away, and most commonly returns around the time of a check-up.

If you find that you are preoccupied to the extent that your fear of recurrence is having a significant impact on your everyday life, do talk to your doctor about getting help to deal with these feelings.

Stress

Stress can be brought on by many aspects of life: financial, social, work, to name just a few. Once treatment is over and you begin to get back to the routine of life, you'll find all the things waiting for you that you didn't get done while dealing with the cancer. Don't feel as though you have to try to do them all at once. Slow and steady is better than crash and burn!



A little stress can be a great motivator, but if you begin to feel that your stress levels are becoming unmanageable, talk to your doctor straight away about getting help to deal with your feelings.

Be prepared for highs and lows

Everyone experiences fears and worries that don't go away, and some of your fears, as a cancer survivor, will recede but then come back and hit you when you least expect it. The important thing to recognise is that this is normal. Don't worry. It's all right to be scared *again*, get angry *again* and just want to go and hide in a corner for a while *again*.



Colin



Alison

PATIENT TIP:

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



Susan



Keith



Lorraine

PATIENT TIP:

'I got my energy back and just wanted to do things, have new experiences, celebrate being me.'



Rebecca



Ron

**We've all been there.
And we've all come out fighting.**

STOP SMOKING



It is crucial that you think about your smoking habits. If you are a smoker, do please STOP. There will be a best way for you, so talk to your CNS or your GP and ask for support and advice.

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

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

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

It includes the reasons why you should give up – especially the risks of developing cancer, heart and lung disease and the fact that smoking increases the risk of the cancer returning.³

Most importantly, it also tells you about all the different methods you can use to help you stop; the support on offer; your local stop smoking services; Facebook, Twitter and YouTube support; FAQs; and stop smoking aids, including patches.

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

PATIENT TIP:

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

PATIENT TIP:

'I've settled back into work and am getting out more; keeping busy is the key for me and I'm starting to really feel like me again.'

PATIENT TIP:

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

A happy future

As well as joining us at **Fight Bladder Cancer's online forum** (find out more on page 20) and in other reputable cancer forums, talk to your doctor about what you can do to improve your health and cut your chances of your cancer coming back.

For many, this is a good time to take a look at your lifestyle and make changes – exercise and diet can be a good place to start. There is no magic food that will keep the cancer from coming back, but a healthy balanced diet will help. Take a look at another booklet in this series, *Diet & nutrition for bladder cancer patients*.

Go to all your check-ups, even if you are stressed because you are worried about a recurrence. Not going will only make that fear worse in the long run. Admit to yourself that the stress is there and find ways to deal with it. Joining a support group can be very beneficial as it gives you a place to talk about your feelings.

Getting your thoughts out and into words helps a lot of people, so many like to write their personal story for us here to read. You might find that helpful too.

Above all, keep busy! Too much time to think about your fears can make them feel more intense.



Techniques for managing stress can be as simple as a cup of tea with a friend, quiet meditation or a long walk.

Remember ...

life is going to be as good as you make it. Every day has the possibility to be great, full of fun, laughter and love. Enjoy each day, and then tell us at FBC about it.



Teri (and Tanni)

Clinical trials

Research is vital to increase our knowledge base, to help with prevention of disease and to develop new and better forms of diagnosis, treatment and after-care.

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

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

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

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

Always discuss your suitability for a trial with your doctor or medical team!

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



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 exciting scientific discussions and new clinical trials of immunotherapy and targeted therapy drugs for advanced cancer.

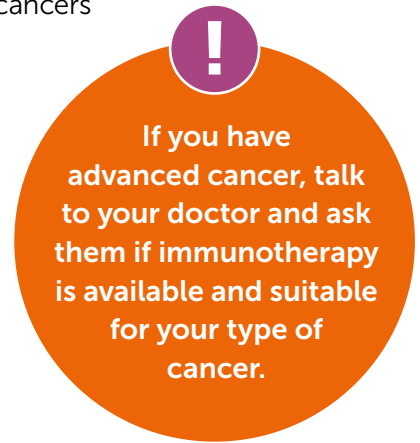
Immunotherapy drugs are synthetic antibodies that effectively 'alert' our immune system to cancer. Some examples of immunotherapy drugs that are currently authorised or in clinical trials for advanced bladder cancer include: atezolizumab (Tecentriq®), pembrolizumab (Keytruda®), nivolumab (Opdivo®), durvalumab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



National Cancer Registry & Analysis Service (NCRAS)

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

Information recorded includes the name, address, age, sex and date of birth of patients; data about the type of cancer and how advanced it is; and the treatment received. It is derived from medical records from

GPs and various hospital departments, including independent hospital and screening services.

