



# 02

WE LOOK AT  
**QUALITY  
OF LIFE &  
CHOICES**

**fight**  
MAGAZINE

## **THE NICE GUIDELINES**

ARE THEY JUST A WORK  
IN PROGRESS?

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## **ENHANCED RECOVERY**

DR JOHN McGRATH  
EMPOWERS PATIENTS TO  
TAKE A MORE ACTIVE ROLE

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## **TOO YOUNG FOR BLADDER CANCER?**

WE INVESTIGATE THE YOUNG  
PEOPLE BEING MISDIAGNOSED

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## **MAN VS. CANCER**

ANDY QUICK MAKES THE  
CASE FOR A GOOD CRY

DR ALISON BIRTLE ...

# **CYSTECTOMY: IS IT THE RIGHT CHOICE FOR YOU?**

The **ONLY** magazine for people affected by & working with Bladder Cancer

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If you have an idea for an article, or have a topic you think needs discussion, 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.*



### Fight Magazine

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# Bigger & better!

What can we say but a BIG thank you to everyone who has responded so positively to the launch of the first edition *FIGHT magazine*. Almost as soon as we emptied the boxes at the British Association of Urological Surgeons (BAUS) annual conference in July, the requests from hospitals, clinicians, nurses and patients came flooding in. But these requests were nothing compared to the number of downloads of the magazine that have been requested from our website, which started the evening we went live. In all, between hard copy and digital, close to 15,000 copies had been read across the UK and internationally by the end of September.

The really positive part of the response to the magazine is that we have been able to keep up the quality of the articles from across the range of professionals and patients. There were so many good articles that we have DOUBLED the number of pages in this second edition!

Happy reading and thank you!

You can find out more about the charity and get help, information and support on our website:

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

Fight Bladder Cancer (FBC) has grown through the support and help of fellow patients and carers across the country, together with a growing band of medical professionals who see the value in a strong patient voice, who support and advise us along the way. Together we can make a difference.

Team FBC

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

[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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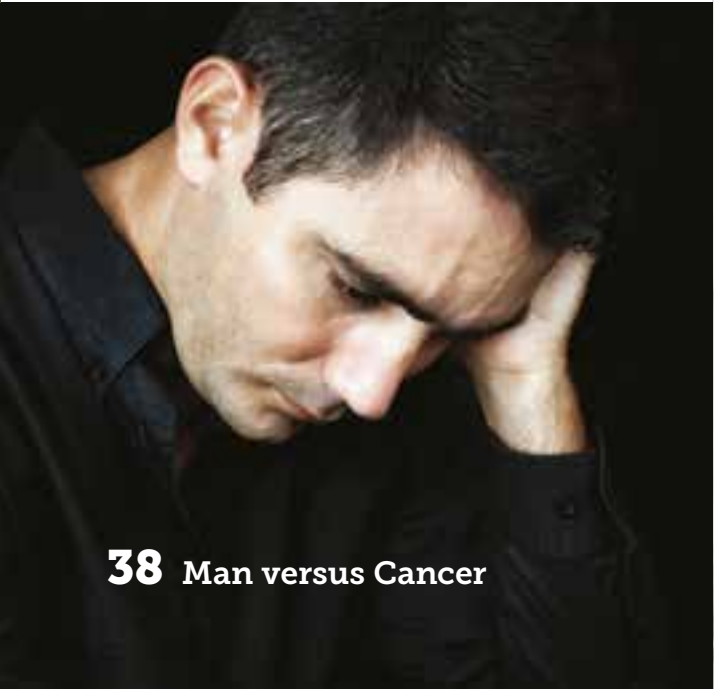
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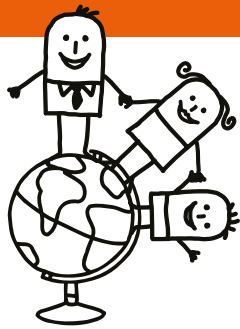
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# FBC round up

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



## SUPPORT



### BLADDER BUDDY SERVICE

For those less confident or for personal help and advice we offer a nationwide one-on-one service, where we connect you with another patient or carer who has been through the same treatment, experience or emotional issues. Because of the growth of the service we are now looking for additional volunteer Bladder Buddies. You can find out more about what's involved and how you can help in our special article on page 36.



## AWARENESS



### IN THE SPOTLIGHT

Fight Bladder Cancer was under the floodlights in August when the talented Wiley Wolf Productions staged the runaway Broadway success *Urinetown* at the Hazlitt Theatre in Maidstone to critical acclaim. Not only were collections made for FBC at every single performance of the show, but the cast also made donations every time they went to the loo during rehearsals! Bravo guys!

### THE WEE BOOKSHOP AND CAFÉ EXCEEDS EXPECTATIONS!

If you saw the last edition of our FIGHT magazine you will have been able to read about the launch of our rather special Wee Bookshop and Café that is getting noticed for changing the face of charity retailing. We have been amazed at its success over the summer, with people visiting to experience all our wonderful food and drink whilst also being able to buy great value books. We can't believe it, but we now employ 22 members of staff (full and part time) to run the café and have another 20 or so volunteers helping with sorting books and keeping the shelves stocked up!

### TEAM FBC ON THE ROAD

The team at FBC have clocked up thousands of miles over the last few months, with attendances at conferences and specialist study days. We have also visited GP surgeries, hospital urology and bladder cancer awareness days and local health awareness events. If you know of an event that we should attend to spread awareness and the patient perspective, do let us know!

### TURN THAT RADIO ON

We all know that it is quite difficult to get the media to show interest in bladder cancer so we are over the moon that Andrew Winterbottom – who with his wife Tracy founded FBC – is now a regular guest every month on the Kat Orman show on BBC Radio Oxford, which covers the area where the charity is based. Keep an eye on our Twitter feed to find out when he's up next.



## CHANGE

### FBC IN POLAND

Fight Bladder Cancer were in Warsaw in October where we made the keynote speech to launch the three-day 3I Pathways conference, *How do we improve patient care?*

### NICE TO SEE YOU, TO SEE YOU NICE

With the new immunotherapy treatments being developed for bladder cancer, FBC is being involved at every stage of the NICE process for the potential approval and funding of these therapies with ground-breaking possibilities. The early data is certainly looking promising.

### THE VOICE OF CANCER PATIENTS IN EUROPE

Fight Bladder Cancer is a full member of the European Cancer Patients Coalition (ECPC) and this year our founder, Andrew Winterbottom, was elected to the board of the organisation where he heads up the ECPC Bladder Cancer campaign.

ECPC's speciality and primary mission is to be the voice of cancer patients in Europe.

In 2017, ECPC will focus on developing main policy themes:

- inequalities in access to quality cancer care;
- innovation in oncology;
- survivorship and rehabilitation issues;
- cancer patients' participation in decision making;
- patient-centred research.

Earlier this year we worked to produce the ECPC 2016 White Paper on Bladder Cancer, which listed clear recommendations for improvement of prevention, diagnosis and treatment of bladder cancer in Europe.

### Cancer patient advocacy groups

Most of these recommendations will have to be met by governmental and professional bodies but there is one area where FBC and ECPC will lead over the next few years, namely pioneering the formal development of bladder cancer patient advocacy groups in Europe and co-ordination among them as well as with similar groups in other countries.

Both FBC and ECPC consider that this is critical to sustain awareness in local communities as well as help to achieve the overarching goals outlined in the 2016 White Paper.

Fight Bladder Cancer will lead the development of this project and ensure that the skills and knowledge of FBC are reflected in the final strategy and deliverables.

Some activities that are being implemented by the group include:

- a pan-European patient experience survey;
- an annual European bladder cancer conference;
- building local and national capacity.

The working group will support advocacy activities at national level to:

- introduce bladder cancer to national stakeholders;
- provide support to countries that are setting up new bladder cancer patient advocacy groups;
- explore how the platform might assist with the advocacy concerns of national organisations;
- report on opportunities to encourage the EU to contribute to bladder cancer programmes;
- invite national stakeholders to join and become actively involved;
- support the development of a pan-European patient website.

The URL [www.ecpc.org/bladder](http://www.ecpc.org/bladder) will be an information source on bladder cancer. It will be produced in conjunction with EU-based professional bodies and signpost patients to where they can get further local information and support.

Fight Bladder Cancer has made a big difference to bladder cancer in the UK and is honoured to be part of this initiative to expand patient advocacy across Europe and to develop a Global Patient Voice for Bladder Cancer.

## 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

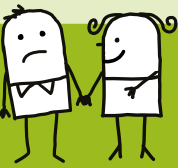
Not everyone is happy to talk and ask questions within our confidential forum, so we provide a nationwide Bladder Buddy Service where we match people up on a one-to-one basis with someone who has been in the same situation or has had the same treatment. Someone to talk to privately, either on the phone 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. Check out our website to find your nearest Fight Club.

Find out more about how we can support you at

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





# Is cystectomy the best choice?

Cystectomy is the default procedure for bladder cancer, but is it the right choice for you?

ARTICLE  
DR ALISON BIRTLE,  
Consultant Clinical  
Oncologist, Lancashire  
Teaching Hospitals

About 25% of patients diagnosed with bladder cancer will have muscle-invasive bladder cancer (MIBC) and a significant number of patients with superficial bladder cancer go on to develop muscle-invasive bladder cancer.

For many patients, the news that they have MIBC comes as such as shock that their first thought may be to 'just get rid of it and cut it out', a view supported by many urologists. However, is this the only way? Should you be asking your urologist about other options and, in particular, the possibility of keeping your bladder?

Let's start off by defining some terms in which to discuss the options.

## Radical cystectomy

The operation to remove the bladder together with some of the lymph glands and different parts of other adjacent organs, depending on whether you are male or female.

## Potentially curative treatment

It is a procedure that, even with modern techniques, is associated with significant side-effects, which is a small but important element in your decision.

## Radiotherapy/radiation

Using external x-ray treatment to damage the building blocks of cancer (DNA). This is usually given over a 4 to 6½-week period, on a daily basis as an outpatient.

## Chemoradiation

A dose of drug treatment delivered into the veins using a drip during the course of radiotherapy. The potential side-effects of treatment are discussed in detail on the Fight Bladder Cancer website.

There are other aspects of this to consider. The patients treated with cystectomy were likely to have been younger and fitter than those undergoing radiotherapy. Secondly, when you look at the stage or extent of the cancer, this cannot be compared accurately between the two different groups of patients, as those who had a cystectomy had the extent of their cancer evaluated by looking directly at the removed organs through a microscope.

In the radiotherapy group, the assessment of the extent of the cancer was reliant on older types of scans, which are far more likely to underplay the extent of the cancer. Therefore, it is impossible to compare the two groups directly. Finally both surgical and radiotherapy techniques have improved dramatically over the 30 years that have elapsed since the last patient in these studies was treated and the data are largely irrelevant to modern practice. Isn't it time, therefore, to re-evaluate the options?

## Can we do a trial comparing surgery and radiotherapy?

There has never been a head-to-head trial of radical cystectomy versus radiotherapy. In the UK there was a trial called the SPARE study, which tried very hard to do this but had to close early due to low levels of recruitment. The problem was that both urologists and oncologists tended to think they already knew which one was the better option and this deterred patients from entering the trial. We will probably never know the answer from a trial.

## There has never been a head-to-head trial of radical cystectomy versus radiotherapy.



## Informed choice

The NICE bladder cancer guidance published in February 2015 states that a full discussion between the patient and a urologist who would perform a radical cystectomy, a clinical oncologist and a clinical nurse specialist (CNS) should take place to discuss the benefits and risks of each approach, in order to help patients make an informed choice.

Of course, there are risks associated with any form of treatment and these should be fully discussed with your oncologist.

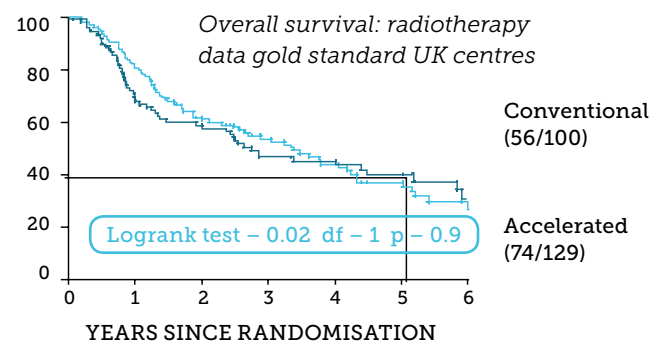
## Cystectomy as the default option

Many patients, however, are swayed by the fact that urologists almost always recommend a radical cystectomy and it is the number one option for treating MIBC in most official guidelines. This prominence is misleading, however.

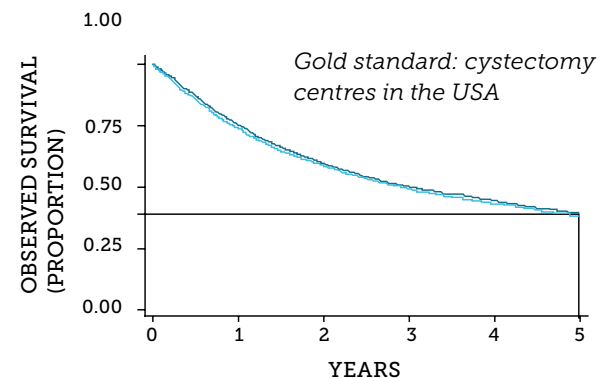
Many urologists quote a very old analysis of three studies which gave pre-operative radiotherapy and then surgery or radiotherapy alone followed by cystectomy if the cancer came back, and this analysis was in favour of surgery. However, only three trials were found, they were from many years ago, there were few patients in the studies, and many patients who were allocated to receive one treatment, in fact, refused and went on to have another.



### Accelerated Fractionation in Localised Bladder Cancer Overall Survival



### Cystectomy



### What about UK data?

When we look at evidence published from respected radiotherapy and surgical centres, the outcome for MIBC looks very similar. In 2008, Kotwal and colleagues published single-institution data from Leeds comparing outcomes between patients receiving radical radiotherapy or primary cystectomy for MIBC. In 169 patients, there was no difference in overall survival at five years, despite the radiotherapy group being older (median age 75.2 years versus 68.2 years).

In a more recent review by the same authors, the median age in the radiotherapy group was even higher (median age 78.4 years versus 68.2). So although patients having radiotherapy tended to be older and less fit, their bladder cancer survival was just as good as the surgery patients.

### Time to look at helping patients to keep their bladder

Bladder preservation is a very attractive option, especially for patients who have good bladder function at their time of diagnosis. Also bladder cancer is what we call a systemic disease, which means that despite radical cystectomy, up to 30% of patients relapse with secondary cancer elsewhere in the body. Adding chemotherapy to radiotherapy can help reduce this risk and, of course, all patients having chemoradiation – a combination of both drugs and x-ray treatment – should also be considered for neoadjuvant

chemotherapy – treatment given before surgery – which should also be evaluated before radical cystectomy, in both cases improving the patient's chance of survival by 5% at five years.

### Concerns with using radiotherapy for MIBC

If a patient undergoes radiotherapy, there is the concern from surgeons that the cancer may become inoperable, and future surgery may be compromised and more hazardous. However, one study from Addida et al showed that as long

as a very experienced surgeon did the operation, the bladder cancer survival should be the same whether the patient has a cystectomy at the start, or at a later stage if radiotherapy is not effective.

There is also concern that the bladder may be very damaged after radiotherapy and make the patient's life miserable. Looking at the long-term bladder function of patients treated in a number of large studies, 75% of them kept good bladder function when assessed fully using questionnaires and ultrasound tests of the bladder.

### Which markers seem to predict a good response to radiotherapy?

When MIBC is diagnosed, this is usually done by a transurethral resection (TURBT). The people who seem to respond the best with chemoradiation/radiotherapy seem to be those who have had as much of the visible cancer on the inside of the bladder removed at TURBT.

When we look at the survival from MIBC, the outcomes at five years look very similar, irrespective of whether the patient has had radical cystectomy or chemoradiation, and bladder function appears to be good for many patients.

Isn't it time therefore for patients to ask the question: can I keep my bladder?

# Cystectomy & Radiotherapy: One size does not fit all

## How do you choose which treatment will suit you best?

Invasive bladder cancer can be an aggressive cancer that is only be cured by what we call 'radical treatments', the main choices being surgery and radiotherapy. Surgery (radical cystectomy) involves removal of the bladder and adjacent organs. In men, this includes the prostate and seminal vesicles. In women, it means part of the internal vagina and usually the womb, tubes, cervix and perhaps ovaries. In either case, it will have implications. Urinary drainage is restored through a stoma (an 'ileal conduit' or 'urostomy') or with a new bladder (neobladder) or some other route.

Radiotherapy is usually combined with drug treatment to improve response. The radiotherapy kills the faster-growing cancer cells, leaving the normal cells behind. If it works, then no more treatment is needed. However, the bladder and bowel tissues can be affected and some patients need bladder removal at a later date.

### One size does not fit all

In the article on page 6, Dr Alison Birtle has detailed the need to discuss both treatments when deciding which is the right one for you. I fully support her points, and suggest it is likely that the overall cancer outcomes are similar both. But that doesn't mean that each treatment is suitable for each patient. There are factors that point towards one or the other treatment.

### 1 Your cancer

Not all bladder cancers are the same; some are more and some less aggressive. Some have features to suggest they will not respond to radiotherapy, others appear sensitive to chemotherapy. For larger and more aggressive cancers, surgery tends to be the best option; the bladder may not recover well from radiotherapy (it could be small and low volume).

Conversely, single cancers that have responded to the initial treatment (telescopic/endoscopic resection) tend to be more suited to radiotherapy; it is also likely to work without affecting the bladder volume.

### 2 Your bladder

Some bladders could be small (with a frequent need to pee), overactive (urgency and some incontinence), infected or the cancer can bleed. If your bladder function is not good, then surgery may improve your quality of life. I have many patients who sleep better and are more active after cystectomy than before it. Radiotherapy could make the bladder function worse, as it can reduce the bladder volume.

Conversely, if you have good bladder function, you might not want a stoma or a neobladder. Both can leak at night or during the day, and you will need to carry medical accessories with you.

Another issue is if the cancer is blocking one or both kidneys, then surgery is probably the best approach, as it will unblock and divert the flow away from the blockage at the same time.

