

# 05

# fight

## MAGAZINE

### RESULTS ARE IN!

DISCOVER THE RESULTS OF OUR  
SURVEY ON THE EXPERIENCE  
OF BLADDER CANCER  
PATIENTS WORLDWIDE

### CNS SHORTAGE

WHERE HAVE ALL  
THE SPECIALIST  
NURSES GONE?

### SURVIVORS

TREATMENTS  
THAT OFFER  
A NEW LEASE  
OF LIFE

### QUIT NOW!

6 WAYS TO REDUCE  
YOUR RISK OF  
BLADDER CANCER

WE PUBLISH  
OUR MANIFESTO  
& GET SET FOR  
BLADDER CANCER  
AWARENESS  
MONTH IN  
MAY

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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.*

# Join with us

to turn the spotlight on bladder cancer & promote improvements in prevention, diagnosis, treatments, quality of life & survival

Welcome to this special edition of our *Fight* magazine. If all has gone to plan, you will be reading this edition of *Fight* as we see the start of our work for this year's Bladder Cancer Awareness Month in May. And the month will see our most extensive campaign ever to turn the spotlight on bladder cancer and the issues that matter to the patient community, to the general public, the medical profession and to the national funding bodies.

Bladder cancer has spent too much time being hidden and we will not rest until this has changed so that we can achieve the much-needed improvements in prevention, early diagnosis, treatments, quality of life and survivorship.

Our plans for the Awareness Month include ways in which everyone can get involved to grow the campaign, to grow the patient voice. Much of the improvement in cancer care – in areas such as breast and prostate cancer – have come about because of the strength of the patient voice and we are determined to create a movement for people affected by bladder cancer, or working within the field, that will raise this voice and achieve the change we need.

**It's time for us to fight for bladder cancer. Join us.**

Also in this edition are some ground-breaking articles, including the first results from the global bladder cancer patients' experience survey that we have been running in conjunction with the European Cancer Patients Coalition. It has been developed with bladder cancer advocacy groups from across Europe and North America and its findings are significant in that they support our belief that bladder cancer really is the Cinderella cancer, with serious problems and poor patient experiences.

Building on previous work by Fight Bladder Cancer, we have used this data to help us define our Manifesto for Bladder Cancer, which is the main feature of this edition and sits alongside the other articles that illuminate the many challenges on the road ahead.

Finally, this edition is special in another way, as we will be doubling our print run so that we can get these important messages out to many, many more people.

Please do read about our plans and join in with our work where you can. Together we can make a difference.

Team FBC

## LET'S MAKE OUR VOICES HEARD

The leading articles in this edition outline our Manifesto for Bladder Cancer and look at what we need to do to raise the status of bladder cancer and improve the patient experience.

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](https://www.facebook.com/FightBladderCancer)



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



**bladder  
CANCER**

Registered charity 1157763



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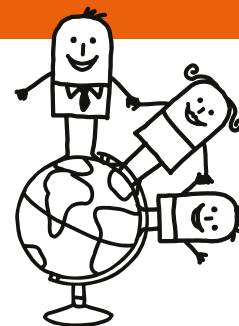
A directory of current open bladder cancer trials across the UK

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# FBC round up



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

## SUPPORT

### NEW FIGHT CLUBS

Following on from our last announcements about the growth of our local Fight clubs, we are very happy to announce that we now have confirmed plans for clubs opening up in these new locations in the next few months.

- Bedfordshire
- Hampshire
- Northamptonshire
- Hertfordshire
- Sheffield
- Liverpool
- London
- Manchester
- Birmingham
- Buckinghamshire
- Oxfordshire
- Eastbourne

If you want to know more about the plans for these Fight clubs, email [support@fightbladdercancer.co.uk](mailto:support@fightbladdercancer.co.uk) for more information.

We aim to establish Fight clubs across the whole of the UK, so if you want to see one set up locally to you and you are happy to help, drop us an email and we will work with you to make it happen!



## AWARENESS

### MAY – OUR BIG AWARENESS MONTH CAMPAIGN!



The big news, of course, is our Awareness Month campaign in May. Working with our friends at ECPC, we have designed a campaign that will be the biggest we have ever seen for bladder cancer and will run across Europe, Australia and into North America as well as in the UK.

For more details of all the activities and events for our Awareness Month in May, see the article on page 16.



If you have any contacts with local or national media who might help us spread the word, email:

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

### BECOME A BLADDER BUDDY

With the growth of FBC we are now looking to recruit more people to join us as Bladder Buddies across the country. Bladder Buddies are either patients or carers who are happy to be put in touch with someone who has recently been affected by bladder cancer or just simply needs someone to talk to. This isn't about giving medical advice but, having experienced it yourself, being happy to lend a listening ear and be someone to talk to. We all know how a bladder cancer diagnosis can make you feel very alone, and having a Bladder Buddy can make all the difference.



To find more about being a Bladder Buddy, please email us at [BladderBuddies@fightbladdercancer.co.uk](mailto:BladderBuddies@fightbladdercancer.co.uk) and we will send you an information pack about the application process and how we would support you in the role.

## WORLD BLADDER CANCER PATIENTS' COALITION

The plans for the formation of this international umbrella are gathering pace and we have now appointed a Brussels-based agency to manage the process of its legal formation as a non-profit organisation and to help us project manage the required activities for our launch.

This initiative between Fight Bladder Cancer, Bladder Cancer Canada and BCAN in the US, is now reaching out to all the other bladder cancer patient advocacy groups that we know exist, to join us in this important growth of the bladder cancer patient voice.

So far, we have interest from as far afield as Australia and from groups in France, Germany and across the whole of Europe. If you are part of a patient group, do get in touch to find out more. Email [support@fightbladdercancer.co.uk](mailto:support@fightbladdercancer.co.uk).



### FBC AT THE EAU

We were very pleased to be asked by the European Association of Urology to present a keynote speech to nearly 14,000 delegates at their annual conference in Copenhagen in March. Alongside our friends from kidney and prostate patient organisations, we were able to talk to the delegates from the patient perspective and provide concrete suggestions on how they can make a difference to the patient experience.

With our friends from the ECPC, we followed this with a workshop where we talked about our Bladder Cancer Awareness events in May and worked on ideas that would enable countries across Europe to take part.

You will find a brief outline of the types of bladder cancer on the inside back cover

## RESEARCH & POLICY

### STUDIES & RESEARCH UPDATE

This edition of *Fight* contains a report (see page 20) on the early data we have from the Bladder Cancer Patient Experience Survey that we have been carrying out in conjunction with ECPC and other patient groups. The early data certainly highlights the common problems for all patients and establishes the areas where we need to direct our focus.

We are building a research team here at FBC and the first study of our own is our analysis of the current evidence on environmental causes of bladder cancer (see page 40). The study has been researched by our post-graduate medical student intern from Oxford University, Josie Elliott, who is supporting FBC alongside her university studies.

Leading another important piece of research is thoracic surgeon Jane Atkins, who is assisting us whilst on a career break from surgery. Jane is currently scoping a study for our 'My Diagnosis Counts' policy work, where she is looking into collecting robust data on the actual number of bladder cancer diagnoses there are each year in the UK. This work is essential as the basis of many of our policy initiatives as the authorities do not currently register all case of bladder cancer in the UK.

## Giving you support

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

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

### BLADDER BUDDIES

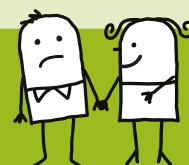
Not everyone is happy to talk and ask questions within our confidential forum, so we provide a nationwide Bladder Buddy service where we match people up on a one-to-one basis with someone who has been in the same situation or has had the same treatment. Someone to talk to privately, either on the phone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

### LOCAL SUPPORT GROUPS

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

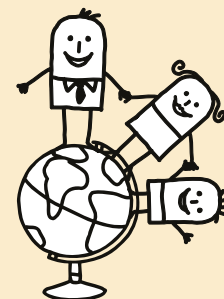
Find out  
more about  
how we can  
support you at

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





# Fundraising catch up



Personal donations and fundraising are the mainstays of the income here at Fight Bladder Cancer. We would not be able to do what we do to support people affected by bladder cancer – raise awareness, support research and campaign to get policy change at the highest level – without all your help.

You are all very special to us because there are not that many of you!

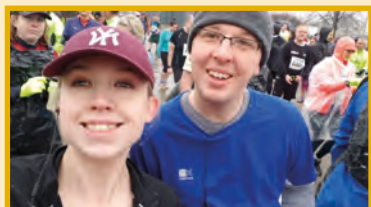
Bladder cancer is currently a cause that not many people know about so your support is vital until we build the awareness.



**Juliet Forsyth** ran the Edinburgh Half Marathon with her friends Martin, Susan and Dawn.



**Ivy Duffield** ran the Great North Run in memory of her father Alf.



**Zoe Tinline** and **Chris Porter** ran the Farnborough half marathon in 2 hours and 25 minutes in the rain and snow.



**Maria Welsh** bravely shaved her head.

Urology nurse **Shievon Smith** gave up alcohol for the whole of January.

**Ros Bruce** and **Lynne Sprysak** turned their birthday celebrations into Fight Bladder Cancer fundraisers. Thank you so much FBC birthday girls. Best wishes to you both.



**Paula** and **Brenda Michaels**, with the help of their family and friends, hosted a sell-out quiz night with a fish and chips supper for 170 people in aid of the charity.

## CINDERELLA CANCER

We have recently carried out some research with the Charity Commission and discovered that for every breast cancer patient in the UK, approximately £1,800 is donated to breast cancer charities. For prostate cancer the figure is just under £800. For bladder cancer, the latest figure is just £20 per patient diagnosed, because of its Cinderella status, with so little awareness about the disease there is a need to raise money to make the changes that are so vital for all patients.

So a HUGE thank you to you all out there who keep us going. Thank you for your continuing support and for helping us spread the word. As more people become aware of FBC and our work, this figure will grow and we will be able to do even more: support more patients, increase awareness, increase our support for research and become more impactful in shining the light on bladder cancer and getting the policy changes we need.

# 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 to get people together so that you can meet others affected by bladder cancer. These party nights are brilliant fun and a chance to meet up informally with people to share experiences.

