

# fight

## MAGAZINE

WE TALK  
ABOUT  
**SEX,**  
RELATIONSHIPS  
& FAMILY

JOIN US AS WE PEEK UNDER  
THE COVERS & FIND OUT HOW

**BLADDER CANCER  
CAN AFFECT  
YOUR SEX LIFE**

### **BEYOND BCG**

HUGH MOSTAFID LOOKS AT WHAT  
THE FUTURE HOLDS FOR PATIENTS  
NEEDING BCG TREATMENT

### **IS PENILE PROTHESIS SURGERY RIGHT FOR YOU?**

ASIF MUNEEB ADDRESSES END-  
STAGE ERECTILE DYSFUNCTION

### **REAL STORIES**

FBC FORUM MEMBERS SHARE  
THEIR EXPERIENCES OF LIVING &  
LOVING WITH BLADDER CANCER



## THIS MONTH'S CONTRIBUTORS

**Dr Alison Birtle**

Consultant Clinical Oncologist, Lancashire Teaching Hospitals

**Jim Catto**

Professor of Urological Surgery, University of Sheffield

**Kathryn Chatterton**

Bladder Cancer Nurse Cystoscopist, Guy's Hospital

**Andrew Winterbottom**

Founder & Director, Fight Bladder Cancer

**Fiona Sexton**

BAUN President & Independent Urology Nurse Specialist

**Kate Bohdanowicz**

Journalist & FBC Confidential Forum Member

**Dr Sally Appleyard**

Specialist Registrar in Clinical Oncology, Sussex Cancer Centre

**Dr Ashok Nikapota**

Consultant Clinical Oncologist, Sussex Cancer Centre

**Dr John McGrath**

Consultant Urological Surgeon, Chair of BAUS Working Group on Enhanced Recovery

**Shievon Smith**

Urology Oncology Nurse, Broomfield Hospital

**Melanie Costin**

FBC Trustee & Support Co-ordinator

**Andy Quick**

FBC Confidential Forum Member

**Tracy Staskevich**

Co-Founder & Chairman of Fight Bladder Cancer

**Richard King**

FBC Confidential Forum Member

**Ann Moore**

CNS Warwick Hospital & FBC Confidential Forum Advisor

**Fight Magazine**

Fight Bladder Cancer

36 Station Road

Chinnor

Oxon OX39 4QH

+44 (0)1844 351621

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

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

**Editor**

Wendy Hobson

**Deputy editor**

Susie Williams

**Stock photography**

Shutterstock.com

**Print**

Henry Stone Ltd

**Advertising**

Contact

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

find out about our advertising rates  
and get a media pack.

**Subscriptions**

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me for free online at

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please just drop us an email at [info@fightbladdercancer.co.uk](mailto:info@fightbladdercancer.co.uk)

*This magazine is not intended as a substitute for the medical advice of doctors.  
Readers should consult their medical team in relation to their treatment.*

# Why we need to talk about sex & relationships

Let's be honest, bladder cancer diagnosis and treatment is by its nature very intimate and invasive, which can have a major effect on relationships and on family life. But, with the right support, we can mitigate that impact.

All the tests and the essential treatments can seriously affect our emotional state as well as the physical side. Combined together, relationships and family life are often put under immense strain.

That is hardly surprising when both investigation and treatment are highly invasive. With bladder cancer it's all about your 'private bits' – things poked up here, liquids pushed up there, things cut out from here, radiation beams targeted there. Catheters, stomas, erectile dysfunction, vaginal shortening, incontinence, pain, tiredness and more pain.

From talking to the 1000's of patients who we support directly each year, we know that this affects the whole family, especially those closest to us. The treatments themselves can have a profound impact on our bodies in the most physical of ways, some short term and some life changing. Self worth and body image can be impacted alongside the physical side, all resulting in the potential of a traumatic effect on our sexual and emotional relationships.

Yet it is a subject that is hardly ever talked about except between patients themselves.

Bladder cancer comes at the bottom of the NHS Cancer Patient Experience Survey and we know that the quality of life that flows from diagnosis and treatment is a big part of the problem. We wait for a diagnosis, we wait for results, we wait for treatment, we feel alone with our cancer.

Bladder cancer can be a very lonely diagnosis and the effect on relationships can make it much worse. If you are a patient or carer, be brave and talk to someone about getting any help or support you need. If you are a medical professional, do take notice of the reality of this disease and signpost your patients to the care and back-up they deserve.

Support for bladder cancer patients for any emotional, relationship or sexual problems is few and far between. This must change, but it needs us as patients to talk about it with our medical teams and for the clinicians and nurses to listen and ensure that we get the support we need.

## LET'S GET THIS OUT IN THE OPEN.

This is important and this is why we have dedicated a large part of this edition of the FIGHT magazine to sex and relationships.

As a charity, Fight Bladder Cancer's aims are simple. We have four key objectives:

### SUPPORT

Supporting all those affected by bladder cancer

### AWARENESS

Raising awareness of the disease so it can be caught early

### RESEARCH

Campaigning for and supporting research into this much-ignored disease

### CHANGE

Affecting policy at the highest levels to bring about change

Team FBC

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

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

We take great care to provide up to date, unbiased and accurate facts about bladder cancer.



[FightBladderCancer](#)



[BladderCancerUK](#)



**bladder  
CANCER**

Registered charity 1157763



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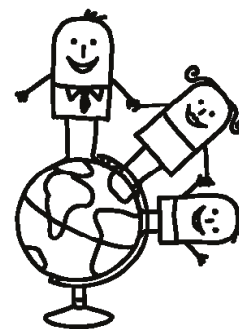
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# FBC round up



Find out what's happening with the charity both here at home and across the globe.

## SUPPORT

### FIGHT CLUBS EXTEND THEIR REACH

With the help of a Big Lottery grant, we are now increasing the number of FIGHT clubs across the country and are happy to announce that we have our first Scottish club launching on 27 June in Glasgow at the Maggie's Centre at the Gartnavel Hospital followed soon after by one in Canterbury on 26 July (hosted for us by our friends at the local Waitrose store in the St George's Centre). For more details, do contact the FBC offices (see inside front cover).



## AWARENESS

### WALK FOR BLADDER CANCER LAUNCH

As we write this, we are coming to the end of an amazing Bladder Cancer Awareness month. Without a doubt, it's the biggest series of events we have ever organised here at FBC, concluding in the launch of the new Walk for Bladder Cancer that we intend to repeat every year and grow to become a significant part of our awareness campaign strategy. Look out for more pictures in the next edition of FIGHT.



### GLOBAL SUMMIT FOR BLADDER CANCER

For the first time ever, we were able to bring together in London in March representatives from bladder cancer patient advocacy groups from across the world. This initiative was organised with the help of our friends in the ECPC and funded by Roche. It was great for us in the UK to meet up and exchange ideas with our friends from America, Canada, Spain, Italy, Romania, Greece, Turkey, Belgium and the Netherlands.

Great strides were made in joining up our work and we are all now working to have May as a global Bladder Cancer Awareness month that concludes with our Bubbles for Bladder Cancer initiative.

## RESEARCH

### BLADDER CANCER PATIENT EXPERIENCE SURVEY

Fight Bladder Cancer is a keen supporter of the ECPC (European Cancer Patient Coalition) and our founder, Andrew Winterbottom, sits on their board as treasurer. FBC leads on bladder cancer for ECPC, and this year we are setting up a pan-European working group of bladder cancer patient organisations and experts, to help us develop a bladder cancer patient experience survey, so that we have some really robust data on the reality of the patient experience. This will provide vital data for campaigning for improvements, which will always be a core objective of FBC.

### PATIENTS SUPPORTING RESEARCH

FBC has been involved with medical research for many years now through the Bladder Cancer Clinical Studies Group and by supporting individual trials. With increasing numbers of trials being started and with being asked by NICE to be engaged with the review of the many new immunotherapy drugs, we have launched a panel of Patient Representatives who will help scope trials and sit on trial management boards across the UK. If you are interested in joining this panel as a patient or carer, please do get in touch.

## FBC GROWTH



### WE'VE MOVED!

If you are sharp eyed, you will see that our address has changed for this edition because we have moved the charity out from the offices behind the Wee Bookshop and Café into our own offices to allow us to grow and succeed in all our charity objectives. One of the great things about the new offices is that we have space for two graduate interns, who are joining us for the summer, and for other volunteers who will be helping us out for one or two days each week.

If you want to  
join our volunteer  
team, do get in touch.  
We have a desk  
waiting for you!



### NEW BOARD OF TRUSTEES

With the growth of FBC, our board of trustees has recently changed with a number of our Founding Trustees stepping down to allow us to strengthen the knowledge, skills and talents of the board to ensure that we have the best governance possible. We'd like to say a big thank you to them for their many years of hard work and support.

#### FBC's new trustees and roles are:

##### John Hester (Chair)

Financial controller by profession and bladder cancer patient

##### Deborah Major (Vice Chair)

College lecturer and bladder cancer patient

##### Melanie Costin

(Support services manager)

Artist, musician, draftsman and bladder cancer patient

##### Val Hester (Secretary)

Carer and previously senior nurse within NHS in Wales

##### Paul Major (Treasurer)

Learning skills assistant, previously IT guru and carer

##### Hilary Baker

Lead clinical nurse specialist for urology at UCLH

## AND FINALLY ...

### A VERY HAPPY BIRTHDAY TO THE WEE BOOKSHOP AND CAFÉ!

It doesn't seem possible but our Wee Bookshop and Café that helps raise funds for FBC and promotes awareness, is now a year old. And what an amazing year it has been.

Not only has the café and bookshop gained the status of being No 1 on Trip Advisor in the area, but we have had over 54,000 visits by customers and community groups. It also still makes the very best cake and coffee in the county!

## Giving you support

### 24/7 SUPPORT, 365 DAYS A YEAR

Over the last six years we have helped more than 5,000 people on our **Confidential Support Forum**. The forum is a core component of our patient and carer support services with a strong community of people affected by bladder cancer. Patient, carer, family or best friend, the forum is there for you to get and give support.

### BLADDER BUDDIES

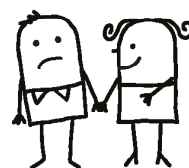
Not everyone is happy to talk and ask questions within our confidential forum, so we provide a nationwide Bladder Buddy Service where we match people up on a one-to-one basis with someone who has been in the same situation or has had the same treatment. Someone to talk to privately, either on the phone or over a coffee, about worries or concerns, treatments and side-effects.

### LOCAL SUPPORT GROUPS

Fight Bladder Cancer started as a small local support group so we know the value of face-to-face interaction with fellow patients. We have launched a linked network of local support groups that offer a more sustainable group support service to the bladder cancer community. Contact the FBC office to find your nearest support group.

Find out  
more about  
how we can  
support you at

[fightbladdercancer.co.uk/  
get-help](http://fightbladdercancer.co.uk/get-help)





# BEYOND BCG

## What does the future hold for patients needing BCG treatment?

Bacille Calmette Guérin (BCG) was originally developed in the 1920s from cow tuberculosis as a vaccine to immunise humans against TB. Doctors noticed that patients with bladder cancer previously immunised with BCG seemed to do better than those who hadn't been immunised, and in the early 1970s a urologist called Morales reported the first use of BCG as a treatment for high-risk non-muscle-invasive bladder cancer (NMIBC).

### ARTICLE

HUGH MOSTAFID MSc FRCS (Urol) FEBU  
Consultant Urologist, Honorary Senior  
Lecturer, Royal Surrey County Hospital

BCG was the first effective immunotherapy against any cancer – ironic given the fact that drug companies are spending hundreds of millions of pounds to develop new immunotherapies, such as the immune checkpoint inhibitors.

### Coping with shortages

There have already been two BCG shortages this decade. In 2012 a flood in Sanofi's manufacturing plant led to a world-wide shortage of their Connaught strain of BCG. This left MSD as the manufacturer of the only other BCG licensed in the UK – Oncotice. However in 2014, production problems with Oncotice led to another UK BCG shortage. The British Association of Urological Surgeons (BAUS) worked closely with the Department of Health (DoH) to produce guidelines for this unprecedented scenario. Having slowly seen a return to normal levels of BCG production in the last year, Sanofi have announced that they are ceasing production of their Connaught strain of BCG but have enough BCG stockpiled to last until the end of 2018. In the meantime, a German company called Medac have a BCG that is licensed for use in Europe except for the UK. They are working closely with the DoH and BAUS to ensure that their BCG is licensed in the UK as soon as possible.

These problems stem from the fact that BCG is a live organism that has to be produced in sterile conditions – very nearly a contradiction since most methods used to achieve sterility by definition kill all living micro-organisms including BCG. Added to this is the fact that the BCG dose for bladder cancer requires colossal amounts of BCG – an initial treatment course of six vials of BCG for a single patient with bladder cancer uses the same amount of BCG as is required to provide all the UK BCG vaccine needs for one year! Given these problems and increased regulation, it is likely that BCG shortages will occur more often in the future, so what are the alternatives?

**... the BCG dose for bladder cancer requires colossal amounts of BCG – an initial treatment course of six vials of BCG for a single patient with bladder cancer uses the same amount of BCG as is required to provide all the UK BCG vaccine needs for one year!**

### **More judicious use of BCG**

Although it is common in America for patients to receive just a six-week induction course of BCG, in Europe and the UK most patients go on to receive maintenance BCG. There is increasing evidence that for most high-risk NMIBC patients a one-year maintenance course of BCG is perfectly adequate unless the patient also has carcinoma in situ, which is a particularly persistent type of bladder cancer, in which case they should receive three years of maintenance BCG. This more judicious use of the BCG we have should mean that available supplies are used more effectively.

### **Mitomycin and device assisted therapy**

Some patients with intermediate-risk NMIBC are offered BCG and could safely be offered Mitomycin chemotherapy bladder instillations, which are as effective as BCG in this group. For high-risk NMIBC patients, Mitomycin on its own is not as effective as BCG. However, using device assisted therapy (DAT) with either a heating device (hyperthermia) or an electrical current (electromotive therapy) seems to increase its absorption into the bladder lining and hence its effectiveness. We are still not sure that DAT with Mitomycin is as effective as BCG but there are trials under way which will hopefully answer this question.

### **Robotic radical cystectomy (bladder removal)**

Radiotherapy does not work against high-risk NMIBC so the only other option other than BCG for such patients is total removal of the bladder (radical cystectomy). In the past this involved a two-week stay in hospital and a prolonged recovery but using a robot to help perform the operation using a keyhole technique means that patients can go home in as little as four days with a much shorter recovery period.


In addition, in selected patients it is possible to construct a reservoir (also called a neo-bladder) so that the patient can pass urine as before and does not need to wear a urine bag afterwards. The development of robotic radical cystectomy in high-volume specialist centres is a major advance for bladder cancer patients and is likely to mean more high-risk patients may choose this option at the outset rather than BCG. Ironically, the DoH have not yet decided to fund robotic cystectomy on the NHS. This would be simply inconceivable if this was an operation for breast cancer – another example of how bladder cancer patients lose out when compared to other cancers.

### **Immune checkpoint inhibitors**

These drugs have been developed by pharmaceutical companies at a cost of hundreds of millions of pounds and are the next generation in cancer drugs. The currently used drugs – called PD-1 inhibitors – work by stopping cancer cells from ‘switching off’ the body’s immune cells (called T-cells), which normally recognise and attack cancer cells. These have shown great promise in more advanced bladder cancer and there are now trials under way in using them for high-risk NMIBC. These drugs are extremely expensive and it remains to be seen whether using them in high-risk NMIBC is cost-effective. Positive campaigning by bladder cancer patients and charities will be important to ensure that they are made available to patients if they prove to be effective for high-risk patients.

### **Conclusion**

It seems likely that we will face regular BCG shortages in the future. Although there is no ready-made replacement, medical developments including device assisted therapy, robotic cystectomy and developments in immune-oncology drugs may well offer effective alternatives.

A photograph of a couple lying in bed, partially covered by a white sheet. The man is on the left, and the woman is on the right. Two thought bubbles are present: one above the man saying "Will I ever feel sexy again?" and one above the woman saying "Will I stop having orgasms?".

Will I ever feel  
sexy again?

ARTICLE

ANDREW  
WINTERBOTTOM  
Founder & Director,  
Fight Bladder Cancer

Will I stop  
having orgasms?

# Will bladder cancer affect your SEX LIFE ?


Let's start by dispelling a myth. Treatment for bladder cancer across the whole pathway can affect relationships and sex for us patients. It is not just radical surgery or radiotherapy for muscle-invasive bladder cancer that causes these problems.

Cystoscopies, TURBTs, Mitomycin and BCG installations and the whole rollercoaster of physical effects and emotions that follow can take a serious toll on our quality of life. But notice the word 'can', because some people have a much easier ride than others. What is crucial to avoiding problems, or solving them quickly if they arise, is

that everyone understands that they may need advice and support.

Sexual dysfunction and intimacy problems are not only experienced by the patient – they are a couple's disease. When a man or a woman is suffering from sexual dysfunction, problems with intimacy or a relationship, it is crucial that both partners are





Is it safe to have sex  
when having BCG?

I just feel embarrassed,  
is this forever?

involved in understanding and dealing with the issue. It doesn't matter if it's for non-muscle-invasive bladder cancer or even for muscle-invasive disease, it is always better that both partners are involved in the conversation, because this affects both men and women.

**We asked how having bladder cancer has affected our forum members and their sex lives ... here are some of their replies.**

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

'The whole bladder cancer experience has made me value what is really important.'

'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 I'm still here and enjoying every day.'

## Men, sexuality & performance

Sexual dysfunction in men goes beyond that of just erectile dysfunction. Our sexual 'performance' is often hard-wired into our self-worth. Whether this is nature or nurture can be debated endlessly, but this is the reality. Consequently, the nature of a bladder cancer diagnosis and treatment can have a dramatic effect on our emotions, in addition to any physical effects.

From the moment bladder cancer is suspected, we can feel that our dignity has to take second place to the need for investigation and treatment. Investigation and treatment that for most of us involve things being inserted into our penis. We soon get to realise that this will be an ongoing round of cystoscopies, TURBTs and installations of Mitomycin or BCG. We know that we will have to endure it but we don't like it. Just way too invasive. Just wrong.

And for those of us who need radical surgery or radiotherapy for muscle-invasive bladder cancer, well, that is something none of us would ever sign up to if we were given a choice. The results are fundamental and life-changing. No more erections. Loss of self-worth. Embarrassment.