### 3 You

We are all different. Radical cystectomy in good hands has excellent outcomes, but is the physiological equivalent of running a marathon. I ask my patients to increase their activity levels before surgery and push them afterwards to get them home quickly and safely (recovery). But recovery takes three to six months and, on rare occasions, there are complications. The best outcomes are in those with motivation and a sense of humour, not necessarily in the youngest or fittest. Not all patients are up to this and given that radiotherapy is well tolerated and works well in many patients, then perhaps they are better suited to radiotherapy.

### It's the service that matters most

There are more deciding factors than I can list here. But I feel the most important choice is to find the right team. I suspect you will do best if you have the treatment your team specialises in and performs most regularly. Try to find units with experts you can talk to, who care about you as an individual and who get you involved in clinical trials, which is a sign of an active specialist unit and can help your care. Good luck.

ARTICLE  
JIM CATTO,  
Professor of  
Urological  
Surgery,  
University  
of Sheffield

# Developing the role of nurses in bladder cancer

Kathryn Chatterton puts the case for surveillance bladder cancer cystoscopies being carried out by nurses.

ARTICLE  
KATHRYN CHATTERTON,  
Bladder Cancer Nurse  
Cystoscopist, Guy's Hospital

You may think that the primary reasons for allowing nurses to carry out flexible cystoscopies was to reduce hospital waiting times, free up junior doctors and potentially save money. They may be all valid reasons. However, as a nurse cystoscopist, I think there are far more important reasons.

I truly believe the most vital aspects within the management of care for our surveillance patients are continuity, timely consultation and having a specific point of contact.

## REFERENCES

- Chatterton, K, 'A bladder cancer nurse-led flexible cystoscopy service', *European Urology Today* (2010), Volume 22 – No. 3, p32
- Gidlow, A, 'Urology nursing update: advancing nursing practice. National guidelines for nurse cystoscopy', *Professional Nurse* (2000), 6, pp992–993
- Gidlow, A; Laniado, M; Ellis, B, 'The nurse cystoscopist: a feasible option?', *British Journal of Urology* (2000), 85, pp651–654
- Smith, T; Streeter, E; Choi, W; Evans, H; Eddy, B; Krishnan, R; Shrotri, N, 'Are specialist nurse-led check flexible cystoscopy services as effective as doctor-led sessions?', *International Journal of Urology Nursing* (2016), Vol 10, No 2, pp65–67
- Taylor, J; Pearce, I; O'Flynn, KJ, 'Nurse-led cystoscopy: the next step', *British Journal of Urology International* (2002), 90, pp45–46
- Taylor, J, 'An evaluation of a nurse-led cystoscopy surveillance service' *Professional Nurse* (June 2003), 18 (10), pp580–583
- UKCC, *The Scope of Professional Practice* (1992), UKCC: London

## Reducing anxiety

This group of bladder cancer patients requiring surveillance is unique, as they are unlikely ever to be discharged and will need lifelong hospital visits and ongoing regular flexible cystoscopies. For example, a 60-year-old man requiring surveillance until he is 80 means he would undergo at least 20 flexible cystoscopies. Hospital attendances are inevitably associated with anxiety, pain, or fear of learning that the cancer is recurring. The worry about who will be doing the flexible cystoscopy need not be added to that.

Having spoken to regular patients over the years, I know that they find great comfort in knowing they are coming back to clinic to see the same person each time for their flexible cystoscopy. Junior doctors and registrars are forever rotating and their clinical demands are high, so having a familiar nurse cystoscopist certainly reduces some of the anxiety patients feel when they visit the clinic for their check-up cystoscopy.

## Where is the evidence?

There are no studies specifically surrounding patients' anxieties regarding nurse-led

flexible cystoscopy. However, there is a study demonstrating that nearly 97% of patients (the study involved 187 patients) preferred nurses over doctors performing their cystoscopy (Taylor 2003). Data from a small cohort (of 36), which I audited in 2010, identified 97% of patients also said that they would be happy for the nurse specialist to perform the cystoscopy again in the future. Following the procedure, the result was 100% – as the one patient who was unsure changed his mind and confirmed that they would be more than happy for the nurse cystoscopist to do the procedure again.

## Trust is built through continuity

Literature supports that in flexible cystoscopy surroundings, nurses are safe, precise and can improve services with consistency (Gidlow 2000; Gidlow et al 2000; Taylor et al 2002; Chatterton et al 2010). Personal audit has shown that patients appreciate the same point of contact and continuity of care. As a specialist bladder cancer nurse, I am in the very fortunate position of being able to meet the patients at the beginning of their journey, from initial diagnosis in clinic to joining the flexible cystoscopy cohort and can therefore provide that all-important continuity.

## What about money?

The question has to be asked, though, about cost-effectiveness; resources are finite and must be used judiciously. Recent studies have shown that while a nurse may not see as many patients in a clinic as a doctor, the number tends to increase with more experience (Smith et al 2016). But this is not the whole picture. It could be argued that the nurse is providing a more holistic approach by allowing more time for this consultation, giving greater benefit to the patient. It was concluded that the nurse-led sessions are comparable to the doctor-led sessions, which clearly has implications on current financial demands and the cost effectiveness of the service, which we are always aiming to improve within our local departments.

## Putting patients at ease

During my cystoscopy consultations, I always ensure that the patient understands what is going to happen and feels comfortable. Where appropriate, I use distraction techniques, engaging in different topics of conversation not related to the procedure. I recommend the

## Nearly 97% of patients preferred nurses over doctors performing their cystoscopy

patients watch the cystoscopy and I give them as much or as little information as they require, gauged by our initial conversations. This often helps and we are frequently complimented on our professionalism. Many patients remark, 'Oh, have you finished? That was quick!' As a rule, it was no quicker than any usual cystoscopy, but the way the procedure was handled at a personal level reduced their anxiety and they felt they were in good hands and could think about other things.

If patients have adequate preparation – including psychological preparation – continuity of care, a reliable and constant point of contact, and high-quality care given while undertaking this lifelong journey, I believe anxieties can be significantly reduced by nurse-led surveillance cystoscopies.

With this in mind, I know who I would want to do my flexi ... do you?!



# The Life & Bladder Cancer Project

## ARTICLE

JIM CATTO,  
Professor of Urological Surgery,  
University of Sheffield

A new study based in  
Yorkshire aims to focus care  
on what the patients define as  
best for their quality of life.

## REFERENCES

Black, N, 'Patient reported outcome measures could help transform healthcare', *British Medical Journal* (2013), p346  
Hadi, M; Gibbons, E; Fitzpatrick, R, 'A structured review of patient-reported outcome measures for colorectal cancer', *University of Oxford* (2010)

Bladder cancer is a common disease that is expensive to manage. Whilst the NHS spends large sums of money on caring for patients with this disease, often the focus of this spend is on service delivery pathways, rather than the patient. The impact of symptoms and treatment side-effects on the daily lives of bladder cancer patients is unclear. We know that cancer affects a person's physical, emotional, social and cognitive well-being, but we do not know how this affects bladder cancer patients in the months and years following a diagnosis.

In order to plan meaningful and appropriate follow-up care we need to find out what sort of life a patient has after diagnosis, the quality of that life and how it changes over time. Research that measures this in patients is known as health-related quality-of-life research and typically uses Patient Reported Outcome Measures (known as PROMs) to do this. PROMs are questionnaires that measure health and establish patients' views of their symptoms, functioning and health-related quality of life (Black, 2013). PROMs provide patient perspectives of their own health and can also be used to identify other patient needs (Hadi, Gibbons and Fitzpatrick, 2010).

There have been a number of studies that have investigated the health-related quality of life of people with bladder cancer. Studies have mostly focused on patients who have had a radical cystectomy and have often compared the quality of life of patients with different types of urinary diversion. Less is known about the quality of life of patients with non-muscle-invasive bladder cancer or patients who have conservative treatments.

## The Project

Yorkshire Cancer Research has recently funded a three-year project to collect quality-of-life information from bladder cancer patients from across Yorkshire. The vision of Yorkshire Cancer Research is, 'to ensure that people in and around Yorkshire have the best chance of living a long and healthy life with, without and beyond cancer'. One of the advantages of carrying out this work in Yorkshire is that it is the largest county in England with a diverse multi-ethnic population (of more than 5 million people) living in both rural and urban communities. Such a large and diverse population provides a great opportunity to find out what life is really like for people with bladder cancer.

The Life & Bladder Cancer project is being led by Professor Jim Catto (University of Sheffield) and Professor Adam Glaser (University of Leeds). There are two studies planned and the project is the largest PROMs study to be carried out in the UK.

## STUDY ONE:

**following up newly diagnosed patients for one year**

Study one aims to look at how patients' quality of life changes as they go from diagnosis through treatment to routine clinical review. About 900 people are diagnosed with bladder cancer in Yorkshire every year. The plan is to invite as many people as possible to take part over a one-year period. Potential study participants will be contacted by their clinical team either face to face or by letter. Those who agree to take part will be surveyed at three, six, nine and 12 months following their diagnosis.

## STUDY TWO:

**a cross-sectional snapshot of people diagnosed over a year ago**

Study two aims to compare the quality of life for different patient groups and highlight common issues that arise in the years following their initial bladder cancer diagnosis.

In order to plan meaningful and appropriate follow-up care we need to find out what sort of life a patient has after diagnosis, the quality of that life and how it changes over time.



There are around 7,000 people living in Yorkshire who have been diagnosed with bladder cancer for at least a year. Many of these people will no longer be attending hospital and so an approach involving two steps is required to identify and invite these people to take part. Step one is to invite the clinical teams from each hospital in Yorkshire to get involved in the study. The second step requires help from the National Cancer Registration and Analysis Service (NCRAS). NCRAS, part of Public Health England, holds strictly protected records of everyone diagnosed with cancer in England.

The plan, subject to ethical approval, is for NCRAS to generate a list of Yorkshire bladder cancer patients from each hospital who were diagnosed more than a year ago. This list will be checked against a list of patients held by NHS Digital (part of the Department of Health) to make sure that no one is included who may have died or who has objected to their information being used in research. This list will be provided to a company approved by NHS England. The company will have been provided with general letters of invitation to the study; signed by a clinician from each of the hospitals who agreed to be involved. These letters will be sent to the patients on behalf of their hospital clinical team.

All surveys will be returned to this company who will anonymise the information before sending it to the research team for analysis. It is estimated that around 3,000 people will take part.

### What will the participants be asked?

The surveys will include cancer and bladder-cancer specific questions about urinary, bowel and sexual function, but also how people feel physically, emotionally, socially and cognitively.

To better understand the wider impacts of bladder cancer on everyday life, the survey will include questions such as the impact on finances, relationships and on social life. In order to map how bladder cancer and its treatment affects the quality of life of a range of people with different backgrounds and circumstances, the survey will also ask about age, marital status, employment status and other illnesses that people have.

### What will the PROMs information be linked with?

The survey responses will be linked to their clinical data (for example, date of diagnosis, stage and grade of tumour, treatments). The linkage will be undertaken by authorised staff only working in Public Health England and adhere to high ethical standards. No identifiable information will be available to the research team.

The analysis of the surveys and linking to clinical information will provide a useful and insightful picture into the lives of different patient groups in Yorkshire. This information will be valuable for service providers, giving them an understanding of the patient journey after diagnosis, which will help to identify the kinds of information and support that patients require.

In addition to this, the information will present service providers with a clear indication of what is important to patients, which may identify gaps or barriers in care giving.

Potentially, the information will help service providers to make their services more patient focused and shape how care is provided.

If you live in Yorkshire and the hospital who provided your care is involved you may be invited to participate. If you have any queries about this or if you would like to know more about this work please get in touch with the LABC team at [S.J.Mason@leeds.ac.uk](mailto:S.J.Mason@leeds.ac.uk)

# The NICE Bladder Cancer Guidelines

## A Work in Progress?

### OPINION

ANDREW WINTERBOTTOM,  
Founder & Director,  
Fight Bladder Cancer

In February 2015 the long-awaited *Nice Guideline (NG2) Bladder Cancer: Diagnosis and Management* was published. This guideline offered evidence-based advice on the diagnosis and management of bladder cancer in adults (18 years and older) with suspected bladder cancer, and those with newly diagnosed or recurrent bladder or urethral cancer.

We cheered, we clapped. At last we had guidelines that we could check to make sure that we are getting the best advice and treatment for our bladder cancer. A set of 'rules' that we could use to help all those affected by bladder cancer no matter where they lived. A consistency of treatment for all that was based on good scientific evidence.

So what were the key priorities for implementation? The guideline identified these against five subject areas.

- Information and support for people with bladder cancer.
- Diagnosing and staging bladder cancer.
- Treating non-muscle-invasive bladder cancer.
- Follow-up after treatment for non-muscle-invasive bladder cancer.
- Treating muscle-invasive bladder cancer.

A good list of priorities which sit alongside the full document can be found at: <https://www.nice.org.uk/guidance/ng2>

### Following the guidelines

As you can imagine, there are areas that still concern us as patients. This is natural.

We expected that everyone would begin to implement the guidelines with immediate effect, but 18 months on we are still getting wide variations in adherence. Take the specific point in the Diagnosis and staging bladder cancer section:

*'Offer people with suspected bladder cancer a single dose of intravesical mitomycin C given at the same time as the first TURBT (transurethral section).'*

This is still very patchy, with some people not being offered it at all through to others being given it more than 24 hours after their TURBT. The guidance is clear that they *'are confident that, for the vast majority of patients, (the) intervention will do more good than harm, and be cost effective'*.

Simple and effective things should not be hit or miss for us patients. If we still can't get this right, what is the reality of hospitals all paying attention to the guidelines across the whole pathway?

When we look at the follow-up after treatment by radical cystectomy (RC), the guidelines state that this should include:

*'monitoring for metabolic acidosis and B12 and folate deficiency at least annually'*.

In a random group we interviewed, not a single RC patient had been offered this since the guidelines were published.

For these two issues, it would not be difficult to achieve better adherence to the guidelines. Our concern is that if this cannot be achieved in 18 months, adherence across the whole of the guidelines is more than unlikely – especially in areas where, as patients, we would not be aware that the rules were not being followed.

As you can imagine, there are areas that still concern us as patients.



## BCQS monitoring

But we have the Bladder Cancer Quality Standards, you might say. Surely this will be how we can tell how well the guidelines are being implemented? Yes, but they only cover a small number of the issues to be measured. The Quality Standard for Bladder Cancer came out in December 2015 and contained the following statements.

**Statement 1.** Adults who are having transurethral resection of bladder tumour (TURBT) have detrusor muscle obtained during the procedure.

**Statement 2.** Adults with suspected bladder cancer are offered a single dose of intravesical mitomycin C, given at the same time as the first transurethral resection of bladder tumour (TURBT).

**Statement 3.** Adults with bladder cancer have access to a designated clinical nurse specialist.

**Statement 4.** Adults with newly diagnosed non-muscle-invasive bladder cancer have a risk classification of their cancer completed.

**Statement 5.** Adults with high-risk non-muscle-invasive bladder cancer discuss intravesical Bacille Calmette-Guérin (BCG) and radical cystectomy with a urologist who performs both treatments and a clinical nurse specialist.

**Statement 6.** Adults with muscle-invasive urothelial bladder cancer discuss neoadjuvant chemotherapy, radical cystectomy and radiotherapy using a radio-sensitiser with a urologist who performs radical cystectomy, a clinical oncologist and a clinical nurse specialist.

**Statement 7.** Adults who have had low-risk non-muscle-invasive bladder cancer and who have no recurrence of the bladder cancer within 12 months of their initial transurethral resection of bladder tumour (TURBT) are discharged to primary care.

There is no doubt that the selection of these seven statements as the Quality Standard covers probably the most important aspects to be measured. However, it is really important that all clinicians read the whole Quality Standard in detail and not just assume that the above statements are all that matters.

## Looking at patient discharge

Take Statement 7 as an example. The decision to discharge patients with low-risk non-invasive bladder cancer who have not had a recurrence for 12 months after their initial TURBT has

been controversial and probably the one recommendation of the whole guideline that has made patients very nervous. What do you mean I'm not going to have any more check-ups? But bladder cancer almost always comes back. This can't be right?

Now, we understand the analysis that went behind this decision and we are not going to argue the pros and cons of it here, but what is essential is that the secondary care team all know what the Quality Standard says in detail.

*'Discharging adults who have had low-risk non-muscle-invasive bladder cancer and who have no recurrence of the bladder cancer within 12 months to primary care reduces the need for follow-up cystoscopies in secondary care. It is important that the discharge is discussed with the patient beforehand, and that written information about the patient's care is sent to the GP who will be taking over their care when they are discharged.'*

The sentence we have highlighted is one that we felt was essential if discharge at this stage was going to be recommended. Indeed, we feel that the communication between the secondary and primary care teams at all stages in the pathway, whether or not the patient is being discharged, needs to have its own procedural guide to ensure that the reality of treatments for bladder cancer patients is understood by all so that the required support can be given.

We campaign for better awareness of bladder cancer at primary level to ensure early diagnosis but being able to know that GP practices understand the different treatments for their patients with bladder cancer would be enormously welcomed by patients and carers.

## Progress on research

Research recommendations were also included in the NICE Guidelines as it was clear that there are many holes in our knowledge about bladder cancer. We are pleased that work has begun on a number of these issues although we accept that any conclusions might take some time.

However, what was really interesting about the section on research recommendations was that the first one identified was on patient satisfaction. This we believe is the most significant part of the whole guideline as it reminds us all about the reality of bladder cancer prevention, diagnosis, treatment, after care and quality of life.

It is really worth reading the statement in its entirety:



## 2.1 Patient satisfaction

**What are the causative and contributory factors underlying the persistently very low levels of reported patient satisfaction for bladder cancer?**

### Why this is important

The urological cancers grouping (which includes bladder cancer but excludes prostate cancer) has consistently appeared near the bottom of the table of patient satisfaction comparisons of all cancer types in national patient experience surveys. Prostate cancer (which is also managed in urological services) is recorded separately and has continued to appear near the top of the tables.

It is uncertain why this is the case, except that there is now an accepted link between the level of clinical nurse specialist allocation, information and support provision and patient satisfaction. The urological cancers grouping has the lowest level of clinical nurse specialist allocation in comparison with all other cancer types or groupings (including prostate cancer). The prolonged pattern of intrusive procedures that dominate investigation, treatment and follow-up regimens for bladder cancer may also contribute to this position. Additionally, there is concern that people with bladder cancer at or near the end of life, who are by that stage often quite frail and elderly, may not always have access to the full range of palliative and urological support and may, at times, be treated in general wards in hospital and experience significant symptoms of pain and bleeding (haematuria).