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

## WHY WE NEED YOUR SUPPORT

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

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

## OUR FUNDRAISING PROMISE TO YOU

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

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

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



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



# THE FBC Manifesto for Bladder Cancer

Without a clear statement of objectives, progress is always going to be hampered, so one of FBC's major new initiatives is to begin the development of a fully integrated manifesto

Fight Bladder Cancer was founded by patients and carers, and their health and well-being is always at the centre of all we do. In the short time we have been around and developing our knowledge of bladder cancer, we have been struck by the lack of a co-ordinated agreement of what is important to patients and what needs to happen to create the improvements we both need and want.

As Roger Wilson argues in his article on page 35, it is essential that patients are involved at the core of cancer research projects. However, until recently, the lack of an organisation like Fight Bladder Cancer has meant that there has

been a huge void in discussions between patients, researchers and clinicians even about essentials, let alone what is desirable.

We are putting this document out for discussion with the whole bladder cancer community – to clinicians, specialist nurses, researchers, policy-makers, patients and carers – and asking for their responses. What have we missed? Where have we gone wrong? Help us refine these fundamental directions of travel that will enable us to achieve the essential improvements we have seen in other, better funded, cancers.

This is just the first step.

We know there will be changes, additions and refinements but without a 'starter for ten', the discussion cannot move ahead, so this is our statement to open the discussion. It is our top 10 lists of wants: the 10 top subjects that we want patients, carers and our professional colleagues to focus on over the next few years.

ARTICLE  
ANDREW  
WINTERBOTTOM  
FBC founder  
& director

This manifesto is our first co-ordinated statement of what we believe are the most important areas for action that will have the greatest impact for the patient and carer community.

We have a long way to go to get the quality of care that we deserve; a quality of care that can be given in other cancers but is missing from bladder cancer.



## Where do we start from?

Bladder cancer kills 14 people every day in the UK and the prognosis has hardly changed in the last 40 years.

At present we don't even know accurately how many people are given a bladder cancer diagnosis every year as not all cases are registered in the national cancer registration database. We believe that it is somewhere between the 10,000 being registered and the 17,000 estimated by a representative from Public Health England's Cancer Registration team recently at a bladder cancer working group meeting. At 17,000 this would make it the fifth most common cancer in the UK after breast, prostate, lung and bowel cancers. Certainly, bladder cancer is not a rare cancer.

Prognosis varies wildly depending on how early it is caught (between 80% and 10% survival averages between Stage 1 and Stage 4) and is worse for women than for men. More men get bladder cancer than women and it is still quite rare in the young. Why this is we don't really know.

There is also a hypothesis that, if we screened for bladder cancer in the same way that we do for breast, bowel and prostate cancer, the numbers would be even higher as it could be that there are many people who live with a bladder cancer that does not kill them but remains undiscovered.

What we do know is that bladder cancer has the highest recurrence rate of any cancer and is the most expensive for the NHS to treat on a per patient basis and this high recurrence rate continues because the existing treatments are just not adequately effective.

Research into the causes of bladder cancer and for new and better treatments is pitifully low, currently getting just 0.6% of cancer research spend in the UK. As a contrast,

leukemia gets 17% of research spend and affects a smaller number of patients.

We do know that there are holes in our knowledge about bladder cancer, many of which were identified in the development of the NICE guidelines in 2015, with many others being identified by patients as we travel on our journeys through the pathway.

## So, why is bladder cancer such a 'Cinderella' cancer?

The FBC/ECPC Patient Experience Study (see the report on page 20) has shown that the majority of people have never heard of this common cancer and that access to effective treatments is one of the biggest causes of concern. Historically, bladder cancer was known as the 'poor man's' or 'working man's' cancer. This came about because of the links found between certain industrial processes, working practices that didn't take heed of the risk of exposure to carcinogens, and from smoking.

Importantly, many of these causes have now been or are being taken out of the environment but we still do not know why it is that bladder cancer remains so common. Whilst we understand about the huge risks associated with smoking, the research into other causes is limited. Environmental factors are potentially an area where we need to look further, especially with regard to air pollution that the World Health Organisation has indicated could be a cause of bladder cancer. FBC has now produced a report on the current evidence on the environmental risks for bladder cancer (see the report on page 40).

As we write this article, we hear that the MASH actor, David Ogden Stiers, who played the character Major Charles Winchester, has died aged 75 following his battle with bladder

## Bladder cancer continues to struggle to get media attention that would help with our campaigns. Cancer in the media is dominated by a small number of cancers and all the others struggle to get a space in the spotlight.

cancer. He is probably the most famous person internationally who we have seen to have lost their lives to the cancer since the rise of social media, and this one announcement has generated more social media traffic about bladder cancer than any other news item ever. Bladder cancer continues to struggle to get media attention that would help with our campaigns. Cancer in the media is dominated by a small number of cancers and all the others struggle to get a space in the spotlight. The huge, and welcomed, improvements in prognosis and quality of life for those affected by breast or prostate cancer can be directly related to the strength of their campaigning voice in the public domain and with the national policy-makers.

We need to strengthen the orange voice for bladder cancer patients to aid us in our campaigning for improvements.

It has always been difficult for us to generate a list of celebrities who have been affected by bladder cancer, as there is this deadly silence about the subject. It can't be that celebrity status means that you are less likely to get bladder cancer, so why is it that we just simply do not hear of examples as we do with breast and prostate cancer? Is this silence something we can change?

## What is the current patient experience?

Every year the NHS carries out a cancer patients' experience survey. And in every year that it has been produced, bladder cancer has been at the bottom of the satisfaction table, indicating that something is wrong with how our patients are being looked after and treated. Of course, the lack of research and effective treatments must come into play with this, but it is across the whole experience that bladder cancer care seems not to be up to the standard of other cancers.

At FBC, we interact with thousands of patients each year and we know that the quality of care varies across the country and across the globe. From almost perfect early diagnosis, through good-quality information, support, treatment, after care and quality-of-life issues, we also see examples of delays, poor guidance, an almost total lack of support, and problems with access to the best treatment. We expect to see variations between countries due to different economic pressures, but the variations within a country are just not acceptable.

So while we may start from an improving landscape of care and treatment, we have a long way to go to get the quality of care that we deserve; a quality of care that can be given in other cancers but is missing from bladder cancer. This is why we need this manifesto: we need to turn the spotlight on bladder cancer. **And it is also why we are asking you to join us in this campaign that we are launching as part of this year's Bladder Cancer Awareness Month in May.**

# Our manifesto PLEDGES

One major problem is that bladder cancer is simply not on the radar. Most people understand very little about it, or the risks they face as they get older. There is also, unfortunately, a very real legacy of neglect to overcome within healthcare and research. Reliable tests for diagnosing bladder cancer at a GP level just don't exist and the general public does not know the symptoms. The many different potential symptoms need to be fully understood at a primary care level. Your GP will know about blood in your wee but how many know about the other symptoms?

Prevention is better than cure so we need to ensure that the general public understands the known causes and symptoms of bladder cancer. To achieve this, we need to work together to gain the required media coverage of bladder cancer in order that the general public understands this subject. We then have to identify the other causes to establish whether there are different ways of prevention by changes in lifestyle, work practices or environmental factors.

For breast cancer and prostate cancer, significant improvements in prognosis and quality of life have been achieved in the last 20 years and we know that a lot of this has been because of the strength of the patient voice. Pink power and Movember have made a substantial difference and we want the same for bladder cancer.

## Manifesto pledge 1

### GROWING THE PATIENT VOICE

**We will campaign for dedicated and robust awareness of this common and deadly cancer. This will include a call-out for celebrities affected by bladder cancer to 'come out' and join us in talking about the disease. Silence is deadly.**

But what do we want if we get the attention for bladder cancer that it deserves? Prevention is so crucial and is where we must start. There is great ignorance about the causes of bladder cancer and we still have restricted knowledge of all the causes. What do we know? About 30–50% of bladder cancers are due to smoking and then about 10% are due to industrial processes, such as exposure to specific chemicals and dyes. But for about half the cases, we just don't know why the patient has developed this cancer.

There is growing evidence of some environment factors (see article on page 40) but we need significant research to identify all the causes that can be removed from our lives. Imagine if we could take away 50% of all cases of bladder cancer every year; how much more significant than a new drug giving a 3–4% improvement.



## Manifesto pledge 2

### RESEARCH INTO THE CAUSES OF BLADDER CANCER

**We need investment to discover the causes of bladder cancer. Only then will we be able to prevent people getting it in the first place. This essential evidence will also help us identify those who are at risk and thus we will be able to be more accurate in the risk analysis of symptoms presenting at a GP level.**

Diagnosis is still fundamentally the same as it was in the 1890s, with the physician looking into the bladder with a cystoscope and using his naked eye to see if a tumour is present. Yes, we have recently seen techniques added – such as blue light or narrow band imaging – to improve how good this visual inspection can be, but a less invasive test still seems a long way away.

Whilst we stick to this method of deciding whether someone has bladder cancer, it will always mean that late diagnosis will be common. If, for a GP, the only route forward is for an expensive hospital admission, there will always be pressure to restrict referral unless the symptoms are unambiguous. We need an economical non-invasive test that can be used at a GP level for anyone who shows symptoms that could be a bladder cancer – regardless of age or gender.



We know that this is a false figure but it is the one that sits behind an enormous amount of decision-making as far as resources and profile. If the figure is really something like 17,000 a year, then it makes bladder cancer the fifth most common cancer in the UK. This wouldn't surprise us as the current records shows it as the fifth most common cancer in the Western world.

So we need to find the truth. How many people are diagnosed with bladder cancer every year? How many people do we need to treat every year and what resources of doctors, nurses and specialists do we really need? Surely this is fundamental in any decision-making?

## Manifesto pledge 3

### A NON-INVASIVE TEST FOR BLADDER CANCER

**We will campaign for and support research into the development of a non-invasive test for bladder cancer that can be used at a GP level and for the regular required check-ups following treatment, that reaches or better the accuracy of a cystoscope.**

As the same technique is used at all the check-ups that the patient has to endure for this cancer, this is probably one of the main reasons that there is such a huge cost per patient for the diagnosis, treatment and management of bladder cancer, exacerbated by the fact that it has one of the highest recurrence rates of any cancer.