There are a number of deformities that can occur in a man's penis that can affect how they obtain an erection. Importantly, there are other effects on orgasm or ejaculation that are extremely prevalent in men following surgery to remove the bladder and the prostate.

### Sex, stress and emotions

It is also likely that we will develop disorders of sexual desire or libido, as it used to be called. As men and women get older, sexual desire tends to decrease. This goes beyond just hormonal influence, it also involves our relationships, as well as other ongoing medical conditions.

Other emotional predictors of erectile dysfunction in men are emotional problems or stress. The continuous journey of investigations and treatment with bladder cancer can affect any of us men in this way. We all know that a cancer diagnosis of any type is a very stressful experience, and likely to lead to a decline in erections or even in desire.

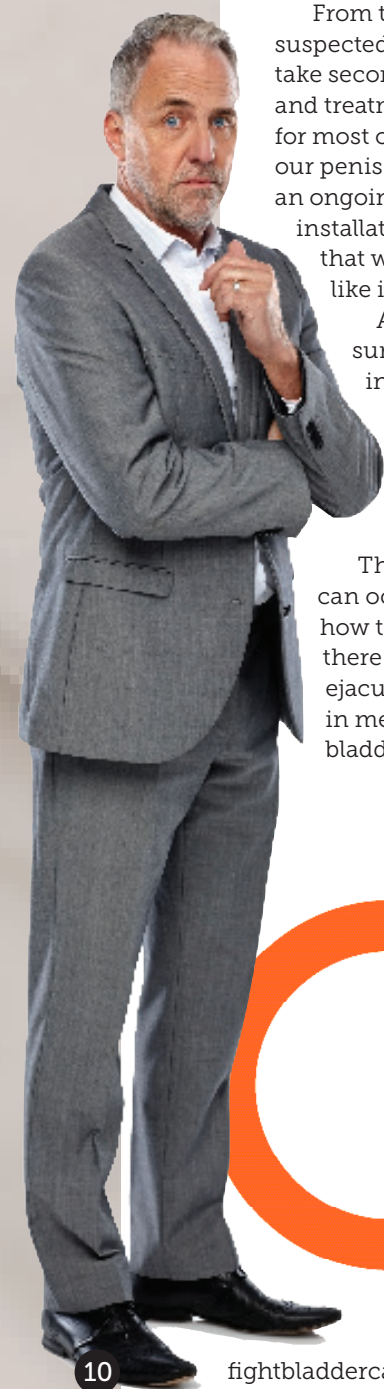
Another common emotional predictor includes depression, which is highly prevalent in bladder cancer patients while they cope with their diagnosis and ongoing medical treatments.

### This does matter

We should never assume that this doesn't matter – it does, almost inevitably. And we need to understand that even older patients who are no longer as sexually active will be affected by this. So it is vital that we take action, even if we don't know how to start the conversation. Because these effects can be mitigated – but only if they are talked about, and talked about openly and honestly between the patient and the medical team.

Treatments for male erectile dysfunction are well established and the physical side can usually be remedied by a range of options from the use of tablets, through mechanical pumps, injections or with penile implants (see page 14). Good signposting of the options and honest advice is essential, together with support on any associated emotional issues.

**Men and women respond to intimacy and sexuality as a result of a bladder cancer diagnosis and treatment in different ways. Is it an exaggeration to say that a man has an on/off switch, whereas a woman has a lot of complexity to their female sexual response?**



## Women, sexuality & body image

Female sexual dysfunction is something that could be said to include a number of different issues, including body image. This makes supporting women with bladder cancer a potentially complicated area. With erectile dysfunction in men, a simple questionnaire will identify if a man has sufficient erections for intercourse, or if he is able to sustain an erection for intercourse. Whereas with female sexual dysfunction, it is a lot harder to diagnose and certainly a lot less talked about because of a lack of expertise, resulting in perceived difficulty in discussing this with female patients and their partners.

### Recognising female sexual disorder

If we look at some of the more common problems related to sexual dysfunction in women, we see very similar things to men: inhibited sexual desire and a lack of desire. When we look at risk factors for a hypoactive sexual disorder in women, we see that there are hormonal changes. As women get older, or post-menopausal, they can experience a decline in their desire. Ongoing medical conditions and treatments, including cancer treatments, will contribute to this, as will depression, fatigue and stress. Another factor in women is inability for the vagina to become lubricated. This can be related to hormones or the nervous system, as well as blood flow to the vagina.

Inability to orgasm is something that can also be related to bladder-cancer treatment in women. A major factor can be the emotional stress and the resultant connectivity with their partner. When women experience problems with orgasm, they often need to have sexual counselling to discuss the contributory factors.

For arousal and orgasm, the clitoris must be stimulated and become erect. This can only occur if there is an intact nervous system or blood flow to the vagina and clitoris, which follows with blood flow and lubrication of the vagina.

The mechanism of female sexual arousal response is almost exactly the same as male sexual arousal response, with stimulation from the central nervous system which then sends a signal through the nerves that stimulate the vagina and clitoris. If there is a problem with

this stimulation, there will be impairment of erection and vaginal engorgement, and therefore sexual dysfunction.

### Subtleties of treatment

Treatment for female sexual dysfunction has to be nuanced according to the specifics of the problem. Treatment of the physical effects can be as simple as the use of lubricants that can be bought over the counter. When it comes to hormonal therapy, local oestrogen is often used and can help with lubrication.

After radical surgery, it is likely that vaginal dilation will be required and guidance will be essential. Pelvic floor exercising to improve blood flow can be effective, and relaxation techniques can help improve both the stimulation of the vagina and clitoris. Various medications can also influence female sexual arousal and orgasm, so these need to be investigated. It is also beneficial to stop smoking.

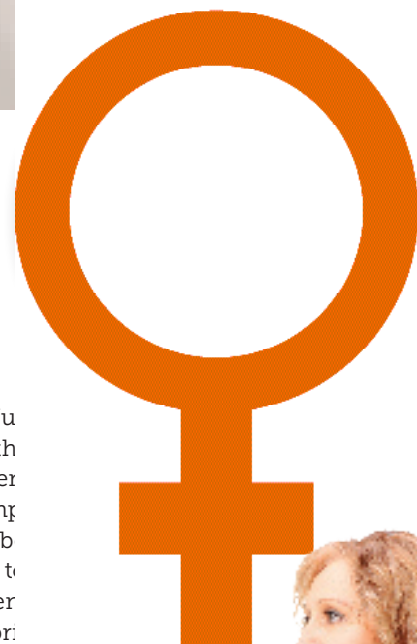
### Emotional support

For the emotional aspects, additional things such as sex therapy and counselling can be a great help in supporting relationship issues. Never just have the physical effects treated. Relationships are crucial.

With sexual dysfunction in both men and women, it always goes beyond that of just organic or surgical causes. Relationship issues are always extremely important. All couples should be offered the support of a counsellor to talk to.

Bladder cancer is an emotional rollercoaster as well as an invasive physical experience. Without treatment and support for both, the bladder cancer patient will continue to have a poor experience and the probability of a reduced quality of life.

**Treatment for the physical effects can be as simple as the use of lubricants that can be bought over the counter.**





# A beginner's guide to ERECTILE Dysfunction

We talk to specialist nurse Joe Kearney about the help available for men with erection problems.

## So Joe, what is erectile dysfunction?

Erectile dysfunction, or ED as we tend to call it, can affect many men at some time in their lifetime. ED is the inability to maintain or achieve a penile erection sufficient for satisfactory sexual performance.

There are many reasons why a man might develop ED over their lifetime. These include age, diabetes, neurological diseases, smoking, cardiovascular disease, trauma and pelvic cancers or pelvic surgery.

Erectile dysfunction is a very common condition, particularly in older men. It is estimated by the NHS that half of all men between the ages of 40 and 70 will have it to some degree.

For male patients who need to have radical treatment for muscle-invasive bladder cancer, it is most likely that they will encounter erection problems. However, there are many things that we can do to help them have a normal, healthy sex life again.

## Tell us about this help you can offer

We hold regular clinics to help men with ED as a result of urological treatments. We started these in 2002 with a visiting specialist but since 2008 we have a dedicated uro-oncology clinical nurse specialist

Men coming to see me include those who have had bladder, prostate, renal or testicular cancers or treatment for these cancers. Most men will experience complete ED following treatment for prostate cancer or muscle-invasive bladder cancer. Some men may have had ED years prior to treatment of urological conditions but for whatever the cause, we can usually find a successful solution.

## What are the different treatment options?

There are many treatment variables, but first-line treatment tends to be by a combination of a vacuum device and trial of one of the

three PDE5 inhibitors: sildenafil (Viagra®), tadalafil (Cialis®) or vardenafil (Levitra®). If these methods are ineffective or unsuitable, then we are likely to consider injections or insertions of Alprostadil. Should that not help the problem, then the vacuum device or the PDE5 inhibitors can be reconsidered before thinking about penile implants.

## Do the simple vacuum devices work?

Vacuum devices used to be prescribed nationally for men with ED, as they were considered very useful to assist with penile rehab and the return of erectile function following treatment for muscle-invasive bladder cancer. They can also be used to enhance the effects of PDE5s and, with the supplied constriction rings, can be used for intercourse. Since 2002, however, some clinical commissioning groups (CCGs) and primary care trusts (PCTs) have stopped funding these on the NHS.

## ARTICLE

JOE KEARNEY

Uro-Oncology Clinical  
Nurse Specialist at Bucks  
Healthcare NHS Trust

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The use of vacuum devices is not recommended in some countries but recent meta analysis and research studies do still indicate their effectiveness. If you want to try a vacuum device you might need to buy one privately but do ask first in case they are still funded in your area. There are very few risks in using these pumps and we know that they are effective once they have been explained and demonstrated.

### **What are PDE5 inhibitors?**

PDE5 inhibitors are a common recommendation for ED. They include well know drugs such as Viagra® and Cialis®. With these drugs it is important to ensure that you take them on about eight occasions before you can decide how effective they are for you. They do come in different strengths so make sure you get a balance that works for you.

We have found that PDE5 inhibitors work best for men who have not had ED prior to

their bladder-cancer treatment. Combining them with using a vacuum device works very well so is definitely worth trying.

Overall these drugs work well for quite a few men but don't worry if you don't have much success, as there are other things we can do to help.

### **What else can be tried?**

There is a drug called alprostadil that can work very well. There are three different ways to take it and one might suit better than another. Alprostadil comes as a simple cream (Vitaros®) that you massage into your penis, a MUSE pellet that you gently insert into tip of your penis or as an injection. The injection is into the side of your penis. I know that this sounds crazy but you do quickly get used to doing this. The fear is certainly worse than the reality!

### **And if none of these works very well?**

The majority of men are able to get a good erection with one or another of these ways to help.

However, if none of these works for you, there is the option of having a penile implant. Quite an expensive operation for the NHS but it is available free of charge in England if the other methods haven't worked.

Penile implants do involve surgery that some might not want but the satisfaction rates are around 90% or more for both the patient and his partner.

### **Any final thoughts, Joe?**

Putting it bluntly, your potential erection problems will not be your first concern after your bladder-cancer surgery but when you are ready, do go and talk to your CNS and get referred to specialist. We can help and we will work with you to find which is best treatment for you.

**We can help and we will work with you to find which is best treatment for you.**

# PENILE prosthesis surgery

## for end-stage erectile dysfunction

With very high patient & partner satisfaction rates (over 90%), a penile prosthesis, or implant, represents a successful final option for the treatment of end-stage erectile dysfunction (ED).

Originally developed in the 1970s, and refined through the following decades, a penile implant provides a durable and safe option for men who have tried and exhausted all the available medical treatment options. Although the original versions of the penile prostheses were not as robust, the modern prostheses have a much higher mechanical reliability and are associated with low infection rates of less than 2% in the largest implanting centres.

Perhaps the most significant improvement has been the antibiotic coating. American Medical Systems (AMS) introduced Inhibizone™ (rifampin/minocycline) coating for their prostheses in 2001 and Coloplast introduced a hydrophilic coating, to allow surgeons to select their own antibiotic coating, around the same time. The results have been a greater than 50% decrease in infection rates for prostheses.

### Patient and implant selection

Penile prosthesis surgery is considered end-stage treatment for ED and specific considerations in the medical background of the patient will often determine the best type of penile prosthesis for each patient. Apart from the patient's own

preference, previous pelvic surgery such as cystectomy or colorectal surgery, manual dexterity, and additional medical conditions such as diabetes mellitus and immunosuppression, or penile disorders such as Peyronie's disease and priapism are taken into careful consideration when choosing the most suitable penile prosthesis.

It is important for patients to review the various implants available with the clinicians and to have enough time to process all the information before making a final decision. It is also recommended that they should be seen with their partner so that both of them are aware of the risks and post-operative expectations. Patients should be shown samples of the implants in order to allow them to appreciate the texture of the cylinders and familiarise themselves with the shape of the pump and the technique of cycling the device.

Malleable implants have fewer components and are easier to manipulate, so are suitable for patients who either have limited dexterity or have had previous surgery which may not allow placement of the reservoir into the abdomen.

### ARTICLE

MR ASIF MUNEEER,  
MD FRCS(Urol)  
Consultant Urological  
Surgeon & Andrologist,  
University College  
London Hospital





## Types of penile prosthesis

### Malleable penile prosthesis (Semi-rigid implant)

This consists of two rods which can be bent but stay semi-rigid all the time. These implants are simpler to place into the penis and do not have any additional components and therefore the risks of device malfunction is lower. However, some patients do not like the idea of a penis remaining rigid all the time.



### Inflatable penile prosthesis

This is the most commonly used implant as it cycles to mimic a natural erection and is concealable when not used. Most of the inflatable implants used will allow rigidity when inflated as well as penile girth but will not give additional penile length. The components consist of two inflatable cylinders made of silicone and a pump, which is placed in the scrotum. When inflated, fluid moves from the reservoir into the cylinders and can then flow in the opposite direction when the deflate button is pressed.



## The surgical procedure

Most implants are performed under a general anaesthetic and require patients to stay in overnight. Often a catheter and drain are inserted and removed the following day.

The incision is performed in the scrotum just under the penis and the tissue within the penis is dilated to create space for the cylinders. This is the only incision required for a malleable implant although with the inflatable implant, a separate incision in the abdomen is sometimes required to place the reservoir.

Patients can go home the following day but can't use the implant for sexual activity for at least six weeks.

### Possible complications

As with all surgical procedures there can be complications. With this particular surgery there is a small risk of a collection of blood around the scrotum, which tends to resolve itself, as well as a less than 2% risk of implant infection which will require removal of the implant. Over 80% of inflatable implants are still functioning at 10 years.

Find out about  
treatment options for  
early stage ED on  
page 12.



**A durable and safe  
option for men who have  
tried and exhausted all  
the available medical  
treatment options**

## If you are considering penile implant surgery?

Penile implants surgery is very specialised but there should be a centre which offers the surgery within your region. There are about 12 high-volume centres around the UK with the largest being at University College London Hospital, which currently has the second largest volume performed annually worldwide.

If you have had major pelvic surgery or have tried all the options for erectile dysfunction that you are eligible for, surgery is an option, provided you meet the criteria related to body mass index and diabetic control. Have a discussion with your doctor about this option and you can request a referral to a specialist. You may also find it helpful to speak to others who may have already undergone the procedure.

# ROBOCOCK

One couple's search for a rock-hard erection after BC

## OP DAY (minus six months)

**Him:** Being diagnosed with invasive bladder cancer meant that all I could initially think about was whether I would still be alive this time next year. The idea of having my bladder removed completely freaked me out and I had no idea how I would live a normal life without it. Six months later, though, and I'm still alive, and being a bloke, sex came back into my brain. But BAM ... I realised quickly that the surgery that saved my life had also lost me my manhood.

We tried everything – with the help of a great specialist nurse. First the little blue pills and a vacuum pump but we couldn't get a firm erection. Next the cavaject injections. Once the nurse specialist showed us how to use the syringe, she left us for twenty minutes to 'see the effect'. It worked! We drove home at breakneck speed with an erection good enough for us to have penetrative sex for the first time in a year. The concept of a four-hour erection made us smile. Life could be fun again. I even quickly got used to putting a needle into my penis to have sex but, unfortunately, the results became less and less effective so we kept having to up the dose. Three years on, I decided that I wanted to find a better solution.

**Her:** Until bladder cancer stomped into our lives unannounced we'd always had a great sex life. In fact, we famously once moved a bed from one side of the room to the other without even noticing. Post radical cystectomy, however, things were more difficult. The nerve-sparing procedure in the op hadn't worked

and although we'd tried every option via Steve's sexual specialist nurse, there was nothing that gave a satisfactory erection and our sex life waned. Then Steve came home one day full of details about this amazing operation – an implant that would guarantee a sturdy erection that would last for hours. I asked where I needed to sign.

## OP DAY (minus three months)

**Him:** I am sitting in a cubicle in London with my flaccid penis being stretched and stared at by my new consultant. 'Hmm, good length,' he says as he makes a note on his pad (I hear Jess cover up her laughter with a cough from behind the curtain). It has taken quite a few referrals to get here and long conversations, first with my GP and then my urologist. My fate is now in the hands (quite literally) of one of the best penile implant surgeons in the UK. I've also been shown the different devices by the nurses, and I chose the pump version rather than the rods – just my personal preference. I've done a lot of research and am excited at the prospect of the reported 90% success and satisfaction rate. But I am very, very nervous.

**Her:** Over the last few weeks we've manhandled all kinds of devices (much heavier than I anticipated) and watched videos of men, young and old, proudly pumping up their erections on the internet in the name of research. We've asked a lot of questions and made copious notes. It's starting to feel real now, and the op date is in the diary. Only a week or two off work and no heavy

lifting for six weeks. We head home, laughing all night about the 'good length' comment. It would make a great t-shirt slogan.

## OP DAY

**Him:** We arrive at the hospital in the very early hours of the morning and wait in a deserted reception. All too soon I am whisked away to a ward where I'm gowned up and sitting next to my bed awaiting my call to theatre. There are three other men waiting and I wonder if they're in for the same op (they look nervous enough). I wander up to one of the guys, 'Umm, are you having an implant too?' He looks around at all the others before he softly answers, 'Yes.' The others nod conspiratorially – we're all in it together.

**Her:** I am really bad at waiting, so when I have to sit with Steve in the huge waiting area for them to call his name, my stomach is doing backflips. Yeuch. I feel sick. It's early on a Saturday, so pretty deserted except for a few other guys, also waiting. I wonder if they are here for the same procedure ... all of them are alone and they look distinctly uneasy. Suddenly a nurse calls Steve's name and after a swift hug he picks his bag up and the little group wander off to the waiting lift. It's showtime. I head home to wait by the phone.