To explore this research question bladder cancer patients need to be identified separately from the generic group of urological cancer patients in nationally collected data sets.

**Don't get us wrong. The NICE Bladder Cancer Guidelines and Quality Standard is a substantial and welcomed body of work that can really make a difference to bladder cancer patients across the UK. But they can't be just a set of documents that sit on a shelf waiting to be updated at some time in the future.**

**If you are involved in the treatment and management of bladder cancer, do read them again. Make sure that you have absorbed them. Make sure that you respect their guidance as you look after your patients. Be part of improving the patient experience so that we don't stay at the bottom of the patient experience table.**



# PATIENTS HAVE RIGHTS

## How will the bladder cancer PHRs benefit you?

**There has been much discussion of the pros & cons of patient-held records – or PHRs. Fight set out to establish how useful they might be for bladder cancer patients.**

### So exactly what is a PHR?

According to the NHS Modernisation Agency, a PHR 'can take a number of forms, from a dynamic tool used by the patient and all healthcare professionals providing care to the patient, to a print out from the patient's medical record or general information sheets. It is designed to inform and involve patients in their care and to facilitate communication between the different groups of people caring for the patient'.<sup>4</sup>

### Why do we need a bladder cancer PHR?

The idea of producing a PHR specific to bladder cancer was designed to support these intentions. It would be used by both the patient and the clinical team responsible for their care, and incorporate all aspects of clinical information and the treatment summary to ensure a single, comprehensive, accurate and up-to-date record is kept:

- of clinical information;
- of the treatment summary;
- of quality-assurance measures.

The primary objectives are to:

- improve communication between the health care professionals (HCPs) and the patient;
- act as aid memoir to HCPs;
- act as a prompt to patients;
- provide ease of access to data for quality-assurance measurement.

**A PHR is not intended to be a comprehensive source of patient information.**

Patient-held records are not new. In obstetrics and diabetes care they have been successfully implemented for many years, and positively evaluated in numerous studies, randomised control tests (RCTs) and meta-analysis.<sup>1, 2</sup> Such studies, however, have failed to show a clear scientific benefit to implementing a PHR in the cancer-care setting, although many patients believe that if they had access to their record they would become more involved in their own care, which could, in turn, benefit self-care. This position is supported by NHS England.<sup>3</sup>

A PHR should play an important role in how patients and the health care team looking after them, record discussions about their care, to ensure that the patients are informed about everything they need to know, with the PHR being updated as treatment progresses. The information should also make patients feel more in control of their condition and follow-up care.

### How was the PHR developed?

A call to the members of the British Association of Urological Nurses (BAUN) to get involved with the project resulted in the appointment of a Lead and the establishment of a working group. We also initiated discussions with the NICE quality standards department regarding potential endorsement of the document.

Having decided on the content required, and taking into account who would be expected to complete each of the sections within the document (the patient/carer and/or a health professional), the sections were allocated to the most appropriate member of the working group and writing began. The submissions were collated and reviewed by the Lead and the first draft compiled.

At this stage, we formally engaged with external groups for the first of three rounds of feedback; this to be followed by document update and review. The organisations involved included the British Association of Urological Surgeons (BAUS), BAUN, Fight Bladder Cancer (FBC), Action Bladder Cancer UK (ABC UK), NICE, and both individual oncologists and patients. The final draft has been sent to NICE for

endorsement (decision pending at time of writing). A review will ensure the document continues to comply with best evidence.

The bladder cancer PHR will be launched formally at the BAUN conference in November 2016 and will be promoted through the BAUN newsletter and social media, as well as the FBC magazine and via BAUS and The Urology Foundation (TUF).

### The sections of the bladder cancer PHR

The PHR contains various sections:

- Introduction
- Symptom questionnaires
- Assessment tools
- Diagnosis and other clinical information
- The multi-disciplinary team (MDT)
- Key worker (usually a clinical nurse specialist (CNS) or other HCP)
- Other useful contacts
- Support groups (local and national)
- Record of assessments
- Record of information given
- Record of appointments
- Holistic Needs Assessment (HNA) questionnaire
- Care plan
- Clinical trials for cancer that are available for particular types of bladder cancer
- Record of information booklets provided
- Patient's questions
- Record of any bladder-cancer-related medication
- Symptom scoring sheets used for assessing any treatment-related symptoms and the planned treatment to deal with these
- Treatment pathway
- Proposed follow-up schedule and treatment record for each treatment type

Great care was taken during the development of this PHR to incorporate all aspects of the care of a person with bladder cancer that are subject to quality-assurance measures. The PHR will therefore also provide a rich source of data for audit and quality control, for example NICE Quality Standards<sup>5</sup> and NICE diagnosis and management of bladder cancer.<sup>6</sup>

### Making it accessible

The bladder cancer PHR is designed to be used flexibly. It is a printable PDF document which the patient keeps and brings to each appointment. An electronic or paper copy can also be held in the hospital, if appropriate.

The intention is that each Trust or MDT download the template from the BAUN site and

### ARTICLE

FIONA  
SEXTON,  
BAUN  
President &  
Independent  
Urology Nurse  
Specialist

incorporate the Trust's logo, local MDT and support groups. It can then be personalised with the individual patient's name and NHS number before printing.

The core information will be supplied to all newly diagnosed patients with additional inserts and pages added as appropriate depending on the progress, follow-up and treatment plan: for example, initial treatment plan, surveillance cystoscopy record, intravesical treatment record. Additional pages for HNAs, questions, comments and treatment records can also be added as required.

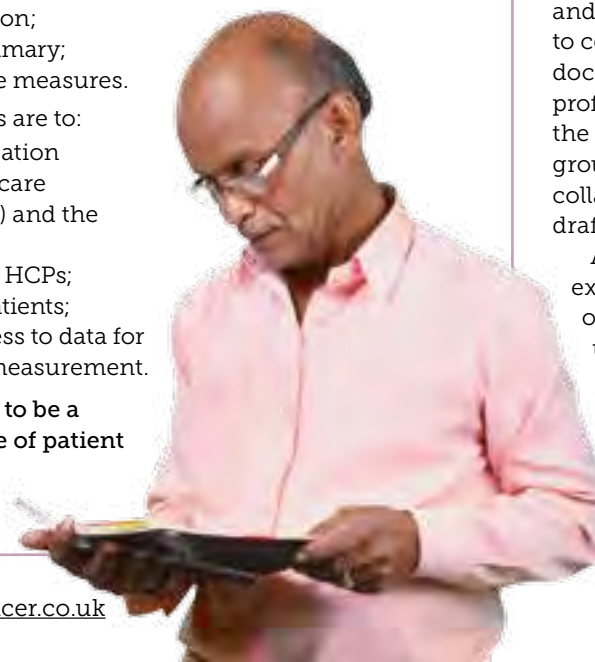
### How to use this PHR

The key worker should offer the PHR to each patient at diagnosis, already personalised with the patient's details. At that stage, the KW would discuss the contents of the PHR as well as any patient information booklets supplied. The KW will help the patient complete the clinical pages of the PHR and explain how it will be used. The patient will bring the document to each appointment so that the KW can help them to complete the relevant sections at each visit.

**We are optimistic that this will provide a useful tool for patients, carers and professionals.**

### REFERENCES

- 1 Gysels, Marjolein MA PhD; Richardson, Alison BN (Hons) MSc PhD RN PGDip Ed RNT; Higginson, Irene J BMBS FFPHM PhD FRCP, 'Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review', *Health Expectations* (March 2007), Volume 10, Issue 1, pp75–91 (open access)
- 2 Ko, Henry; Turner, Tari; Jones, Christine; Hill, Caron, 'Patient-held medical records for patients with chronic disease: a systematic review', *Qual Saf Health Care* (2010), 19, pp1–7
- 3 NHS England Patients Online Group, 'Patient Held Record workshop' (29 July 2015), (available online). Last assessed 25 August 2016 at <http://rippleosi.org/patient-held-record-workshop-with-the-nhs-england-patients-online-group/>
- 4 NHS Modernization Agency, Cancer Services Collaborative Improvement Partnership, 'Patient held records toolkit', (2016) (available online). Last accessed 25 August 2016 at <http://www.qualitasconsortium.com/index.cfm/reference-material/service-transformation/patient-held-records-toolkit/>
- 5 NICE, 'Bladder Cancer: NICE quality standard [QS106]' (December 2015) (available online). Last accessed 30 August 2016 at <https://www.nice.org.uk/guidance/qs106>
- 6 NICE, 'Bladder cancer: diagnosis and management. NICE guidelines [NG2]' (February 2015) (available online). Last accessed 30 August 2016 at <https://www.nice.org.uk/guidance/ng2>





# Are you too young for bladder cancer?

It is dangerous to assume bladder cancer only affects older people – and mainly men – says 44-year-old Kate Bohdanowicz.

When my mother made a routine appointment with her GP and mentioned that her daughter was being treated for bladder cancer, the doctor smiled and said, 'Your daughter is too young to have bladder cancer.' I was 43 at the time.

According to the American Cancer Society, the average age for diagnosis of bladder cancer is 73. Yet, I am living proof (living, thanks to the swift removal of my bladder) that it affects many of us who are nowhere near even to drawing a pension.



KATE: diagnosed aged 43



MANDY: diagnosed aged 49



CORRINA: diagnosed aged 42



MARION: diagnosed aged 47

The Fight Bladder Cancer online support forum is full of people my age and younger who have been diagnosed. For many, treatment was delayed because their symptoms – such as blood in their urine, pain when peeing, an urgency to go and back pain – were considered to be something less serious.

## Bladder cancer DOES affect younger people

Mandy Fleckney was 49 when she returned repeatedly to her GP concerned that her rose-coloured urine was more than an infection. Alerted by the 'Blood in Pee' campaign, which was running at the time, she felt she was being fobbed off with antibiotics and demanded to be scanned. 'I can assure you it isn't bladder cancer,' explained her GP. She was wrong, and when Mandy complained to the practice manager, she was told they'd never considered testing women under the age of 65.

It is odd that, even when many symptoms are present, doctors still fail to test people for bladder cancer if they're not over a certain age. Corrina Feast had suffered two years of bladder spasms, incontinence, urgency, frequency and blood in her pee, when at the age of 42 she was referred to a urologist who told her she was too young to have cancer. She believes her subsequent treatment would have been less traumatic if her bladder hadn't struggled for so long. This is a common complaint. What might have been resolved with minimally invasive treatment requires far more dramatic intervention if the cancer has time to invade the bladder wall. If the cancer has spread to other organs, the prognosis might be terminal.

## ARTICLE

KATE  
BOHDANOWICZ,  
Journalist & FBC  
Forum Member

If you meet a doctor who is unwilling to refer you to a urologist due to your age, he or she could be putting your life in danger.





Marion Brookes was 47 and had spent three years being treated for a urine infection when she put her foot down and insisted on being sent for tests. 'Roughly three-quarters of my bladder was covered with tumours,' she says. When her daughter asked the doctors if the wait had contributed to its development, she was told her GP had been right to hesitate as the symptoms were so similar to a urine infection. 'Why can't they rule out the worst case scenario first?' asks Marion. Not doing so is dicing with death.

The idea that bladder cancer is something that affects older people – specifically older men – is incorrect and dangerous. While the majority of people diagnosed are over 60, not every patient is that age and some are, of course, much younger. Greater awareness means swifter diagnoses and this is saving lives.

### Putting it down to gynaecological problems

My diagnosis came on the back of an unsuccessful attempt at IVF. Plagued with what I thought was a persistent urine infection, I was on antibiotics for months before my GP referred me to a urologist. Women of child-bearing age can find it more difficult to get diagnosed as their symptoms are often seen as gynaecological.



EMMA:  
diagnosed aged 26

**The idea that bladder cancer is something that affects older people – specifically older men – is incorrect and dangerous.**

Elizabeth Goodwin was 45 when she was told her pains and fainting spells were caused by problem ovaries. Even when an ultrasound showed a growth on the bladder, she was told it was most probably endometriosis. Cancer was the last thing to be ruled out.

It took a year for 26-year-old Emma McCormick to be diagnosed correctly. Her GP told her she ticked every box for cancer except her age, so no tests were carried out. She was told her symptoms were gynaecological. By the time a cystoscopy confirmed it was bladder cancer, it had travelled to her lymph nodes. Five months after diagnosis she passed away. Her mother Shelagh, who had badgered the GP to have her daughter referred, promised Emma she would do all she could to highlight how bladder cancer affects the young.

### We take the professionals' word when they say it's nothing serious

Patients begging doctors to treat their symptoms with more seriousness is, sadly, an all-too-common experience for younger cancer sufferers. But the fact is we are not experts and when the medics tell us it's something minor, we take their word for it. We don't want to be seen as time wasters, especially when we've been told there's nothing to worry about. That's what 26-year-old Grace Anscombe was told when she pushed for an ultrasound after discovering blood in her pee. Even when a bladder scan showed something there, she was told 'it would pass'. After another couple of months she was referred to a urologist by her doctor who told her that nine out of 10 people walk out cancer free. 'Turns out I was the one person who didn't,' says Grace, who has since had her tumour removed.

### Young or old, cancer can affect you

Unlike other cancers, such as breast and bowel, there is no national screening programme in place for bladder cancer.

If you have symptoms, you must get them checked out. If you meet a doctor who is unwilling to refer you to a urologist due to your age, he or she could be putting your life in danger. Bladder cancer is not easy to detect – with no visible lumps – and it is easily misdiagnosed. Nor does it discriminate due to age, so young or old – it could affect you.

# And it's not just the girls

Otis was just twenty-one years old when he was diagnosed with bladder cancer.

Hi, my name is Otis. I like women, beer and going out with my mates. I like going to the gym here. I'm just an ordinary lad who likes the odd drink and a fun life.

**'To be fair, for at least a year and a half I was peeing blood, so I was nineteen when it all started. For a long time I was too scared to go and see the doctor.'**

### What were your symptoms?

To be fair, for at least a year and a half I was peeing blood, so I was nineteen when it all started. For a long time I was too scared to go and see the doctor. I knew something was up but I just pushed it to the back of my mind. My mate, though, kept on my case and persuaded me to see my GP. The doctor said I should have gone in to see him earlier. He was great and put me at ease. He booked me straight in for a cystoscopy and four days later they found the tumour. It all went a bit quick.

### What was your initial diagnosis?

I've got Grade 3 Ta, so although it's small it's very aggressive.

### What has your treatment been?

I'm on BCG treatment. The treatments make me feel a bit dodgy the following day, but other than that it's not too bad. I have another few weeks to go on the treatments and then I'm having another cystoscopy to see how they're working.

### How has it changed your life?

It has changed everything, especially with work. I can't really work at the moment. I'm a self-employed builder specialising in insulation, rendering and stuff like that, so it's heavy lifting all day long. After a TURBT procedure I'm not allowed to lift anything heavy for six weeks, so I'm doing odd days here and there between treatments. I really wish I had a different job now!

I'm in the really early stages of diagnosis and treatment and I keep thinking what could have happened if my mate hadn't nagged me to go to my doctor. Because my cancer is aggressive they told me I had two options, BCG or having my bladder removed. I don't really want to have my bladder out because then I can't have kids and that naturally. I really want to have kids so that made the choice for me.

My family is more worried than me. Sometimes I think that I have to make them feel a bit more comfortable about the situation. It's hard to see the people I care about upset.

### Why is this article important to you?

It'll help. I wanted to let young people know, by telling my story, that they can get it an'all. I also thought it would be good for me to help people going through the same thing.

### Are you going to beat it?

Yeah, defo, one hundred percent. I just look at it as an inconvenience. I want to get on with my life.



# Quality of Life in Bladder Cancer (Q-ABC)

## ARTICLE

DR SALLY APLEYARD, Specialist Registrar in Clinical Oncology, & DR ASHOK NIKAPOTA, Consultant Clinical Oncologist, Sussex Cancer Centre

**The Q-ABC Study aims to establish a comparison between the quality of life of patients undergoing surgery or radiotherapy.**

The success of treatment for any cancer is usually measured in terms of survival or the time before the cancer returns or progresses (commonly referred to as Progression Free Survival (PFS)). Although these measures are of utmost importance to patients and families, they don't necessarily capture the whole experience of patients living with and beyond cancer.

The important finer details of the impact of treatment on quality of life can be measured using a variety of questionnaires. However, these are not used routinely in standard care and tend to be used in small groups (sub-studies) of large research trials. Relative differences in quality of life are even more important when different treatments offer similar outcomes in terms of cancer control and survival.

This is the case in muscle-invasive bladder cancer patients, and the Q-ABC study aims to collect high-quality information about quality of life following treatment.

## Muscle-invasive bladder cancer

Cancer which has invaded the muscle wall of the bladder but not travelled outside of the bladder is known as muscle-invasive bladder cancer (MIBC) and accounts for approximately 25% of bladder cancer diagnoses each year.<sup>1</sup> This can either be the first occurrence of bladder cancer for a patient or may follow previous non-muscle-invasive disease (also known as superficial bladder cancer). Most patients notice blood in their urine and are diagnosed via 'haematuria' clinics. The majority of patients will be offered chemotherapy before embarking on definitive treatment in the form of surgery or radiotherapy. This is referred to as neoadjuvant chemotherapy as it takes place before the primary treatment and has been found to improve survival.<sup>2</sup>

## Treatment options

In the past, the standard treatment was surgical removal of the bladder (cystectomy) with either a permanent stoma (draining urine into a bag on the abdominal wall) or one of many forms of bladder reconstruction, which may or may not require the use of a catheter. More recently, the introduction of robotic surgery has reduced the need for 'open'

operations. Whichever the type of surgery, however, it is not without risk.<sup>3</sup> For the majority of patients, this is life-altering surgery as they are no longer passing urine in the normal way. The use of stoma bags, catheters or merely changes in their urinary habits all impact on quality of life.

Bladder cancer is associated with smoking and increasing age and so a significant proportion of patients are not suitable candidates for major surgery. In the past, these patients have been considered for radiotherapy (x-ray) treatment instead.

Over the last decade there have been improvements in radiotherapy, including the addition of chemotherapy and other drug treatments, such that the cancer control and survival rates following radiotherapy treatment are similar to those achieved using surgery.<sup>4,5,6</sup> Radiotherapy involves the use of high energy x-rays to kill cancer cells and is delivered using daily short treatments over the course of six weeks. Radiotherapy causes side-effects in the six weeks following treatment and can also result in long-term side effects involving changes in urinary and bowel function. Thus, despite radiotherapy being a bladder-conserving option, it is not without its impact on quality of life.

