

Fight Bladder Cancer

Research & awareness requirements



Fight Bladder Cancer works hard to support clinical trials and research into the causes, diagnosis, treatments, side effects and quality of life issues for bladder cancer.

One of the strengths of FBC is that as a patient-led charity, we can identify areas where we, the patients, want better information, guidance, treatments and aftercare.

These are not areas of highly sophisticated research, just ones in which we have simple questions. Ideally we would want professionals with an interest in bladder cancer to help move forward on these issues. We know that a simple question might require a lot of research and consideration, but to us, these things are important.

Urologists, oncologists, researchers, industry and funding bodies: we need your help.

The overview

As bladder cancer patients, we feel left out.

- We are a top 10 cancer that nobody has heard of.
- We have the 7th most common cancer, but get just 0.6% of cancer research spend.
- Our cancer that is at the bottom of the NHS Patient Experience Survey.
- There have been no real new treatments for over 35 years.

We want the spotlight turned onto bladder cancer so that we get our fair share of attention. No more, no less.

Who are our champions from the medical profession? We're ready to join you in making a difference.

Causes

What are the causes of bladder cancer?

A high percentage of patients with bladder cancer do not fall into the risk areas currently known.

Which lifestyle or environmental factors can we do something about?

Apart from stopping smoking and working with chemicals, what can we do to help prevent people from getting bladder cancer?

Is there a genetic factor, meaning that it “runs in the family”? If so, is there a logic in screening for these people?

Why is there still too little awareness about the causes of bladder cancer? We could cut the incidence of bladder cancer in half if the message were clear and persuasive.

Diagnosis

Late diagnosis can kill bladder cancer patients. Once a patient gets referred to a hospital, almost all bladder cancers are picked up during a cystoscopy. We need to give GPs and A&E departments a simple tool to identify people who should be referred for detailed checks.

Too often a diagnosis is delayed because the symptoms are so similar to other, less life-threatening conditions. People of all ages get bladder cancer- we need greater awareness that this is not just “an old mans disease”.

We need greater awareness of the whole range of symptoms, not just “blood in your wee”.

The task: Prove to us that it is *just* a UTI.

Treatments

Let’s be honest here, bladder cancer treatments haven’t really changed for over 30 years.

And these treatments don’t work that well. Bladder cancer usually comes back. Survival rates have not improved for ages and lag far behind the other top 10 cancers.

The treatments are invasive, painful, have many side effects and have to be repeated time and time again.

We need every patient to be given the standard of treatment set out in the NICE Guidelines on the Treatment and management of Bladder Cancer as a minimum. Most are not, and we need urologists and oncologists to raise their game on this Cinderella cancer.

What do we want?

NON-INVASIVE BLADDER CANCER

Life with non-invasive bladder cancer is a life of worrying if it will come back, and whether it will spread.

We need something less intrusive than a cystoscopy for regular checks. We need a non-intrusive test we can rely on.

Every bladder cancer patient needs to know and understand the risks associated with their diagnosis. Only then can they become part of the team helping to keep them alive.

Bladder cancer patients have a lifetime relationship with their condition. We need the medical profession to understand how and when to talk about details with the patients and carers. The lack of understanding causes fears and worries. Explanations and ongoing support will stop this cancer from being at the bottom of the NHS Patient Experience survey year after year.

We urgently need a better treatment for high-risk, non-invasive bladder cancer. BCG has a high failure rate, is often not tolerated, is very invasive and has very painful side effects. Should the patient have 1, 2 or 3 years of treatment? What should happen after year 3 if it comes back again?

Our research has shown that patients with high-risk non-invasive bladder cancer feel the most alone and ignored. They feel that they don’t have a champion for their illness. Not having surgery and not having chemo, who is really looking after their interests?

We need a more robust supply chain for BCG in the UK. The fiasco of the recent shortages cannot be allowed to be repeated.

We need an alternative to Radical Cystectomy (RC) for “BCG failures”. Having an RC might be the right way forward. Indeed, it might be a better treatment than BCG for many patients. But how do we ensure that we don’t have overtreatment? Is this not a very blunt instrument for a non-invasive cancer?

INVASIVE BLADDER CANCER

From a patient perspective a diagnosis of invasive bladder cancer makes you feel that you are most likely going to die. We look at the statistics on all the general websites and see the percentages mentioned. But what are the treatments offered?

It’s surgery or radiotherapy, but the medical community still can’t tell you which is best. In fact, most patients still don’t get told that there are alternatives to surgery. The new NICE guidelines on this must be adhered to.

We see it as a big failure that a patient is left trying to make a life-changing choice with no real information. We want the SPARE trial to be started again in some form – and this time to be completed.

What type of surgery? A neo or a stoma?

Where is the advice on these? Is one better than the other? Does either have more complications? What are the quality of life issues? Are these issues short term or long term? How do we choose?

As patients we feel left alone with this decision that has enormous implications for our quality of life post surgery. Anecdotal evidence needs to be replaced by robust research and guidance based on the patient’s particular circumstances.

Communication and support

We call it “being in the waiting room”. Those times when we sit there waiting to hear results, what is going to happen next and waiting to hear when our next essential checkup might be.

We are often not told what our diagnosis actually is. What the risks are. What we should do to help prevent recurrence, or spread. What the best diet should be. What side effects we should report to our medical team and which ones we don’t need to. Are there any side effects that mean that I should go straight to A&E?

We see some very good and very bad examples of communication between medical teams and their patients. Improvements in this area are essential. We need a Quality Standard for Communication and Support.

**Urologists, oncologists,
researchers, industry,
funding bodies: we
need your help. To make
a difference, please
email us at [research@
fightbladdercancer.co.uk](mailto:research@fightbladdercancer.co.uk)**



About Fight Bladder Cancer

Fight Bladder Cancer is the only patient and carer led charity for bladder cancer in the UK.

At Fight Bladder Cancer, we take great care to provide up-to-date, unbiased and accurate facts about bladder cancer. We have a very supportive medical advice panel made up of some of the best professionals working with bladder cancer, and hope that our information will add to the medical advice you have had and help you to make decisions.

To donate, go to our **Just Giving** page:

[justgiving.com/fightbladdercancer](https://www.justgiving.com/fightbladdercancer)

or text **FBCD00 £5 to 70070**

Registered charity **1157763**

Please note that our services are not intended to replace advice from your medical team.

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YOU CAN FIND A WEALTH OF INFORMATION, SUPPORT
AND ADDITIONAL DOWNLOADS ON OUR WEBSITE:

[fightbladdercancer.co.uk](https://www.fightbladdercancer.co.uk)