## OP DAY (plus one)

**Him:** I'm alive! However, things post surgery are a bit well, unusual. I feel okay but my penis is enormous, inflated and swaddled in a heap of bandages. They bring me a cup of tea and breakfast. I am distracted;

my penis looks absolutely huge and it's hard to ignore the magnitude of dressings and paraphernalia between my legs. Dare I take a photo of it and send it to Jess? I message her and add the caption 'The beast' to my masterpiece. I have a bionic cock .... no, not bionic, a robocock! I have to stop myself laughing – it hurts – and I think what a fabulous job the painkillers are doing. I nap. In the late afternoon I am sent home with a suitcase full of painkillers and antibiotics and instructions to rest. Here starts a whole new world.

**Her:** I had some kind of delirious fool on the phone this morning. They really do give out wonderful drugs in the NHS. This was after he sent me a picture of his penis swathed in bandages. Steve finally sobers up and is discharged early in the evening, walking like someone who's been on a horse a really long time, the odd wince as he eases himself into the car. I hear every suck in of breath at the bumps in the road on our two-hour journey home.

### OP DAY (plus five)

**Him:** My pelvis is a kaleidoscope of colour, with bruising from bright yellow to green, dark purple and black – it covers my nether regions. And I am swollen. Not 'ouch' kind of swollen, but an unbelievable 'oh my god my balls are the size of grapefruit' swollen and I can still barely stand to touch my penis. They said I wouldn't be ready to use it for six weeks and I believe it. I'm mainlining painkillers and need cushions wherever I go like some demanding Arabian lord. For my recovery I need to start inflating and deflating the device a little in the bath every day, following a technique the nurse gave me a very intimate demonstration of. It hurt. I caught Jess just staring at me in the shower today. The swelling must go down soon, surely?

**Her:** I can't help staring at Steve's multi-coloured penis. Quite frankly, it's worryingly enormous and I know he keeps saying it's just the swelling

post op but it still looks like it's all been in a fight. He's meant to be back at work at the end of next week, but if you saw how gingerly he lowers himself onto a seat you'd be sceptical. I am starting to wonder if this is worth it ... all this recovery time and him feeling rubbish. He has a check up this week so I'm crossing my fingers for a marked improvement.

### OP DAY (plus three weeks)

**Him:** My first check up and the nurse watches me inflate my penis – a bit strange but I do it. 'Looking good,' she says. I have to agree, given that my penis has reduced from its Frankenstein proportions of the previous weeks and now looks normal. She tells me to keep practising inflation and deflation but remember that I can't use it until six weeks after the op. I add the date to my diary.

**Her:** Steve's back at work and the pain from the surgery is almost gone. One of the biggest wounds is the cut in his abdomen where they placed the saline reservoir, which is taking a while to heal. The hospital are happy, though, as everything looks normal, he's healing nicely and we're progressing according to plan. Thank goodness, the swelling has gone. Today he wore jeans rather than tracksuit bottoms. Progress indeed.

### OP DAY (plus six weeks)

**Him:** Today is the anniversary of my operation and I was planning to try my new penis for real, but it's still too sensitive. I am getting used to inflating and deflating. I found the keyring copy of the device they inserted really helpful in getting the feel and the technique just right, so I have high hopes!

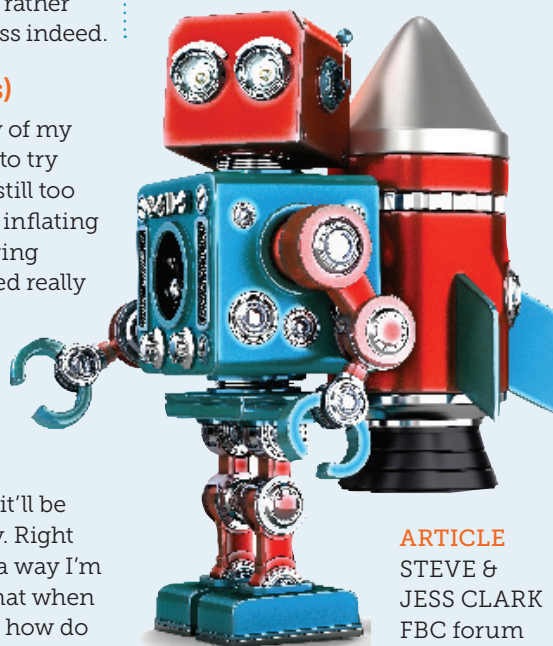
**Her:** In my experience, when hospitals tell you everything will be tickety-boo in six weeks what they mean is that it'll be when your body says it's ready. Right now, Steve's penis says no. In a way I'm glad as I'm starting to worry that when we try it out we'll break it. And how do you explain that to the lady in A&E?

Penile implants are available free on the NHS in England with a referral from your urologist for all end-stage ED patients.

### OP DAY (plus ten weeks)

**Him:** It's Christmas Day. This year we got ourselves the ultimate Christmas present. We did it! And it worked. I am smiling. Now I know why this procedure has such a high satisfaction rate ...it just felt, well, normal. In fact, once I had inflated it, neither of us really thought about it at all, we just had fun. We can't wait to try it out again. I am still smiling. Lots.

**Her:** Well, that was entirely unexpected. I can honestly say that it didn't feel any different to sex before Steve had his bladder removed, in fact I'd say it actually felt better, because we both thought that sex could never be like that again. For anyone out there contemplating this procedure I'd say go for it. You have nothing to lose and everything to gain.



ARTICLE  
STEVE &  
JESS CLARK  
FBC forum  
members





# Resolving female sexual problems

Many women experience sexual problems as a result of bladder cancer treatment and this feature sets out to redress the fact that support and advice is not always readily available.

Researching into this subject was a challenge, as information for female bladder cancer patients appears to be limited to the effect of having a radical cystectomy (RC) or radiotherapy for muscle-invasive bladder cancer.

## What you might expect

This can manifest itself in making you not feel like having sex or you may be worried about sex being painful. This is quite normal. It might help to try relaxation techniques and to talk to your partner about different types of sexual touching to help break down any barriers.

ARTICLE  
SUE WILLIAMS  
FBC researcher

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## NHS Choices

NHS Choices offers the following advice:

### Narrowing of the vagina

Both radiotherapy and cystectomy [for bladder cancer] can cause a woman's vagina to become shortened and narrowed, which can make penetrative sex painful or difficult.

There are two main treatment options available if you have a narrowed vagina. The first is to apply hormonal cream to the area, which should help to increase moisture inside your vagina.

The second is to use vaginal dilators. These are plastic cone-shaped devices of various sizes that are designed to gently stretch your vagina and make it more supple.

It's usually recommended that you use dilators for a five to ten-minute period every day, starting with the dilator that fits in most comfortably first and gradually increasing the size, as your vagina stretches over the following weeks.

Many women find this an embarrassing issue to discuss, but the use of dilators is a well-recognised treatment for narrowing of the vagina. Your specialist cancer nurse should be able to provide more information and advice.

You may find that the more often you have penetrative sex, the less painful it becomes. However, it may be several months before you feel emotionally ready to be intimate with a sexual partner.

Many female patients have told us that a diagnosis of bladder cancer and the subsequent treatment and tests are likely to affect you physically and emotionally and can have a significant affect on relationships and sexuality.



Your bladder-cancer treatment may cause physical changes to your vagina or vulva. This may make sex painful; however, your specialist nurse may suggest creams, lubricants and medicines to help with this.

You may have bowel and bladder problems after treatment or have a stoma or neobladder as a result of surgery. These changes can have a big impact on your sex life. Talk to your doctor or specialist nurse who may be able to treat the side-effects with medicines or suggest ways to help you cope.

### Surgery and its effects

Any type of surgery can affect your sexuality and sex life, even if it doesn't involve the sexual areas of your body. But surgery that directly affects these areas may cause quite noticeable changes. Your surgeon and specialist nurse should talk to you about the surgery and how it might affect you.

During a radical cystectomy, your surgeon may also remove your womb, ovaries, part of the vagina, the urethra (the tube that drains urine from the bladder) and the fallopian tubes. The surgeon will explain this to you before the operation. Your surgeon may do a reconstruction of your vagina. This may make it shorter or narrower than it was before.

Having your ovaries removed will cause an early menopause and menopausal symptoms if you haven't already reached your natural menopause.

If you have your urethra removed, the end where it opens outside the body is also often – but not always – removed. This can affect the blood supply to the clitoris, making it less responsive to arousal.

If you have a stoma, there's a high chance of permanent damage to the blood supply and the nerves in your genital area. It's not clear how this type of operation affects arousal and orgasm. Your surgeon or specialist nurse will be able to give you more information about this before your operation.

**If you're having sexual difficulties, do not suffer in silence. It is important to talk about it with your GP or specialist nurse. A sex therapist or counsellor may also be able to help you with some of these issues.**



## Chemotherapy and sexuality

Chemotherapy uses anti-cancer drugs to destroy cancer cells. Some of the side-effects of chemotherapy can reduce your sex drive. These side-effects include feeling sick, weakness, depression and a lack of energy. Many of these can be reduced or stopped with medicines.

Usually there's no medical reason to stop having sex during chemotherapy. But if you have low platelets or a low white blood cell count, you may be advised to avoid penetrative sex until your blood count improves.

## Radiotherapy and sexuality

Radiotherapy can also cause side-effects that may affect your sex life. It may cause skin reactions. The treatment area can become sore and itchy, which can make sex difficult. This can also affect the way you feel about how you look.

Radiotherapy can also cause extreme tiredness, which can go on for weeks or months. You may find you're too tired to have sex.

Radiotherapy to the pelvic area (the anus, rectum, bladder, vagina, vulva, cervix or womb) may cause other side-effects, including:

- diarrhoea and feeling sick
- pain or bleeding in the bladder or rectum
- vaginal bleeding
- hormonal changes.

Most of these side-effects are temporary and there are ways to cope with them. However, if the ovaries are affected by the radiotherapy, this may cause a permanent menopause. Talk to your nurse specialist about this.

The female sex organs are both inside (womb, cervix and ovaries) and outside the body, in which case such areas, including the vulva, the breasts, nipples and other areas of the body, may become hypersensitive to touch.

Don't be embarrassed  
about bringing up sex with  
your medical team. They are  
there to help you!

Sex drive is very closely linked to how we feel. If you are anxious or depressed due to cancer, you may have difficulty feeling sexually aroused. It may help to talk to someone about these difficult feelings.

## Sexual feelings

When you feel sexually aroused, your body goes through different stages. This may start with feeling turned on and build up to a sexual climax (orgasm). Cancer or its treatment can cause physical and emotional changes that affect your desire for sex. This can make it harder to orgasm. Changes in the level of sex hormones in your body can cause:

- a lower sex drive
- tiredness
- vaginal dryness
- urinary problems.

Your doctor or specialist nurse can advise you on different ways of coping with these changes.



# SEX & BLADDER CANCER TREATMENTS – a quick overview

## AFTER BCG TREATMENT

Treatment with BCG into the bladder does not usually cause any long-term effects on your sex life. However, you will need to take specific precautions during treatment to avoid BCG transfer to your partner. Your CNS will be able to give you the detailed advice.

## AFTER SURGERY

Your sex life might be affected after having surgery for bladder cancer. This depends on the type of surgery you have.

Having a stoma can also affect the way you feel about yourself and how you feel about having sex.

**Men** During surgery to remove your bladder (cystectomy), your prostate gland is also removed. This is because bladder cancer can often come back in the prostate.

Having your prostate removed means you will not be able to ejaculate, so your orgasms will be dry.

During this operation, the nerves that control your erections can also be damaged, so you may no longer be able to get an erection.

There are some options to help you get an erection. You can:

- use drugs such as sildenafil (Viagra®) or apomorphine;
- have injections or pellets that go into the penis;
- use a vacuum pump that draws blood into the penis to stiffen it and give a normal erection.

Your doctor can tell you more about these options and whether they are suitable for you.

During surgery to make a continent urinary diversion (or bladder reconstruction), your surgeon might be able to avoid damaging the nerves that control your erections. But sometimes you still need medicines to help you get an erection.

**Women** After surgery to remove your bladder (cystectomy), sex may feel different. This is because nerves in the area can be damaged during the operation.

Surgery to remove your urethra can narrow or shorten your vagina. Talk to your surgeon about this before the operation. They can try to change your vagina as little as possible. You might also be able to use dilators afterwards to stretch your vagina and keep it open.

Dilators are plastic, cone-shaped objects. They come in various sizes and you use them every day, for a few minutes. You start by using the one that goes in most easily. Over a few weeks, you gradually use larger sizes to stretch your vagina. Sex will do this, too, but you might not feel like having sex soon after your operation.

## AFTER RADIOTHERAPY

Radiotherapy for bladder cancer can cause problems with sex.

**Men** Some men can't get an erection after having radiotherapy to the bladder. Or they might have erections that aren't as strong as they used to be.

There are some options to help you get an erection. Ask your doctor or specialist nurse if you would like to try any of them.

**Women** Some women have vaginal dryness after having radiotherapy. There are gels and creams that can help with this. Your specialist nurse can advise you.

You might also have shortening or narrowing of the vagina. Using vaginal dilators or having regular sex can help with this.

## AFTER CHEMOTHERAPY

Chemotherapy into the bladder doesn't usually cause any long-term problems with sex. But chemotherapy into your bloodstream can make you feel tired and less interested in sex for a while.

Women who haven't already had their menopause can begin it early. This can lower your sex drive and lead to vaginal dryness.

## GET HELP!

You probably find that talking things over with your partner can help. It will take time for both of you to come to terms with all that has happened to you. But sharing how you feel can help you to understand each other better.

You might find it easier to talk to someone outside your own friends and family. Your doctor or specialist nurse can put you in touch with a counsellor or a sex therapist if you feel you would like this type of help.

You can always talk with confidence about sex and relationships on our confidential forum. Go to [fightbladdercancer.co.uk/get-help](http://fightbladdercancer.co.uk/get-help) to find out how you can join.





# The patients' perspective

## A plea to our medical teams

**The moment you hear that word 'cancer', you go cold, your brain stops working and time stops completely. Things just hang there. The word cannot be taken back. Your life with cancer has begun and it will never end. Never.**

This article is based on a talk given to the EAU Conference in London, March 2017

**I have spent the last 10 years living this subject personally, as it was about that time when I had my first brush with the fears and the needs of a cancer diagnosis.**

I'm going to talk about this subject from the point of view of being a cancer patient, and in particular a bladder cancer patient, as well as from my role as founder and director of the charity Fight Bladder Cancer, where we have supported thousands of patients and carers over the last seven years and listened to their stories.

### **What does the patient fear?**

Let's start with fears. The moment you hear that word 'cancer', you go cold, your brain stops working and time stops completely. Things just hang there. The word cannot be taken back. Your life with cancer has begun and it will never end.

We run a Confidential Forum at Fight Bladder Cancer that, at any one time, has close to 3,000

members at different stages of their bladder cancer journey. It is a place where they can be honest in all its brutality. You don't have to worry about upsetting your family. You don't have to worry about asking a question and thinking that you must be stupid not to know the answer already. You can ask the questions you are afraid to ask your doctor. You can explain the reality of the disease and how the treatment is really affecting you. After all, we don't want to worry our doctors or our families.

So if you are wondering about what fears, anxiety or panic your patients are experiencing, here is a brief snapshot, in no particular order:

Death, anger, 'why me?', pain, passing it on to children, having to tell family/friends, tiredness, cancer growing whilst waiting for tests, death, treatment and results, hair loss, operations, diet problems, diet worries, hospital stays, taking drugs, complications, side-effects, job loss, pain control, sickness, time taken for recovery, financial problems, cost of treatment, travel and parking costs, emotional problems, sadness, depression, relationship problems, sex, recurrence, spread, meds, it getting worse, the unknown, treatment failure, drug shortages, treatment being stopped, becoming terminal and death.

And these fears occur at different times, to a greater or lesser extent, for the rest of your life.

OPINION  
ANDREW WINTERBOTTOM,  
Founder & Director,  
Fight Bladder Cancer

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For some these fears never go away. As it was shown in a study from Georgia Regents University in March 2015, when compared with the general population, overall suicide risk was 2.7 times higher for bladder cancer patients, rates were 1.86 times higher in kidney cancer patients and 1.27 times higher in prostate cancer.

An 'all clear' or a 'no evidence of disease' (NED) is great to hear, but we all fear the high recurrence rate so we know we have only a temporary reprieve before the next round of tests and the subsequent wait to hear the results. We know this is forever.

### **So why do we have so much fear, anxiety and panic in our lives?**

As patients and carers, we have a simplistic and limited knowledge about our condition. A knowledge that starts from the global fear of the word 'cancer' that is fuelled every day with media stories, some heartwarming, some desperately sad. But we all know the fundamental mantra that exists out there these days that one in two of us will get cancer at some time in our lives.

**These fears occur at different times, to a greater or lesser extent, for the rest of your life. For some these fears never go away.**

As patients, we then go in two different ways. We either start researching madly for every last scrap of information we can find about the cancer or we decide that we just don't want to know – what will be will be. Both reactions are understandable but neither is particularly healthy.



**If we are brave, we might then start to tell our family and friends. This then unleashes a cavalcade of advice based on anecdotes.**

bladder cancer cure

### **To research or not to research ...**

Dr Google is a very careless physician. He tells you everything and nothing. Should you believe everything or should you believe nothing you read? Which are the correct facts and which are not? When you get five minutes, just type 'cancer cure' into Google and see what comes up. When doing this, try to read without your professional head on. Remember that as newly diagnosed patients, we have no idea what is right or wrong, what is a good source of information and what isn't. Put yourself in our shoes.

### **Good practice**

Hopefully, as you have read the first part of this article, you have been thinking, 'Yes, I know that. We do that to help that. Yes, we understand and we have protocols in place to help.'

Good. All sorted then!

Yes, we see some fantastic exemplars of good practice out there in helping patients with their fears. But, being honest, there is a really wide variation in quality. I'm not talking about the treatments themselves as I know that, as a profession, you will always strive to improve outcomes.

### **Talking about it**

If we are brave, we might then start to tell our family and friends. This then unleashes a cavalcade of advice based on anecdotes. Advice from how you need to start eating certain herbs and spices, stop drinking coffee, keep well away from sugar, don't worry 'it's not a cancer you die from', chemotherapy is worse than the cancer through to 'there is a cure you know, it's just that big pharma can't make money out of it so that's why they won't let you have it'.