## Decision making

Although separate studies of surgery and radiotherapy demonstrated similar rates of cancer control, the results might be affected by differences in the patient population being treated, for example the patients receiving radiotherapy might be older and frailer.

A randomised trial – where patients are allocated to the different treatment options at random – should provide more reliable evidence that the treatments are equivalent. SPARE was such a trial run in the UK by the Institute of Cancer Research and funded by Cancer Research UK. However, the trial was closed prematurely, having failed to recruit sufficient patients.<sup>7</sup>

Investigations into why the trial was unsuccessful have suggested a number of potential problems.<sup>8,9</sup> The two treatment options are very different, as outlined above, and it may be difficult for patients to accept being allocated one at random; anecdotally many patients have a preference for one over the other.

In addition, doctors may have some unconscious preferences relating to the fact that surgery was previously the 'gold standard' treatment, with radiotherapy reserved for those who were less fit. The pathway following diagnosis of muscle-invasive bladder cancer can be complex, with multiple hospitals, teams and treatment types discussed, and so it can be overwhelming for patients to also consider a clinical trial.

Finally, it was found that doctors may judge that one treatment is 'better' in terms of long-term function, despite the lack of good comparative evidence to support this, but as a consequence of their experience.

## NICE guidance 2015

The NICE guidance on bladder cancer, issued in 2015, recommended that patients be offered the choice between surgery and radiotherapy, acknowledging that they were probably equivalent in terms of cancer control and that a randomised trial was not possible.<sup>9</sup> Patients and families are therefore presented with a choice between two very different treatments with equivalent effect in terms of cancer control and survival.

Although patients will be provided with information about the side-effects of both treatments, there is a lack of information about the impact of the treatments on quality of life. Where patients have a choice between treatments, both of which offer a chance of halting the cancer, the long-term effect on quality of life is crucial in helping them to make decisions. Unfortunately the information that is available is generally in small studies; limited to one treatment type; of short follow-up and using questionnaires that are not specific to bladder cancer.<sup>10,11</sup>

## Q-ABC – Study design

Our study will recruit 356 patients across the UK in at least 10 centres. These patients will be evenly split between those undergoing radiotherapy and surgery but they will all have been suitable for both treatments. The treatment they receive will be decided by the patient and family with the support of their clinical

**Where patients have a choice between treatments, both of which offer a chance of halting the cancer, the long-term effect on quality of life is crucial in helping them to make decisions.**



team. Participants in the study will complete questionnaires relating to quality of life before starting treatment and then at intervals over the following five years. These questionnaires will take approximately 20–30 minutes to complete and can be completed at home or at routine follow-up visits in hospital.

We will also offer participants the option of completing the questionnaires directly on a home computer or on paper. This is in response to feedback from some patients that they would prefer to complete questionnaires electronically, and it may also be a more efficient way of collecting the information.





**The questionnaires**

We will utilise standard questionnaires which are used internationally in research. We have selected questionnaires which provide information that is relevant to patients following treatment for bladder cancer. The questionnaires will cover general quality of life, including the ability to do normal activities and specific symptoms including urinary and bowel function and the impact on personal relationships. Participants will also be asked about fear of recurrence, as we know that this is an area which is likely to impact on quality of life. Unfortunately, it is a significant risk following both treatments, which offer an approximately 50% survival rate at five years.

We will also assess the economic, financial and social impact of bladder cancer and treatment by asking participants to complete a questionnaire which captures the costs of treatment, use of the NHS and time needed off work for patients and family. This information will contribute to an analysis of the relative cost-effectiveness of each treatment in the context of the quality of life experienced.

**The Q-ABC study objectives**

This study aims to provide patients, families and health care professionals with detailed information about the impact on quality of life of two very different treatments. Patient groups have been involved in the design of this study, including Fight Bladder Cancer. This study addresses some of the deficits laid out in the NICE Guidance on Bladder Cancer and is supported by the National Cancer Research Network Bladder Cancer Clinical Studies Group. This study also addresses two of the six strategic priorities set out in the independent cancer taskforce strategy 2015: improving the status of patient experience as an outcome measure and supporting people living with and beyond.<sup>12</sup>

**Tracking quality of life**

This study will allow the tracking of change in quality of life from pre-treatment, through the period of treatment and into a time where patients are hopefully living beyond cancer. We will also be able to compare the quality of life experienced by the groups of patients who have had surgery and radiotherapy. However, as treatment will not have been randomly allocated, we will have to be cautious to discuss this in the context of any differences in the two groups (for example in terms of age, other medical problems and previous symptoms) that may also influence quality of life.

**Where we are now**

Despite the recognition that this is an important area of research, particularly as patients with bladder cancer report low patient satisfaction,<sup>13</sup> we are still in the process of obtaining funding for this study. We hope to have funding and approvals in place by mid 2017. In 2016 we are opening a smaller study which will use interviews with patients and carers to explore the impact of treatment on quality of life.

This study will inform the future development of the larger study as it may identify other important issues. The study is funded by the Sussex Cancer Fund.

**REFERENCES**

1 Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bladder-cancer/incidence#heading-Three> (accessed 26 September 2016)  
2 'Advanced Bladder Cancer Meta-analysis Collaboration. Neoadjuvant chemotherapy in invasive bladder cancer: update of a systematic review and meta-analysis of individual patient data', *European Journal of Urology* (August 2005), 48(2), pp202–5

3 Bochner, BH et al, 'A randomised trial of robot-assisted laparoscopic radical cystectomy', *New England Journal of Medicine* (July 24 2014), 371, pp389–90  
4 James ND et al, 'BC2001 Investigators. Radiotherapy with or without chemotherapy in muscle-invasive bladder cancer', *New England Journal of Medicine* (19 Apr 2012), 366(16), pp1477–98  
5 Hoskin, PJ et al, 'Radiotherapy with concurrent carbogen in bladder carcinoma. Life and

death of spare (Selective bladder preservation or radical excision): reflections on why the spare trial closed', *BJU International* (September 2010), 106(6), pp753–5  
8 Parmisivan et al, 'Key issues in recruitment to randomised controlled trials with very different interventions: a qualitative investigation of recruitment to the SPARE trial', *CRUK Trials* (July 2011), 12, p783  
9 NICE guideline, 'Bladder cancer: diagnosis and management',

(published 25 February 2015), [Nice.org.uk/guidance/ng2](http://Nice.org.uk/guidance/ng2)  
10 El-Sayed, M; El-Azab, AS; El-Gammal, MA, 'Quality of life in bladder cancer patients treated with radical cystectomy and orthotopic bladder reconstruction versus bladder preservation protocol', *J Cancer Sci Ther* (2013), 5, pp190–193  
11 Henningssohn, L; Wijkstrom, H; Dickman, PW; Bergmark, K; Steineck, G, 'Distressful symptoms after radical radiotherapy

for urinary bladder cancer', *Radiotherapy and Oncology* (February 2002), 62(2), pp215–25  
12 'Achieving world-class cancer outcomes – a strategy for England 2015–2020. Report of the Independent Cancer Taskforce' (published 9 July 2015)  
13 National Cancer Patient Experience Survey (2015) <http://www.ncpes.co.uk/index.php/reports/national-reports/2489-cpes-2015-national-report-pdf/file>



# Enhanced Recovery

## ARTICLE

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



**Based on a Danish model, ER empowers patients to take an active role in their recovery from bladder surgery – with hugely beneficial results.**

Every year, nearly 2,000 patients in the United Kingdom undergo surgery to remove their bladder as part of their treatment for bladder cancer. In some cases, they have already had to complete a three- or four-month course of chemotherapy. Many of the challenges that they subsequently face are unique when compared to other patients undergoing cancer surgery.

A striking example is the fact that the average time spent in hospital after surgery is significantly longer than for other patients being treated for bowel, prostate or gynaecological cancers. Where the average time in hospital following prostate cancer surgery is around 36 hours, a patient who has had their bladder removed will spend over 12 days in hospital. Those of you who have undergone surgery will already be familiar with the effects that can have on your sleep, eating, privacy and general well-being.

What we also know is that some teams work with their patients to promote a more rapid recovery and be ready for home in around 7 days whereas others tend to take nearly 18 days on average. Why such a big difference?

### The first fast-track programme

Approximately 10 years ago in Denmark, Professor Henrik Kehlet published the results of his fast-track surgical programme. Using a whole host of minor improvements to his patients' care, he reported an average time to discharge of 48 hours in patients undergoing open bowel surgery in his unit. During the same period in the UK, the average length of stay was in the region of 5 to 10 days and in many cases this included overnight admission prior to the actual day of surgery.

In the decade leading up to his publication, Professor Kehlet had been tirelessly researching the body's 'stress response' to surgical trauma and ways in which this response could be minimised.

His fast-track programme brought together the two essential strands of what is now commonly referred to as 'enhanced recovery' (ER) – namely, effective organisation of clinical care coupled with the implementation of the latest and best clinical practice. In combination, they reduced the variation in the delivery of a patient's care and at the same time encouraged a partnership agreement with patients to make them active participants in their own recovery.

### Common sense linked with some contentious elements

Many of the important aspects of ER were just common sense but very poorly practised – elements such as pre-operative patient education, patient information resources, 'buddy patients' and many of the measures that allow us to enter surgery feeling adequately informed and with a recovery plan. Other elements were highly contentious at the time – for example, allowing patients to drink normally right up to the morning of surgery, avoiding the use of surgical drains, restarting normal diet straight after the operation and encouraging patients to get up and walk on the same day as their operation.

Very few of these improvements were novel, but the key was ensuring that all of the measures were applied rigorously all of the time. In doing so, patients could make informed plans for their surgery, set goals for their own recovery and enter programmes that de-medicalised their care by encouraging normal activities with fewer drips and drains.

### Empowering patients to speed their recovery

A key aspect that noticeably changed was the empowerment of patients and their carers to take a more active role in the preparation for, delivery of and recovery from their treatment. For many years, we had seen surgery as 'something that was done to you' – ER programmes have begun to change that philosophy and create the understanding that their treatment is a journey that must be taken in partnership. The patient at the centre is surrounded by their wider clinical team and everyone is aware of the shared plan.

Daily milestones were developed for patients to guide their mobilisation and the level of oral intake whilst also monitoring the return of normal bowel function and overall progress towards a safe, planned discharge date.

The UK was one of the first countries in



Europe to develop these programmes for patients having bladder surgery and their adoption in cancer centres was spurred on by the Department of Health's Enhanced Recovery Partnership Programme that supported teams in making this change to their practice.

As a consequence, we have seen a marked improvement across the UK in the time to recovery following major bladder surgery. However, variations remain and the most rapid recovery is still seen in those hospitals where the entire pathway for the patient has been improved – not just the surgery but, as importantly, the pre-operative information, pre-operative lifestyle and exercise advice, day of surgery admission to hospital, prompt stoma education and rapid support with mobilisation after the operation.

**So much is achieved simply by this shared collaborative approach between the patient, their carers and the clinical team.**

### Follow the guidelines

The British Association of Urological Surgeons and British Association of Urological Nurses have now developed guidelines for hospitals that are available online. In addition, NHS England has specified that cancer centres should have enhanced recovery programmes in place if they perform major bladder surgery. So make sure you are aware of your role in your own recovery and also feed back to your clinical teams where you see room for further improvement.



# Coping with radiation-induced diarrhoea

As a new urology oncology nurse specialist in a training post, Shievon makes sure patients know what to expect when undergoing external beam radiotherapy.

Many patients with a bladder cancer diagnosis choose radiotherapy as their treatment of choice, opting for pelvic radiotherapy over surgery. My particular responsibility in clinic consultations is to discuss all the aspects of external beam radiotherapy (EBRT), and here I am highlighting the problem of radiation-induced diarrhoea.

## What does the treatment involve?

Radiation is a broad term including all types of radiant energy, from a light bulb to an electromagnetic wave. In the case of radiation treatment, high-energy x-rays produce ionisation of atoms as the beam travels through biological tissues, destroying the electrons and therefore the cells. When a cell's deoxyribonucleic acid (DNA) is irreparably damaged, that cell will die.

While the x-rays are very specifically targeted at the cancer cells, the biological effect of the radiation will also have an impact on the normal tissues. Firstly, this will affect how normal tissue recovers. Secondly, it will impact on how cells divide (mitosis) and how they are redistributed around the body. The penultimate stage is repopulation, or replacement of dead cells. And finally, reoxygenation: where radiotherapy causes tumour shrinkage, in turn making it radiosensitive. Tumour cells, like any cells in our bodies, require oxygen, without oxygen cells become hypoxic and die.

## Potential side-effects

Consequently, because of the impact of the treatment on the recovery and repair of normal cell tissues, some side-effects are unavoidable, both acute and long term.

Acute side-effects can occur while radiotherapy is being delivered or within a few weeks, and can have a significant effect on the patient. Such side-effects can include bloating, flatulence, faecal urgency or incontinence. Patients significantly highlight these gastrointestinal (GI) side-effects as very embarrassing when attending clinics. However, they settle rapidly due to the newly growing cells in the gut replacing the cells damaged by ionisation.

Long-term side effects, by comparison, can occur weeks or months after treatment has been completed, and some can be permanent. This is significant as it means that the true numbers of patients affected by radiotherapy-induced diarrhoea are not fully known since the problem may occur some time after treatment. However, it is predicted that growing numbers of cancer survivors with radiation-induced

diarrhoea and GI symptoms will shortly double the figures for patients with diagnosed Crohn's disease which is a chronic inflammatory disease of the intestines displaying similar symptoms.

## The extent of the problem

Of all cancer patients, 60% will be treated with radiotherapy. Henson et al (2011) reported that 17,000 patients were treated with radical pelvic radiotherapy in the United Kingdom from 2009 until 2012. The authors noted that almost 50% of those cancer patients treated with radiotherapy experienced significant GI symptoms, including diarrhoea, that impacted on their quality of life. However, these figures are not broken down to true numbers of patients experiencing radiotherapy-induced diarrhoea.

Acute or chronic side-effects also reported in clinic include cystitis and faecal incontinence. Individuals reporting rectal bleeding or tenesmus (a recurrent urge to empty the bowels) always require further investigation and gastroenterological review. Patients receiving concurrent

chemo-radiotherapy are 50% more likely to experience diarrhoea.

Extreme cases of gastrointestinal toxicity can result in delaying radiotherapy to allow the bowel to settle, however this reduces the therapeutic benefit. Discussion with the patient to stop EBRT should occur when the side-effects are so severe that a patient cannot continue treatment.

## The importance of reporting side-effects

However, it must be remembered that many patients are not reporting side-effects. This could be supported by Faithfull and Wells (2003) finding that 56% of men treated with radical EBRT and 86% of women treated with pelvic EBRT had gastrointestinal disturbances, including diarrhoea. It could be argued that the differences between these two studies could be the length of the course of treatment or the strength of the radiotherapy administered. Moreover, it has been suggested that gender may have a part to play, where male patients are less likely to report side-effects.

## ARTICLE

SHIEVON SMITH,  
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Broomfield Hospital

Data still proves that males are reluctant to pursue health screening, report symptoms or attend for tests.

Reporting toxicities caused by radiotherapy to your clinical nurse specialist (CNS), radiotherapist or consultant allows early symptom management and/or dietician referral which might improve symptoms.

Did you  
know your diet  
can help! Find  
out more  
overleaf ...



Your diet can help

Patients suffering from diarrhoea are encouraged to eat a healthy diet. The London Cancer Alliance (2013) guidelines endorse eating small, plain meals like pasta. Patients are encouraged to stop or reduce intake of lactose products. There is a risk of developing lactose intolerance because the bowel mucosa has been damaged by radiotherapy, (LCA, 2013). We advise avoidance of spices, high-fibre foods and caffeine to improve symptoms, alongside reducing fat intake.

In conclusion, the action of radiotherapy can cause diarrhoea because some degree of toxicity is inevitable. Radiotherapy patients experience varying degrees of symptoms. Many patients can self-manage side-effects from treatment. But don't be embarrassed to report side-effects or seek help. Your healthcare professionals have these conversations every day and are there to support you on your road to recovery. Onward referral or signposting to wider members of the multi-disciplinary team, for example, dietician or gastroenterologist, may improve patients' experience and quality of life and alleviate symptoms.



REFERENCES

Andreyev, J, 'Gastrointestinal complications of pelvic radiotherapy: are they of any importance?'. *Gut* (2005), 54, pp1051–1053

Andreyev, H; Wotherspoon, A; Denham, J; Hauer-Jensen, 'Pelvic radiation disease: new understanding and new solutions for a new disease in the era of cancer survivorship', *Scandinavian Journal of Gastroenterology* (2011), 46, pp389–397

Banfill, K; Duffton, A; Dodds, D, 'Radiotherapy for patients with prostate cancer', *Cancer Nursing Practice* (2016), 15 (1), pp27–33

Burg, M; Adorno, G; Lopez, E; Loerzel, V; Stein, K; Wallance, C; Sharma, D, 'Current unmet needs of cancer survivors: analysis of open ended responses to the American Cancer Society study of cancer survivors II', (2015), [Cancer.doi.wiley.com/11.1002/cncr.28951](https://doi.org/10.1002/cncr.28951)

Faithfull, S; Wells, M, *Supportive Care in Radiotherapy*, Churchill Livingstone: China (2003), pp73–74, pp82–83 and pp247–263

Gough, B; Robertson, S, *Men, Masculinities and Health. Critical Perspectives*, Palgrave Macmillan: China (2010), pp111 and 122

Gupta, A; Muls, A; Lalji, A; Thomas, K; Watson, L; Shaw; Andreyev, H, 'Outcomes from treating bile acid malabsorption using a multidisciplinary approach', *Support Care Cancer* (2015), 23 (10), pp2881–2890

Helgeson, V, *Psychology of Gender* (2009), 3rd edition, Pearson Prentice Hall: USA

Henson, C; Davidson, S; Lalji, A; Symonds, R; Swindell, R; Andreyev, H, 'Gastrointestinal symptoms after pelvic radiotherapy: a national survey of gastroenterologists', *Support Care Cancer* (2012), 20, pp2129–2139

Itano, J; Brant, J; Conde, F; Saria, M, *Core Curriculum for Oncology Nursing*, 5th edition, Elsevier: USA (2016), pp226–228

Kuku, S; Fragkos, C; McCormack, M; Forbes, A, 'Radiation-induced bowel injury: the impact of radiotherapy on survivorship after treatment for gynaecological cancers', *British Journal of Cancer* (2013), 109, pp1504–1512

London Cancer Alliance LCA Acute Oncology Clinical Guidelines (2013), London Cancer Alliance: London, UK. Available at [www.londoncanceralliance.nhs.uk](http://www.londoncanceralliance.nhs.uk)

Miner, M, 'Men's health in primary care: an emerging paradigm of sexual function and cardiometabolic risk', *Urologic Clinics of North America* (2012), 39 (1), pp1–23

Muehlbauer, P; Thorpe, D; Davis, A; Drabot; Rawlings; Kiler, E, 'Putting evidence into practice: evidence-based interventions to prevent, manage, and treat chemotherapy – and radiotherapy-induced diarrhoea', *Clinical Journal of Oncology Nursing* (2009), 13 (3), pp336–341

Murray, M, *Critical Health Psychology*, 2nd edition Palgrave Macmillan: China (2015), p111

Palmieri, C; Bird, E; Simcock, *ABC of Cancer Care*, Wiley Blackwell: Singapore (2013), pp34–35

Pal, S; Adhikary, S; Bhattacharya, B; Basu, J; Ghosh, T; Patra, N, 'A prospective randomized controlled trial to study the role of sulfasalazine in the prevention of acute gastrointestinal toxicity associated with concurrent chemoradiation in carcinoma cervix', *Clinical Cancer Investigation* (2013), 2 (2), pp118–121

Payne, J, 'Current trends in oncology nursing', *Oncology Nursing Society USA: ONS* (2012), p204

Taylor, I; Garcia-Aguilar, J; Ward R, *Fast facts Colorectal Cancer*, 3rd edition, Health Press: Plymouth, UK (2010), p22

Tobias, J; Hochhauser, D, *Radiotherapy, Cancer and its Management*, 6th edition, Wiley-Blackwell: Chichester, UK (2010), p58

ARTICLE

KATE  
BOHDANOWICZ,  
Journalist & FBC  
Forum Member

Up the  
creek ...