Establishing a new diagnostic technique would allow us to reduce the cost of diagnosis and check-ups, remove the invasive nature of the current technique and improve on the speed of diagnosis, thereby improving prognosis for patients as well as their quality of life.

As we mentioned earlier, we don't actually record all cases of bladder cancer here in the UK. So, if you go onto the Cancer Research UK website you will see a figure of just over 10,000 people being diagnosed with bladder cancer in a year. But these are just the cases where it has been registered in the national registration databases.

## Manifesto pledge 4

### CLARITY ON THE BLADDER CANCER BURDEN

**We will work with the cancer registration services across the UK, the professional bodies and individual clinical teams to establish the most realistic figure for bladder cancer diagnosis in the UK per annum.**

The current clinical pathway for the diagnosis and management of bladder cancer was reviewed and set down by NICE in a guideline document issued in February 2015. This document identified what should be the pathway, based on the evidence that was available. The guideline group noted that there were significant gaps in our knowledge that meant that the pathway recommendations were not as robust as they should be.

However, three years later, the reports we get from patients and clinicians is that there are still variances in the reality of the patient pathway. In order to understand what the adherence to the guidelines actually is, we need a comprehensive audit of the patient experience.

In addition to adherence to the NICE guidelines, it is important that we identify those places where the clinical teams have developed systems and procedures that improve the bladder cancer patient experience. These exemplars of service should be showcased and shared so that we can improve the patient experience for all, no matter where you live.



### Manifesto pledge 5

## ELIMINATE THE INEQUALITIES OF THE PATIENT EXPERIENCE

**We will work with BAUN and BAUS to identify the adherence to the NICE guidelines and to identify and showcase exemplars of good practice.**

Essential to the delivery of the guidelines for bladder cancer is the resourcing of clinical nurse specialists (CNS) as identified key workers for every patient.

Unfortunately, the workload of the urology CNS appears to be much greater and the skills required more extensive than CNSs for any other discipline. This could be as a result of the non-registration of many of the patients diagnosed with bladder cancer or the lack of resources for the condition due to its Cinderella status with the funding bodies.

A urology CNS will, most often, have to cover the whole range of urology cancers that include prostate, bladder, testicular and penile cancers. With this wide brief, the urology CNS has a far greater workload than others and also requires a much wider skill set than that required for a singular cancer.

Whatever the cause, this situation must contribute to the fact that bladder cancer comes at the bottom of the NHS annual cancer patient experience survey. It certainly is a subject that comes up repeatedly within our support forums. Linked with the lack of structured support for many patients and the lack of signposting to FBC, bladder cancer is often a very lonely diagnosis.

### Manifesto pledge 6

## ADDRESS THE UNDER-RESOURCING OF CNSs

**We will campaign to strengthen the role of the bladder cancer CNS. This will include working with BAUN to develop specific training and resources for specialist nurses in this role and to campaign for adequate funding together with acceptance of the skills that the CNS can bring to the multi-disciplinary team and in supporting the patient.**

Research into new and better treatments for bladder cancer will always be an ongoing strategy for Fight Bladder Cancer. However, we believe that this should be targeted where it can have the greatest impact.

In our manifesto pledge 2, we called for more basic research into the causes of bladder cancer on the basis that prevention is where it should always start.

In this next pledge, we are calling for greater and

improved research for all parts of the treatment pathway but especially focused on two areas of an alternative to BCG for high-risk non-muscle-invasive bladder cancer and an RCT between surgery and chemo-radiotherapy for muscle-invasive bladder cancer.

These are the two areas where patients currently have the most concerns over treatment from a prognostic point of view.

### Manifesto pledge 7

## IMPACTFUL RESEARCH FOR PATIENT CHOICE

**Research needs to be targeted where it will have the most impact. It is essential that we find alternatives to BCG for the treatment of high-risk non-invasive bladder cancer and carry out research that establishes the situations where either bladder-sparing treatments or bladder removal should be chosen by patients for best prognosis and quality of life.**

Alongside the significant lack of research into new and better treatments for bladder cancer, the quality of life issues around treatment and survivorship for bladder cancer patients is a neglected subject. At most points in the current pathway, the clinical team can only offer limited advice to their patients, as there is simply no robust data about the reality of the patient experience.

Quality of life during and after treatments can be more important than extension of life. QoL information is always crucial to understand at any point in the bladder cancer pathway. Not only does this information prepare you for the reality of the treatment, it is essential to understand when there are treatment choices to be made.

We need to establish, in greater detail, the real world side-effects of bladder cancer treatments for patients of all ages, genders and with other common comorbidities. We then need to develop guidance for patients to manage or mitigate these side-effects and to ensure that this support is readily available for all.

With any research work, we need to improve the extent and the quality of the patient reported outcomes (PROs) by working to make sure that we capture the relevant data. To this end we need to work towards an improved suite of validated questionnaires specific for the different treatment points along the pathway.



## Manifesto pledge 8

### IMPROVE QUALITY OF LIFE DURING & AFTER TREATMENT

QoL data is as essential as treatment effectiveness so we will campaign that robust data should be collected throughout clinical trials and post trials in order to fully understand the real world side-effects. Alongside this, is the need to develop a bladder cancer specific set of validated questionnaires that have had significant patient advocacy group input.

In some ways, these final manifesto pledges are the most critical to gain the greatest impact for all bladder cancer patients in the shortest time. They are the 'low-hanging fruit' for bladder cancer that are currently often missing from the patient experience and, if acted upon, will see a great improvement at zero cost to the NHS.

Communication must be improved. From the earliest symptoms through diagnosis and on to treatment, the world for a bladder cancer patient is all about waiting. Unlike in many other cancer pathways, understanding the importance of speedy and accurate information is often lacking.

The time to a detailed diagnosis, the time to receiving a treatment plan, the time to treatment, the time to see if the treatment has been effective and the time to the next check-up is a continuous emotional rollercoaster as you wait and worry. And the worry increases when the timescales lengthen without reason or explanation. Bladder cancer is a lonely diagnosis, as we know with most people never hearing of the illness before diagnosis and then not being able to find support and information from others who have travelled this path before. We must tighten up on the waiting periods when possible as we know that time to definitive treatment is often much longer than it needs to be.

A clear and unambiguous timescale target should be identified for all the steps in the pathway and should be part of all guidelines for the treatment and management of bladder cancer.

This guideline time target should be provided to every patient alongside the treatment plan. We have to have both so that we can understand and plan our lives. And when a time period says something like six weeks, then we want to be told if that has to extend for any reason. We accept that problems do happen and some things might need to be moved but please make sure the patient is spoken to and things explained.

If you have been told that you will hear your results in two weeks and four weeks go by and you hear nothing, you worry. You worry a lot. A simple phone call, email or text explaining a delay will make all the difference if delays cannot be helped.

## Manifesto pledge 9

### COMMUNICATION

All bladder cancer guidelines have to be updated to include target timescales for all points on the treatment pathway. These targets are to be given to all patients alongside their treatment plans and clinical teams must set up procedures that proactively inform patients of any situations when these targets will not be met.

And finally, the easiest and most effective action we are calling on for implementation: signposting of patients to good-quality, patient friendly information and to support services provided locally and nationally.

At Fight Bladder Cancer we understand that the service provisions possible from a underfunded NHS will mean that the information, advice and support that the clinical teams can provide will be limited by resources available. This is why we exist. We are here to supplement what the healthcare services can do. As patients ourselves we can provide good-quality information that is reviewed by our expert medical advisory panel. We can also provide peer-to-peer support and guidance for all patients no matter where they live or what treatment they are going through. Our online confidential support forum runs 24/7 and is supplemented by our national one-to-one Bladder Buddy service, our local Fight clubs providing a place to meet and chat with other patients and carers, plus our telephone/email helpline service.

So our final pledge is simple.

## Manifesto pledge 10

### SIGNPOSTING TO FIGHT BLADDER CANCER

We will continue to work to build links with all clinical teams to explain our information and support services and to grow these services so that we can get to a stage when every patient knows that they can make contact with us to supplement the work of their medical teams. We will work to ensure that nobody feels alone with his or her bladder cancer.



# I'm forever blowing bubbles



## ARTICLE

MELANIE COSTIN  
FBC trustee & support  
services manager

In memory of the strong and special people who have lost their fight with bladder cancer, Melanie describes how it feels to watch the bubbles – equally beautiful and transient – float away and to experience the joy of being part of the FBC family

The FBC's Wee Bookshop & Café in Chinnor was literally bursting at the seams on the beautiful sunny day in May we had chosen for our first annual walk as part of our Bladder Cancer Awareness Month activities. This was an inaugural celebration of our worldwide Bubbles for Bladder Cancer Day.

As well as the many locals who had turned out to show their support, people were arriving from far afield to help raise awareness and to meet up with new and old friends. As we all gathered together, blowing up balloons and organising ourselves ready to walk around the village, what a great atmosphere there was – we even had a live brass band! I donned an FBC tabard, some yellow horns (as a nod to our friends at Bladder Cancer Canada with their yellow awareness ribbons), grabbed my camera and then we were off ... striding along, walking along, wobbling along, depending on the capabilities of each of us (I was more of a wobbler on this occasion).

## A growing phenomenon

Many of us carried our bubbles with us and blew them as we went along. We definitely made for a colourful group with our orange balloons and clothes – including a couple wearing bright orange tutus – it was hard to miss us, that's for sure! It was a wonderful way to launch the first of our annual awareness walks. This year, it will be even bigger and better, spreading around the UK from a stroll along the prom in Bournemouth to a trek up the mountains of Snowdonia. And more and more people will join with us. You don't have to go far or fast; you set your own pace and distance. It's not about competition, it's about coming together to show support and raise awareness. Even if you can only manage a few steps, you are welcome. It really is the taking part that means such a lot.

It has become an FBC tradition to read a special poem and to blow bubbles at some of our larger events in memory of those we have lost and to support those still fighting. It is a precious time for us to consider the reason we have all come together and it is totally inclusive. No matter where they are in the world, everyone can take part in this symbolic moment of unity.





## The heart of our family

When I blow my bubbles on this day – surrounded by others who have lost someone special and those who are there to support us in our fight against this awful disease – it is my moment to reflect. The bubbles are so beautiful and so transient. They are like the special people that I have come to know and care about who have been lost to bladder cancer. They are strong, colourful and shining ... then they float away. But I remember them as they were and they are never forgotten.