Then there are the friends who simply disappear soon after a cancer diagnosis. Then there are the spouses who disappear. Then there are your friends and families who really do mean well but just don't understand and unfortunately make you feel worse – more afraid, more alone.

Hidden away, there is also domestic abuse and violence. Happily this is quite rare but, as professionals, you do need to know that this happens following a cancer diagnosis. The fear and the anger can come out in destructive ways.

### **What does the patient need?**

So let's move on to the patient needs.

From the years of hearing patients talk honestly about their needs, we can get a snapshot of the most commonly defined needs. Again in no particular order:

Information, understanding, knowing what to ask, explanations 'that I can understand', support, counselling, signposting where to get support and good information, being provided with a patient 'buddy', getting results quickly, getting treatment quickly, better guidance on side-effects, explanations for any delays in results or treatments, being able to contact my medical team whenever I need help or reassurance.

## Good communication

One word sums this all up. Communication.

Good and speedy communication of what you know will provide most of these patient needs. Indeed, at Fight Bladder Cancer, we have a campaign for a new Quality Standard for Communication to be developed. At times you are all brilliant at this. We know because the patients tell us. But at too many times it is easy to fall below the quality that you can achieve because of the pressures of the real world.

But for us patients, this communication is as important as the quality of our treatment. In fact, probably more important. We know that treatment doesn't bring a guarantee of success. When the detail of treatments, side-effects and prognosis is explained to us at diagnosis and during treatment, we understand that you are explaining what the evidence-based research says. We'd love you to be 100% sure of it all but we know you can't. But we do need to understand and we need your help to ensure that we do understand and that we are not suffering in silence.

We can be scared of talking to you, scared of asking you to repeat something because we didn't understand what you just said. We will think of that question that is really important to us a 2am when we can't sleep.

## Great leadership

Diagnosis, treatment and aftercare is a team game. If you are the captain of that team, make sure that the whole team understands the real fears and needs of the patient. Put protocols in place to ensure that your practices are robust for the benefit of your patients and their carers.

Make sure you measure how good you are in what you do to support the patients' fears and needs. Talk to your patients about quality of life issues at every encounter. Work with patient advocacy groups like Fight Bladder Cancer to ensure that you hear the reality of the patient experience. Offer to help your nearest patient advocacy group.

As bladder cancer patients, we spend a good deal of our lives in what we call 'the waiting room'. This isn't just the physical room at the hospital or at the doctor's office. This is the psychological waiting room. Waiting for an appointment, waiting for results, waiting for the results to be explained, waiting to know what treatment we

are going to need, waiting to see the new specialist, waiting for the treatment to start, waiting for the next phase of the treatment, waiting for the next check-up, waiting for the results of the check-up. Waiting for the letter, waiting for that phone call. Waiting to hear if it has come back. Waiting.

Waiting too long to hear what you fear makes it worse. If you take anything from this article, remember to tell your patient what they need or want to hear as soon as possible. Take it from me, that extra day's wait is hell. Sheer hell.

Finally, don't be scared of talking honestly with us patients. It will help us talk honestly with you and together we will get this right.



**But for us patients, this communication is as important as the quality of our treatment. In fact, probably more important.**



# The things people say

Despite all our differences of background, experiences and emotions, those who have had a bladder cancer diagnosis share one common thing: not everyone will know what to say to us any more. Some comments can be forgiven when the emotion of the moment means they don't come out as intended. We may find that understanding words come from those who we would never previously have expected them from. But there are things said that can lead to rifts, sometimes permanent ones.



In the early days or weeks after a finding that you have cancer, emotions can be frayed and erratic and life becomes full of uncertainties, particularly as it can take some time for a full diagnosis and treatment plan to be set up. Not everyone you know will feel comfortable asking about your new situation. This isn't to say that they don't care but possibly the word 'cancer' frightens them or they find themselves unsure of the right thing to say.

After a time, the initial shock may have worn off for those around us. However, the reality for most of us dealing with bladder cancer is that the journey is often a long one, sometimes life-long. It isn't realistic for everyone to keep up the same level of care and interest that they may have shown initially, of course, and they may think you would rather not talk about how things are going, as may be the case. Certainly the demand that you should ring any time you need, night or day, won't be greeted quite so warmly at 3am months down the line. Unfortunately not everything said is helpful and some things can feel like quite a shock, raising the question of whether it is better to say nothing or to ignore the topic at all costs.

For me, one or two words or actions can make so much difference to my state of mind, hopefully in a positive way, although clearly this isn't always the case. For some of us, growing a thick skin may be another challenge that our new bladder cancer life brings.

So this is my personal experience of some of the things that have been said to me by people who genuinely care – as well as those who have wanted to show an interest, or even people who felt they wanted to throw their thoughtful and not-so-thoughtful insights into the mix – and how I have attempted to handle them. On occasion, remarks have been quite bizarre and as I have what is often seen as a strange sense of humour, I think I have dealt with them fairly well ... although some things took longer to deal with than others!

#### ARTICLE

MELANIE COSTIN  
FBC Trustee & Support  
Services Manager

### How are you?

This simple question is sometimes difficult to know how to answer. You may find yourself either becoming exhausted by continually going over how you are actually feeling, glossing over how you are feeling so as to be spared the pained expressions of someone who maybe doesn't really want to know the ins and outs of how you are in any detail, or answering with an 'I'm fine' kind of remark. This response can also be adjusted to suit who is doing the asking, ranging from a monotone 'I'm fine' to a jubilant 'I'm absolutely fine' accompanied with an ear-to-ear grin.

Of course, it can be very unsettling for some people to know what to say; not everyone has first-hand experience of bladder cancer and so I hope that those who know me best will understand if I occasionally respond with an off-the-wall answer. If I'm having a bad day, I'm most likely to be at one end of the spectrum or the other as far as replies go, either coming across as not being in the least bit bothered about my situation, or giving a no-holds-barred reply.

Clearly not everyone wants to be regaled with the minutest of details though, and this probably ensures that I'm not asked how I'm feeling again, except by those brave enough and those who actually do care and aren't just feeling that they should ask how I am out of politeness. There are those times when we all want to offload – that is when I turn to those I can really trust, or I talk to others on the Fight Bladder Cancer confidential forum.

### Stay positive

I've been told this many times. Personally, I aim for neutral whenever possible. It makes any bad news a bit easier to take.

### It's easy to treat cancer these days. I knew someone who was cured straight away

Thanks for letting me know. Well, there isn't usually a 'straight away' scenario with bladder cancer. It took years just to be diagnosed and three years of painful treatments later I'm still trying to keep going and let's not even get into the waiting, the everlasting waiting! Wait for chemo, wait for pre-op, wait for biopsies, wait for results, wait to start treatment again ... cup of decaf tea during the wait anyone? I think I just answered with 'what great news it was about your friend's friend's sister' or whatever. Of course, it was good news, but even so!

Alternatively I have also met those who would like to tell me of everyone they know who has died, which isn't exactly uplifting! When this gets a bit much I tell them that I'm fully aware of what cancer is and it's not, in fact, my first time around the C block. 'Oh no, that must be awful,' they will say, before continuing on with more cheeriness.

**When this gets a bit much I tell them that I'm fully aware of what cancer is and it's not, in fact, my first time around the C block.**

### **I knew someone who had bladder cancer ten (20, 30 ... ) years ago and it's the best one you can get**

Well, that's lovely for them and fantastic if you were lucky enough to have had a small low-grade tumour that was eradicated with no recurrence. Not so helpful for the rest of us, though, and not helpful for me being told this by a stranger eavesdropping and who knew nothing about my situation. I responded politely – which was difficult!

### **If anyone can do it you can**

It? What on earth does 'it' mean? Cope? Survive? Get through without completely losing my marbles?

### **What doesn't kill you makes you stronger**

Oh please! This made me feel insulted that ridiculous platitudes could be quoted at me as if these words of wisdom were helpful. Bladder cancer has the highest recurrence rate of any cancer, and with an aggressive grade, my treatment so far and the side-effects I've had to just about everything they have thrown at me hasn't made me feel stronger. Maybe they were referring to my resolve? Well that has stayed about the same; we all have better days and worse days though.

### **You are the strongest person I know**

Actually this is slightly more acceptable for me personally. If I have handled things even a fraction as well as some of my role models, I would be doing all right. Bit of a worry if I don't fancy being strong and coping; would that mean time is up then? If I cried and panicked regularly would that mean that the C war is lost?! I think that all strengths and weaknesses are acceptable, constant treatments and surgeries can bring the best of us down, then of course the sleep deprivation from nocturnal toilet visits isn't a foundation for warrior strength really.

### **Wouldn't it be awful if you found out that you were actually ill?**

Er, well yes, I suppose it would be, as opposed to getting bladder cancer, then?

### **Try not to think about it**

Oh okay, because that is so easy. It's not as if I only need to use the toilet once a week. During chemo with instructions to drink water I'm in and out of there so many times that I'm thinking of putting a duvet in the bath and sleeping there to save myself staggering around in the dark. Bladder cramps and spasms can also helpfully occur to assist in the not thinking about it. Actually I try not to think about it and am now succeeding most of the time. It's still easier said than done and easier still coming from someone else who has no personal experience in such matters yet can make such a comment.

### **We need to make lots of memories**

A similar empty and worried feeling ensued. The problem is that it's not always realistic to be going here, there and everywhere if we are in pain or frightened of what may come and all we want to do is to curl up in a ball and try to get our head around things. We often find ourselves doing things in an effort to please other people maybe, or to put up a front of normality so they feel better about everything. In reality, it isn't always glamorous like in a film, where people skip around happily with friends and family surrounding them doing wonderful things. We have many treatments to go through and some of them knock us for six!

### **It stresses me out knowing what you are going through**

I'm sorry to be causing anyone stress by getting bladder cancer; I'll try very hard not to do it again! Actually it's a horrible feeling knowing that people you are close to are affected. I do try to put on a face and laugh about things as much as I can but it's also good to be allowed to have off days or to discuss your fears and opinions. Not everyone you know is up to the job and that's okay; it's not as if most people get training for this kind of thing. I was lucky to find the support forum in a moment of need and be able to offload without the fear of being judged and to take the pressure away from friends, who generally find it difficult or upsetting to hear me talk frankly about my feelings.

**I do try to put on a face and laugh about things as much as I can but it's also good to be allowed to have off days or to discuss your fears and opinions.**

## Will you be losing your hair?

### You will look good bald

So many bladder cancer patients get comments like this and people seem so interested to know why our hair hasn't fallen out. Not all therapies make your hair fall out and for those that do, it can be a thinning rather than a total hair loss. For this reason, many people are upset that others don't take their illness seriously and don't give them the support that they might do if there was an obvious visual sign. Often friends and family feel the need to instantly rush off and do various acts on behalf of people diagnosed with one of the more well-known cancers, a team of smiling people showing their united solidarity to help give strength to their friend or loved one. Whilst this is very admirable and I'm certainly not knocking it, bladder cancer patients rarely get this level of enthusiastic support. Our treatments often go on for life, there is always the concern that the nicknamed 'Cinderella cancer' will return, and whilst we don't necessarily expect everyone to stick by us for the long haul – as I have unfortunately found out very quickly – there isn't the same 'we're all in this with you' feeling shown to most of us. It can feel like a lonely place to be.

Maybe you have to look ill to be considered ill. Therefore I look well so I must be feeling well. I do feel well at times; at other times I'm sure not going to let too many people know about it – that's just my way. So, I have saved for last the comment made to me that has stayed in my mind more than the others.

### Is your wig made of real hair?

I was stunned for a moment when I was asked this little gem. I was almost lost for words ... almost. I answered that no, my hair was in fact made out of real hair. I then started tugging at it in an attempt to prove to her that it was all mine and I had grown it myself! Now, of course, I'm slightly paranoid that people will presume I'm wearing a wig. Maybe then there are times that it is better not to try and say something ... that probably would have been the time.



**I was stunned for a moment when I was asked this little gem. I was almost lost for words ... almost.**

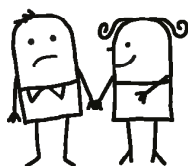
### You should make a bucket list

A choice little remark, it also made me think: what did this mean? Did this mean that I was just about to kick the bucket? Was I to fill a bucket full of things I wanted to do before I, well, kicked the bucket? What an empty feeling that gave me!

### You are looking really well

I often laugh to this remark. As opposed to what? How I looked before diagnosis? Well, that wouldn't be difficult! My weight loss was extreme with all my bones showing. At the time, I didn't know what was wrong but I also thought it was great that I fitted into age 13 clothes and had razor-sharp cheekbones. Although I probably resembled a head on a stick. After my first operation I began to put weight on very quickly. I remember discussing this with other forum members and on average we were putting on around 16kg (2½ stone) at the beginning of treatments.

Many people with a bladder cancer diagnosis look well. Sometimes people look to be blooming with health when actually they are very ill or in pain. Obviously I don't want to be an object of pity and get the sideways glances of 'oh look she must have cancer', but it can be upsetting for some people when their appearance of apparent wellness means that their health issues aren't taken seriously. It can certainly confuse people when they expect to see me looking worse rather than better than I did before. Thankfully they don't get to see me on the days that I have BCG or Mitomycin. I'm definitely not looking my best then!



**You are never alone with bladder cancer. Find out more about how we can support you at [fightbladdercancer.co.uk/get-help](http://fightbladdercancer.co.uk/get-help)**



# Me, myself & cancer

## ARTICLE

Darren Roberts  
Sky TV transmission  
controller, FBC  
forum member

**I'm just your average guy. I have a great job, I have a tolerant girlfriend and a home in a lovely part of Surrey where we live happily with our dog Betsy.**

**I'm active: I ride to work everyday and I run. I eat relatively well and I try to avoid too much excess, so I'm pretty happy with the way my life is panning out. So was it fate, or was it something I did that prompted the words, 'I'm sorry, Mr Roberts, but you have cancer'.**

It was last September and I'd ridden to work as I did every day – nothing unusual there. I went to the loo and it was then I noticed blood in my urine. It wasn't a lot, but it was enough to startle me and prompt me to raise it to management, who suggested I went straight to the hospital.

That morning I looked pretty rough, having ridden the 10 miles (16km) to work and chosen to get to my desk first before I took my morning shower. Those born in the seventies who remember Steptoe and Son will understand that my morning look was not too dissimilar to Mr Steptoe Snr.. In the hospital I gave some blood

and was sent into a cubicle and told that I was going to be examined by a doctor – okay so far. Laying in my NHS garb I was horrified when a Penelope-Cruz look-alike nurse walked in donning some latex gloves. She introduced herself to me and told me that she was going to take a look 'down there' and did I mind? 'No,' I said, secretly petrified that I wasn't prepared (I hadn't man-scaped and had as yet not showered). After some coughing, inspecting and probing she asked me if I minded if she 'took a look behind?' 'Not at all,' I said, 'but shouldn't you be buying me dinner first?', to which she looked at me and reminded me that she did this to tramps every day and I'd be okay.

So nothing was found and I was fast-tracked to another hospital to undergo a cystoscopy – a procedure that entails a camera being inserted in your manhood to explore the bladder.









**It was that day when I was told that I had bladder cancer, to what degree was still unclear, but the surgical biopsy would reveal that.**

But that day my life changed for ever and the cancer circus arrived in town.

I was booked to have a full CT scan to see if my unwanted guest had settled anywhere else in my body. And I was also introduced to 'the waiting game'. Everyone with or living with cancer will understand this.

I believe in fate and this part of my story is quite incredible. I was out walking my dog and I'd been crying. I did all my crying whilst walking Betsy as she doesn't judge or comment. I was in a state of 'mental limbo' as I was living with the cancer diagnosis but as yet didn't know to what extent, or what my situation was, or what the next stage of treatment would be. I knew I'd have surgery pending but that was it. I knew nothing more.

I bumped into my neighbour who noticed that I was upset and she asked me why. I told her that I had been diagnosed with cancer. She asked me where my cancer was and I told her it was in my bladder to which she said, 'Do you mind if I speak to my father about it?' I asked why, to which she replied, 'My father is a Professor of Urology.' It transpired that her dad had lectured and written papers on bladder cancer and the subsequent treatments. Most urology consultants in the UK had been trained by or knew her father, and were practised in the procedures that I would be facing in the not-too-distant future. 'Did I mind?' she asked. Bloody hell, no. As tormented, confused and angry as I was, I was completely open to having some advice from such an amazing and respected man.

We spoke that evening on the phone and it was like speaking to an angel. He put my mind at rest and pointed me in the direction of a consultant whom he recommended without question.

I was introduced to Mr Matt Perry, who would be conducting my bladder surgery. My mind was completely scrambled, but knowing I had these amazing people in my corner made the journey to this point a tad easier to deal with.

So me and Babs (my adopted mum) went to the hospital together to get the cancer out of my bladder. But just before I went under my general anaesthetic, Matt had some more news for me, news that would rock me to the core and send me into a spiral of uncertainty and fear. The full CT scan had found another tumour – a bigger, more dangerous one. It was attached to my left kidney and was 9cm (3½in). I knew nothing more than it was the size of a small grapefruit and it was nothing to do with the cancer in my bladder. I had cancer, but in two places in my body.

The bladder was successfully cleared of cancer and I was then recommended to another amazing consultant who practised in kidney issues.



Mr Chris Anderson explained what was inside me, describing it as a 'renal tumour' and, because of its size, I would be losing the kidney. Wow, what a smack round the face. All of this in four weeks. Four weeks earlier I was jumping around the gym and riding my bike 20 miles (30km) a day. Simply unbelievable. No outward signs of illness, but a slightly uncomfortable back ache and high blood pressure. I put the back ache down to my soft mattress and chose to sleep on the floor for a while. The high blood pressure I assumed was hereditary, as my mother has it.

I was booked for a surgery on 21 November to remove the kidney using keyhole surgery. The tumour was successfully removed along with the kidney. I spent five days recovering, then had to wait a further 10 days to learn what my journey would entail going forward. Cancer makes you wait – it's all about lab results. The waiting takes you to the darkest corners of the mind; it's a very scary but significant part of the journey.

The results of my biopsy were very favourable. I'd been very lucky. The blood in my urine simply highlighted the ticking time bomb growing inside me.

The tumour removed was T3a aggressive – that's not good – but incredibly my margins were clear and my lymph nodes negative. This bastard that had attached itself to my kidney had grown uninterrupted and by an absolute miracle wasn't ready to announce its arrival. I was as close as you can get to my life being very different with a very bleak outcome. The bleed was from my bladder tumour and my prompt action to get to hospital had most certainly saved my life.