Many patients are entitled to free NHS pads but, as Kate Bohdanowicz discovered, it can be a battle to get them.



When I was discharged from a London hospital following my cystectomy and neobladder formation, I was told my district nurse would prescribe incontinence pads to deal with its inevitable leaks. Four months and numerous phone calls later, I was still waiting for a delivery. While I'd been aware that my neobladder – an internal bladder built from my small intestine – would need time and patience to train, I hadn't expected it to be so costly. I was spending up to £100 a month on protective equipment.

Bladder cancer patients who deal with incontinence for whatever reason, should receive four free pads a day. Yet when I tried to get mine, I was met with all sorts of excuses, with the continence service (CS) blaming the district nurses for not filling in the form correctly, to the nurses blaming the CS for ignoring the form in the first place. I was sent to my GP, who directed me back to the nurses, and it was even suggested I contact my local chemist and ask them to refund

me for the mountain of Tena pads I'd purchased recently.

Fellow neobladder owner Neil, from Birmingham, was told by his cancer specialist nurse to cut the wings off his baby's nappy and use that to mop up any leaks. 'Nobody prepares you for how incontinent you are at first,' he says. 'I felt as though I'd been left to deal with it on my own and buying pads every day was expensive.' His district nurse told him he didn't qualify for NHS pads although a complaint to the confidential Patient Advice and Liaison Service (PALS) and a hastily written letter from his GP

It's annoying and frustrating to be chasing up something as simple as incontinence pads, when you're undergoing debilitating cancer treatment.



changed that. 'I was then contacted by the continence team who said I was entitled to four free pads a day,' explains Neil.

'The problem is different people tell you different things and no one seems to know all the facts.'



### Given the run-around

According to a spokeswoman at the International Continence Society, 'there isn't a single national recommendation on this as yet. It will be for each Clinical Commissioning Group (CCG) – who are responsible for the delivery of NHS services – to develop local policies.' Without a blanket rule, no patient can guarantee that pads will be provided.

Once I received my initial delivery, I tried to claim back for the four months I'd missed.

A surgical complication meant I was using far more than the four a day prescribed and my three-month delivery was lasting just five weeks. I took the matter to my local CCG but drew a blank, with one person suggesting I go back to the hospital from which I'd been discharged months before, and ask for their supplies.

Another person at the CCG told me I was 'lucky' to get these products free, yet this is a prescription to which we are entitled just as we are an ointment or tablet. Frustrated, I complained to my local MP who contacted the CCG, only to

be met with the response that this is a 'common' problem for people with continence issues, be they bladder cancer patients or otherwise. How that makes it acceptable is quite beyond me.

### Eventual success – at a price

I did get my pads in the end but it took a lot of work on my part. It's annoying and frustrating to be chasing up something as simple as incontinence pads, especially when you're undergoing invasive and debilitating cancer treatment. I was sent on a wild goose chase, calling various organisations, even including the delivery company! It's highly likely some people would be too tired, confused or embarrassed to do the same. Yet this is about dignity and hygiene and, yes, it's about money. Cancer is an expensive business. From taking unpaid days off work to spending a fortune on hospital parking, paying for pads just adds to the bill. And if you're shelling out for products you should be getting free, it's even more painful.

### Don't give up

So what can be done? Bring up the subject of NHS pads with your Cancer Nurse Specialist (CNS) before you leave hospital. Ask your district nurse for a pad assessment as soon as possible and ask to speak specifically to the continence team. If nothing happens, speak to your GP or your local PALS. Healthwatch England is an independent organisation that helps patients' voices be heard and make sure their needs are met. Find your local branch at [www.healthwatch.co.uk](http://www.healthwatch.co.uk).

**Yet this is about dignity and hygiene and, yes, it's about money. Cancer is an expensive business.**

### Incontinence products: The official rules

You may be able to get incontinence products on prescription from the NHS but it will depend on the rules of your local NHS organisation.

To qualify you will need to be assessed by your GP or your local NHS Continence Service. Once you have been assessed, the healthcare professionals treating you will say which incontinence products are available to you on the NHS. Your local CCG (Clinical Commissioning Group) may have criteria that you need to meet and they might limit you to certain products and to a certain number per day. Do remember that the support you get should include any training requirements that would help with your incontinence as well as the provision of products.

If you are not happy with what you are being provided with, you have every right to be reassessed to have your prescription changed. If you are still not happy, you should ask both your specialist cancer nurse and PALS (Patient Advice and Liaison Service) to intervene.

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## Combating Bladder Cancer with Hyperthermia



Delivering warmed chemotherapy fluid, safely and effectively to enhance treatment outcomes for some patients with non-muscle invasive bladder cancer<sup>1</sup>.

1. Sousa, A. et al. Int. J. Hyperther. 6736, 1–7 (2016).



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# Bladder Buddies

You don't have to face cancer alone. Sharing experiences, giving mutual support, comfort and understanding, there's nothing quite like your Bladder Buddy to help you through the difficult times.



ARTICLE  
MELANIE COSTIN  
FBC Trustee & Support  
Co-ordinator

It is comforting to be able to share their experiences with someone who is going through a similar procedure, or who has been through it already.

Originally a name coined by a forum member, our Bladder Buddies service has grown from the help experienced by sharing stories and concerns with others who have a similar diagnosis to a popular extension of our confidential online forum, accessible to everyone over the phone or by email.

Not everyone feels comfortable using social media and, although our forum is private, it may still feel to some like an alien place to visit for help. If you prefer to have a direct contact with someone, as many people do, particularly immediately after a diagnosis, when everything feels so uncertain and surreal, then the Bladder Buddy service is more likely to be suitable for you.

### How does it work?

We start by asking you to fill in a brief description of yourself on the form found on our main website. If you don't have access to the internet, just give us a call as we are happy to be contacted by phone or email. Fill in as much detail as you can, then one of our team will get in touch. If you have a specific query, you may find that we can answer your questions straight away. If not, we will do our best to find you a suitable Bladder Buddy to talk to.

A quick chat can be all that is needed for a bit of reassurance or to ask questions. For others, however, it is comforting to be able to share their experiences with someone who is going through a similar procedure, or who has been through it already. This can be invaluable for both patients and carers, as the thought of a new life after a bladder cancer diagnosis and all that it may entail can make them feel very scared and raise all kind of immediate questions. A Bladder Buddy will not offer you medical advice but will talk about things based on their own experiences and can offer tips and suggestions. There certainly isn't any need to feel alone and worried as there will always be someone to talk to, no matter how big or how trifling your concerns may seem.

Bladder Buddies are not just for patients. Family, friends and carers are on this journey with you and they need support and questions answered too. It can be very difficult when they don't know how to be of the best help to a loved one, or they want to have things explained so that they have a better understanding of what is going on or what may happen next.

Many people are so frightened and confused that they cannot grasp what may happen after their diagnosis. Even the terminology itself brings with it another worry, as there are so many new words to try to understand and new acronyms to decode. (We have an ever-growing list of acronyms and a glossary here in the magazine on page 61, which may be helpful.) I hope that we are able to give them the information, explanations and comfort they need at the time they most need it.

I have met some very special people through running the Bladder Buddy service. I will often talk to newly diagnosed people myself and if they feel happy with this then we continue to keep in contact, as often or as little as is needed, or I will do my best to connect them with a suitable Buddy.

### Let's laugh together

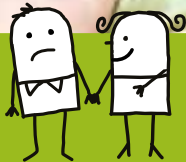
Although some queries are very complicated, others can be simple questions about the basics of having an operation, or what treatments may feel like. Perhaps surprisingly, some frantic conversations can end in laughter, such as the time when one woman had focused her thoughts on what to pack in her overnight bag for hospital. (I checked whether she minded our little story being included and she was only too pleased to share it!)

Among the items she intended to pack was a pair of flip-flops, and I had to explain that perhaps that wasn't the best idea for wandering around the ward in, given that she would have to try to squeeze her toes around a flip-flop toe post in extremely tight surgical stockings. That kind of detail simply hadn't occurred to her – and why should it? But flip-flops, it was decided, could be a potential disaster! So I hope that reassures you that there aren't any questions that would be strange for you to ask.

If you think we can help you, get online, get on the phone and get in touch. We will do our very best to quickly find a Bladder Buddy for you to talk to. We also are happy to take requests from medical professionals who wish to refer a patient.

**Become a Bladder Buddy**

If you are interested in becoming a part of our voluntary Bladder Buddy service then please email me at [melanie@fightbladdercancer.co.uk](mailto:melanie@fightbladdercancer.co.uk), setting out a brief description of yourself and your diagnosis. The area you live in can help for those that want to discuss their local hospital or to meet, but generally communication will be by email or phone. I will always contact you first to ensure you are happy to talk to a particular person and to go over the guidelines with you. You will always have full support in this role when you need it. There may be a length of time before someone needs your help but we will keep your name on our database for as long as you wish.



Find out more about the different ways we can support you and your family and friends at [fightbladdercancer.co.uk/get-help](http://fightbladdercancer.co.uk/get-help)



# Man versus Cancer

**Waking up to the new reality of bladder cancer, Andy Quick calls on the male of the species to throw out the traditional masculine role and not be afraid to show and share your emotions.**

My story began in February 2015 when I found blood in my urine. The problem lasted a few days, but by the time I got an appointment with my GP a couple of weeks later, my urine was clear. This happened another four times, just like clockwork: every two months, I had a couple of days with blood in my urine, which then was clear when I got to the GP. I was urinating deep red but couldn't prove it to anyone apart from my partner, who saw my anguish. I was fobbed off by the doctors, who insisted it was just something that happens from time to time. But eventually saw a GP who took me seriously and sent me for tests. Subsequent scans revealed a large growth on my left kidney. Within weeks I was in hospital having it removed. I had the pre-op cystoscopy and that was clear. I could live with one kidney, so the solution was simple: get it out and move on.

That's the back story. Yes, it was a hard time and the moment the urologist said it was cancer was when I cried in front of a professional for the first time. But I had a great chance. The results came back and the tumour was big but was outside my kidney and hadn't gone into my ureter so, apart from the recovery, all looked good.

The planned follow-up cystoscopy happened at the beginning of 2016. It's an uncomfortable procedure and revealed three tumours on the screen. The clinical nurse specialist (CNS) described two of them as being not a lot to worry about but the third was an issue. I cried again. My wife was waiting outside when I came out from the consulting room. I had to hold in my tears as I said to her, 'It's back. It's in my bladder.'

So, we waited for the rigid cystoscopy to come and take the tumours away and for biopsies to be sent to the lab. We got the news some weeks later that it was non-invasive but still malignant. I cried again, but in my car alone as I phoned the CNS for the news I dreaded and yet desperately needed to know.

I phoned my wife straight away and told her the news. Her strength was invaluable. She said we will deal with it – and we did. And we go on dealing with it as we are now going through the chemotherapy, with a few hiccups along the way.

## **This is not happening**

But this is nothing to do with why I am writing this. You will have heard similar stories before of other people experiencing bladder cancer, some of them 'lucky', like me. The reason I am writing this is to highlight the emotional effect this whole thing has on you, most especially from a male perspective. As a rule, we find it very hard to tell people how we feel, to open up and to let people see us cry.

But that has all changed for me. I have cried alone, with my wife, in front of my boss and before my employees. I won't say I'm proud of it; I will say I am very proud of it because it means I care about them and about myself. We bottle so much up and try and keep it real when our own body is ignoring us. Men typify a children's tantrum: 'I won't. I can't. I will never admit it.'

Most men will wait to the last minute to see a doctor, blaming it on work, not having the time, or any other spurious reason that springs to mind.

**We bottle so much up and try and keep it real when our own body is ignoring us. Men typify a children's tantrum: 'I won't. I can't. I will never admit it.'**

We will use any excuse in the book to deny that our manhood, our 'bread-winner' status may be revoked by some vile disease that we can't control. We are unfairly programmed by society to be strong and admit nothing.

But the fact is we are not responsible for what is happening to us. We are not being arrested for any wrongdoing. We just have cancer. But while the brain cannot cure cancer, it can certainly help us to deal with it better.

When we fight and tense, we are only thinking of one thing – survival against an external threat. When we ignore a threat and don't show how we really feel about it, we ignore what is wrong and let our internal guard down. But when we admit and accept what is happening, we understand what needs to be done subconsciously.

As men, we need to accept that we are not letting our family down. We are not letting ourselves down. I have learnt that from these eight months of pain and emotional struggle, and I hope someone can take something from this.

## **Let reality get to you**

We will never know what our future holds. We have been dealt this card and we have to play it as best we can. I feel I have the chance now to love the family I have and it has taught me not to be blasé about it like I used to be. Don't get me wrong, I loved them before. But did I really appreciate those little moments? Or did I let them pass because I was too busy thinking about other stuff. Stuff that turned out to be so unimportant when you suddenly realise the things that really matter.

And I love my reality now and I live every moment of it. So don't be afraid, gents, of letting reality get to you. Yes, cancer is hardly the best thing to happen – but it does make life clearer. And you will not be alone in dealing with it. The support not just of family and friends but also of FBC is amazing, and I'm not saying this to blow smoke – the community let me have my tantrums and laughed and cried with me.

**Wee are family #sistersledge**



# The Carers' A to Z Survival Guide

Tracy shares her moving and inspiring FBC alphabet to help others find the shortest route to coping as the carer of someone they love.

ARTICLE  
TRACY  
STASKEVICH,  
Co-Founder &  
Chairman of  
Fight Bladder  
Cancer

I forgot to tell him I love him. That's all I can think of as I start the endless wait for the call to tell me he's out of surgery and that he's okay. It looms large, this particular bout of self-berating nonsense, and for a while I can think of nothing else except that. God, what if ... yes, the stupid, ever-present what ifs ..... what if I never get the chance to tell him that again? This thought brings on another bout of sobs and I reach for the crumpled tissue mixed in with discarded sweet papers among the dregs at the bottom of my handbag.

A whistling traffic warden wanders past and turns to double check on his watch. He smiles kindly at me through the windscreen and makes an attempt at the international mime for Are you okay? (As usual involving vigorous gesticulating and a vague thumbs up in combo with a hopeful grin.) I manage a half-baked smile in return, nodding furiously to convince him all is well and realise how I must look: a crazy blubbing woman, rocking silently in her car on a London side street in the wee small hours. I really need to get out of here. I turn on the engine and check the clock. Damn it, I am only twenty minutes into the magic hour.

'What on earth is the magic hour,' you may ask? Ah, let me explain. In the many years of Andrew's appointments, mad dashes to A and E, operations, results clinics and the like, I have realised the impact of those first sixty minutes. Not that I would ever fall apart in front of my bloke, oh no. In front of him, I am a rock – steadfast and strong, constantly waving my virtual 'you can do it' pom poms in a frenzy. Cartwheeling hope and positive mental attitude in every direction like a Duracell-powered cancer-beating cheerleader.

The magic hour is what I never let him see ... the first hour I am alone with the news. I remember the very first magic hour, when the consultant told us it was a large tumour. So large they had been unable to remove it all with the TURBT and they were pretty sure it had grown out into the prostate and beyond the bladder wall. So large that on the chart on the wall it was the very last diagram in the set, ominously labelled 'Stage 4'. (There was no Stage 5.) We sat huddled together on his hospital bed as we discussed what we'd do between now and the six weeks we had until they'd remove his bladder in an eight-hour operation. We joked about the size of the parties we'd have, how much we'd drink and then we decided to get engaged. I left at the end of visiting time with a kiss and a smile, waving my way down the corridor.

Even now I'm not sure how I made it back to the car park from the urology ward. As I unlocked the car door, my legs crumpled beneath me and I wailed. Sobbing into the steering wheel I pounded my fist on the dashboard and screamed at the sky at the utter unfairness of it all. In the midst of this meltdown, my dad called to find out what the news was. I was a snivelling wreck, hiccupping my way through the details, gasping, 'I can't lose him ... I've only just found him,' before disintegrating into a pile of salty tears and snotty gulps. It took me fifty-six minutes that day.

Three thousand, three hundred and thirty messy seconds to get a grip, get myself together and start formulating a coping plan. I left the magic hour behind and entered my other new default setting as a carer ... War mode.

A carer. I still find it a strange concept, but I guess being married to a bladder-cancer patient technically makes the label a no-brainer. To be honest, being a carer is not something I am very good at. For a start, I'm a massive control freak and having to stand by and watch terrible things happen to the man I love (that I can do absolutely nothing about) is horrifying. I also make an exceptionally poor nurse, running low on both sympathy and patience in equal measure, so as you can probably tell this is a role I find extremely challenging. Nothing in life can prepare you for it.