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

What do patients say?

We chatted with Ros Bruce about her experience of bladder cancer.



What did it feel like to find out you had bladder cancer?

I felt numb and scared when I found out I had bladder cancer ... these things usually happen to someone else ... I'd never heard of bladder cancer so it came as a shock. I didn't know what to expect and thought I would die. I battled through on my own ... I had family and friends for support but they didn't really know how I felt.

After numerous hospital appointments, I was told my only option was to have my bladder removed and a hysterectomy, which meant I would have a stoma and bag for life.

How did Fight Bladder Cancer help?

About a year after the operation I saw an advertisement for a new UK bladder cancer support group. Little did I realise just how Fight Bladder Cancer would change my life. At the time there were very few members but we all soon realised that the group was our wee family. Everyone was going through the same difficulties, and – after a year alone that I wouldn't wish on anyone – it felt so good to know it wasn't just me.

Fight Bladder Cancer has given me my life back.

I have an aim in life now: to support and fundraise for the charity. I had my bladder removed in 2011 and I value life more than I ever did. I welcome and rise to every challenge. I even did a sky dive with the Red Devils two years ago ... I'd never have done that if I had not had bladder cancer.

I was 42. I lived in my wee bubble, oblivious of what was going on around me. When I had the op, it was the hardest thing I've ever gone through.



How Fight Bladder Cancer can support YOU

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

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

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

PATIENT TIP:

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



Fight Bladder Cancer Support – our private forum

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



PATIENT TIP:

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

Join our private online forum at:
[facebook.com/groups/BladderCancerUK](https://www.facebook.com/groups/BladderCancerUK)

Can you help us in the fight against bladder cancer?

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

Listen to what Ros said about FBC:

'I am living proof that you can do even more than you did before you had bladder cancer – even with a stoma and bag. Thanks to Fight Bladder Cancer, I'm making every day count and every day raising awareness of the support and help Fight Bladder Cancer offers you to make sure you can say with confidence: "I can do this". Now I'm away to think of my next fundraising challenge.'



Your donations matter

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

Ways that your donations can help:

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

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

Fundraising with transparency & credibility

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

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

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

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

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

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



Finally ...

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

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

We are here to help.

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

or to engage with us in fighting bladder cancer

via our website at

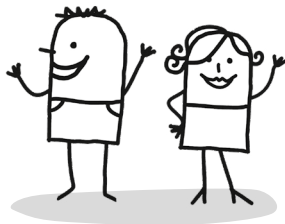
fightbladdercancer.co.uk

via our online forum at

facebook.com/groups/BladderCancerUK

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

by phone on **01844 351621**



References:

- 1 Mossanen, M., & Gore, J. L. (2014). The burden of bladder cancer care: direct and indirect costs. *Current opinion in urology*, 24(5), 487–491
- 2 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
- 3 [sciencedirect.com/science/article/abs/pii/S0302283811007470](https://www.sciencedirect.com/science/article/abs/pii/S0302283811007470)

PATIENT TIP:

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

Life after treatment

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



Kelly



Anita & Tim



Eric



Jacqui



Barry



Johnstone



Mick

My patient tips

Jot down anything you have found particularly useful and send us your ideas by email, post or on the forum.

My useful information

Hospital number _____

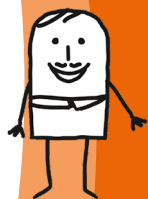
NHS number _____

GP _____

Consultant _____

CNS _____

Other MDT members _____



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

fightbladdercancer.co.uk/glossary

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

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

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

THE SERIES INCLUDES:

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

Fight Bladder Cancer

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fightbladdercancer.co.uk

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

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

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Urological Surgeons

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Urological Nurses

British Uro-Oncology Group



MSD



MERCK

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.

Fight Bladder Cancer is a registered charity in England and Wales (1157763)



fight bladder
CANCER