I always imagine that I am going to stand tall, show strength and not shed a tear, but this small and gentle act of watching my bubbles drift away gets me every time. I feel strangely lonely for a moment and then look around at everyone else and feel so glad to be a part of something that means so much to so many of us. I feel as though I have found a huge family. OK, so it may be a family of orange-wig-topped, balloon-toting, tutu-wearing people madly blowing bubbles as bemused motorists drive by, but I wouldn't change any of them. Wee are family!

Bubbles for Bladder Cancer now has an official day and time to help raise awareness. On 20 May 2018 at 10 o'clock, wherever you are and whoever you are with – on your own, in groups, with strangers or with those you love – blow some bubbles to recall absent friends and to give a boost to those fighting this much over looked cancer.

The bubbles are so beautiful and so transient. They are like the special people that I have come to know and care about who have been lost to bladder cancer. They are strong, colourful and shining ... then they float away. But I remember them as they were and they are never forgotten.





# BLADDER CANCER awareness month

**This year sees our biggest awareness campaign ever – and you can help it grow!**

**Raising awareness about bladder cancer here in the UK is really difficult. Not many people have heard about bladder cancer, let alone the causes and symptoms of the illness.**

So we are caught in an almost impossible situation.

Without an interest, the main media outlets won't give any coverage. But without media attention, we cannot generate the interest in the first place! We need to get stories out there with the same regularity as those for breast and prostate cancer.

But what has made breast and prostate cancer household names whilst so few people know about bladder cancer?

We believe that it is mostly as a result of the strength of the patient voice in campaigning for awareness and for improvements in diagnosis and treatment. This isn't a problem for the UK alone as this Cinderella status of bladder cancer is a global issue.

## **Let's make some noise!**

So Fight Bladder Cancer is joining up with our friends across Europe, North America and in as many counties as we can to make a noise, a united patient voice to promote knowledge of bladder cancer.

Working in conjunction with the European Cancer Patients Coalition (ECPC), we have established a Bladder Cancer Working Group of patient advocacy groups to network and co-ordinate our activities. With Bladder Cancer Canada and the Bladder Cancer Advisory Network (BCAN) from the US, this working group will grow to become a substantial voice for bladder cancer.

So, we have developed this year's Bladder Cancer Awareness Month of activities in conjunction with the ECPC, who have been able to secure funding from industry partners to support this initiative.

## **What's going to happen in May?**

Our campaign in May needs to reach two different audiences. Firstly, we need to reach people who currently

have no knowledge of bladder cancer, which, as we know, is the majority of people out there. But it is essential that they start to hear about bladder cancer, to have it on their radar and to make sure that they hear the key facts about the causes and the symptoms.

Secondly, we need to reach out and engage with the community that does have some awareness or experience of bladder cancer so that they can join in the campaign to make our voice louder. This second group will, of course, include health teams, policy-makers and politicians as well as us, the patients and carers.

The campaign will be seeking to get the attention of our two target groups and then to provide them with clear information about bladder cancer and how they can help to turn the spotlight on the disease so that we can progress in getting the changes we need.

## **Launch events**

The awareness activities will start with two launch events in the UK and in Brussels and continue through a detailed plan of events and PR activities across traditional and social media for the whole month of May.

If you want to be kept informed about all the month's activities, please do go to the designated Bladder Cancer Awareness Month 2018 page in the Get Involved section – [goo.gl/uTLDkR](http://goo.gl/uTLDkR) – where you can sign up to receive all the details of how you can get involved.





## Blowing bubbles for bladder cancer

It is important for us that the whole bladder cancer community can join in with this campaign in a simple but effective way no matter where you live. We do this with our Bubbles for Bladder Cancer challenge.

You can read all about our Bubbles for Bladder Cancer history in Melanie's article on page 14, but it is a time that we come together across the world to support everyone dealing with bladder cancer and a time to remember all those we have lost to this disease.

All we are asking you to do is to take a bit of time on Sunday 20 May at 10am (GMT) to blow some bubbles. This can be just you and a few friends at home or you might be able to get a few people together and make a more public display of solidarity for our bladder cancer family. We would ask you to take some pictures of the bubble blowing and send them to us plus, if you can, get them posted on social media in places like Facebook, Twitter or on Instagram using **#bubbles4bladdercancer**.

And if that day isn't convenient, any time will do just fine!

Remember to send your pictures to **bubbles@fightbladdercancer.co.uk**



## BLADDER CANCER

We come together across the world to support everyone dealing with bladder cancer



## Walk for bladder cancer

One of the major events we are planning for Cancer Awareness Month is our growing Walk 4 Bladder Cancer, and walks are being planned in many areas across the UK. It is free to register and join any walk and we know that you will be warmly welcomed.

At the time of going to print, we have confirmed walks in Oxfordshire, Dorset, Kent and Norfolk with two specialist walks up Snowdon and into the fells above the Lake District.

To find full details of this year's walks, checkout the Awareness Month page on our website.

It doesn't take much to organise a small walk with family and friends, so if there is no major event in your area, why not arrange something yourself? If you do want to give it a go, our team at FBC will help you get it organised and make sure you have fun at the same time. Email **walk@fightbladdercancer.co.uk** to get things started.



## BLADDER CANCER

It doesn't take much to organise a small walk with family and friends, so if there is no major event in your area, why not arrange something yourself?



## Show your true colours

Orange is FBC's colour and it is now becoming recognisable as the bladder cancer colour in many countries across the globe. So during May, we want to turn as many things orange as possible!

Our aim is to have the maximum possible number of buildings or monuments floodlit in orange for at least one evening. We are in negotiation with the owners of a number of iconic buildings so keep an eye out for our breaking news, but you can help too. Anyone can contact the owners of a local building that is lit up at night and see if they will turn it orange for us for one night. This might be a local church, the town hall or just a building in your high street. Size isn't important so have a go at turning something orange for us during May. And don't forget to let us know and to send a picture to us if you are successful!



## Shine a light on bladder cancer!

During May we are also hoping to turn a number of floodlit buildings and monuments orange in support of the campaign. We have it confirmed that the Kelpies in Scotland will be lit up orange for us on the 2nd May and the "Winking Eye" bridge in Gateshead on the 20th. If you think you can help us turn a building orange in your area, get in touch!



## Wear it with pride

For Awareness Month, we are producing a new t-shirt and wristband design, so make sure you order yours from the shop on our website!

## Help us get the attention of the media

We won't reach the vast majority of the general public unless we can get the attention of the media.

Why not get in touch with your local newspaper or radio station and let them know how you are supporting our Bladder Cancer Awareness Month. Tell them about the bubbles, the walks and why it is so important for them to help spread the word. Don't worry if you don't know what to say, we can give you all the details you need and help draft any emails or letters you want to send.

Newspapers and radio stations always like to hear a patient story so if you are happy to have your story told, get in touch!

## GET INVOLVED!

Let's join together  
and make some  
noise!



**BLADDER CANCER**  
awareness month

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## COMBAT Bladder Cancer with Hyperthermia



"HIVEC™ offers a new treatment option for patients with high and intermediate risk Bladder Cancer. For patients where BCG is not tolerated, not available or has failed, HIVEC™ offers a promising well tolerated alternative bladder preserving treatment in selected patients."

Mr D Wilby, Consultant Urologist, Portsmouth General Hospitals NHS Trust.

Recent data cited **COMBAT HIVEC™** treatment as an effective and well tolerated option for BCG unresponsive or intolerant patients, or those unsuitable for a radical cystectomy. A retrospective analysis of 145 patients cited **HIVEC™** treatment as an attractive alternative to BCG in certain patients. All acknowledged that results from large scale randomised controlled trials are eagerly awaited.

**COMBAT** has recently finished recruitment of 598 patients on the **HIVEC I & II** trials.



For further information on **HIVEC™** and to see recently presented data in more detail, please contact us directly or visit [www.hivec.co.uk](http://www.hivec.co.uk)

HIV010-03EN0318



# What is it really like to have bladder cancer?

The results of our Global Survey on the experience of bladder cancer patients and their carers represents a huge step forward in our patient-based knowledge

## ARTICLE

JOSEPHINE ELLIOTT  
Oxford University  
Medical Student

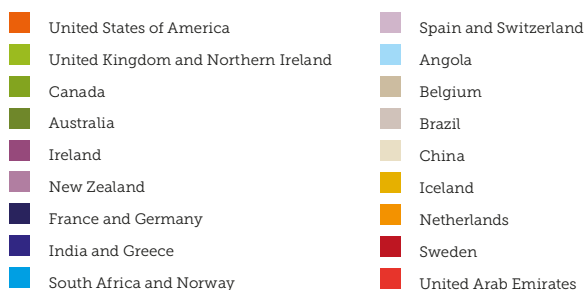
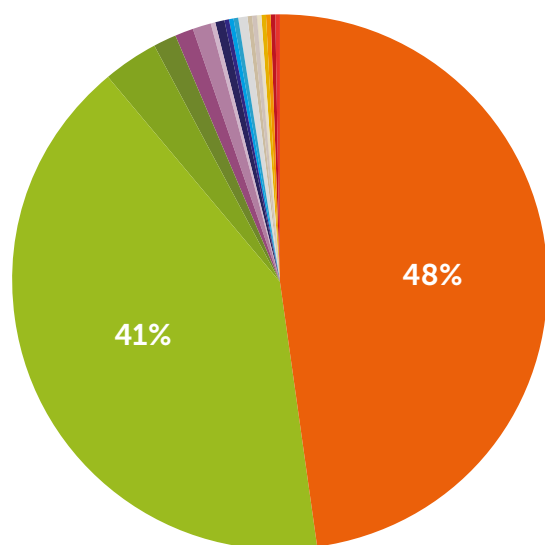
Since September 2017, Fight Bladder Cancer and ECPC have been conducting a global survey on the experience of bladder cancer patients and carers. To date, there have been 915 responses from 22 different countries; 85.09% of these responses came from patients, with 13.58% from carers and 1.33% from others. Of the respondents, 55.33% were male, while 44.51% were female. These responses are vital in understanding and improving the treatment of bladder cancer victims and we share here the questions and responses.