In front of him, I am a rock – steadfast and strong, constantly waving my virtual 'you can do it' pom poms in a frenzy.

Seven years down the line, though, and I am armed for the battle as best I can be. I have learnt the hard way the best route to staying sane in a situation over which you have absolutely no control. Andrew and I have talked a lot over the years since his diagnosis about the difficulties of loving someone with a cancer diagnosis and we agree that emotionally it's as tough a journey as being the patient ... in fact sometimes it's worse.

So what can you do to navigate this rocky path in your role as carer? Here's my essential A to Z survival guide.

## A is for anger

I have always been something of an angry young woman so although it wasn't a surprise that I was angry at Andrew's diagnosis, the sheer extent of my rage was. I was outraged that this could happen to us and that cancer had stomped its way into our lovely life, broken everything and then walked away.

When your partner is diagnosed, it's normal to feel as though you have been cheated of your future and to strike out at those you are closest to, often the person who has been given the cancer diagnosis themselves. Let yourself feel this way and acknowledge the change in your lives rather than trying to cover it up and hope it will go away. (It won't.) Talk openly about it. Then try and use the emotion to make positive differences in your life, focusing on the things you have both always wanted to do. Often cancer can be the impetus you need to make significant changes in life outlook ... for the better.

## B is for build

Build a support network – as big as you can and as fast as you can. Remember, this network is for YOU, not the patient. When Andrew was

in hospital initially, I tried to do everything myself. I thought I had to be some kind of caring superhero. I managed to keep it up for a month and then I was signed off by my doctor for six weeks with exhaustion.

So, build that network and take every scrap of help offered to you. Let someone come and do your housework or take a few loads of washing from you. Welcome friends who offer to cook you dinners or drop in something for the freezer. It's good for you and it actually also helps them, as they feel they are actively doing something useful. So, next time someone utters that immortal line, 'Well, if there's anything I can do ...' make sure you take them up on it.

## C is for cry

You cannot keep this emotion locked inside of you. It's much too big. Wail, shout, curse the gods and let it out. Scientists still don't know why crying makes us feel better, there are all kinds of theories about tears containing excess stress hormones which are washed away when we cry. Whatever the science behind them, tears do help, so grab a box of tissues, wrap yourself in a duvet and as Elsa in *Frozen* so wisely advises, 'Let it go.'



## D is for depression

There is a vast difference between having a bad day and slipping into a constant state of darkness through which there seems no escape. When you are a carer it's easy to ignore the warning signs that accompany depression until you are sucked beneath its suffocating hold. You are busy concentrating on existing, surviving one day at a time. If you feel constantly overwhelmed, are unable to cope, aren't sleeping, or feel you cannot carry on, then please go to see your GP straight away. There is so much they can do to help and often talking about these feelings is enough to start loosening their grip.



## E if for educate

What did you know about bladder cancer before it came into your life? For most people it's nothing, and one of the key problems with the disease is that no one really talks about it. If we are ever to improve outcomes and treatments, we must make a significant change – that means talking about it as much as possible. So tell people. Talk about your loved one's diagnosis and treatment. Yes, you might feel weird at first but you'd be surprised by the number of people who have also had the disease affect someone in their life. Remember, bladder cancer is the seventh most common cancer here in the UK.

If we all started talking more about bladder cancer, it would raise awareness, not only with individuals but also GPs, which in turn could make a big difference to early diagnosis. By educating yourself about bladder cancer, you will also feel better prepared for what the disease may throw at you both in the future. Knowledge is power.

## F is for friends

A cancer diagnosis can really clarify relationships with friends and family. Friends you have been close to for years can suddenly disappear from your lives with the appearance of the C word. Many people are unable to cope with the reality of a friend's mortality and refuse to accept any change to the status quo. On the upside, we found many friends stepped up in a way we couldn't have imagined, becoming stalwarts in our battle ... they laughed with us, they cried with us and celebrated all the little steps to recovery along the way.

Be prepared for this kind of shake-up and be honest with your family and friends. It can be

**If you rely on Dr Google for advice, not only will you scare yourself half to death on what's going to happen to your loved one, but you will probably end up thinking you're also developing a brain tumour.**

incredibly upsetting to lose people over something you cannot control, but you may find by talking to them about what's happening you can get things back on track. FBC have a great downloadable booklet that tells you more about talking to family and friends about bladder cancer.

## G is for Google

Do not sit alone at your iPad/laptop of an evening searching for everything you can about bladder cancer on Google. Especially not if you've had a glass or two of wine. If you rely on Dr Google for advice, not only will you scare yourself half to death on what's going to happen to your loved one, but you will probably end up thinking you're also developing a brain tumour. (Ask me how I know!) Do use only reputable sites like [fightbladdercancer.co.uk](http://fightbladdercancer.co.uk) and [BCan.com](http://BCan.com) to get good information on every aspect of bladder cancer and don't forget to talk to your medical team. They are there to help you both.

## H is for hospitals

When Andrew was first diagnosed, my worst phobia was hospitals. Just the smell as I walked in was enough to make my stomach clench with fear and send me scurrying to the nearest loo where I would try hard not to be sick. You can imagine, then, that his cancer diagnosis and subsequent surgeries was one of the most effective forms of aversion therapy ever!

Within a few months, the hospital was like my second home, I knew all the staff and would happily while away the hours at my bloke's side with nary a care. An important thing to remember about hospitals is that they are generally full of people who care. Your medical teams and support staff are the front line in any cancer



battle and they will have your back. Remember, too, that you are all on the same side, so if things aren't going to plan or you feel concerned in any way about treatments or medical care, talk to them at once. If you don't get the right feedback, then go higher up the management team. You should feel confident and happy with the treatment your loved one is receiving, and if you are in any doubt at all, you can always ask for a second opinion.

## I is for inner strength

Personally I am not religious, but I do have an inner resilience that sees me through (it comes to the fore when I enter war mode). For others, this is their belief in a god or other faith. Whatever it is that gets you through a tough patch, you need to rely on it now. Remember to focus on other times in your life when you have overcome difficulties and faced problems. Remind yourself that you are bigger than what is happening to you and that you will get back to your real self soon. Be mindful and trust that you will move past this.

## J is for journey

I'm not going to lie ... this is going to be tough. Being a carer will test your relationships in ways you haven't imagined, and with it your own resilience. But it is a journey. At the start of it, things may feel insurmountable and you might not be able to imagine ever reaching the end. But you can ... and you will.

Day by day you will learn more, grow more, gather more support and be a little further ahead. Slow and steady in this instance definitely wins the race. Just take one step at a time.

## K is for kindness

Be kind to yourself. You do not have to be the living reincarnation of Florence Nightingale to be a good carer (so step away from the lantern, okay?). Set yourself realistic goals and do what you can. Luckily there are no carer police so you will not be arrested on the days you cannot bring yourself to be nice or look after anyone (not even the cat). Some days are just like that. Tomorrow is another day and it will be better, I promise.

## L is for laughter

Just because cancer has come into your life doesn't mean you can't have fun any more. And what did your nan say? Laughter is the best medicine. It is okay to still live life, go out with friends, get a little tipsy and laugh. In fact it's probably more important now than ever. In the midst of treatments, medication and surgeries, it's easy to forget that there is life outside of the cancer bubble you are living in. Try and schedule some time for activities and things you both like that are fun. Even staying in and watching a good comedy DVD can be therapeutic.



## M is for money

Depending on your job situations, cancer can put a huge strain on the household finances. The best advice here is to act sooner rather than later. Don't bury your head in the sand and hope for the best. Taking an active role in planning your finances through test, treatment and beyond will put you both back in the driving seat and eliminate an area of stress for both of you. Both Macmillan and the Citizens Advice Bureau have dedicated financial helplines with advice for carers and cancer patients.

## N is for news

One of the most exhausting roles for a carer is that of news. It seems there are so many people you need to keep updated with what's happening that it can be completely exhausting. Then there is the emotional drain of repeating the same information over and over on the phone while listening to people repeat how sorry they are.

Take control of this and make it easier for you to keep everyone up to date. A closed Facebook group can be a brilliant way of getting the current status out there with minimal effort – you post once and then everyone can see the information and comment on it. Alternatively, why not start a blog that details your whole bladder-cancer journey. This can be a great news tool and can be therapeutic in itself, both as a carer and for the patient. We both had blogs in the early days of diagnosis and it's a constant good reminder of just how far we have come.

## O is for operations

If anything is likely to derail you, it will be the sight of your beloved fresh out of theatre hooked up to a gargantuan pile of cables, machines, drains and devices, all the while emitting a cacophony of beeps. Utterly terrifying. So be prepared when it comes to operations. There is no law that requires you to sit at the hospital waiting for news while the patient is in surgery.

**Be kind to yourself.  
You do not have to be  
the living reincarnation  
of Florence Nightingale  
to be a good carer.**

In fact I recommend you don't. Instead gather someone from your support network and be busy. Go shopping, go to the movies, try a new dance class. Do anything you can to take your mind off what's happening. Otherwise the time will drag in a way you didn't think was possible.

It's amazing what you can accomplish in the time you are waiting to hear from the surgery team (I have just written this article and decorated the front hall in the duration). See, productive!

Oh, and don't freak out if it takes longer than you think. This is why I recommend you keep busy. It's highly likely there's been a delay in getting the patient to theatre or the op start time, which knocks on to recovery. Maybe there just isn't a porter free to take them back to the ward. Try and relax if you are several hours past time and you haven't heard. This is generally an instance of no news is good news.

Lastly, when you do go and visit, remember that the patient is not going to be looking their best. They are probably awake at this point but may well be giving you the run down on past girlfriends or asking for a chicken curry (ring any bells Mr Winterbottom?). Take it easy on them, they've just had some class A drug equivalents so are riding 'high'.

## P is for planning

Like all good battles, you are going to need a plan. You need to know who is on your side (see B is for build) and you need to know exactly what you are fighting against. First of all, speak honestly and openly with your medical team about what to expect both for your loved one and for you as a carer.



They'll be able to give you a good idea about the road ahead and the tests and procedures that come with it.

Then do your research. Go back to the reputable sites and read as much as you can about what's going to happen. Talk again to the medical team if you have questions. If there are any questions you don't want to ask, you can always head to the FBC forum where you can ask anything. Then plan in where you will need support and start asking for help: someone to do an extra visit to hospital when you need a night off, or to drive you to a results appointment. These little things can really make a difference when you are in the thick of it. Getting a plan puts you back in control.

### Q is for Quack

Sure, I'd love to be able to tell you that there's a magic pill you can give to your loved one that'll make cancer disappear. I'd also like to believe there's another type that'll get rid of fat the way that sun melts butter, but we both know that that's about as real as the tooth fairy. When you are reeling from an initial diagnosis, it's natural to search around for anything that could make a difference. You are desperate for a cure and consider them all – cannabis oil, broccoli juice, turmeric tablets – once you start Googling, the list seems endless and there are hundreds of unscrupulous companies and individuals out there who will take advantage.

I can tell you what is true ... there is no conspiracy over this ... Cancer is not caused by sugar and the pharmaceutical companies are not in a grand plot to deny us cures. The truth is while some research is being undertaken to see if certain diets, lifestyles or substances mean you have a reduced risk of developing cancer, there is currently no scientific evidence to support any of these other claims. The only evidentiary data in bladder cancer supports quitting smoking and eating a healthy, balanced diet, low in processed meats with fruit, vegetables

and wholegrains at its heart. Being blunt, I have seen a handful of people over the years turn their back on traditional medicine and treatments to pursue regimes sold to them by quacks and charlatans. Everything from clean water to cannabis oil. Want to ask them how that worked out for them? Well, unfortunately we can't because they are all dead. Evidence enough?

### R is for results

If there is anything guaranteed to make your mind turn immediately to mush it is results day. Bad enough for us carers but worse still for the patient. I remember on one check-up on a six-monthly scan, we went in to see the consultant and he was fiddling with his pen a lot and seemed unable to look at us. He proceeded to tell us that they'd found something in Andrew's liver but it was too small to say what at this point, and we'd have to wait another three months for an additional scan to see how much it had grown and whether they needed to biopsy it. When we came out, Andrew turned to me and asked me where the thing was in his body. His brain had gone into shut down at 'we've found something'.

This kind of results amnesia is very common and the best way round it is a two-pronged approach. Firstly make a list of all the questions you want to ask before you go in and take the paper and pen in with you. Ask the questions and write in the consultant's response on each point. Ask again if you need further explanation. Secondly, many urologists and oncologists also have no objection if you record the meeting on your phone, although you should always ask their permission first. This means that you can go back over what they've said in the comfort of your own home. If there are any outstanding issues or questions you have, you can then pop your medical team an email for clarification. Remember, there are no silly questions.

### S is for sex

If it's your partner who has cancer, it is going to affect your relationship, especially intimacy. And realistically, you will both have to work hard to make sure that cancer doesn't come between you in that way. Obviously, operations and treatments can have a very real physical impact on the patient. They may be tired, suffering from side-effects or feel very weak. What is important during these times is not to become isolated from each other. Try to continue to be tactile, hold hands, give a gentle massage, a tender hug, or lean in for a soft kiss. All of these are fantastic ways of sharing intimacy and keeping the physical bond between you.

You may also have concerns about what you can and can't do sexually during treatments. Your clinical nurse specialist (CNS) is the best person to ask about this. You have no need to feel embarrassed as they'll be able to provide you with the information you need to make sure both you and your partner are safe when you are intimate. Perhaps treatments have led to difficulties with the physicality of having sex? Don't let this become a barrier in your relationship. Urology teams always have a sexual health expert who can help with specific problems such as erectile dysfunction and other issues. Again, they see these problems every day and have a variety of treatments designed to get you up and running again!



### Try to continue to be tactile, hold hands, give a gentle massage, a tender hug, or lean in for a soft kiss.

### T is for today

Have you jumped in a puddle lately? Kicked leaves around? Gone outside after dark and gazed at the stars? If you don't keep an eye on it, cancer can consume your life and you become just a carer, forgetting who you really are in the process. Even through treatment and recovery, it's important that both you and your loved one do things that are 'normal', as it's these moments and memories that give your life balance. Give yourself a break from worrying, take time off thinking about the future and just live for the day.

### U is for uncertainty

You may be wondering how you can continue everyday life, with no idea about what the future holds. But actually, if you think about it, that's true for every single one of us. No one has any guarantees about what's going to happen tomorrow, next week or next year with or without a cancer diagnosis. Don't worry about your mortality. Get busy living and enjoy every day.

### V is for virtual friends

It was seven years back when I needed help the most, and there was no support here in the UK dedicated to bladder cancer patients. That was the main reason we set up the charity. One of the first things we did was start a confidential online forum. The FBC Confidential Forum is full of patients and carers living and dealing with bladder cancer. I am proud to say it is one of the very best charity forums in the world and the advice and support offered on a daily basis is astounding and inspiring. When you are wondering how to get through the next day, or waiting for results or any other problem you can think of, there is a virtual member of the wee family on hand to pick you up, dust you down and put you back on your

feet. Often the best answers come from someone who has trodden the same path, and with every type of age range and diagnosis represented, the shared wisdom is awe-inspiring. Just go to [fightbladdercancer.co.uk/getsupport](http://fightbladdercancer.co.uk/getsupport) and join up.

### W is for waiting

I hope you are patient as you are going to get really good at waiting. For every test you must wait for results, then wait for letters to arrive detailing appointments and then the wait for possible operations. After all this, there is still the longest kind of waiting, the surreal time between check-ups when you can almost convince yourself that things are back to normal (until the pre-check-up nerves kick in). Added to this for the carer is the waiting to visit in hospital, waiting to find out how your loved one is, waiting for the doctors to tell you how it went ... I've tried every way of dealing with the waiting ... to be honest, there's no quick fix. It just comes with the territory. Try being patient. If all else fails learn to crochet ...

### X is for X-rays, tests & treatments

Remember the feeling of hopelessness as you watch the person you love so dearly struggle with their diagnosis? Well, when you enter the tests and treatments phase of operations, it's going to get worse. Again, knowledge is your friend. By finding out any potential pitfalls up front you can be well prepared for every eventuality. It's the little tips that help immensely, for instance knowing what kind of food is appetising to someone going through chemo, or the right kind of bed sheets to protect against night-time leaks for someone with a radical cystectomy. If you don't know where to begin, you can be partnered with a Bladder Buddy, a carer whose partner has had the same diagnosis and treatment as your loved one.

They can help you navigate these unknown waters and put your mind at ease. Find out more on page 36.

### Y is for YOU

Being a carer is a demanding job. While everyone else is focused on the patient, you must make sure that someone is also looking out for you. And don't forget that you need to take care of yourself, too! Make sure you eat a balanced diet and take regular meals. This can be particularly challenging when you are managing hospital visits but this is where that wonderful network of supporters comes in. I remember returning home after a very challenging day and collapsing in the chair, then hearing the doorbell ring only to be presented with a plate of delicious Sunday roast from a stalwart friend. Wonderful! Take time out for yourself in the day even if it's just for short walk and some fresh air to gather your thoughts. Me time is as important as ever. And sleep ... To be on tip-top form as a carer you need to get good-quality and substantive sleep. Don't put your own needs last.

### Z is for zen

It comes down to this peculiarity – having been through seven years fighting bladder cancer together, when Andrew and I look back we still agree that cancer was one of the best things to happen to us. It has been immeasurably hard at times. On the blue-light dashes to A and E in the middle of the night and arriving at the hospital to find him in resus as they fought to save him, I though we would never survive it. But we did.

It has taught us so much about what in this life is real and important. About friends who become like family. About good people who are so brave and fight so hard but yet don't make it. About sadness and immense pain. But most of all about love. We have transformed our lives as a result. Life is a thing of beauty and something to treasure. So go on out there and LIVE.



# It'll never happen to me ... or will it?

It's something that happens to other people, isn't it? They tell you that they (or someone else) have been diagnosed and you give them a hug and you tell them it will be ok.

You buy cakes at coffee mornings, you sponsor people dressed in pink running round parks but you never think it will be you. Then BAM, you get the news. I likened it to being hit by a heavyweight boxer: my body went numb, my mind an incomprehensible foggy mess. Their lips were moving but I couldn't hear. 'Sorry? What does that mean?' 'It's not good news Mr King ...' That was the moment my life changed.