So I'm here. My life is very different now. Someone said that surviving cancer is like you're being followed but every time you turn around, no one is there. I just have to learn never to look back. Cancer is something I have to live with. The blood tests and the scans will not go away until this evil has gone and until the clever people say the coast is clear.

**Until that day I will deal with whatever it throws at me.**

I will eat and drink with more consideration and do whatever I can to ensure my body is fit and in the best condition it can possibly be. I won't live in fear and I won't let it define me. There are millions of people fighting cancer every day and I owe it to each and every one of them never to give up. Life is precious.

I am also planning to run the New York Marathon in November to raise as much awareness and money as I can for bladder cancer, which is still one of the more mysterious and unrecognised cancers.

**My contribution will go a long way to raising the profile of Fight Bladder Cancer – this fantastic charity which provides so much essential support to people with this terrible disease.**





# You get by with a little help from your friends

Cancer is a lonely business. Here, Kate Bohdanowicz, 44, explains how her friends helped her get through diagnosis and treatment. All except for one.

She knew we were trying for a baby and she knew that the endless appointments at the fertility clinic were taking their toll on me physically and emotionally.

At 42, time wasn't on my side and when we heard it had failed, it also left me with a persistent urine infection (or so I thought), until months of antibiotics and visits to the GP culminated in a referral and diagnosis of bladder cancer. I'd turned 43 three weeks before and had already enquired about a final go at IVF. That was called off. Babies were out the question. Now I was fighting for my life.

I can't remember who, other than close friends and family, I contacted when I was first diagnosed. Instead, I blogged about it and posted it on my Twitter account. That way everyone would know in one fell swoop. The messages came in thick and fast. Friends shared my blog and sent their condolences.

**Offers of support poured in from friends old and new – and friends of friends I'd never met.**

Cancer isn't a shock – half of us will get it in our lifetimes – but at my age, it is less common and, of course, people were

concerned. I was overwhelmed with the responses. Literally everyone I knew (and many I didn't) got in touch. Everyone but her.

She wasn't a colleague or an associate. She was a friend, and a close one. We'd holidayed together, partied together and been there for each other when both our dads died within a couple of years. I even put her up for three months and helped her out financially when she was broke. That's what friends are for, right?

A few weeks after diagnosis, it went from bad to worse: the cancer was aggressive and my bladder had to come out. I'd never been so scared in my entire life. The operation was upon me before I had time to think and I stopped communicating directly with all but family and my partner, who updated my friends with group texts and Facebook posts. They understood I didn't want visitors in hospital.

And when I got home and faced the most difficult part – my recovery. I struggled to come to terms with what had happened and my hospital arranged counselling. All the time, flowers and chocolates were delivered daily to my door. I hadn't asked or expected them but my friends wanted to let me know they cared and seeing

vase after vase of bright colours did help lift me out of my darkness. That's when I realised my friends were great, they really were. All but her.

## Restoring normality

Eventually I pinged back into normal life and started to see people for coffee, lunch or the cinema. Friends came over when I was too tired to go out and drove me to the station if I needed to go to hospital. Then the doctors said I was clear but just to be sure, they wanted me to have chemotherapy. What? This crap is endless! I agreed but I decided to make the best of it by taking a different family member or friend with me every time. We'd have a nice lunch before I was summoned to the comfy chair where we'd play cards or watch *Pointless* as I sucked on boiled sweets.

**Just having people around me made it so much better.**

## Moving on

It's now 18 months since this tedious journey began. A problem with my neobladder meant I had to wait six months for corrective surgery but hopefully that's the end of it (aside from the regular scans and lifetime of worry). It's true that in times of need, you find out who your real friends are and, generally, people have been great.



#### ARTICLE

KATE BOHDANOWICZ,  
Journalist & FBC  
forum Member

I'm not expecting everyone to drop everything and pander to my needs just because I got cancer. A few distant friends disappeared, which is fine. We've all got a lot on. But this person was different. We were close. And when I heard from her friends, one of whom lives abroad, I know that she must know I was ill and yet she chose not to get in touch and that hurts.

I haven't heard from her at all. Actually, I tell a lie: I received an email from a donation site asking me to fund one of her latest adventures (did I tell you she travelled the world: a free spirit who never liked to be pinned down?). Suffice to say, I didn't reply.

### Cancer can be a lonely experience

No matter how many people are there for you when you sit in hospital waiting rooms or cry into your coffee cup, it's you who wakes up at night, your head full of fear and what-ifs. It's you who slips on the gown to endure the scans, ops, treatments and endless needles, and sometimes you feel as though you've just had enough. You can take no more. That's when a friendly face, a reassuring pat on the arm (mind the cannula bruises) or a joke that makes you throw your head back and laugh really helps. Friendships have meant so much to me in the past year and a half. I feel incredibly lucky to have so many mates who have stood by me. A couple of my friends are now having their own troubles and I like to think I'm there for them.

Yet throughout this, it's the friend who dumped me that really rankles. I know we'll bump into each other at some point and I'll say I'm pleased to see her. Really pleased. Because I've got a few things I'd like to get off my chest.

# Coping ALONE

## Michael's story

**A new study shows that older, single, white men with advanced bladder cancer have the highest suicide risk among males with diagnoses related to the genito-urinary system. The average age of bladder cancer patients is 73.**

### **Here, Michael, 68, talks about dealing with illness on his own.**

I took early retirement and for three years I volunteered with Age UK, driving people to hospital in Devon and Cornwall, up to five days a week. The busiest department was oncology and I think I took 200 cancer patients there. I always thought that if I were diagnosed with cancer, I'd be prepared for it. I was wrong.

In March 2015, when I was told I had non-invasive bladder cancer, I broke down.

I was talking to a support nurse at my local hospital near Liskeard in Cornwall when I just started crying. She held my hand and she said: 'It's such a personal, emotive word, the c-word. This is like a tsunami for you, isn't it?' And it was. It was overwhelming.

I'm a single man and I've never married. I live alone with my 12-year-old dog Jacki and my family is 300 miles away in London. Although I can pour my heart out to them over the phone, they're not

nearby and while I do have some friends here, if the truth be known, it's a quiet, lonely existence.

I could always cope with my own company but since the diagnosis, I do feel isolated. I was very friendly with one chap and when I told him I had cancer, he said: 'Oh I'm sorry to hear that. We must get together. I'll check the diary with my wife. Come over and have a meal.' But nothing ever happened. We're both on Facebook and a couple of times I asked if he was still up for meeting and he said, 'Yes, we must organise that.' But there comes a point when, if it doesn't happen, you drop the subject.

When I told my cousin, she said: 'Why on earth did you mention you had cancer?' She told me I should have kept the diagnosis secret so I didn't get rebuffed. But that's completely contrary to my idea of friendship. By telling him, I was reaching out for support.

You're better off saying, that person dropped me. Fine. I don't need them in my life. But that's a hard thing to do. And after diagnosis I went into a depression and my GP prescribed antidepressants.

There have been a couple of other people who have suggested meeting and it's never happened. I don't know why. Either they think they're going to get burdened in some way or they're too busy or they're scared because cancer is so emotive and people's reactions are so individual.

When I explained to my counsellor about my friends, she said that different people act in different ways. She's heard of family telling patients: 'We won't come and visit you in case we catch it.'

I might ask Living Well if they can find someone to attend hospital appointments with me. At the moment it's me that needs the cherishing.

Michael's found support in a variety of places. Here are his tips ...

I could always cope with my own company but since the diagnosis, I do feel isolated.

## Finding support

There are lots of ways of finding support and you must ask the professionals for help, but you also have to take the initiative yourself. If you live on your own, you'll already be used to that!

- **Fight Bladder Cancer:**

For me finding the Fight Bladder Cancer online support group was great. It demystifies cancer and allows you to talk freely.

- **Counselling:**

My GP also suggested counselling, which I have with Macmillan Cancer. They also have a drop-in centre near me, which I use as it's nice to have a coffee and chat. I find that people who are survivors of cancer are more understanding as they know what I'm going through. I can't do this on my own.

- **Gardening:**

I try to keep busy and volunteer at a local garden centre, growing organic vegetables. People go there to get exercise or when they're recovering from illness and I've met people there who I can talk to about anything.



- **Joining interest groups:**

I also joined the University of the Third Age and I'm involved with a lunch group and a debating group. It's so much better than being stuck between four walls ruminating.

- **Living Well:**

There's a programme near me called Living Well, set up by various organisations including the NHS and Age UK. It supports people who are having a difficult time, so someone visits you to see what you need to make your life better.

- **Man's group:**

I joined a man's group, too, which helped for a while but unfortunately has had to stop due to lack of funding.

- **Helping others:**



I dropped in on a gentleman with dementia for a couple of hours a week to give his wife some respite.

- **Volunteering:**



I wonder if I should go back to the volunteer driving as I did enjoy it, but my treatment is ongoing and I don't want to let anyone down.



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1. WS Tan. Safety and Tolerability Analysis of Hyperthermic Intravesical Mitomycin to Mitomycin alone in HIVEC I and HIVEC II. Data Presented at EAU London 26/09/2017.

HIV010-01EN0317



ARTICLE  
ROS BRUCE  
FBC forum  
member

# Random thoughts & memories

If I could go through it all again – knowing what I know now – it would be so different. Once I found **Fight Bladder Cancer**, I never looked back. If you are trying to build up the courage it takes to get out there and get in touch, read my story.

If only six years ago I'd have thought about searching on Facebook where I could have found Fight Bladder Cancer and their support group, things would have been very different. But I had shut myself away and didn't go back on Facebook for over two months after my surgery.

When I did, there was FBC waiting for me. I'm not saying it didn't take courage to get in touch, but I am so glad I did, and that I went to the Northern Bash and Soirée to meet fellow bladder cancer buddies. It made all the difference.

As for my children, Matty was five, turning six and didn't really understand. He was happy to play about on the hospital bed and watch the TV. Ross was nearly 16 and still at school. He didn't talk about it. Laura was 18 and at college. I only found out much later that she had been reading texts on my phone in case I wasn't telling her everything.

**With the help and support that is out there you find you can do it.**

I tried to carry on as normal for all of them, and they were happier after I'd had the operation and was home again, where they could see I was okay. They all mucked in and helped out, which was great. And we managed to keep our sense of humour, which was important sometimes. Now they are all used to how it is here and can tell stories about disastrous bag leaks that make

us all laugh. It wasn't so funny at the time but it helps you cope.

(By the way, I've also discovered a cover band you can buy from Cornfizz ([www.cornfizz.com](http://www.cornfizz.com)) which hides the bag for the most intimate times.)

Coping with bladder cancer is the hardest thing I've ever done. I never felt so alone as when I was going through treatment and I nearly gave up more than once. I kept thinking: I just can't do this. I felt so tired and so alone.

Looking back, I wasted so many years thinking 'I can't do that'. But with the help and support that is out there – if you take your courage in both hands and allow yourself to be supported – you find you can do it. Now there is no stopping me. Especially now I've got to five years clear – that was a real boost.

Okay, life isn't exactly how it was (but we can cope with bag leaks now!). In a way, you could even say it's better, because despite the added extras you have to deal with, you value life more. Each moment has become more precious.

And the best thing ever is that now I have so many friends who know exactly how I feel. Wee are family, thanks to Fight Bladder Cancer. And now I can give something back, too. It's good to fundraise and have something to keep you busy – that keeps me going.

There are sad times, of course, for those who haven't been so lucky, but we keep going for them too.

# An emotional

When I was diagnosed at the age of 56, I didn't feel too shocked or alarmed. My brother had had low-grade bladder cancer (BC) for some years and we know enough people with cancer (some cured, some incurable) to be well aware how common it is, especially as we age.

We also know people our age who have died suddenly of a stroke, aneurysm or heart attack, or have a degenerative condition such as motor neurone disease, which I felt was far worse. With a background in health care, working in a hospital, I felt reasonably at home being a patient. I chose to attend appointments alone – I felt I could absorb the information better without worrying how my husband was receiving it. In our household, I am the planner, the organiser and control freak.

Even so, BC has had a big impact on my life and those around me. Here is a snapshot of some of the major effects it had on my emotions.



**SHOCKED:** I remember feeling sick when the consultant told me it was high grade, it could recur, progress, spread. Thinking momentarily, philosophically, that this could be death within a few years and I'd had a good life.

**RESTLESS:** Even before knowing whether I had a choice between BCG or radical cystectomy (RC), I spent hours searching the internet, and many sleepless nights mulling it over.

My husband obviously did not want to discuss it – but said he'd support whatever decision I made. My friends and colleagues were better as sounding boards for my deliberations. It was my younger son who asked sensible questions like, is the surgeon experienced at this op?





# ROLLERCOASTER



**RELIEVED:** Feeling a weight lifted from my mind when I decided on surgery. Choosing to regard it as a positive project to work towards.

**REASSURED:** Having the longest and friendliest conversation with my brother for years. It meant a lot to me that he said he would have chosen surgery too.

**FRUSTRATED:** Feeling like a ticking time bomb when I was booked for yet another biopsy to see if neo (neoadjuvant chemotherapy) was an option, when I felt getting on with the main op was urgent.

**ABANDONED:** And feeling abandoned when I had a query but my CNS was on holiday. After a CT scan, I popped into the local cancer support centre and burst into tears.

**SURPRISED:** Surprised when my friends commented how brave I was, facing this major surgery.

**WORRIED:** When my husband said he didn't want to lose me. Instead of feeling glad of his love, felt that his worry and that of my elderly mother was a burden. It wasn't as though I could influence the outcome.

**SUPPORTED:** Feeling supported by my husband when I was frustrated at waiting for the next date – for an appointment, for the op itself.

**EXCITED:** Not scared, but excited at going into hospital. How bizarre. Suddenly felt how real it all was, seeing the surgeon and registrar scrubbing up in the adjacent room.

**TOUCHED:** Moved by how many people came to visit in hospital, sent cards, flowers or other gifts, and offers of company for walks.

**MORE RELIEVED:** Relieved that I still felt I was 'me' – no mourning lost bits.

**PLEASED:** A little loath to leave hospital – late in the evening by the time I was finally discharged – but so happy to be home again.

**VOLATILE:** Experiencing the ups and downs of recovery – pleasure at each achievement, but inexplicable low moods. My husband once commented I was a bit short – I thought I'd been extremely restrained when he wasn't doing the household chores as I would, or sat clicking away on his laptop when I wanted peace and quiet. I couldn't cope with stress and burst into tears at the GP over an appointment mix-up.

**DESPONDENT:** Desperate to have praise from my consultant with my neo training, but coming away from my appointment despondent, feeling he considered my progress unsatisfactory.

**DEFLATED:** Felt oddly flat at his pronouncement that it was a 95% likelihood that I was cured. Family seemed unmoved too; friends were generally more exuberant to hear the news.

**SENSITIVE:** Feeling a bit frail, but it was wonderful to return to work, where I could feel normal again (even though colleagues asked how I was in that special way they do when someone's been seriously ill.)

**GRATEFUL:** For having my family always there, available to do anything I asked.

**FLATTERED:** So pleased to be asked to buddy a fellow patient. The CNS told me the consultants had specifically asked for me as I had always been so positive. Delighted to be asked to be filmed for a patient information project a year post op. At the launch, my consultant praised my 'sterling work' – a high accolade. It's hard to become a person after having been a patient.

**REFLECTIVE:** Still occasionally brought up short thinking how momentous all this has been reminding myself why I made each particular choice.

**... but I've never had any regrets about my decision.**

## Restoring normality

I can't help feeling that I have got off lightly. I am fortunate to have had choices, to have had no significant complications, to be fit and well and getting on with my life. When tackling a strenuous task or generally pursuing all my various work and leisure activities, I still occasionally feel grateful to be able to do so.



# Till DEATH us do part

## TODAY I TRIED SOMETHING TOTALLY NEW

For the last three-and-a-half years, since my diagnosis for BC, I have tried every trick in the book to kill this little f8%%4er.

I have tried to have him sliced out on no less than seven separate occasions, on the last of which I even sacrificed my bladder, prostate and 40 lymph nodes to be sure of getting him. I have tried to poison him with BCG on no less than 19 separate occasions. Not satisfied with BCG, I then went and tried to poison him with three different sorts of chemo over a two-year period, including the very nasty MVAC.

I have tried to starve him out. I have overdosed him on turmeric, veggie juice and linseed with cottage cheese. I have deliberately ignored his existence when out with friends and, in doing so, no doubt made him feel neglected and unwanted.

But despite all these efforts, it appears that we are joined by a bond that will not easily break. Maybe we are destined to stay together till death us do ... and so on (sorry if my humour offends).

Anyway, the point of this little article is to

let you all know that today I decided to take my cancer snowboarding.

Why the bloody hell I didn't do this years ago, I don't know. It was amazing! Every single cell in my body (or at least the good healthy ones) rejoiced as we stood on top of the mountains in Turrach taking in the spectacular views and absorbing the sunshine. My cells screamed in ecstasy as we flew down the piste, my wasted muscles screamed in agony and other skiers screamed in fear as we almost bowled them over in our out-of-control run. I used to know where the brakes were but chemo-brain and all that ... enough said.

After a couple of hours of redefining piste hooliganism, I decided to indulge my cells in a treat of hot chocolate, venison sausage and sauerkraut and, of course, the obligatory schnapps. They loved it ... they lapped it up.

I think that if the not-so-healthy cells in my body enjoyed

themselves as much as the healthy cells did, then it may motivate them to be less set on destructive growth in favour of communal pleasure. But then, I have had some schnapps :) :) :

My post or posts are in no way intended to trivialise the seriousness of this or any shitty disease. I apologise in advance if my warped humour offends.

Love, light, peace  
(and schnapps) for all.

**I really feel that inviting my cancer to come snowboarding today as part of the family and not as an unwanted guest may change the balance of things in our relationship.**

ARTICLE  
JOHN  
FBC forum member

# The cancer WHIRLWIND

First kidney cancer and then bladder cancer a few months later – picking us up in a frantic flurry of appointments and operations, then dumping us on the ground, our heads spinning with no idea which way to turn.

## ARTICLE

EMILY

FBC forum member

There were a lot of bad days at first, ranging from tears of despair to furious anger. The worst part is feeling so helpless when Andy is suffering. I want to do everything in my power to ease his pain but sometimes there is nothing I can do. It's heart-breaking. Andy feels guilty because I have turned into a carer overnight. 'Sorry' is a familiar word in our house.