## Global response

The majority of responses came from the United States and Britain, although participants were recorded from a total of 22 countries, including the United States of America (47.92%), the United Kingdom and Northern Ireland (41.18%), Canada (3.21%), Australia (1.6%), Ireland (0.96%), New Zealand (0.96%), France (0.48%), Germany (0.48%), India (0.32%), Greece (0.32%), South Africa (0.32%), Norway (0.32%), Spain (0.32%), Switzerland (0.32%), Angola (0.16%), Belgium (0.16%), Brazil (0.16%), China (0.16%), Iceland (0.16%), the Netherlands (0.16%), Sweden (0.16%) and the United Arab Emirates (0.16%). It should be noted that 20.67% of participants chose not to answer which country they lived in, therefore this data does not represent every survey participant.







### Had patients heard of bladder cancer prior to diagnosis?

Of the 640 responders to the question whether they had heard of bladder cancer before being diagnosed, the majority (54.84%) answered that they had not. Similarly, out of the 287 participants who answered, only 36.95% knew someone with bladder cancer before they were themselves diagnosed; however, this did not represent all the participants who filled in the rest of the survey. Later in the survey, of the 638 respondents who responded to the question, 359 (56.27%) reported that they had a sibling who had also been diagnosed with cancer.

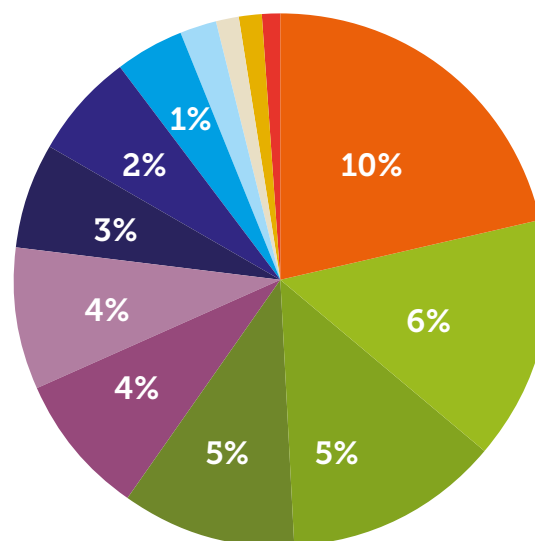
### What are the current diagnoses of participants?

Of the 634 participants who answered this question, the majority (56.15%) are currently diagnosed with non-invasive bladder cancer, 20.82% have a diagnosis of locally invasive disease, 4.42% have metastatic bladder cancer, whilst 17.19% reported a diagnosis of 'other', the majority of whom were in remission, with many patients reporting having undergone a cystectomy (removal of the bladder).

### What are the patients' occupations?

Several occupations have been identified as increasing bladder cancer risk, such as workers in the rubber and dye industries. The survey attempted to assess how many patients experienced these occupational hazards. Of the 633 participants who answered this question, results showed that the majority of respondents (72.20%) were not at heightened risk due to an occupation related to increased risk of bladder cancer.

Of the occupations thought to potentially increase bladder cancer risk, 9.32% of participants were engineers, 6.32% were construction workers, 5.21% were painters, 4.58% were mechanics, 4.11% were metalworkers, 3.79% were professional drivers, 3.00% were electricians, 2.37% were textile workers, 1.26% were hairdressers or barbers, 0.79% were railway workers and 0.63% were miners. These results suggest that there are other important risk factors than the currently identified occupational hazards.



## Is the patient currently a smoker?

Despite smoking being the most common risk factor for bladder cancer, only 59 of the 637 respondents reported being current smokers. However, the survey did not ask about previous smoking patterns, therefore this does not negate the link between smoking and bladder cancer.

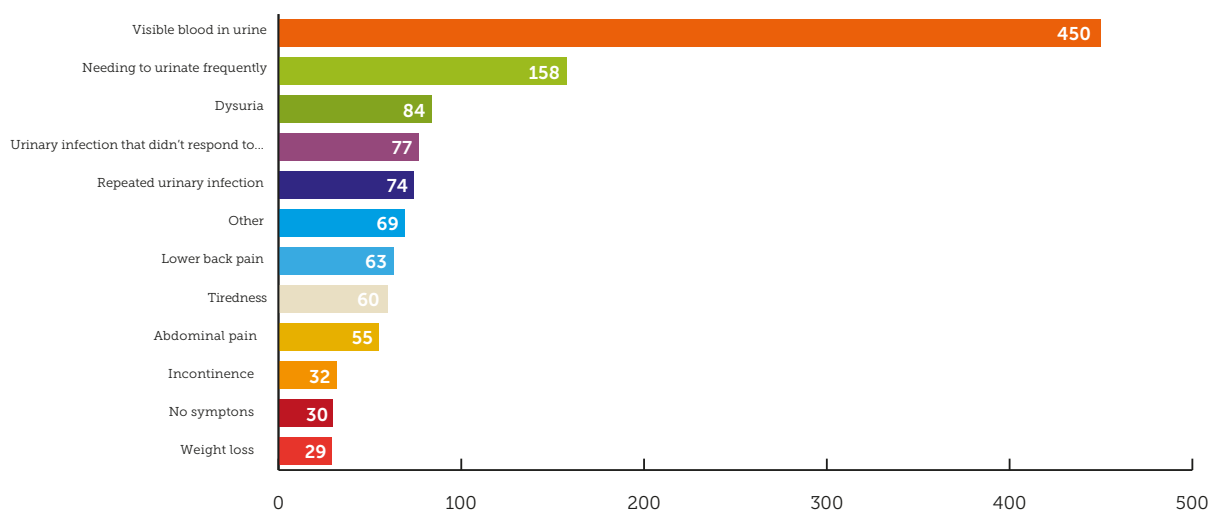


## What were the first symptoms observed?

The next part of the survey studied the first symptoms of bladder cancer that patients experienced. The most common first symptom was haematuria (blood in the urine), which was the first visible symptom for 70.31% of the 640 patients who answered this question, with an additional 2.8% of participants discovering blood in their urine only when tested because the blood was in microscopic amounts. Other first symptoms included polyuria (increased frequency of urination – 24.69%), dysuria (discomfort or burning sensation when urinating – 13.13%), urinary infection that didn't respond to antibiotics (12.03%), repeated urinary infection (11.56%), lower back pain (9.84%), tiredness (9.38%), abdominal pain (8.59%), incontinence (5.00%), weight

loss (4.53%), or no symptoms (4.69%). Although these were the first symptoms listed in the survey, symptoms described under 'other' included: skin rash, inability to pass urine, blood in semen, severe pain in the left groin which radiated to the left hip and overnight swelling in the legs. It is of note that many of the participants only discovered their bladder cancer during a check-up or examination for another condition.

The multitude and diversity of these first symptoms, particular of the ones listed in 'other', suggests that more research should be done into the manifestations of bladder cancer and to encourage patients to look out for these symptoms, even if they are not those that would normally be expected.



## Which month did patients first observe symptoms?

Of the 604 responses to the question of which month these responses were first experienced, there did not appear to be a significant difference between the months, although December was the least likely month in which symptoms were observed at 6.95%, and January was the most common at 11.42%. One could postulate that with the start of a new year we become more aware of ourselves, our bodies and our goals in life as people make New Year resolutions, however June was the second most likely month in which first symptoms were observed (10.6%).

## Which month did patients first consult a healthcare professional about their symptoms?

As in the previous question, there was not a significant difference between months in which participants first talked to a health professional about their symptoms. June was the most common month (12.66%) with August (9.42%) and January (9.25%) respectively being the next most common months for seeking professional advice on these symptoms.

This data does not show how long patients chose to wait before seeking a professional consultation, which future studies can aim to do, as the time between observing symptoms and seeking help is critical – the sooner patients are diagnosed, the better the prognosis.

The most common health professional spoken to about the symptoms was a family doctor/GP, which was reported by 70.19% of the 634 participants. However only 22.7% of participants were believed, from their first consultation with a healthcare professional, to have bladder cancer. The majority of patients were thought to have a urinary tract infection, which is a more common condition.

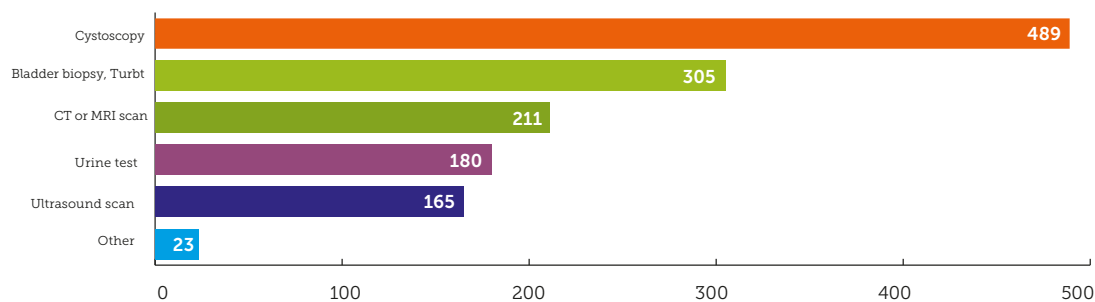
Other participants were initially thought to be suffering from kidney stones, an enlarged prostate, a gynaecological condition, or side-effects from prescription drugs, with some patients being told the symptoms were nothing to worry about. Responses from the 637 participants responses shows that the majority of patients (74.25%) were referred to a urologist for investigation. This data suggests the importance of referring on patients with these symptoms in the likelihood that the true diagnosis is bladder cancer.