I'd originally gone to hospital to investigate blood in my urine. I'd seen it a few times but wasn't too concerned, and neither was my GP, it seemed – 'probably kidney stones that make small cuts as they pass through'. An ultrasound was inconclusive so I was referred to a specialist and was invited for a cystoscopy. Little did I know how well acquainted I was going to get with that little camera over the following months. I'd gone alone. No need to inconvenience others, I can cope with being told I've got kidney stones. Lying on the table with a 12-metre screen either side of my head I could see the whole thing. At that

time I had no idea what the inside of a bladder should look like but I was certain it wasn't that. It looked like something from my marine aquarium; all that was missing were the fish swimming around.

## Days in a daze

I sat in a daze drinking what was without doubt the worst cup of tea I'd ever had the misfortune to drink, waiting for the Macmillan nurse to come and talk to me. She came with a handful of leaflets, soothing words and an offer to phone my wife. No, that was something I had to do myself. Except I couldn't. I dialled, I tried to speak but the words got stuck in my throat (something I would experience a lot over the coming days). What just happened? What do I do now? I felt my world collapsing around me.

After a few days of mental numbness, not really knowing what was going on, feeling angry at life, feeling scared of what the future would hold, trying to stay composed in front of the kids, something happened and to this day I still don't fully understand it.

**ARTICLE**  
RICHARD  
KING, FBC  
Confidential  
Forum  
Member



*Rich King and Team Rocky pose next to Eric Morecambe's statue overlooking Morecambe Bay.*

**The anger I'd felt was replaced by determination. The self-pity was replaced by positivity.**

## The turning point

It was a lovely sunny, late summer's day. Fed up of being in the house, I headed out to the seafront (the advantage of living on the coast). I sat on a bench in the sunshine for what seemed like hours, watching people go about their business. I met my wife for lunch – fish and chips, obviously – and I laughed for the first time in ages. It was like someone had flicked a switch; I suddenly felt at peace with my life.

The anger I'd felt was replaced by determination. The self-pity was replaced by positivity. I could do this. And if I was going down I was going down with a bang not a whimper.

When we were kids, Mum used to do yoga, much to the amusement of my sister and me (Google 'lion pose' and you'll see what I mean). But the thing that stuck most was her mantra, 'Mind over matter'. Even now when I'm sitting watching a game of

football, frozen by the North Sea winds, I 'think pink' to feel warm. And it really does work. In the modern world of social media, positive messages and motivational memes have become a bit of a cliché, but away from all that, the basis of success is belief. If you don't believe you will, then you won't. I'll leave that there before I start sounding like David Brent, but it's a methodology that has served me well.



Needless to say, it wasn't all plain sailing. I doubt I'm in the minority when I say I hate hospitals. On every sensory level they are horrible, so when the appointment letters started to arrive, it's fair to say my bravery for the fight was severely tested. You quickly get to recognise the letters and you don't ever get over that sinking feeling when you pick them up off the door mat. Some days I could receive three different letters inviting me for various procedures: CT, MRI, ultrasound, with/without contrast, with/without fluids, and then finally TURBT – the surgical removal of a tumour.

Up to this point, I'd gone through life never having had serious ailments so the thought of general anaesthesia petrified me. I needn't have worried, I had a great team looking after me and the whole scenario is one of the most serene things I have experienced. Waking

up to find a mass of tubing hanging out of me was less so... Overnights in hospital became the norm, and along with weekly BCG instillations, this thing was taking over my life. In fact, for a while I think it became my life. This is where I decided I needed a goal to focus on, something away from my battle, to channel my energy.

### Looking for a win/win situation

I'd made the decision early on that I was going to be open about my illness among family and friends. I wasn't looking for sympathy; I didn't want sympathy. With every person I told I added the line, 'This hasn't changed who I am, I'm still me. Please don't treat me any differently to how you always have'. What I did want was for people to be aware of the disease. I'd never heard of bladder cancer before my diagnosis, I didn't even know

of its existence, let alone its prevalence. Luckily I came across Fight Bladder Cancer early on and the info on their website, along with advice from the support group, was invaluable to me. I wanted people to know about this, to know the symptoms, and know that if they were affected to seek medical help.

This is where the streams crossed. If I could have a target and raise awareness at the same time it was a win/win situation. This is where 'Team Rocky' was born. Back in 2012, I had helped out as support for a group of friends tackling a John O'Groats to Lands End cycle ride. In the pub on the last night I announced I was going to attempt my own challenge of cycling coast to coast. For three and a half years I got no closer to planning it until everything fell into place: ride coast to coast in aid of the Fight Bladder Cancer charity, raising

awareness and hopefully funds along the way. The guys I had supported on JoGLE all said they wanted to help and the team was formed. I planned the route to go from Morecambe to Scarborough, 160 miles (260km) over three days. The traditional route goes to Bridlington, but my parents live in Scarborough so I wanted to give it the personal touch.

The furthest I had ridden before this was 22 miles (35km) – once – plus a few 5-mile (8-km) jaunts on a bike I'd been inspired to buy post JoGLE, so I wasn't a cyclist (you could argue I'm still not!). I was just an armchair sports fan. Bradley Wiggins is my sporting hero but I'd never had the drive or determination to get off the sofa and on the saddle out into the rain. This had to change if I was to achieve my goal. I also had to work out how to balance training for the event with my treatment. BCG made

me feel really awful, and each instillation seemed to make me feel worse than the previous one. The last thing I felt like I wanted to do after treatment was get on a bike!

Determination kicked in, though, and as the sun rose on the first Friday in July, we were in Morecambe ready to start the long ride. The story of the ride would need another chapter, but suffice to say on the Sunday afternoon we rolled along Scarborough foreshore and into the Spa to finish the route.

I was met by my wife and my daughter (my son had helped out a lot along the way in the support van) and I experienced a feeling I will never be able to put into words. My emotions throughout the ride had been all over the place: I cried, I laughed, I ached, I suffered. But knowing the team of family and friends I had supporting me, I never doubted I'd get to the finish.

**What I do know is that if and when it returns, I will fight just as hard next time (and the next time and the next time).**

### Now I'm choosing my next challenge

The thing with goals is once you've achieved them you need to replace them in order to stay motivated. I've recently ridden RideLondon 46 but now I want to do the 100 miler (160km). I want to climb the mountains of the Tour de France – though I think I'll start with the Buttertubs in Yorkshire.

I'm keeping appointments at the hospital and thankfully my last scan came back all clear. My cancer was high grade, though, so I'm under no illusion that I have beaten it. What I do know is that if and when it returns, I will fight just as hard next time (and the next time and the next time).





# Beware of talking to Andrew Winterbottom ... it may lead you to jump out of a plane!

I have known Andrew for many years and have watched the Fight Bladder Cancer charity grow enormously in this time. I joined the confidential Facebook forum some time ago, although I rarely comment unless I'm asked to or I think it needs a medical answer. It was on the Facebook page that I saw lots of support about previous sky dives and jokingly mentioned to Andrew that maybe I should do it one year. Then I thought no more of it – not least because I am terrified of heights.

Then my 50th birthday loomed. I was arranging lots of different activities and decided if I was going to do it, now was the time. I challenged myself to get up there and just do it.

## Spreading the word

Andrew was obviously the guy to help me get the ball rolling, so I made the first of many phone calls (many, many phone calls – he must have been sick and tired of my messages before the dive actually happened). He arranged for posters and sponsor forms.

I also had a charity box for ad hoc donations and set up a JustGiving page. I was fortunate to have the support from colleagues and some of my patients, but what really worked well was making it an event on Facebook. This allowed me to easily tag in all my friends (my Facebook posts didn't always get to everyone) so it sparked a lot of interest. I was pleased with the total we raised.

## A little bird told me

Andrew also put out notices on Twitter. I advertised my dive in the hospital's internal magazine and also thought about the local press – worth thinking about for your campaign. I could probably have made more of the fact



If you are scared of heights, perhaps the first fundraising stunt you undertake should not be a sky dive – or perhaps it should!

ARTICLE  
ANN MOORE,  
CNS Warwick Hospital  
& FBC Confidential  
Forum Advisor



I was the first ... but not the last ... nurse to jump on behalf of FBC. I didn't realise at the time, but I was also jumping with the first bladderless patient as well. Anything that makes an event unique and interesting will make it more likely that you will get media coverage.

## Am I really doing this?

To be honest, I was in denial about the dive for a long time. But eventually, the big day arrived!

I was beyond terrified and started asking scarcely relevant questions! What should I wear? Andrew advised me they insist on clothes! But he recommended something comfortable and to wear trainers.

When we arrived at the take-off site, it was overcast and raining. There was a high probability that the dive would be cancelled – some morning divers had already gone home. Having dreaded the approaching dive, the disappointment that I might not dive was awful. I couldn't go through this again. But suddenly, before I knew it, the weather improved and I was registered, had the safety talk, was strapped in a harness and walking to a plane. It was so quick and professional, you had no time to think about it, which was a big plus.

## I'm flying!

You really can't describe what it's like – you have to be there! My buddy was amazing; he chatted away to me as though it was something to do every day (which, of course, he did!), making me feel a little calmer. He was obviously very experienced and clearly enjoyed his job. The plane seats 12 and you sit on a bench between the instructor's legs (so be prepared to get up close and personal). During the ascent, which took about 15 minutes, he was constantly adjusting the harness and telling me about the dive and what to expect ... all very chatty and friendly. Suddenly you realise the instructors are getting serious as the helmets go on, your goggles go on, the harnesses are adjusted and he gives you final instructions on how to position yourself. The light on the plane turns red ... amber ... green ... then your feet are out of the plane, you are leaning into your instructor and ... you are flying!

OMG its cold. The air rushes into you and it's hard to breathe; I was conscious of taking short breaths. The instructor had told me to scream if this panicked me because if I was screaming I was breathing! The trouble was I was conscious of the video man signalling us to put our thumbs up. I don't think I managed it. I couldn't

concentrate: I was plummeting to earth, it was so cold and so noisy!

Suddenly you go hurtling back up as the instructor pulls the cord to release the parachute. That was a really weird feeling. Then silence ... and the most incredible sensation that is hard to describe. You have no idea of having a buddy behind you. It is as if you are floating.

## Cloud walking

The instructor then decided we should jump onto the clouds, quickly altered the harness and – swish – away we went over the clouds, then we descended into a rainbow circle. He showed me the villages around. 'Welcome to my office,' he said. What a wonderful office to have. He offered to loosen the harness but I said was happy with being strapped in tight. He loosened it anyway and then I had no sensation of being in a harness at all and was truly floating gently to earth. Surprisingly enough, I was not scared. It was just too beautiful.

It's hard to put the emotions into words but the closest I can come to it is proud. 'I have just jumped out of a plane,' I said.

## A smooth landing

As we got nearer the ground, we ran through our landing instructions once more. As I looked down, I could begin to identify people on the ground and I think this is when my brain registered how high I was. Suddenly I felt quite sick. But no sooner had I begun to feel the fear, than it passed. The landing was so easy: the instructor put his feet down first, then I followed, so no strain on my back (one of my biggest worries). And (once I had done a quick inventory to make sure all my limbs were still there) I felt so relieved, excited, exhilarated, emotional.

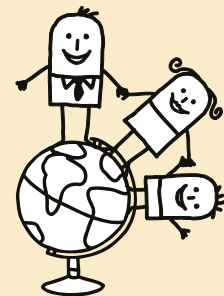
It's hard to put the emotions into words but the closest I can come to it is proud. 'I have just jumped out of a plane,' I said. And I said that many times over the coming days. I was so grateful to Andrew and FBC for giving me the opportunity to do it, and I know many more will.

## DON'T FORGET GIFT AID

If you are raising funds, it's good to do it so that you can claim Gift Aid.



# Fundraising catch up



You will have read the stories from Rich King about his epic coast-to-coast bike ride and Ann Moore's brave parachute jump on the previous pages but we'd also like to mention just a selection of the many, many others who have recently put themselves out to support our cause. We'd all like to say a massive THANK YOU!



**Tash Steer-Frost** who ran over 140 miles in 27 days in July (her target was 80!).

**Martin Cater** who cycled from London to Paris.

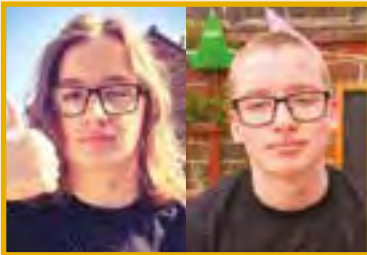


FBC Trustee **Kieron Stanger and Lucy King** who ran the Colour Rush in Windsor.

**The Shrewsbury young persons Community Team** for their 'Sweat' event in August of zumba, running, cycling and a host of other activities!

The **amazing McGee family** and their friends for all their fundraising for the research fund in memory of Clive.

**Emma and Charlotte** who took on the London to Surrey Prudential cycling challenge.



**Dillon Parkin** who bravely shaved off his beautiful long hair for us (let's hope he's got some hats for winter!).

**The Ashford Rotary Club** ramble in September.



**Terry Edmonds** who jumped out of a plane for us in August, our first 'bladderless' jumper!

**Eilis Dolan and Bessie** for their Duathlon to help support our dedicated Research Fund.

**Dr Alex and her colleagues** at the Royal Derby Hospital for their cake sale. (We like cake!)

The six great girls from **Mill Lane School in Chinnor** for their cake sale. (We REALLY like cake!).

**Robert White** for his sponsored head shave!



**Clive Broad** who ran the Glasgow 10k.

And finally to **Mandi Cracknell, Sue Southway, Ann McCullough and Deborah Major** who put on the Southern Soirée social event down in Bournemouth in October (plus all the people who came along) so that we could have a fabulous time and dance the night away whilst raising money!



At Fight Bladder Cancer we rely on our supporters from across the country giving donations and taking on, sometimes crazy, fundraising events. Without this 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.

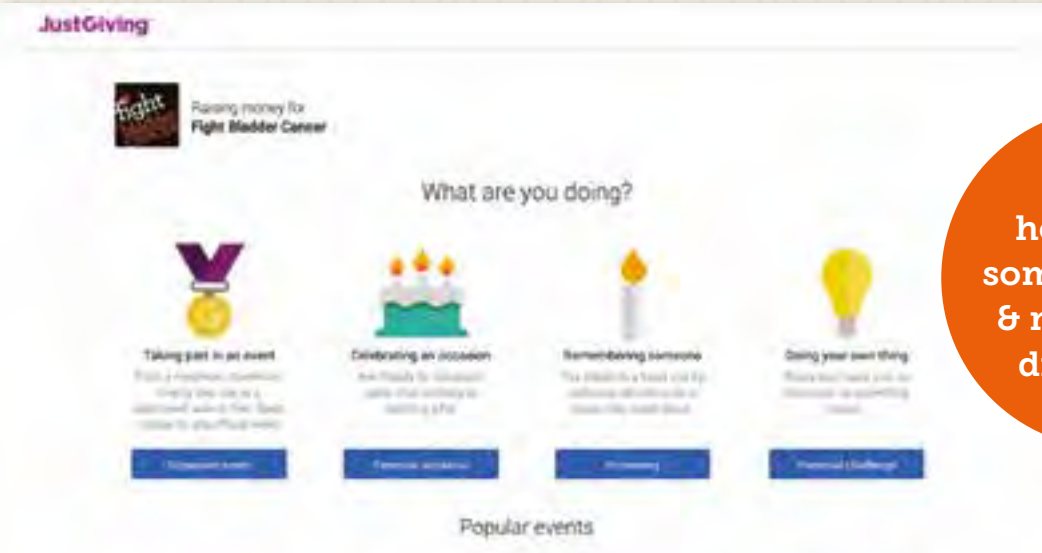
## How to set up a Just Giving page

Just Giving is our preferred online donation platform. It is slightly more expensive for the service than some of the other donation sites but their service is one of the best for us as a charity and reduces our workload for donations and claiming gift aid. And, being just patients and carers ourselves, anything that reduces our admin workload is very welcome!

Setting up a Just Giving fundraising page is very easy. Go to the Fight Bladder Cancer page on the Just Giving site by clicking this link. [www.justgiving.com/fightbladdercancer](http://www.justgiving.com/fightbladdercancer)

Here you can see other current fundraising events set up by our supporters. To set up your page just click on the **Fundraise for us** at the top right of the page.

This takes you to a page where you can choose the type of event you are organizing. Simply click on the link that best describes your event. Then complete the next section with your details and then click the **Create your page** box at the bottom. That's it! You're all done! Time to tell friends and family what you're doing and get support.



You can help us. Do something fun & make a real difference.

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)



# FBC's Report & Accounts

## – a brief summary

Every year, as a registered charity, we have to produce a detailed report and accounts for the Charity Commissioners. The full document will be ready for submission soon but we are happy to publish the highlights now that our accountants have finished doing the number crunching!

2015 – 2016 has been another significant year. Building on the success of the last year, we have been able to significantly increase our activities across all the objectives of the charity

Launch of 2 dedicated research funds

New FIGHT clubs and support of local support clubs run by hospitals themselves

Increased involvement in supporting clinical trials across the country

Launch of our new FIGHT magazine for the whole bladder cancer community which is sent free to UK hospitals and is a free download from our website

2,800+ followers on Twitter (including large medical following)

Increased usage of our Bladder Buddy Service which provides one-to-one peer support to patients and carers

Supported Bladder Cancer clinical trials & promoted campaigns to increase recruitment

Over 10,000 patient information and awareness leaflets sent free to hospital clinics

Our online confidential forum now supports over 2,600 people, 24 hours a day, 7 days a week





# Financial review

During the year the charity has received income of £174,257 from a combination of donations, sponsorship, grants and earned income from sales, including profit from the Wee Bookshop and Café. This has been a substantial increase from the previous year when we had a total income of £54,160.