On bad days, emotions run high and we can be short-tempered without meaning to be. We never really argued before but now there can be times when we snap at each other. But that is why it's so important for us to voice our fears and feelings, because cancer becomes the main focus if we allow it to.

## With him every step

I may not be the one with cancer but I am living it through the man I love. I remind Andy that I am not going anywhere, I am not better off without him, and helping him in the bath, with a catheter or anything else doesn't bother me at all. I am with him every step of the way.

What gets to me the most is when I can sense a bad day coming but know there is nothing I can do about it; he is already on the downward spiral. On days like that, FBC steps in to help both of us. It helps him to share how he is feeling and the support is always there. He doesn't always cope well but there is no text book to say how you should act and feel. Days like that take a lot of time to recover from but as soon as he feels more positive and I see his smile, it is like the brightest summer's day and my mood is lifted in an instant.

## Let children be part of it

Explaining it to Meg was the hardest part. We told her in a way that she would understand and told her school, too. They have been amazing with the support they have given her. We have promised not to keep things from her and she has promised us that if she is worried about anything she will come to us, her teacher or she can write it in a worry book if she doesn't want to say it out loud. I am so proud of how she handles everything cancer has thrown at us. She has seen more tears and emotion than I would like but it has made her so kind and caring, never afraid to offer a hug and a kiss to make things better.

Making plans and goals in between the hospital visits gives us something to look forward to.



## We all need support

I have learned that I am not invincible and I cannot do it all. I can't support Andy and Meg if I'm not looking after myself. Some friends and family have taken a step back but some have stepped forward to offer support. I have tried not to take it to heart; cancer makes everyone react differently. Not everyone can understand that a cancer diagnosis never goes away no matter how many all clears you have. The good days do come but we have to make the effort to find them.

Life now is about making memories that will last a lifetime for all of us and enjoying quality family time.

## Talk, talk, talk

If I was to give any advice to a partner, family member or friend of someone with cancer it would be to communicate about everything: the good, the bad and the ugly. Talk to each other, family, friends, medical staff and support groups. Remember that you are not alone.



# My cancer journey

... from kidney and bladder infections through UTIs and pneumonia to self-catherisation and the big C ...

ARTICLE  
JAMES PLAYLE  
FBC forum member

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Right, so here goes ...

I'm a 36-year-old male with a pretty damn average physique. I'm not a gym bunny, but nor am I a butterball. The dinner-party description of my job would be: 'I'm an audio visual installation engineer' which, after a few glasses of whatever, turns into 'I mess about with wires and stuff ...'.

Around two years ago, I was on a building site in Kensington, London, when I came across mildly dizzy, sweaty and felt like I was about to throw up. I put it down to being stuck in a dusty and dingy plant room and inhaling the surroundings. I battled on through the rest of the day and drove home.

### A strange kind of food poisoning

That night I was lying in bed and started to get a strange pain in the rear lower back area which, coupled with dizzy sweatiness, made for a really crap night's sleep and I was convinced I had food poisoning.

I decided to take the next day off as I wasn't quite right and couldn't face the two-hour drive back to the old building site where my tools had been left the day before.

I was unusually thirsty but not in the slightest bit hungry – which was odd for me. The more water I drank, the more I sweated it out, so I never really got much use from the toilet as fluids were just coming out in sweats.

It got worse that night, with the lower back pain getting quite intolerable and making it impossible to get comfortable. I also had a mild dose of the shivers starting to creep in. What on earth had I eaten to give me this bad a dose of food poisoning? Still, it'll pass in the next day or two, I thought.

Over the next few days, the shivers got so bad that I'd wrap up in a duvet with a woolly hat on to try to keep warm. With hindsight, this didn't help as it caused me to sweat out more! The shivers became so violent that I was permanently exhausted but couldn't get any rest because of them. Catch 22, I believe they call that.

After a week of not getting any better, my wife decided that she'd had enough of my blokey 'it'll-be-fine' attitude, bundled me into the car and belted off to A&E. On a Friday night.

The first nurse I saw looked a little confused as to why I hadn't come in earlier and why I was wearing a woolly hat. She invited a colleague over and they proceeded to question me on my symptoms.

They looked perplexed and the one question that kept being repeated was, 'Have you been anywhere tropical?' – which I found slightly worrying.

They took some bloods, hooked me up a drip to replace the fluids I was losing and fetched the general doctor. At that point, I had no idea I'd be in there for the next six days.

### All change, please

The doctor arrived, removed my woolly hat and repeated the tropical question; after which I was wheeled upstairs to my own private room as they weren't sure what was wrong, so 'isolation it is for you, sir!'

My bedding was being changed hourly as it was soaked through with sweat and I thank the nurses who suffered and endured that task.

Being a Friday night, they were on skeleton staff and the doctors weren't able to come until Monday morning.

That night I suddenly felt really hot, so pressed the buzzer and along came the sister. My temperature was taken and was nearly 40°C (104°F) and the shivers had started to take hold again. The sister hit the panic button and nurses came running. They smashed into the next ward, turned on the lights and ripped out all the desk fans they could find, returning and pointing them all at me.

I later found out that it was nearly game over that night.



The shivers became so violent that I was permanently exhausted but couldn't get any rest because of them. Catch 22, I believe they call that.



## The charge sheet blamed pneumonia

Over the next few days, the drips I was wired to kept me fed and topped up with fluids. The shivers hadn't stopped, but I was oddly used to them now. The doctor popped in for five minutes a day and arranged more blood tests and x-rays, but little was given away as to the cause of this craziness.

## Eventually my chest started to crackle and it became hard to breathe. It turns out that the sweats, shivers and constant wet bedding had now caused pneumonia.

The combination of fluids and random drug drips (they tried quite a few!) eventually made the shivering and pain subside and I heard mutterings of kidney infections, bladder infections and UTIs – but no one would actually say it was any of them that was the problem, the charge sheet blamed pneumonia.

## Fixed up this time

Six months passed by with me back to my old self. But then I could feel the early signs of this trying to creep back in. No blokey nonsense this time! Straight to the GP who did a urine test and then gave me some ridiculously strong antibiotics (the type that forbid you from driving) and yet more blood tests.

Antibiotics fixed me within a week. Result.

By now, I'd had more blood tests than I care to remember but not a single result was hinting at the big C. To be honest, it wasn't even mentioned.



## Perhaps it wasn't a result after all

Three months passed by and once again, it started to rear up. Straight to the doctors again, but this time the conversation went more like this ...

**Me:** This is the third time I've had this.  
Is there a specialist I should be seeing?

**Dr:** The specialist you should be seeing is called a urologist.

**Me:** Awesome name, I've not heard of that before! How do I get to see him?

**Dr:** We refer you.

**Me:** Great, can we do that then, please. And how long do you think it'll take for an appointment?

**Dr:** Around three to four months.

**Me:** COME AGAIN?! Do you not remember this nearly killing me within two weeks? I think the wife has private medical insurance from her work that we've never used. If I was a 'named driver' would that speed up the process?

**Dr:** Yes it probably will. Please check and I'll get you the referral letter if you have.

## Next stop: urology department

I was seen the next week by the urologist.

Now, for somebody who doesn't know about these things (me), I perhaps should have prepared a little better for the check over, especially the ominous words 'please lay on your side with your knees up to your chest'. He also sent me for blood tests, but they all came back clear again.

I was sent for an MRI scan of the bladder; that came back clear too.

The scan also caught part of my lungs and showed some dark patches – so I ended up with another referral to the lung doctor. Luckily it was only scar tissue from the previously contracted pneumonia.

He then said the only way to prove the bladder was okay would be to take a look inside, so we'd need to schedule an operation.

Great, I thought, then mistakenly asked, 'How do you do that, then?' to which he explained about the cystoscopy and possible urethral widening procedure and my knees went a bit weak.

The way I had to look at it was you can either freak out for three months or just get on with it. You won't be able to change the outcome so why flap? The bins still need taking out whatever happens.

### Stretching a point

Anyway, surgery was booked for a few weeks' time. Went in. Went under. Woke up after.

After I had come around, he explained that there was some stricture which had now been expanded and he also found a lump on the bladder wall that was stopping the bladder from emptying fully. This was causing urine to remain inside and go stale, leading to the infections I'd previously suffered.

They had taken a biopsy of the lump and sent it away for testing – the results would be back in a week or two. So once I was passing clear urine, I could leave.

Weeing blood was a new one for me, but luckily it didn't last long in hospital and only a tiny bit in the following days.

### Let's follow this up

I was invited back in a couple of weeks to discuss the operation and follow up. The consultant reiterated that the stricture may also have been assisting the infections and, by the way, you have bladder cancer. Just like that. My wife threw her arms around me and started sobbing and mumbling, 'It'll be okay'.

What did I do? I felt I had to 'toughen up' for everyone at that point, because if I crumbled, she'd crumble, and the kids would crumble. We couldn't have that. I took her arms off me and softly but firmly said, 'Pity is the last thing we need. Let's just hear what the options are.'

There were no options. The urologist said he removed all of the tumour whilst he was in there, so there wasn't anything left. He said we need to leave it three months for the next cystoscopy, which should give it enough time to heal or grow or whatever is going to happen. He'd then confirm the all clear. Or not.



### Pack it up

In the meantime, he gave us a list of things to pack up:

- smoking (directly linked apparently)
- drinking (affects the tablets he's prescribed)
- fizzy drinks (not good for the healing bits)
- red meat (try to keep it minimal – I ended up giving it up!)

The hardest thing to give up was the red meat – it gets everywhere!

It was also very difficult to remain brave-faced for the three months; not knowing was the worst. The way I had to look at it was you can either freak out for three months or just get on with it. You won't be able to change the outcome so why flap? The bins still need taking out whatever happens.

### All clear

Three months later, and the second cystoscopy is all clear. I now have to go back in six months, then annually if it is clear again. And I'm still taking out the bins!

# Sarah's ADVENTURE



Sarah was a young lady who was diagnosed at just 27 years old with bladder cancer. A great supporter of Fight Bladder Cancer, Sarah worked tirelessly to support other patients and carers, helped to raise awareness of the disease and represented us at medical conferences. In her short life with bladder cancer, she inspired many people to all work hard to change outcomes for bladder cancer patients. This is her mother's heartfelt story.

Sarah was an outgoing, fun-loving girl, with a passion for life. She loved scuba diving, and although I always worried when she was going on a diving trip to explore wrecks, I knew she would be sensible and not take risks. She used to drive her diving buddies mad with her attention to detail. Alex, her brother, would probably say she was 'bossy', although he always respected Sarah's big sisterly advice when he needed it.

Sarah loved being a primary school teacher, and cared about her pupils' psycho-social needs, not just their educational needs. Her first teaching post was at a school in a deprived area of Rotherham, where some of the children turned up for school without having had breakfast. Sarah ensured that each of them received a piece of fruit, usually a banana, without embarrassing them, by giving them away as 'prizes' for good work. The children loved Sarah, as she was firm but fair, and never shouted at them. She would entertain the other teachers in the staff room with humorous stories about her two little dogs and their antics, as well as stories about what she had done with her friends. We never in our wildest dreams thought that anything bad would happen to Sarah. But it did.

David and I returned from a trip to France in the summer of 2013, and called to visit Sarah and her partner, Simon, on our way back home. We were eager to meet Sarah's new puppy, Belle, bought as a playmate for their three-year-old dog Rosa. Rosa was a very mature young lady with regal social skills; the small black and tan bundle of fluff whirling about like a tornado was Belle.

**Sarah decided to view the impending treatments and investigations as an adventure, which she was determined to face with courage and dignity**



## Breaking the news

It was during that visit that Sarah told us that her GP suspected that she had kidney stones, and was referring her to a urologist; this was the first time she had mentioned a problem. It transpired that she had visited her GP when she saw blood in her urine, and treatment for a nasty UTI had been ineffective. Although we were concerned, it never crossed our minds that it could be anything sinister. Even when the ultrasound scan revealed a 'lesion' in her bladder, we remained positive, as did Sarah.

But I must have had a nagging doubt because it was enough to send me to Google, only to find that every hit brought up websites about cancer. A cystoscopy, CT and MRI scans followed, then a TURBT proved I was right. My beautiful daughter had cancer and would need to have her bladder removed. What's more, the tumour was high-grade aggressive. We took hope from the fact that the tumour had not spread to other parts of her body and Sarah decided to view the impending treatments and investigations as an adventure, which she was determined to face with courage and dignity.

Sarah had a cystectomy in April 2014, following three months of neoadjuvant chemotherapy. Her first chemotherapy cycle was the week before Christmas. We anticipated a different kind of Christmas, with Sarah being tired and nauseous. We could not have been more wrong. Little did we know then that that Christmas was to be her last. This is something that we will remain grateful for, as we did not behave or treat Sarah any differently.

## Coping after the operation

Sarah referred to her new stoma as 'Rocky'. I am not sure why, but the name stuck, and many a conversation centred around Rocky

and its unpredictable antics, usually at inopportune times. Luckily for Sarah, she was supported by Abbie, a lovely stoma nurse, who visited her regularly and was always a phone call away.

Sarah was determined to return to 'normal', albeit her new normal with Rocky. Sarah gave no outward sign of the traumas she had been going through. Not only did she summon the energy to sit through a new production of *Brassed Off*, but she also walked back to the car after the show, managing to get stuck in the lift with Simon and his parents for half an hour!

## Wedding plans

In September 2013, one month after Sarah was referred to the urologist, Sarah and Simon got engaged, and began planning their wedding for 3 April 2015. We did not realise it at the time, but planning a wedding was to be an excellent distraction. Sarah knew exactly how she wanted her wedding to be, and chose her bridesmaids, venue and flowers with care. The only thing she hesitated on was choosing her dress, as she wanted this to be special.

Sarah had chosen dusky pink and cream as the colour scheme, so we walked the length of Oxford Street with the bridesmaids, going into every store. After who knows how many dresses tried on – they were too short, too long, too pink (?) or 'minging' (yes, I learnt a new word that day) – the girls decided that the first dresses they had tried on were perfect! It was lovely to see Sarah so happy, and the day is a memory I will never forget.

Wedding fairs featured regularly during the plans, some at superb locations down long country lanes. At one, Jess, Sarah's chief bridesmaid who came with us, invented a fiancé for Jess so she could get bags of free goodies, as well as Sarah.

## Chemotherapy and cystectomy

Sarah's journey was 'one step forward; one step back' all the way through. The three cycles of chemotherapy she had prior to surgery proved to be less daunting than either she or we had anticipated. She actually enjoyed her sessions at the hospital, always making sure that she had a packet of 'Percy Pigs', which we bought on the way into the hospital. Very good medicine, although I'm not sure who ate the most, me or Sarah. I can't recall specific details, but we always ended up laughing during Sarah's chemotherapy sessions. On one occasion, we were laughing so much that Sarah had tears rolling down her face. Anyone who knew Sarah knows that her laugh was not the quietest, and was extremely contagious. Consequently, other patients in the chemotherapy bay would end up laughing, even if they did not know what we were laughing at. Sarah had a warmth about her which radiated to others around her.

By the time Sarah was scheduled to have her surgery, she had got used to the idea of having a urostomy and a bag attached as opposed to a reconstruction. Always looking on the bright side, Sarah told her friends that at least she wouldn't have to queue for the disgusting toilet facilities next time they all went to an outdoor music festival. Despite her brave exterior, however, she felt apprehensive.

The neoadjuvant chemotherapy had had some effect, but not as much as any of us had hoped for, and subsequent scans showed that the tumour was still evident. Waiting for the call from the hospital informing us that she was out of theatre was one of the worst waits we have experienced. The surgery had gone well, but the surgeon had had to remove her uterus, an option they

had discussed before. She looked so vulnerable when we had to tell her the news. Sarah was in hospital for one week following her cystectomy, and then discharged home to get on with her life – learning to live with Rocky – until the next consultation.

## Second opinion

Four weeks after surgery, Sarah had another MRI scan and, despite all the lymph nodes that had been removed at surgery, she still had enlarged lymph nodes in her pelvis so would need further chemotherapy. It is almost impossible to put into words how we felt when she rang us to tell us this news. We tried to convince ourselves that the enlarged nodes were a result of the trauma of the surgery, but I think that was because we didn't want to acknowledge the reality of the situation.

We all felt a second opinion was needed, so her oncologist sent her to Dr Robert Huddart at the Royal Marsden Hospital, a world-leading cancer centre, for a second opinion. Dr Huddart reviewed Sarah's scans and arranged for a PET scan. He switched her adjuvant chemotherapy to Accelerated MVAC, which would be administered every two weeks, involving an overnight stay in hospital each time. Sarah was upset to read that MVAC causes hair loss. However, she felt this was a small price to pay for something that could save her life, so we made an appointment with the hospital for Sarah to choose a wig in a style and colour most like her own hair.

During the journey home, Sarah suddenly announced that she was not frightened. I assumed she was talking about further chemotherapy, but she actually meant that she was not frightened of dying. On reflection, I wish that I had allowed Sarah to continue with this conversation, but it came as a shock and I cut her short. However, it prompted me to arrange support for Sarah from a clinical psychologist. Sarah found her conversations useful and told me about things she had discussed.

**She lit up a room with her infectious laugh and her ability to lead. She would have been so proud.**

## Finding FBC

By this point, Sarah had joined Fight Bladder Cancer's online support forum and – of course – gave back by helping with fundraising. She was too unwell to take the skydive she had organised, but James, an FBC friend, stepped in, wearing a blonde wig, fake boobs and a skirt, and calling himself 'Sarah' for the day.

In June 2014, whilst still undergoing chemotherapy, Sarah attended the BAUS (British Association of Urological Surgeons) conference in Liverpool, to help run the FBC stand. She also helped to organise a fundraising dinner-dance for the following year. It is ironic that the arrangements for the dinner-dance were finalised the day that Sarah died on 5 December 2014. We feel extremely humbled that the event was dedicated to Sarah's memory and we will never forget that evening, which brought mixed emotions, both happy and sad. Sarah would have been the life and soul of the dance. She lit up a room with her infectious laugh and her ability to lead. She would have been so proud.

## MVAC

Sarah's first cycle of MVAC was administered whilst she was an in-patient in hospital. For a few weeks prior to admission she had been complaining of a pain in her left thigh, which sometimes responded to pain killers and at other times responded to a heat pack. The catalyst for admitting her onto a ward was when her leg swelled and she became pyrexial. The medical team suspected that it may be a DVT (deep vein thrombosis). This was when my ability to cope was put to the test, as my knowledge and experience and over-active mind suspected other, more sinister causes. It was difficult

to remain positive, but even more difficult to think about the alternative. Tests revealed that a DVT was not present, and the oncologist concluded that a node within the pelvis was causing pressure. Please MVAC, do your job! She had three cycles of MVAC, with no recurrence of any leg swelling during this time.