## Which month were patients diagnosed with bladder cancer?

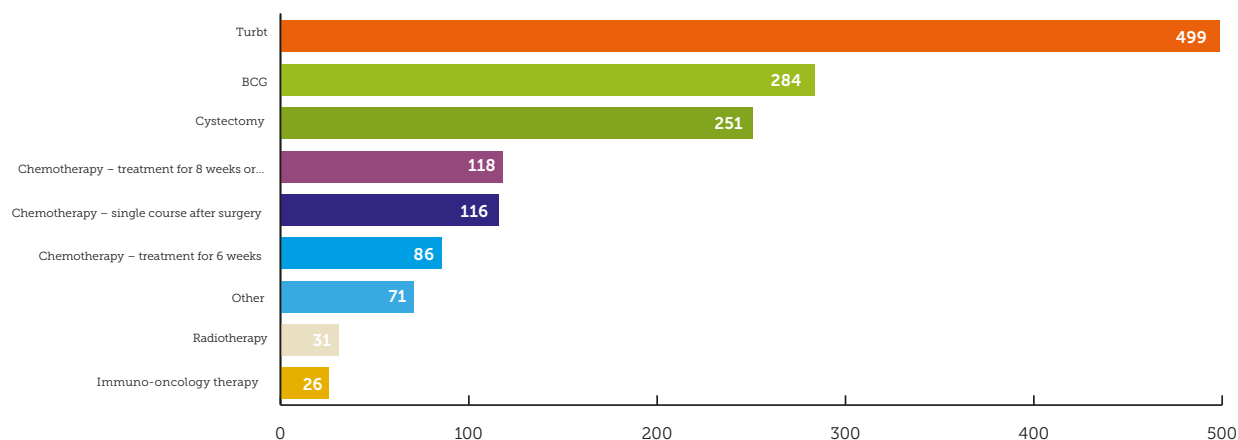
In correlation with these previous questions, there was not a significant difference between the months in which patients were diagnosed with bladder cancer. The most common months for a bladder cancer diagnosis was June (10.86% of participants), with November (9.90%) and October (9.74%) as the respective next most common. May was the least common month for diagnosis, with only 5.91% of the 626 participants who responded to this question reporting a bladder cancer diagnosis in May.

## Which tests did the doctor use to diagnose bladder cancer?

Of the 640 participants who responded to this question, cystoscopy was the most common diagnosis method, used to diagnose 76.41% of these participants. A cystoscopy is the insertion of a thin tube, with a camera and light attached, through the urethra into the bladder to examine the inside of the bladder. Other diagnostic tools used included: bladder biopsy - TURBT (47.66% of participants), CT or MRI scan (32.97%), urine test (28.13%), ultrasound scans (25.78%) and 'other' (3.59%). Responses for 'other' included descriptions of the above tests, but initially carried out to investigate a different condition.







### What treatments had participants received?

Of the 641 participants who answered this question, 77.85% received a transurethral resection of the bladder tumour (TURBT), with the next most common treatment being Bacillus Calmette-Guerin (BCG) therapy, received by 44.31% of patients. Other treatments received were cystectomy (39.16%), chemotherapy – treatment for 8 weeks or longer (18.41%), chemotherapy – single course after surgery (18.10%), chemotherapy for 6 weeks (13.42%), radiotherapy (4.84%), immune-oncology therapy (4.06%) and 'other' (11.08%). The 'other' treatments described included: neobladders, removal of ureter and kidney, prostate removal, participation in clinical trials, diet changes, acupuncture, pelvic exenteration and no treatment.



### Inability to access effective treatments

The unfortunate second part to this question is that, of the 631 respondents, 89.70% reported that they were unable to access recommended treatments. This suggests that bladder-cancer treatment may need more funding to enable more patients to receive the most effective treatments. Of the treatments that participants were unable to receive, the most common was BCG; 22 out of the 49 patients who answered the second part to this question reported being unable to receive BCG treatment. Other treatments that patients were unable to receive included: chemotherapy single course after surgery (9 participants), immuno-oncology therapy (8 participants), radiotherapy (6 participants), TURBT (5 participants), cystectomy (4 participants), chemotherapy for 6 weeks (3 participants) and chemotherapy for 8 weeks or longer (3 participants).

The reasons for being unable to receive desired treatments included: treatment being out of stock (13 participants), treatment not recommended or thought inappropriate by physician (12 participants), treatment being unavailable (3 participants), too much blood in the urine to finish treatment (2 participants), inability to schedule an appointment (2 participants), contra-indication due to existing medical condition (2 participants), tumour not identified (1 participant), an allergy to the treatment (1 participant), too sick to finish treatment (1 participant), treatment being too expensive (1 participant), treatment being delayed (1 participant) and that the tumour was too advanced for treatment (1 participant).

## What methods helped patients cope with their diagnosis?

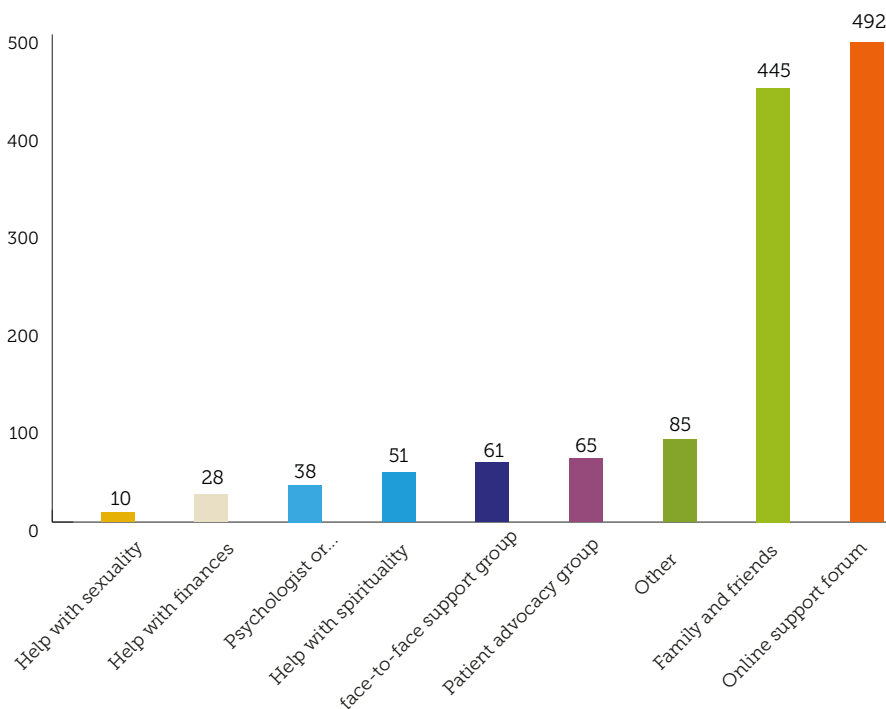
Two things stood out as the most useful coping mechanisms from this survey for the 634 participants who answered this question. The first was an online support forum: 77.60% of participants found this a useful coping tool. The second was friends and family, which 70.19% reported being helpful in coping with their diagnosis. Other key coping tools included: patient advocacy groups (10.25%), face-to-face support groups (9.62%), help with spirituality (8.04%), a psychologist or psychiatrist (5.99%), help with finances (4.42%), help with sexuality (1.58%) and 'other' (12.62%). The majority of 'other' responses included support from medical staff in clinics or hospitals (4.89% of total participants who answered this question), however also mentioned was faith, Macmillan staff, anxiety/depression medication, hospice support, diet change, Fight Bladder Cancer, cancer centres, talking with survivors, alternative treatments, research and a positive attitude. Only 6 participants reported that they felt they had no support; this shows that there is still much work to do to provide patients with the support they need.

We hope that the suggestions from these bladder cancer patients can provide coping mechanisms for readers who find they are in need of support, but readers should also be aware of the support systems that Fight Bladder Cancer has to offer (see page 5). No one should have to go through cancer alone.

## Summary

One key limitation of this survey is that not every participant completed every part of the survey, as tends to be a limitation when working with such a large cohort. However, from the responses given, clear themes are emerging.

- There needs to be more awareness of bladder cancer – one of the main aims promoted by Fight Bladder Cancer – particularly as the prognosis is better the earlier the cancer is diagnosed.
- The high percentage of patients unable to receive certain treatments, particularly due to a shortage of the necessary treatment, suggests that bladder cancer requires more funding than it currently receives to provide patients with the treatment they deserve.
- Furthermore, results show that patients need to be aware of and able to access better support systems.





## **Abstract for international survey of people with bladder cancer about awareness, symptoms, treatment, and support**

The size of the abstract is limited to 3,000 characters (this includes title, body of abstract, spaces). Each author should have contributed substantially to the represented work in terms of conceptual design or analysis, writing of the poster, and final approval of the poster in order to take public responsibility for the content.

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*The personal experience of people affected by bladder cancer is largely unknown. The experience of people with bladder cancer was examined using a structured questionnaire.*

*The structured questionnaire was divided into areas of interest such as awareness, symptoms, treatment and support.*

*The study was designed by the European Cancer Patient Coalition and Fight Bladder Cancer UK, in collaboration with the Bladder Cancer Advocacy Network USA, the Norwegian Bladder Cancer Society (Blærekreftforeningen), the Italian Bladder Cancer Society (Pazienti Liberi dalle Neoplasie Uroteliali) and Bladder Cancer Canada. The English version of the survey was translated into Dutch, Finnish, French, Greek, Italian, Norwegian, Polish, and Spanish and disseminated electronically by local cancer patient organisations.*

*As of February 2018, there were 871 responses from people with bladder cancer and 250 responses from carers of people with bladder cancer. Of the people with bladder cancer, 57% (n=434) responded that they were male and 43% (n=325) responded that they were female. 56% (n=425) of people with bladder cancer reported that they had at least one of their parents or siblings diagnosed with cancer. 12% (n=92) of people with bladder cancer reported that they currently smoked cigarettes. The most common professions reported by people with bladder cancer were engineer (8.8%; n=66), construction worker (5.3%; n=40) and professional driver (5.2%; n=39).*

*The most common symptoms reported by people with bladder cancer were visible blood in urine (71%; n=580), needing to urinate frequently (27%; n=224), and pain or burning when urinating (13%; n=107). For 66% (n=526) of people with bladder cancer, the family doctor was the first health professional that they spoke to about their symptoms, while 18% (n=140) spoke to a urologist. 37% (n=285) of people with bladder cancer reported that their doctor initially believed that a urinary tract infection was the cause of their symptoms, and 71% (n=552) of people with bladder cancer were initially referred to a urologist. The most common diagnostic tests were cystoscopy (74%; n=581), bladder biopsy (45%; n=352), and CT/MRI scan (34%; n=264). The most common treatments reported by people with bladder cancer were TURBT (76%; n=592), BCG (43%; n=336) and cystectomy (36%; n=280).*

*45% (n=378) of people with bladder cancer had heard of bladder cancer before they were diagnosed, and of these, 40% (n=153) knew someone with bladder cancer. The most common sources of support were family and friends (71%; n=535) and online support forums (65%; n=491).*

*Most people with bladder cancer surveyed reported that they were unaware of the disease before they were diagnosed. There is a need to empower individual patients and patient associations by producing more information on the early symptoms of bladder cancer.*

# Fight Bladder Cancer

**You are not alone. FBC is there to help you at every stage in your fight.**

Visit [fightbladdercancer.co.uk](https://fightbladdercancer.co.uk) to find out about the range of information, support and help for patients, carers and families.