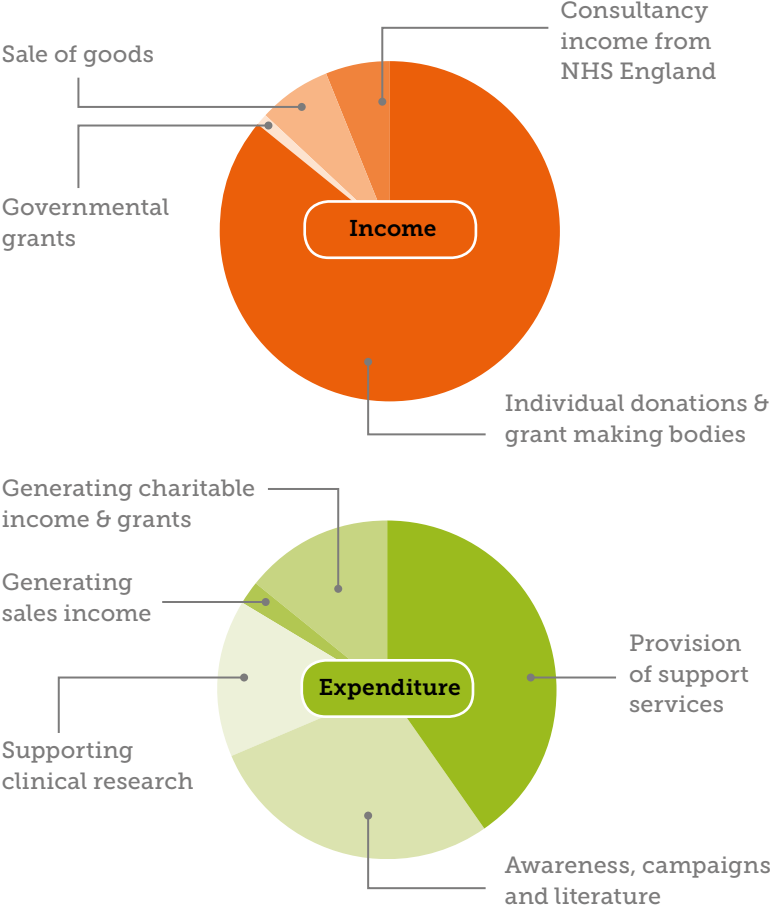
This income has allowed us to extend all our activities across the core objectives of the charity, update our website to provide what we believe is the most comprehensive bladder cancer information and support portal there is globally and to launch our new FIGHT magazine to promote a robust and honest conversation between patients, clinicians, specialist nurses and researchers about bladder cancer.

Included in the income is the first stage of a capital grant of £35,000 that is being provided to help fund the building works and fit out costs of the enlarged Wee Bookshop and Café. It is anticipated that the balance of this grant will be received during 2016/2017.

Total expenditure for the year was £65,584. During the reporting period the charity had one paid full time employee at a cost of £14,250 for the year.

The following diagrams indicate the breakdown of the charity income and expenditure during the year.

Figures for 2015/2016



Just keep on doing what you are doing, it provides a source of information and support that is lacking anywhere else.

I LOVE this group! There are such caring members who are ready to support and lift up any time of the day or night. They answer questions, give advice, and seem to offer humour at the moment it is needed most. I consider them as friends even though I have never met them. I will meet them some day, though, because I have set a goal to cross the pond and meet everyone.

I could never have gotten through this without the group. You are a gift from God.

Since I was unable to find a support group here in the USA, I was very grateful when I found FBC. I found incredible information and an amazingly supportive group of people who even helped me through the sudden death of my husband. I cannot imagine how awful my cancer journey and my life would be without these dear friends.

I honestly couldn't have got through this without the support and knowledge I have found on this page.

Just a simple thank you to all who set up FBC.

Website and forum literally assisted with making my treatment decisions. Meant everything to me.

Wouldn't be where I am today without Fight Bladder Cancer.

Just a huge thank you, it's so good not to feel alone.

Without FBC I would have been completely in the dark about bladder cancer, the information I received from my medical team has been useless.

# FBC Appreciation & Impact Survey

To ensure we keep improving what we do, FBC carries out regular impact reviews.



**FBC Website**

100% said they would recommend the site.

97% said it provided good-quality information.

97% said that it helped them gain more knowledge.

82% said it helped them gain confidence.

**FBC Forum**

100% said they would recommend joining to someone recently diagnosed.

88% said it provided support to cope with diagnosis and treatment.

86% said it helped them feel less alone with diagnosis and treatment.



# Will you or won't you?

Each year in the UK about £2billion is given to charities in the form of legacies. This money is spread amongst about 3,300 organisations. On average there were three charitable bequests per Will, although overall, only 7% of people die with a gift to charity in their Will.

In a recent survey, 74% of the UK population support charities financially in one form or another and, when asked, 35% of people said they would happily leave a gift in their Will once family and friends had been provided for. If we all put that into practice and left some money

in our Wills to charity – as well as our family – we could make a huge difference. In fact, just a 4% change in behaviour would generate an additional £1 billion for good causes in the UK every year.

And it is important to note that even the smallest contribution is of value. We don't have to be rich and famous to make a contribution that can make a difference. We can all do something amazing for the world by remembering our favourite cause when making a Will.

HELP!  
I'd like to leave some money to the charity in my will. How do I go about doing this?

## What should I consider when making a Will?

Obviously you will specify who will be your beneficiaries. You can also make provision for the age at which young beneficiaries receive their gift or share of your estate, as well as providing for beneficiaries with particular needs, means-tested health provisions or care provisions.

You may choose to use your Will to pass on business interests: for instance you could leave shares in a family company to a son or daughter who has come into the business. This is a very tax-efficient way to leave your assets to your intended beneficiaries. You can also specify family and friends who you wish to pass on personal items to. You might also want to consider passing on your digital assets when making a Will, such as online bank accounts and digital music collections.

## More than just your assets

But making a Will isn't solely about passing on your assets. There are other areas you can consider, such as organ donorship and funeral arrangements – whether you prefer burial, cremation or the use of your body for medical research. You may want to appoint legal guardians to care for your children if you and your partner should die before the children are 18.

## Executors

Another important consideration when making a Will is the appointment of your Executors – the people who will deal with your estate in the event of your death. Ideally, these should be business-minded family or friends, or could be professional advisors. If you want to appoint a professional advisor as an executor, make sure you find out their charges first.

## Charitable gifts

After you've looked after your family and friends, you may wish to leave a gift to a charitable cause that is close to your heart. Legacies from supporters make up an important income stream for many charities. If you do want to leave a charitable gift when making a Will, the donation can be as small or large as you like.

**It is important to review your Will regularly – at least once every five years. After all, life never stands still.**

## How should I go about making a Will?

Thankfully it is easy and inexpensive to have a Will drafted by a properly qualified professional. You should check that the professional you choose:

- has been trained and is qualified in making Wills;
- has undertaken ongoing training in making Wills;
- has professional indemnity insurance of at least £2million;
- is a member of an organisation that has an independent complaints procedure.

Solicitors who are members of the Society of Trust and Estate Practitioners and Will writers who are members of the Institute of Professional Will Writers meet these requirements.

## What about homemade / online Wills?

While it is possible to draw up your own Will, Wills can be complex and some mistakes can render the Will invalid. If this happens, long and expensive court cases to resolve matters may result. In addition, you may omit important details such as what should happen if the main beneficiary does not survive.

Increasingly it is possible to get your Will written online, but you should remember that a Will is an individual, personal document, that is tailored to suit your particular needs and it may be difficult for an online system to cater for this. In addition, questions need to be clearly understood before being answered. For example, if you were asked 'how many children do you have?', you must include all children, including any from a previous relationship who may not live with you.

## What happens if my circumstances change?

You can easily change your Will at any time. In fact, it is important to review your Will regularly – at least once every five years. After all, life never stands still. Your family circumstances may change, as may the relevant taxation laws.

## Getting started

Before seeing a professional adviser, it is worth considering the following points.

### 1 What do I have to leave?

The entirety of what you own is known as your estate. If you own your own home, how much is it worth? Have you any other savings, shares or other investments? What about valuables such as jewellery? Remember to take into account any debts and liabilities you may have.



**2 How do I want my estate to be distributed?**  
Your Will is your chance to take care of everything that's important to you, so you need to consider how you want your estate to be distributed. Your family and friends always come first. Make a list of their full names and addresses for your professional adviser.

**3 Who has made a difference to my life?**  
Has a charity helped you or somebody you love? Which causes are important to you? Which appeals have really moved you? If you know them, make a note of their official charity name, address and registered charity number to give to your professional adviser.

**4 Executors and guardians**  
Write down the full names and addresses of those you would like to be executors of your Will and guardians for your children (if appropriate). Talk to them and make sure they are happy to take on the role.

**5 Storage**  
Once your Will is written, most professional advisers will offer to store it for you so that the Will is not lost, but it may also be worth considering storing your Will with the HMCS (Her Majesty's Court Service). You can also register the location of your Will with one of a number of commercial organisations that operate Will registration schemes.

**6 Communicate your wishes**  
Talking about death is one of the last great taboos, but it helps to break that down by raising it yourself. You should tell your family and friends what you would like to happen, including practical issues like where your Will is stored, the name of your solicitor and the numbers of your bank accounts, and so on.

WILL JARGON BUSTER

- When it comes to making a Will, you might come across some terms you haven't heard before. Here are the explanations for some of the most common terms used in Will making.**
- beneficiary** The person or organisation to whom you leave something in your Will.
- bequest** A gift that you leave to a person or organisation in your Will. There are quite a lot of different types of bequest.
- codicil** A document used to change a Will that has already been made.
- estate** The sum total of your personal possessions, property and money minus any liabilities.
- executor** This is the person or people you appoint to ensure your final wishes are carried out. These can be professionals, friends, family members or institutions such as banks and some charities.
- guardian** Someone who is responsible for children until they become 18.
- inheritance tax** The tax paid on the portion of your estate that is above the nil-rate band.
- intestate** Someone who has died without making a Will.
- legacy** Another word for a gift or bequest left in your Will.
- probate** When somebody dies leaving a Will, their executors will usually need to apply for a grant of probate. Once this is obtained, the executors can deal with the wishes expressed in the Will and distribute the gifts that have been left.
- residue** What is left of your estate after any outstanding debts, taxes, pecuniary and specific bequests have been distributed to beneficiaries.
- testator** The person who has made a Will.
- trustee** One or more people who manage a Trust.

How to leave a gift in your Will to Fight Bladder Cancer

It's easy to remember Fight Bladder Cancer in your Will. If you have any questions at all, we are on hand to help you through the process.

- Step 1**  
Once you have cared for your family and friends, decide if you would like to include a gift to FBC (or another charity) in your Will.
- Step 2**  
Decide what type of gift you'd like to leave. Some people leave a specific amount or item, but many people choose a share of their estate, as this type of gift won't lose its value over time.
- Step 3**  
Visit a solicitor to have your Will drawn up, and ask them to include the people and charities you'd like to remember.
- Step 4**  
Please let us know if you've remembered Fight Bladder Cancer in your Will – we would love to thank you properly. Contact us via our website at [www.fightbladdercancer.co.uk](http://www.fightbladdercancer.co.uk).

Thank you.

FBC glossary & acronyms

- BAUN** British Association of Urological Nurses
- BAUS** British Association of Urological Surgeons
- BCQS** Bladder Cancer Quality Standards
- CCG** Clinical Commissioning Group
- CNS** clinical nurse specialist
- CT** computerised axial tomography
- DNA** deoxyribonucleic acid
- EBRT** external beam radiotherapy
- ECPC** European Cancer Patients Coalition
- ER** enhanced recovery
- FBC** Fight Bladder Cancer
- GI** gastrointestinal
- HCP** health care professional
- HNA** Holistic Needs Assessment
- ITU** intensive therapy unit
- KW** key worker
- MDT** multi-disciplinary team
- MIBC** muscle-invasive bladder cancer
- MRI** magnetic resonance imaging
- NCRAS** National Cancer Registration and Analysis Service
- NICE** National Institute of Health and Care Excellence
- PALS** Patient Advice and Liaison Service
- PFS** progression-free survival
- PHR** patient-held record
- PROMs** patient-reported outcome measures
- RCTs** randomised control trials
- TURBT** transurethral resection of bladder cancer: a surgical removal of a tumour

- adjuvant** after initial treatment to prevent secondary tumours
- Atezolizumab** a chemotherapy drug
- basal** relating to the base
- baseline** starting point for comparison
- biomarker** something by which the disease can be identified
- Cabazitaxel** a chemotherapy drug
- checkpoint inhibitors** drugs that prevent cancer cells from disabling protective T-cells
- chemoradiation** combination treatment of drugs and x-rays
- chemotherapy** treatment with drugs
- Cisplatin** a chemotherapy drug
- cystoscopy** a procedure to examine the inside of the bladder
- durable response rate** the length of time a response is observed
- dysuria** painful or frequent urination
- expressed** active
- fMRI** functional MRI
- Gemcitabine** a chemotherapy drug
- haematuria** blood in the urine
- histology** the microscopic examination of cells
- histopathological** microscopic examination of tissue to identify disease
- immune component** part of the immune system
- inhibitory pathway** a situation in which defensive cells are preventing from attacking foreign cells
- intolerable toxicity** the point at which the treatment becomes more painful than the disease
- lines [of treatment]** treatment regimens
- luminal** relating to the hollow inside an organ such as the bladder
- metastatic** a cancer that has spread to an unrelated organ
- Mitomycin C** a chemotherapy drug
- MPDL3280A** a chemotherapy drug
- muscle-invasive bladder cancer** cancer that has spread from the lining to the muscles of the bladder
- neoadjuvant chemotherapy** chemotherapy given before surgery
- neoantigens** newly formed cells that are not recognised by the immune system
- neopeptides** newly formed cells
- Nintedanib** a chemotherapy drug
- PDL-1 inhibitor** an antibody that helps T-cells recognise cancer cells
- PET** positron emission tomography
- primary endpoint** answers to the primary questions posed by the trial
- refractory** resistant
- resection** surgical removal
- SGI-110** a chemotherapy drug
- 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
- transitional cell cancer** cancer of the kidneys and ureter
- tumour microenvironment** the cellular environment in which the tumour exists
- urothelial** of the urinary tract
- visceral** of the nervous system



# 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.**

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.

### How clinical trials work

Clinical trials are carried out in phases, usually phases 1 to 3 although occasionally there is an earlier phase 0 or a later phase 4. These phases cover issues from what side-effects a drug might cause to testing whether a new drug is better than an existing treatment.

#### PHASE 1

After a treatment has been tested in the laboratory, a phase 1 trial would be set up to look at things like: the safe dose of a drug, the side-effects and how the body copes with the drug, and whether the drug will affect the cancer. This testing has to be done first before moving to the next phase of the trial, which tests the effectiveness of the drug in treating the cancer.

Phase 1 trials can take a long time to complete even though a small number of patients are involved. The trial will work with small groups of patients, increasing the dose of the drug slightly with each group, as long as the results go well; this is called a dose escalation study. The results of these studies will indicate the best dose for this particular drug. Patients in a phase 1 trial may or may not benefit from the new treatment.

#### PHASE 2

A phase 2 trial would compare an existing treatment with the new treatment or with a placebo. It will move into a phase 3 trial if the treatment proves to be as good as or better than an existing treatment. Some phase 2 trials might be randomised trials, where participants are put into groups at random. One group receives the new treatment, while another receives the current, standard treatment (that is, the best treatment which is currently available). If there is no standard treatment, the control group may be given a placebo. Phase 2 trials will look at whether the treatment works well enough to go to a larger, phase 3, trial.

#### PHASE 3

These trials will compare the new treatment with the existing standard treatment or compare a standard treatment in a new way or in different doses. These trials are usually much larger than phases 1 or 2 and might involve thousands of patients in hospitals across the UK and even abroad. Success rates or percentage changes may be small, so a much larger trial group is needed to show these differences accurately. Most phase 3 trials are randomised trials.

## 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/>

### 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

#### 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.

### MRI SCANS and PET-CT SCANS

MRI scans are important scans for doctors wanting to look at cancer. Researchers in this study have developed some new ways of looking at tumours using a type of MRI scan called a functional MRI scan (fMRI). They believe that fMRI may be better at showing how well cancer treatment is working early on. They now want to see how reliable these scans are when looking at bladder cancer.

The study is also looking at how well a new type of PET-CT scan can show up bladder cancer and give them more information about it.

#### NEOBLADE

Neoblade is a study of neoadjuvant chemotherapy for patients with bladder cancer which has grown into the muscle but not to elsewhere in the body. These patients will ultimately go on to have either



a cystectomy or chemoradiation treatment, and the neoadjuvant chemotherapy is given prior to either of these. The usual treatment is to start with two drugs as upfront chemotherapy and NEOBLADE is looking at adding another drug called Nintedanib to see if this makes the treatment work better.

**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**

**CAB B1**

This trial is looking at a chemotherapy drug called Cabazitaxel. It is for people who have transitional cell bladder cancer or cancer of the urinary system that has spread into surrounding tissue or another part of the body despite chemotherapy. The aim of the trial is to see if Cabazitaxel helps people with transitional cell cancer that has spread and has got worse despite having platinum chemotherapy.

**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.

**Locally advanced and metastatic bladder cancer**

**PLUMMB**

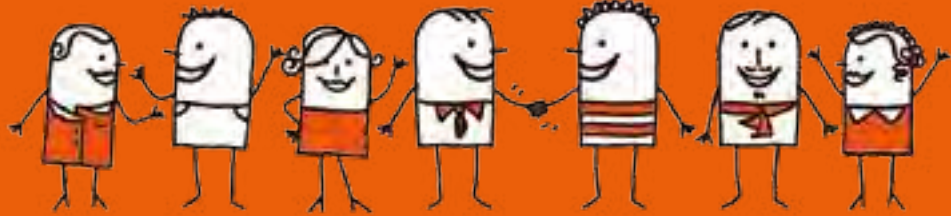
PLUMMB is a phase I trial to investigate the safety, tolerability and effectiveness of an immunotherapy drug called Pembrolizumab used in combination with radiotherapy. The study will also investigate two different doses of Pembrolizumab, starting at 100mg and increasing to 200mg for the next cohort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

Help us Fight Bladder Cancer!



- Make a donation
- Fundraise
- Become a bladder buddy
- Volunteer
- Run awareness events
- Distribute support materials
- Start a support group
- Fund research
- Join a clinical trial

Every time you work with us, from giving a simple donation to helping distribute our posters and patient information booklets, you are helping make a big difference to all those living with and affected by bladder cancer.

Whether you are a medical professional or someone directly affected by a bladder cancer diagnosis, your help is invaluable. Working together we can make big changes and stop people dying of this disease.

Email [info@fightbladdercancer.co.uk](mailto:info@fightbladdercancer.co.uk) to find out more.





# 10,000 PEOPLE 1 FIGHT

Each year,  
10,000 people are diagnosed  
with bladder cancer in the UK.

We salute the vital work of Fight Bladder Cancer  
on behalf of patients and their families.