In between cycles of MVAC, Sarah arranged for a hairdresser to visit her at home and shave off her hair as it had started to come out in chunks. A good friend stayed with her whilst she was having her hair shaved to offer support. She always wore her wig outdoors, but at home, she would occasionally take it off, as it made her hot.

We were hopeful that the MVAC chemotherapy had been effective in killing off any cancerous cells, especially when Sarah's oncologist wanted to continue with a fourth cycle, following yet another MRI scan. Sarah had more side-effects from MVAC than gemcitabine and cisplatin – she felt nauseous and much more tired – and was not overly keen on further cycles. On reflection, she may have been better not having the fourth cycle, as she was never as well after this, but if she had not, we may have forever wondered if she should have had it.

## The final outings

In September 2014, Simon and Alex took part in the Challenge Cancer 100km overnight cycle ride from London to Brighton. David, Sarah and I drove down to Luton with them, and got the train into London, where we had booked a hotel for the night. We were going to go out for a meal, but Sarah suggested that we go to a show, so while Alex and Simon rested in the hotel, then found their way to the start of the cycle event, David, Sarah and I went to see Billy Elliott. Sarah stayed awake the whole time and



thoroughly enjoyed the show. No one would have guessed how ill she was. The only sign she was not her usual energetic self was when she stayed in bed until late the following day.

Everything about Sarah's wedding was honed to the last detail and the final thing was to choose the dress. We had been given a double appointment as she needed to rest between trying on each one. I will always be grateful that I took photographs of her in the dress she chose, which happened to be my favourite. I enthused with Sarah regarding her wedding plans, whilst deep down, I knew that the plans may not come to fruition.

### The last weeks

Sarah had wonderful support from her friends and stayed active as long as she could but gradually things became more of a strain. In October, we had planned to go to the launch of the Wee Bookshop in Chinnor, then decided a day out would be less arduous. However, our trip ended up being to Derby Royal Hospital, where she stayed for three weeks, undergoing radiotherapy daily, and having several transfusions to try to rectify her low platelet and magnesium levels.

It was during this admission that the palliative care consultant asked David and me: 'What is your understanding about what is happening with Sarah?' I knew immediately that this was not what I wanted to hear and the rest of the

conversation is a blur. I recall going back into Sarah's room and acting 'normally'. I did not want her to sense that anything negative had been discussed and she did not ask.

I have reflected since Sarah died and have come to the conclusion that she knew her prognosis. She was perceptive and would have picked up on things around her. If she was told that her prognosis was poor, she did not tell us. David does not like to think that she knew, possibly to protect himself from the pain of thinking that she was suffering psychologically.

The day that Sarah was discharged home, she called me at work, distressed because she felt too weak to get up off the sofa. At first, she declined to come home with us, but two days later she relented. All the signs that she was approaching the end of her life were there, but still we did not see them. She was scarcely eating and was becoming physically weaker. All she wanted to do was sleep.

We took Sarah to see the Christmas lights at Chatsworth House and Castleton on the Saturday before she died, with Simon and Sarah's friend Jayne. It was a lovely crisp, dry day, and we looked around the house and gift shop, finishing in the restaurant for a hot drink. Sarah bought a fragrant orange wreath, which we will treasure forever.

Four days later, Sarah was admitted to Derby Royal Hospital as she said she wanted to be 'looked after'. She was alert and able to talk to us, and drank apple juice. The

last thing she ate was a Macdonald's chip, fed to her by Alex. She told us all to go home at midnight, which we did. This was the last time we saw Sarah awake. The following morning, Sarah was unresponsive. We could no longer mistake the signs that she was approaching the end of her life.

Sarah died at lunchtime the following day, on Friday 5 December, with David and Simon's mum holding her hands.

### We will remember her always

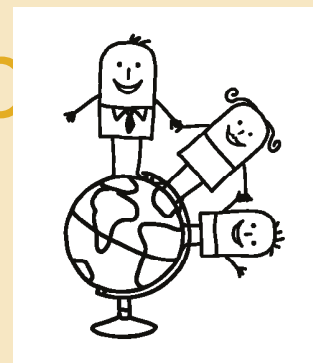
I have always thought of myself as someone who would crumble if faced with serious problems, and I have surprised myself with how strong I was during Sarah's illness.

One of the hardest things I had to do was to tell Alex that his sister was going to die. We sat in Costa Coffee in the hospital foyer, and to this day, I dislike going into a Costa. Through it all, Sarah never felt sorry for herself, and was able to see humour in most things.

**This was Sarah's adventure although her life was cut far too short. Sarah will always be our beautiful daughter, and will never ever be forgotten.**



# Fundraising catch up



Being affected by bladder cancer can shake your world and for most of us it will be the toughest fight we ever face. Now, more than ever, we need people like you to join our team and help us make sure no one faces bladder cancer alone and that we can ensure that diagnosis and treatments are improved.

An amazing way to join us is to organise a fundraising event – perhaps a personal challenge or even as a group. Thinking about it? There are lots of ideas in our fundraising packs that you can download for free from our website at [www.fightbladdercancer.co.uk](http://www.fightbladdercancer.co.uk) or you might get inspiration from these examples where our supporters have put themselves out to make a difference.



**Alison Crellin and Ros Bruce**, who continue to use crocheting to make blankets and some other amazing other wonders in wool. They have even set up a Crochet, Knit and Natter Facebook Group to encourage others to get involved and raise money from their craft work.

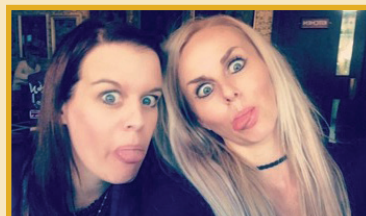
**Will Reed** ran the London marathon for us in memory of his Auntie Teresa and crossed the line in his bright orange FBC running shirt.

**Eilis Dolan** ran the Richmond half marathon in memory of Eamon Dolan.



**Pete Massera** got very dirty in the Wild Mud Run.

**Hayley Parkin** is being joined by her friend of 33 years (yes, another Hayley!) to take part in the Wolf Run. Double trouble?



Urology nurse **Shievon Smith** and **the urology team at Broomfield Hospital** have run a number of events including orange and black dress-down day and name the bone with lots more planned over the summer.



**The McGee family** continue to raise funds for our research fund in memory of their dad, and Hazel has organised 11 of her family and friends to join her for the West Highland Way challenge of 96 miles (155km) over the rugged but beautiful Scottish landscape.

**Kate Bohdanowicz** did a sponsored silence, and if you know Kate, you will know that this was a supreme personal challenge!

**Sue Thompson** gave up alcohol for a month! Now that was a challenge!

**Ceinion Thomas** took part in the Manchester marathon in memory of his dad.



A UK, or more likely a global, first this summer when a whole team of our online support group members, **Ros, Sue, Robin and Colin** are skydiving with the Red Devils and only half of them have bladders! Cheers guys, enjoy the ride!



**Without your support we wouldn't be able to do what we do to fight bladder cancer!**

# Raise some money & have some fun!

There are many fun and easy ways you can raise money to support our cause. And, of course, you can also run marathons, jump out of a plane or climb a mountain to help raise awareness and funds!

You can join in any event, large or small, across the country and raise money for FBC or you can arrange your own. Whether it is running a marathon, taking part in a bike ride or joining a sponsored walk, why not wear the FBC logo and help spread the message at the same time.

We arrange our own fundraising and social events throughout the year, when we try and get people together so that you can meet others affected by bladder cancer. These party nights are brilliant fun and a chance to meet up informally with people to share experiences.

However, most of the fundraising is still with supporters organising their own local events. From bake sales to coffee mornings, bag packing at local supermarkets to beard and head shaving – the list is almost endless.

## WHY WE NEED YOUR SUPPORT

Bladder cancer can be a killer and we are committed to ensure that it is prevented wherever possible, ensure early diagnosis, the provision of advice and support and to be a strong supporter of clinical trials and research to get more effective treatments.

We rely on voluntary donations so we can only achieve our goals with your support. Whatever you choose to do, fundraising, donating, volunteering or raising awareness, thank you.

## OUR FUNDRAISING PROMISE TO YOU

We are open, honest and transparent – we will tell you what we're trying to raise each year, how much we've raised and what it's been spent on.

We are committed to ensure that we meet the requirements of the Fundraising Regulator and follow their Code of Fundraising Practice to ensure we meet the highest standards, so you can give and fundraise for us with confidence and trust.

**Our key principle is that our fundraising work is: Legal, Open, Honest and Respectful.**



Please do get in touch if you need any help, sponsorship forms, posters etc. for your event at [info@fightbladdercancer.co.uk](mailto:info@fightbladdercancer.co.uk)

## ARTICLE

RAKESH HEER, PhD, FRCS (Urol)  
Consultant Urologist and RAHUL  
GUJADHUR Specialist Urology Registrar

# Does blue light cystoscopy (BLC)

reduce bladder cancer recurrence  
& progression rates?

We asked  
two consultant  
urologists to  
examine the results  
of a PHOTO trial  
to give us the  
answers.

It is well established that patients with 'superficial' non-muscle-invasive bladder cancer are at risk of disease recurrence and in those with high-risk features there is a concern about progression into life-threatening muscle-invasive disease. Over the years, different strategies have been developed to address these issues: the use of adjuvant chemotherapy with Mitomycin C, immunotherapy in the form of BCG, early re-resection, intensive surveillance protocols and using more experienced surgeons to improve the quality and tumour clearance at the initial endoscopic resection<sup>[1]</sup>.

It is thought that a significant proportion of tumours recur because of incomplete tumour excision and over the past decade

there has been the emergence of new imaging modalities that are designed to help improve the identification of tumour and guide resection such as blue light cystoscopy, narrow band imaging, optical coherence tomography and 'confocal laser endomicroscopy'<sup>[2, 3]</sup>. It has been suggested that these new methods can help to reduced recurrence and progression rates<sup>[4]</sup>.

Of these, blue light cystoscopy, also referred to as photodynamic diagnosis (PDD), has shown the most promise. Despite a number of randomised trials showing promise, prospective data about the long-term efficacy of blue light cystoscopy in comparison to conventional white light cystoscopy is lacking. There is a school of thought that suggests that

photodynamic diagnosis helps to achieve a more accurate diagnosis at cystoscopy in comparison to white light cystoscopy but does not result in lower recurrence rates in the longer term – as there are alternative molecular mechanisms that leave the bladder prone to form new tumours<sup>[5]</sup>. Given the significant medical and financial implications of implementing expensive equipment for photodynamic diagnosis for routine use, a well-powered randomised trial was of paramount importance. The PHOTO trial (described below) has filled this void and its findings should help clarify the value of routine PDD-guided resection.



## What is photodynamic diagnosis (PDD) and how does it work?

Photodynamic diagnosis makes use of the instillation of a photosensitive agent such as Hexaminolevulinate into the bladder one hour prior to tumour resection. The principle is that the photosensitive agent will accumulate in cancer cells rather than normal ones. During resection, blue light illumination, with a wavelength of 380–450nm, causes the photosensitive agent to fluoresce and malignant cells are then identified as red lesions on a blue background<sup>[2, 3, 5, 6]</sup>. Such significant contrast between normal and abnormal tissue allows better identification of tumours, especially aggressive carcinoma in situ (CIS) ('flat tumour') that could otherwise easily be missed.

The short-term benefits of blue light cystoscopy are well documented and hence its recommendation in several guidelines. There is considerable debate about its definite benefits in the long term, especially as regards reduced recurrence rate and progression. The PHOTO trial is specifically aimed at assessing this and its findings could not only result in significant cost savings for the National Health Service but also changed practice in the treatment of bladder tumours.

PHOTO is a UK-based randomised trial that aims to recruit 533 patients with newly diagnosed intermediate or high-risk non-muscle invasive bladder cancer over 2½ years from 20 centres and allocate them to either blue light cystoscopic resection or white light cystoscopic resection in the ratio of 1:1. The patients then undergo standard NHS follow-up protocol to keep the evaluation as close as possible to current practice and make the finding as

relevant as possible for the typical patient with a new bladder cancer. This is planned for 36 months. Recruitment started in October 2014 and is expected to close in December 2017.

## What will the study look at?

The main objective of the study is to evaluate the difference in recurrence rates at three years between blue light cystoscopy and white light cystoscopy groups. In addition to this, the trial will also assess the following:

- Rate of disease progression.
- The effect on quality of life of patients over three years. This is an extremely important aspect of the trial and will be achieved by using validated questionnaires.
- The safety of PDD resection compared with the standard approach by analysing the complication rates up to 30 days following the surgery.
- Use a mathematical model to predict the longer-term benefits of PDD by assessing progression rates, quality of life and freedom from cancer over a patient's lifetime. This model in conjunction with the study results will also allow evaluation of the financial benefits of using PDD.
- Impact of urologists having to learn the new technique. This will be achieved by comparing patient outcomes after surgery by surgeons who are experienced and those who are less experienced in the use of photodynamic diagnosis.

The findings of the PHOTO trial should enable patients, clinicians and policy makers to evaluate the merits of PDD in the treatment of bladder cancer and settle the ongoing debate about its real clinical and financial benefits.

## References

- 1 EAU guidelines on non-muscle-invasive bladder cancer 2016.
- 2 Kołodziej AWM et al. Review of current optical diagnostic techniques for non-muscle-invasive bladder cancer. *Cent European J Urol.* 2016; 69(2): 150–156.
- 3 Liu JJ, Droller MJ, Liao JC. New optical imaging technologies for bladder cancer: considerations and perspectives. *J Urol.* 2012; 188: 361–368
- 4 Witjes JA, Babjuk M, Gontero P, et al. Clinical and cost effectiveness of hexaminolevulinate-guided blue-light cystoscopy: evidence review and updated expert recommendations. *Eur Urol.* 2014; 66: 863–87
- 5 O'Brien T, Ray E, Chatterton K, Khan MS et al. Prospective randomized trial of hexylaminolevulinate photodynamic-assisted transurethral resection of bladder tumour (TURBT) plus single-shot intravesical Mitomycin C vs conventional white-light TURBT plus Mitomycin C in newly presenting non-muscle-invasive bladder cancer. *KBJU Int.* 2013 Dec; 112(8): 1096–104.
- 6 URL <https://www.hexvix.com>

# Why should I take part in a BLADDER CANCER TRIAL?

Most patients know that advances in medicine come from clinical trials but they may be uncertain how such trials work and how they, as a patient, can benefit directly from participating in a trial. Bladder cancer has a particularly strong history of clinical trials which have shaped the treatment of every bladder cancer patient. We put your questions to Hugh Mostafid.

**Q Surely my doctors should know how to treat my bladder cancer. Why should I take part in an 'experiment'?**

**A** Medical knowledge is not 'fixed'; it is advancing all the time and there is room for improvement in every branch, including bladder cancer. There are many areas where we don't know the best treatment. For example, whether surgery or BCG is best for high-risk superficial bladder cancer. In other areas, the established treatments have undesirable side-effects, such as chemotherapy for advanced bladder cancer. In order to make improvements to bladder cancer treatment we have to try new drugs, operations and tests and see if they perform better than the current options. This is the basis of performing clinical trials.

**Q Clinical trials are testing treatments the effectiveness of which are not known and so I may be getting a suboptimal treatment for my bladder cancer**

**A** Before patients are allowed to take part in any clinical trial, it goes through a very rigorous process of assessment by experts. This includes review by an ethics committee which includes patient representatives and members of the public. It is impossible for a patient to be offered a trial that knowingly offers an inferior treatment for a patient than they would normally receive. In other words, in most cases the clinical trial is expected to show an improvement.

**Q I've heard that I can't choose what treatment I get and it may be a dummy treatment (placebo)**

**A** There are different types of trial but broadly speaking they fall into two categories. Firstly you may be offered a treatment in addition to the treatment you would normally receive. This is usually straightforward in that you can only be in the clinical trial if you receive the treatment.

In many cases we want to compare the new treatment with current treatment and this has to happen in an unbiased way, otherwise we would end up with most doctors and patients choosing the new treatment and we would not know how it compares to standard treatment. In this situation the treatment is often allocated by a third party to keep the numbers balanced, usually in a preordained fashion such as a sequence of envelopes which are opened in turn. There is a frequent misconception that this is a totally random process, partly because the medical term for such a trial is a 'randomised trial' but it is important to stress that the process is anything but random and is designed to produce an unbiased and therefore reliable result.

**Q I don't want the hassle of taking part in a trial; there are lots of visits and it will delay my treatment**

**A** It is true that being in a clinical trial does require more tests and often more visits than 'normal' treatment but it's worth looking at the positive side of this. You will always be seen by someone who is a consultant and an expert in bladder cancer and the dedicated research nurses can spend far more time explaining your tests and treatment to you than is often possible in a busy outpatient clinic.

The cost of any extra visits to hospital, including travel costs and parking, are reimbursed so you will not be out of pocket. There are also very strict timelines once you are enrolled in a trial, so although initially it may appear that you are having a lot of tests, this would never delay your treatment. Indeed, being part of a trial means that you will receive your treatment, and especially your follow-up tests, in a timely manner without the uncertainty of being on a waiting list.

**Q I've heard of healthy volunteers falling very ill after taking experimental drugs and don't want the same to happen to me**

**A** Although there was a recent example of a new drug causing severe unexpected side-effects in healthy patients, in the vast majority of cases the clinical trials are testing treatments that are already known to be safe and indeed are often already widely used. For example, we know that bladder chemotherapy instillations are safe but clinical trials are carried out to find out the best dose and length of treatment.

**Q Taking part in a clinical trial won't benefit me directly**

**A** It is true that in most clinical trials we cannot be sure if an individual patient will definitely benefit from the proposed treatment. However, the treatment most bladder cancer patients receive today was the result of patients participating in clinical trials 30–40 years ago and their altruism has benefited many thousand of patients. However, there is a more immediate and positive benefit for patients taking part in clinical trials. Even if the patient is allocated 'standard' treatment as part of the 'control' arm of a trial, patients in clinical trial consistently do better than patients receiving the same treatment in a normal outpatient setting. The reason for this is fairly clear – you are under much greater scrutiny from your doctors during a clinical trial, with more tests and very careful follow-up so problems are detected and treated sooner.