**LEARN:** Go to [fightbladdercancer.co.uk/learn](https://fightbladdercancer.co.uk/learn) to find out all you need to know about bladder cancer so you can make informed choices.

**GET-HELP:** Go to [fightbladdercancer.co.uk/get-help](https://fightbladdercancer.co.uk/get-help) if you are newly diagnosed or need information and support at any time in your cancer journey.

**GET-INVOLVED:** Go to [fightbladdercancer.co.uk/get-involved](https://fightbladdercancer.co.uk/get-involved) to add your support to the thousands already working to build a supportive community that helps patients and carers fight this disease.



# The positive role of the CNS

Pauline, a clinical nurse specialist, examines the vital role played by the CNS in the care and treatment of patients

## ARTICLE

PAULINE BAGNALL  
Uro-onology clinical  
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The most important basis of patients having a more positive experience of being diagnosed with and treated for cancer is having access to a clinical nurse specialist (CNS). This was the conclusion of the National Cancer Patient Experience Survey 2016 (NCPES 2017) which, in turn, led to the NHS recommendation that 'all patients have access to a CNS'.

So this article looks at the role of the CNS and how that contributes to a more positive experience and outcome.

One difficulty of exploring the specific experience of patients with bladder cancer, or the numbers of patients with bladder cancer who do have access to a CNS, is that, in the survey, patients with bladder cancer are grouped with all patients diagnosed with a urological cancer; the Specialist Nurse Census (Macmillan 2014) also groups CNSs caring for patients with bladder cancer with all urological cancer nurses. This reflects the reality of bladder cancer nursing practice, where patients with bladder cancer are in the main cared for by uro-oncology specialist nurses, whose caseload includes care for patients with bladder, kidney, ureteric, prostate, testicular and penile cancer.

### What is a CNS and what do they do?

The National Cancer Action Team (NCAT 2010) describes a CNS as a registered nurse who is educated to at least graduate but usually Masters level. They are experts in evidence-based nursing within a specialist area, in this case uro-oncology. The role of the CNS is to practise independently, using their specialist cancer skills and knowledge to assess, diagnose, treat and manage patients' health concerns and support their health and well-being throughout their treatment pathway.

CNSs have significant influence on the quality of patient care and have demonstrated their financial worth on many occasions by reducing the number of emergency admissions, readmissions and length of hospital stays, the number of outpatient appointments and the number of medical consultations (Henry 2015).

**CNSs have significant influence on the quality of patient care and have demonstrated their financial worth on many occasions**

### THE CNS – A quick guide

**The role of the CNS is complex as it covers everything relating to diagnosis and treatment, and many uro-oncology nurses are involved in the patient pathway from their first referral from the GP.**

They carry their own patient caseload and also follow up patients who have been treated for other urological cancers, such as prostate cancer. Many CNSs caring for patients with bladder cancer also carry a caseload of patients with benign urological disease, such as urinary symptoms, kidney stones, etc.

#### **Maintaining focus on the patient**

In the complex world of cancer support, it is sometimes easy to lose focus on the individual rather than the disease. It is the job of the CNS to ensure that care remains patient-centred so that the patients' individual values, beliefs, needs and goals are central in the process of making treatment decisions.

#### **Co-ordination**

Investigations, treatments and follow-up of bladder cancer can be carried out across a number of NHS Trusts and patients can be cared for by a number of health professionals – sometimes over the course of decades. CNSs must have good communication skills to ensure that patient care across the hospital sites is co-ordinated, acting as the key worker across the whole pathway.

#### **Support in decision-making**

Many people will have choices to make regarding treatments at key points in their pathway and their CNS will play a vital role in providing specialist information about managing symptoms, treatments and potential side-effects so that the patient can make informed decisions that are right for them.



## THE CNS – A quick guide

### Self-management

The cancer patient also needs to be proactive in their own care and lifestyle choices and the CNS can deliver patient education and training so that patients are empowered to self-manage their symptoms and treatment side-effects, and to act as patient advocates.

### Psychological support

A cancer diagnosis brings mental as well as physical pressures and the CNS provides specialist psychological support for patients (and sometimes colleagues) to help them through the difficult times.

### Specialist education and training

In addition, CNSs provide specialist education and training for the wider team, which includes student nurses, non-specialist nurses, other speciality nurses, medical students, junior hospital doctors and GPs.

### Logistical support

CNSs are involved with the administration and implementation of care, triaging GP referrals, identifying appointments patients should be booked into, arranging investigations, assessing symptoms, putting patients' names on waiting lists, writing to GPs, checking, interpreting and actioning results of investigations and informing patients of their results.

### Leadership

CNSs are expected to demonstrate leadership by identifying areas for service improvement and leading the necessary changes by auditing practice and by sharing good practice and improvements in care (National Cancer Action Team 2010).

### Cross-discipline referrals

Where necessary, the CNS can refer patients to other specialists for additional treatments.

### Performing procedures

CNSs undergo special training so they can perform flexible cystoscopies and other procedures.

### Maintaining patient histories

As members of the urology multidisciplinary team (MDT), they prepare patient histories for discussion in the team meeting, present the patient histories and advocate on behalf of patients within the MDT meeting.

### Overseeing targets

More recently, many CNSs have become responsible for ensuring patients cancer pathways meet cancer waiting time targets, so they are diagnosed within 31 days and treated within 62 days of referral.



## Access to a CNS

NICE (2015 a and b) recommends that all adults with a diagnosis of bladder cancer are allocated a named CNS. The most recent NCPES (2017) demonstrates that only 81% of patients treated for a urological cancer during the survey period in 2016 were given the name of a CNS who would support them through their treatment. This compares to 90% of all patients treated for cancer during this period.

Anecdotally, patients complain that their uro-oncology CNS is not easily contactable, although the survey demonstrates that 85% of patients found it easy to contact their CNS. Although 15% of patients surveyed did not find it easy to contact their CNS, this figure demonstrates that uro-oncology CNSs are achieving approximately the same rate as the national average, which was 86%. The highest result was for patients treated for skin cancer, where 89% of patients found it easy to contact their CNS.

## The impact of cancer

The NCPES (2017) demonstrates that the needs of many patients living with and beyond urological cancer are not being met, with only 72% of patients being given information on the impact that cancer could have on their day-to-day activities compared to 85% of patients treated for breast cancer and 81% of patients treated for all cancers.

Only 35% of uro-oncology patients were given information about financial help, compared to 56% of all patients treated for cancer, while 67% of patients were told they were eligible for free prescriptions compared to 80% of patients who were treated for all cancers.

## Heavy patient caseloads

The national CNS census in 2014 (Macmillan 2014) demonstrates that uro-oncology CNSs have the highest patient caseload compared to other cancers. The average patient caseload per one full-time uro-oncology CNS is 159 newly diagnosed patients per year compared to the next CNS caseload, lung cancer, where each CNSs has 125 new cases per year, followed by 87 for breast cancer and 82 for gynaecology new patients per year.

In addition, uro-oncology CNSs have the highest number of patients living with a urological cancer for up to two years following their diagnosis, with at least 170 patients per Clinical Strategic Network and as many as 426. This compares to 51–120 for lung cancer, 39–254 for breast cancer and 95–232 for gynaecological cancers.

**The most recent NCPES (2017) demonstrates that only 81% of patients treated for a urological cancer during the survey period in 2016 were given the name of a CNS who would support them through their treatment.**

## A call for a separate study

As indicated at the outset, the experience of bladder cancer patients is integrated with that of all patients diagnosed with a urological cancer, therefore this article has focused on the role of the uro-oncology CNS and their effect on patients who have been diagnosed and treated for a urological cancer.

The NCPES demonstrates that the high patient to uro-oncology nurse ratio is having a negative impact on patients diagnosed with a urological cancer.

In recognition of this, the Bristol Myers Squibb (2017) Expert Round Table advisory group recommended that the NCPES surveyed and reported patients with bladder cancer experience separately to other urological cancers, as is already done for patients with prostate cancer. They also recommended that a comprehensive study be carried out to examine the job titles and workload of nurses caring for patients with bladder cancer.

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# TRUE FRIENDSHIP

## can come from mutual support

Jenny's ambition was always to set up a support group and raise the profile of bladder cancer for all those affected – and her success went far beyond her expectations

I qualified as a registered nurse in 1999 and my first posting was on a urology ward. In 2001, I was appointed as senior staff nurse and assisted with the development of the urology Hospital at Home team. I worked on a rotation system on the ward and urology Hospital at Home team for a further two years. I then began working with the urology advanced nurse practitioners in 2003. Initially this was a secondment post but soon after I was made a permanent member of the team.

Since then I've continued to develop my skills, knowledge and education, studying at both degree and masters level. Since qualifying, I have always had a special interest in bladder cancer and wanted to improve the support and care offered to this group of patients. I trained as a stoma nurse in 2004 to ensure patients requiring cystectomy surgery were offered continuity of care and ongoing support. In 2009 I commenced extensive training with the urology consultants to develop as a nurse cystoscopist.

### ARTICLE

JENNY AKINS

Urology advanced nurse practitioner,  
New Cross Hospital, Wolverhampton



## Overwhelming support from the outset

In May 2012, I organised a bladder cancer focus group and asked anyone affected by bladder cancer to attend. I wanted to appreciate their views and needs in order to identify what they really wanted from a support group and how they would like it to be run. The response to the focus group was incredible with over 100 people attending! I started off the meeting with an apology ... I wanted to say sorry it had taken so long to get something started. At that time there were no other local bladder cancer support groups.

I took inspiration from the clubs for patients experiencing prostate cancer. My main hopes were to offer a supportive group, and I also wanted to help improve the consistency in supporting patients undergoing bladder cancer treatment. On a practical level, I needed some input on the logistics: how often should we meet, where, and what did people want from the group?