#### ARTICLE

HUGH MOSTAFID MSc FRCS (Urol) FEBU  
Consultant Urologist, Honorary Senior  
Lecturer Royal Surrey County Hospital

Medical knowledge is not 'fixed'; it is advancing all the time and there is room for improvement in every branch, including bladder cancer.





## Medical Enterprises, a 28-year-old research firm, is proud to invest over 70% of its revenue in bladder cancer research and clinical trials

We are a group of scientists who pioneered the use of Radiofrequency (RF – a non-ionising radiation) in bladder cancer, creating what is commonly known today as Synergo®.

Following our failed attempts at healing the bladder with a chemotherapy agent, Mitomycin-C (MMC) at 85°C, and the experience of others with isletions (up to 100°C<sup>1,2</sup>), we pursued more feasible methods.

First clinical article following a feasibility study, shows selective damage to tumours, whereas healthy tissue remains unaffected<sup>3</sup>. Since then, over 40 articles demonstrate its clinical potential.

Long-term follow up (10 years) on the randomised patients of the 2003 trial, showed durable outcomes<sup>4</sup>.

1988

1989

1991

2003

2010

Radiofrequency (RF) found to be feasible and controllable means to heat the bladder tissue, in combination with a constantly cooled MMC instillation<sup>5</sup>. This also bypasses problematic heating of the urethra, and further degradation of the drug when directly heated<sup>6</sup>.

Randomised trial results show that certain types of patient, stayed cancer-free substantially longer, compared with one-year of MMC instillations without the RF. Side effects reported were comparable; generally mild, transient and self-healing<sup>7</sup>.

### Your needs is your most valuable asset

As your doctor explores treatment options, as well as their risks, benefits and clinical evidence,

only your doctor can determine whether Synergo® is appropriate for your situation.

Medical Enterprises is interested only to support patients with evidence-based information for an ongoing patient-doctor dialogue.

We aim to continue to strive for better minimally-invasive results as in bladder cancer patients – it is in our core to you.

For further information and more references please visit: [www.synergo-medical.com](http://www.synergo-medical.com)

Breakthrough proving RF is the predominant mechanism of action in most 'hyperthermic' treatments, with non-thermal effects selective to cancer cells<sup>[24]</sup>.

Randomised trial results show that certain types of patient, remained cancer-free for a longer period of time, compared with one-year of BCG instillations when given as a primary treatment<sup>[25]</sup>.

2014

2014

2015

2016

2017

Study shows that a variety of patients given RF treatments remained without bladder cancer (appearing anywhere in the body) for a longer period, compared with patients whose bladders were removed, with durable, long-term outcomes after 5 years<sup>[26]</sup>.

Discovery of RF harnessing the immune response, differentiating it from MMC instillations<sup>[27]</sup>.

The European Association of Urology (EAU) guidelines present RF-assisted chemotherapy instillations as the only proven efficacious technology for treating Non-Muscle Invasive Bladder Cancer<sup>[28]</sup>.

<sup>[24]</sup>Wang J, et al. The Hyperthermic Instillation of BCG in the Bladder. *Urology*. 2014;83(5):1013-1020. <sup>[25]</sup>Wang J, et al. Synergy of Hyperthermic Instillation in Treatment of Recurrent Bladder Cancer: An Evaluation in a Randomized Phase III Trial. *J Clin Oncol*. 2014;32(15):1551-1559. <sup>[26]</sup>Wang J, et al. The efficacy of hyperthermic intravesical chemotherapy in the treatment of bladder cancer: a randomized phase III trial. *Urology*. 2014;83(5):1013-1020. <sup>[27]</sup>Wang J, et al. The efficacy of hyperthermic intravesical chemotherapy in the treatment of bladder cancer: a randomized phase III trial. *Urology*. 2014;83(5):1013-1020. <sup>[28]</sup>Wang J, et al. The efficacy of hyperthermic intravesical chemotherapy in the treatment of bladder cancer: a randomized phase III trial. *Urology*. 2014;83(5):1013-1020.



EAU  
EUROPEAN ASSOCIATION OF UROLOGY

SYNERGY-CPM  
FOR BLADDER CANCER

# Clinical trials

## Developing vital research for bladder cancer



**Fight Bladder Cancer supports evidence-based medicine for all those affected by bladder cancer. Consequently, we are passionate about the development of vital research that is needed to increase our knowledge base, to help with prevention and to develop new and better forms of diagnosis, treatment and aftercare.**

**Fight Bladder Cancer supports bladder cancer clinical trials in the UK in many ways, including being key members of the National Cancer Research Institute's Bladder Cancer Clinical Studies Group where all trials are reviewed.**

We also provide patient input into specific trials and research by training and mentoring Patient Representatives to help develop and manage trials. We are currently growing our panel of patients and carers for this work and for the increased need for us as patients to be represented at NICE meetings to review potential new treatments.

If you wish to specifically donate or fundraise for bladder cancer research, we have a dedicated fund that ensures that 100% of any monies received goes towards our research activities.

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

A clinical trial is not something to look at when all else fails. Many treatments we use today were developed as part of a clinical trial. For example, the use of chemotherapy at the same time as radiotherapy treatment was developed in the UK as part of a large study (called BC2001) and has changed practice around the world.

There are a number of clinical trials in bladder cancer. These usually compare a new treatment that has the potential to work better, or with fewer side-effects, than what is used as the 'gold-standard'. Different trials are available in different hospitals. All studies have particular tick boxes to confirm whether this study is the correct one for you and your cancer. It may be that you and your type of bladder cancer do not match what we call the eligibility criteria for the study.

Knowing about what is on offer is very useful and you can find out information in the UK by going onto the website for the National Cancer Research Network and clicking on the portfolio map for bladder cancer. This gives an up-to-date overview of studies.

Remember that you should ask your doctor if you are suitable for a clinical trial, and it is always helpful to take information to show your doctor in case the trial is not familiar. If it looks as though you may be eligible for a study that is not available locally but is open elsewhere in the UK (and you are prepared to travel), you could ask your doctor to refer you.

If you are interested in joining this panel, please email [research@fightbladdercancer.co.uk](mailto:research@fightbladdercancer.co.uk) for more details and an application form.





# Current open trials

Current UK trials for bladder cancer are outlined here. For more details or eligibility criteria, please contact the appropriate trials team whose details can be found via the UK Clinical Trials Gateway at <https://www.ukctg.nihr.ac.uk/home/>

## DETECT 1

DETECT 1 is an diagnostic study to assess the performance of the UroMark assay to rule out bladder cancer in patients with haematuria. The study will recruit consecutive patients attending haematuria clinics as well as patients referred to urology outpatient clinics for investigation of haematuria.

## Non-invasive bladder cancer

### BRAVO

The BRAVO trial will study the choice between BCG treatment or bladder removal for high-risk, non-invasive bladder cancer. The initial part of the study will look at the feasibility of undertaking a randomised trial of BCG and radical cystectomy as treatment options for high-risk, non-muscle-invasive bladder cancer and what information from a patient, nurse and clinician point of view is necessary to enable patient randomisation for this comparison.

### CALIBER

The CALIBER study is for people with low-risk, non-invasive bladder cancer, which has returned after initial treatment. People who take part will either have surgery or a course of Mitomycin C. Mitomycin C is a chemotherapy drug, has been used in bladder-cancer

treatment for many years and is normally put into the bladder following surgery for bladder tumours. CALIBER aims to find out whether a course of Mitomycin C treatment might be an alternative to surgery for people whose low-risk bladder cancer has returned.

### HIVEC II

HIVEC II is a study in non-muscle-invasive bladder cancer looking at hyperthermia treatment. This trial is for people with newly diagnosed early bladder cancer or bladder cancer that has come back after initial treatment. Hyperthermia is a new treatment where the bladder is heated to between 42°C and 44°C and Mitomycin C is washed through the bladder.

The trial is comparing hyperthermia and Mitomycin C with Mitomycin C alone. The aim of this trial is to find out which treatment is better at controlling cancer growth, as well as more about the side-effects and quality of life.

### PHOTO

The PHOTO study is for people with a new diagnosis of non-invasive bladder cancer which has a medium or high risk of returning following treatment. Everyone taking part will have surgery to remove their tumours. The surgery will be done either using a white light to see inside the bladder, or a blue light. PHOTO aims to find out whether using blue light in surgery reduces the likelihood of the cancer returning.

## Muscle-invasive bladder cancer

### BISCAY

This is an open label, multi-drug, biomarker-directed, multi-centre, multi-arm, randomised Phase 1b study in patients with muscle-invasive bladder cancer (urothelial) who have progressed on prior treatment. This study is modular in design, allowing evaluation of the safety, tolerability, pharmacokinetics and anti-tumour activity of multiple agents as monotherapy and as combinations of different novel anti-cancer agents in patients with muscle invasive bladder cancer.

## Quality of life after bladder cancer (Q-ABC)

**The aim of this study is to use in-depth interviews to explore the 'lived experience' of patients and carers who have undergone, or supported someone through, treatment for bladder cancer.**

### BRISTOL BLADDER TRIAL

This trial is looking at the chemotherapy drugs cabazitaxel and cisplatin before surgery to remove bladder cancer.

Cisplatin is a chemotherapy drug often used to treat bladder cancer which is usually given together with another drug such as gemcitabine. This trial is testing the combination of cisplatin and a drug called

cabazitaxel and how well this combination works for treating invasive transitional cell bladder cancer before surgery and more about the side-effects.

### IDEAL

The IDEAL trial is looking at combining three different ways to plan radiotherapy treatment for bladder cancer. This is so that doctors can target the cancer more accurately and give a higher dose of radiotherapy than they are normally able to.

### SPIRE

SPIRE is another study of neoadjuvant chemotherapy for patients with bladder cancer who are due to have neoadjuvant chemotherapy. This study is in set up and involves an experimental drug called SGI-110 in addition to the two standard chemotherapy drugs gemcitabine and cisplatin. This is a very early study looking at how well the combination is tolerated and what its ideal dose is.

### ABACUS

ABACUS is a study for patients who are not able to receive neoadjuvant chemotherapy prior to cystectomy, usually because their kidney blood tests are not good enough to have cisplatin chemotherapy. In ABACUS, another drug is given for 6 weeks or so before cystectomy to see if this improves the results of the surgery and to see if there are any side-effects that might make the surgery more difficult. The drug in ABACUS is MPDL3280A, a PDL-1 inhibitor.

### RAIDER

The RAIDER study is for people with muscle-invasive bladder cancer who choose to have daily radiotherapy as treatment. Everyone taking part will have daily radiotherapy five times a week. People who take part will be in one of three treatment groups: standard radiotherapy, radiotherapy with the highest radiation dose focused on the tumour, or radiotherapy with a higher dose than normal focused on the tumour. RAIDER aims to confirm that this higher dose radiotherapy is safe and can be delivered at multiple hospitals within the NHS.

## Advanced muscle-invasive bladder cancer

### ATLANTIS

ATLANTIS is an adaptive multi-arm phase II trial of maintenance targeted therapy after chemotherapy in metastatic urothelial cancer. A randomised phase II biomarker directed umbrella screening trial of maintenance therapy in biomarker defined subgroups of patients with advanced urothelial cancer. The primary endpoint is progression-free survival.

### MPDL 3280A

(The IMvigor Trial)

MPDL 3280A (IMvigor) is a study for patients who have undergone a radical cystectomy for muscle-invasive bladder cancer and who have high-risk features on their surgical specimen, meaning that

microscopic examination of the bladder, after removal, suggested that the cancer had a higher rate of coming back in the future. This study is looking at whether giving a new drug called atezolizumab, an anti-PDL-1 antibody, reduces the chance of the cancer coming back.

### PLUMMB

PLUMMB is a phase I trial to investigate the safety, tolerability and effectiveness of an immunotherapy drug called Pembrolizumab used in combination with radiotherapy. The study will also investigate two different doses of Pembrolizumab, starting at 100mg and increasing to 200mg for the next cohort of patients, if the first dose is well tolerated.

## Invasive upper tract urothelial carcinoma

### POUT

The POUT study is for people with invasive cancer of the upper urinary tract (ureter and kidney). Everyone taking part needs to have recently had surgery to remove their ureter and kidney. People who take part will either be given chemotherapy immediately or will be closely monitored and only given further treatment if their cancer comes back. POUT aims to find out if giving chemotherapy soon after surgery reduces the likelihood of the cancer returning.

# FBC glossary

<b>adjuvant</b> after initial treatment to prevent secondary tumours	<b>ED</b> erectile dysfunction
<b>antiemetic</b> a drug to counteract nausea and vomiting	<b>ER</b> enhanced recovery
<b>basal</b> relating to the base	<b>expressed</b> active
<b>baseline</b> starting point for comparison	<b>FBC</b> Fight Bladder Cancer
<b>BAUN</b> British Association of Urological Nurses	<b>fMRI</b> functional magnetic resonance imaging
<b>BAUS</b> British Association of Urological Surgeons	<b>GI</b> gastrointestinal
<b>BC</b> bladder cancer	<b>haematuria</b> blood in the urine
<b>BCG</b> Bacillus Calmette-Guerin, a treatment for early-stage bladder cancer	<b>HCP</b> health care professional
<b>BCQS</b> Bladder Cancer Quality Standards	<b>histology</b> the microscopic examination of cells
<b>biomarker</b> something by which the disease can be identified	<b>histopathological</b> microscopic examination of tissue to identify disease
<b>biopsy</b> a sample of tissue taken for examination	<b>HNA</b> Holistic Needs Assessment
<b>BLC</b> blue light cystoscopy	<b>immune component</b> part of the immune system
<b>cannula</b> a thin tube inserted into a vein in the arm or hand	<b>inhibitory pathway</b> a situation in which defensive cells are preventing from attacking foreign cells
<b>CcG</b> clinical commissioning groups	<b>intolerable toxicity</b> the point at which the treatment becomes more painful than the disease
<b>checkpoint inhibitors</b> drugs that prevent cancer cells from disabling protective T-cells	<b>ITU</b> intensive therapy unit
<b>chemoradiation</b> combination treatment of drugs and x-rays	<b>KW</b> key worker
<b>chemotherapy</b> treatment with drugs	<b>lines [of treatment]</b> treatment regimens
<b>CIS</b> carcinoma in situ or flat tumour	<b>luminal</b> relating to the hollow inside an organ such as the bladder
<b>CNS</b> clinical nurse specialist	<b>lymph nodes</b> small glands that store the white blood cells that help to fight disease and infection in the body
<b>confocal laser endomicroscopy</b> an advanced imaging technique for diagnosis	<b>MDT</b> multi-disciplinary team
<b>CT</b> computerised axial tomography	<b>metastatic</b> a cancer that has spread to an unrelated organ
<b>cystoprostatectomy</b> surgical removal of the bladder and prostate	<b>MIBC</b> muscle-invasive bladder cancer
<b>cystoscopy</b> a procedure to examine the inside of the bladder	<b>MRI</b> magnetic resonance imaging
<b>DAT</b> device assisted therapy	<b>muscle-invasive bladder cancer</b> cancer that has spread from the lining to the muscles of the bladder
<b>DNA</b> deoxyribonucleic acid	<b>MVAC</b> chemotherapy treatment involving methotrexate, vinblastin, doxorubicin and cisplatin
<b>durable response rate</b> the length of time a response is observed	<b>narrow band imaging</b> imaging enhancement to aid diagnosis during a cystoscopy
<b>DVT</b> deep-vein thrombosis, a blood clot in a deep vein in the body	<b>NCRAS</b> National Cancer Registration and Analysis Service
<b>dysuria</b> painful or frequent urination	<b>NED</b> no evidence of disease
<b>EAU</b> Emergency Assessment Unit	<b>neoadjuvant chemotherapy</b> chemotherapy given before surgery
<b>EBRT</b> external beam radiotherapy	
<b>ECPC</b> European Cancer Patients Coalition	



**neoantigens** newly formed cells that are not recognised by the immune system

**neobladder** a replacement bladder formed from a segment of the small intestine

**neopitopes** newly formed cells

**NICE** National Institute of Health and Care Excellence

**NMIBC** non-muscle-invasive bladder cancer

**OCT** optical coherence tomography, a medical imaging technique

**PALS** Patient Advice and Liaison Service

**PCT** primary care trust

**PDD** photodynamic diagnosis

**PDE5 inhibitors** drugs that block the negative action of chemicals in the muscles that prevent blood flow

**PDL-1 inhibitor** an antibody that helps T-cells recognise cancer cells

**penile prosthesis/implant** malleable or inflatable rods inserted within the erection chambers of the penis

**PET** positron emission tomography

**Peyronie's disease** a disorder of the penis resulting in bent or painful erections

**PFS** progression-free survival

**photodynamic diagnosis** BLC or blue light cytосcopy

**PHR** patient-held record

**platelets** small, disc-shaped cell fragments in the blood responsible for clotting

**priapism** a persistent penile erection not necessarily associated with sexual arousal

**primary endpoint** answers to the primary questions posed by a trial

**PROMs** patient-reported outcome measures

**pyrexial** feverish

**radical cystectomy (RC)** surgical removal of the bladder and lymph nodes, as well as the prostate in men

**RCTs** randomised control trials

**refractory** resistant

**resection** surgical removal

**stoma** an artificial opening from the bladder (or other organ)

**surrogate markers** a reliable substitute for the disease

**T-cell** a cell that can attack a cancer cell

**tachycardia** abnormally fast heart rate

**TNM system (TNBM)** tumour node metastasis, a way of defining the size, location and spread of a tumour

**transitional cell cancer** cancer of the kidneys and ureter

**tumour microenvironment** the cellular environment in which the tumour exists

**TURBT** transurethral resection of bladder cancer: a surgical removal of a tumour

**urethra** the tube connecting the bladder with the outside of the body

**urostomy** a surgical procedure to create a stoma, or artificial opening for the bladder (or other organs)

**urothelial** of the urinary tract

**UTI** urinary tract infection

**visceral** of the nervous system

## Main chemotherapy drugs

These are the generic drug names you are most likely to encounter, with some of their most common brand names.

**alprostadil** Vitaros®

**avanafil** Spedra®

**atezolizumab**

**cabazitaxel** Jevtana®

**carboplatin** Paraplatin®

**cavaject**

**cisplatin**

**doxorubicin** Adriamycin®

**gemcitabine** Gemzar®

**Ibhibizone™**

**methotrexate** Maxtrex®

**minocycline**

**mitomycin** Mitomycin C Kyowa®

**nintendanib**

**paclitaxel** Taxol®

**pembrolizumab**

**rifampin**

**sildenafil** Viagra®

**tadalafil** Cialis®

**vardeafil** Levitra®

**vinblastine** Velbe®