## Slow but sure

In fact, it took about a good 18 months for the group to get going and to truly establish its objectives but since then, it has really developed. I am delighted that it has been such a success.

The Wolverhampton Bladder Cancer Support Group (WBCSG) meetings are held about every eight weeks and are well attended, with around 40 members at each meeting. Committee meetings are held between each of the group meetings.

The committee currently consists of six members who are all bladder cancer patients.

Peter, Mike, Sylvia, Brian, Gordon and Keith are crucial in the success of the group. The individual contributions include treasurer, website designer, social event organiser, secretary and 'buddy'.

## Setting up a support group

In offering advice in setting up a support group, I would recommend speaking to bladder cancer patients and carers. The framework used for the Wolverhampton group has worked well for its members and has been fundamental in its success. This is due to listening to the members and identifying their needs.

Encourage members to be involved in the group, form a committee and meet regularly. Ask health professionals to be involved, for example by speaking at the meetings to inform, educate and update the members. Spread the word to promote the group and ensure patients are notified of the support available. Finally, speak to other local support groups for advice and ask for help from the national charities.

## We've become true friends

When the WBCSG group met up for our summer dance social event in 2017, it really felt like a gathering of true friends. Bladder cancer had brought the members together in the first place, but the final outcome was a generous and rewarding helping of friendship and support!

If you would like to speak to Jenny for any advice regarding setting up a local support group or would like to attend one of the Wolverhampton meetings she would be happy for you to contact her via email at: [jenny.akins@nhs.net](mailto:jenny.akins@nhs.net)



## My greatest rewards

There are many rewarding aspects of my role but I would have to single out among the best:

- establishing a trustworthy relationship and rapport with my patients and their families;
- bringing bladder cancer patients together to share experiences and support each other;
- raising the profile of bladder cancer locally with education, social events and through the meetings;
- and, most important of all, improving patient care and experience throughout their bladder cancer pathway.

**The final outcome was a generous and rewarding helping of friendship and support!**



## Free online bladder issues clinic 4 to 15 June 2018.

# talkhealth

Do you suffer with bladder issues or have any questions around the subject? We are pleased to announce that Fight Bladder Cancer is joining forces with **talkhealth** to provide another route to good-quality information for people affected by bladder cancer or who have bladder issues of one kind or another.

The **talkhealth** website covers a wide range of health issues, including bladder problems, and they want to do all they can to support Fight Bladder Cancer. So they have teamed up with charity partners, Fight Bladder Cancer, Bladder & Bowel UK, ERIC and The Urology Foundation for their latest online clinic around the subject of bladder issues.

Bringing together experts in the field, the online clinic allows those with questions about bladder concerns to connect directly with leading professionals, from the comfort of their own home.

The clinic will offer support and advice around a number of issues, including:

- Bedwetting
- Cystitis and UTIs
- Urinary incontinence
- Bladder cancer
- Overactive bladder syndrome
- Bladder stones
- Catheters

No matter what your bladder-related questions or concerns, **talkhealth's** online clinic will be able to provide support and answers from an extensive range of experts taking part in the event.

To find out more about talkhealth's online clinic for bladder issues, search for 'talkhealth' on Google, or head to **[bit.ly/OnlineClinics](https://bit.ly/OnlineClinics)**



# Why **PROs** must take centre stage in cancer research

## How we can make significant improvements for patients

### ARTICLE

ROGER WILSON,  
CBE, HonMD, HonLLD,  
Cancer patient advocate

The role of patients in research is crucial. The medical experts can look at technical quality, but it is the patients who can bring the benefit of their experience and the ability to stand back and take a view of the broader picture. After 15 years as an involved patient in cancer research, I came to the conclusion that I was in a strong position to give an informed view of the realities of cancer research. When I started looking around, I found I was asking myself where the next significant leap in real patient benefit was going to come from? And my conclusion? That PROs – patient reported outcomes – are where real and lasting progress can be made.

I am full of admiration for the ingenuity and scientific quality of current research activity. It is making a difference to some of those with metastatic disease and a few more who are at an earlier stage in their disease experience, but it has been achieved at a high cost, both financially and in terms of the impact on patients.

Research tends to be made up of a lot of scattered activity and while there are active consensus groups among academic researchers, there is no coherent vision. And within that research, quality of life (QoL) and PROs stood out as a critical development area. Patient involvement in this area of research needs to develop and become more effective. The idea that you can include PROs in your research without patient-provided inputs to inform the methods and processes used is irrational and probably unethical.

Dr Ian Tannock gave a keynote talk at the National Cancer Research Institute (NCRI) conference in 2014 on randomised controlled trials (RCTs), the gold standard for new therapies in oncology. His team reviewed RCTs in breast, lung and colon cancer published since 1975 in major journals. He had some stark findings (my summary in the box, right).



Patient  
Reported Outcomes  
(PROs) are a vital  
element in research  
programming



- We are looking for smaller benefits AND we are ignoring older drugs which might have the same effect.
- We are using surrogate endpoints which are difficult to analyse AND drug approvals are based on them.
- Harmful side-effects are under-reported BUT – don't worry – they are identified after approval.
- Author bias favours experimental arms AND publication bias favours positive results.
- Quality of life is under-researched AND QoL methods are poor.

As a detached appraisal, this analysis suggests that data are garnished to claim fancy conclusions, and a few weeks' longer life is hyped as a big benefit, while data on the outcomes patients actually worry about are missing.

The direction of clinical cancer research is taking us away from big RCTs towards looking at small effects from more targeted interventions based on biology and genetics where response is probable, although side-effects and recurrence are still real issues. The current clinical research headline themes are immunology, genetics and personalised medicine. As a result, there may be a cure for a few more cancers, there may not. We have no long-term experience and side-effects are a big issue. My concern is that in a year or two we may feel as though we have been standing still.

### Delivering treatment locally

Treatment in local hospitals – district general hospitals in the UK – is the heartland where patient benefit has to be realised. It is easy for patients focused on involvement in research to forget this fact. Cancer centres in university hospitals, which predominate in research, are very different environments from the routine of a local hospital. Doctors work under different pressures, there is limited access to research studies, and few have interests which push at the boundaries of treatment and care.

**Earlier diagnosis, more accurate diagnosis through better imaging and pathology, & new surgical and radiotherapy techniques are all contributing to this improvement.**

A recent follow-up study by the National Cancer Registration and Analysis Service (NCRAS) shows that practice in some places has hardly changed in recent years. For example, how do clinicians support patients making decisions about treatment? A Dutch study describes collusion between patient and physician when discussing chemotherapy. This collusion 'may facilitate unrealistic optimism and unjustified hope'.

In addition, doctors do not adequately explain prognosis. The concept of 'winning the battle', created by social pressures, reinforces the acceptance of toxic therapy at the end of life. Consider the Temel study (2009) of palliative care in advanced lung cancer, where patients were randomised to standard treatment plus or minus proactive palliative care. Hardly surprising that the palliative care group had better quality of life, used fewer drugs and lived longer. Even so, this lesson seems to be fading from memory.

### Improving survival rates

We must not overlook the fact that at ten years following diagnosis, 50% of all cancer patients are surviving and this percentage will improve. Earlier diagnosis, more accurate diagnosis through better imaging and pathology, and new surgical and radiotherapy techniques are all contributing to this improvement. The indisputable fact is that in many cancers, a cure is achieved through primary treatment, most frequently involving surgery.

**There is a new emphasis on 'survivorship' in which self-management and quality of life appraisal have key roles to play.** This area is generally under-researched and patient experience is not described in ways which allow 'pathways' through survival to be defined.



## The role of PROs

Quality of life appraisal in research is not integrated and it lacks a coherent vision. Tannock made the point that QoL is under-researched and research methods are poor. A recent systematic review suggests that awareness of the importance of QoL among cancer research clinicians remains poor. There are too many tools and no clarity on how any of them can lead to changes in clinical practice. There is a great variation in the quality of implementation and a pressing need for consistent improvement in overall standards. If we unpack it we find:

- a multitude of tools;
- criteria are defined by academics and doctors not by patients;
- data are cherry-picked to support a pre-determined clinical or commercial view;
- piles of data which cannot be compared or aggregated – even assuming they are published or made available.

**After 20 years, we still cannot describe a life-quality pathway through any cancer treatment.**

The efforts of the All Trials initiative (2017) to get all clinical studies, past, present and future, published in full are to be welcomed. There are moves involving journal editors to develop standardised approaches to reporting research, including such vital elements as publishing adverse event data rather than hiding it away; and not side-lining QoL data because it produces results which conflict with the desired outcomes. Most academic and charitable sponsors and funders have committed to support the All Trials principles.

The problems that researchers face in implementing an effective QoL element in their research have been described in a systematic review (2014) of available PRO guidance (not specific to cancer):

*PRO-specific protocol guidance is difficult to access, lacks consistency and is unwieldy; with over 160 recommendations spread across 54 different publications. It is therefore extremely challenging to implement in practice.*

In the last twenty years, QoL research has come a long way and progress since the European Medicines Agency (EMA) and US Food and Drugs Administration papers (2005 and 2009 respectively) has been substantial. However, the core criticisms indicated above remain largely unaddressed.



**The first priority is that we must have a single, consistent quality-of-life approach.**

## Influencing cancer care

***I believe that the biggest impact on patient benefit, which patients involved in research can enable, is through involvement in the development of structured quality-of-life assessment and PROs which explore the detail of patient experience.***

The experience focus must be on studies into any kind of diagnostic approach, treatment, survival and important palliative and end-of-life care. Patients must be in a position to contribute to such research to make it valid. As established patients and patient advocates or representatives, we need to move actively beyond patient involvement to becoming patients with a clear purpose and influence in the design process. We must use our influence to ensure that recent patients – the ones whose experience is fresh and intense – actually contribute to defining content and making decisions. As patient advocates of long standing, we can be involved in establishing direction and providing oversight but we must recognise that we may not be the right patients to supply the definitions. The further role of the experienced involved patients is to ensure that PROs data are analysed and are published, ideally in the main study publications. Recognising that there are these twin levels of involvement will make an impact on patient benefit.

We need to move quality-of-life research forward to become a new centre of influence in cancer care. **The first priority is that we must have a single, consistent quality-of-life approach.** The data must be produced and analysed in a way which facilitates comparison between studies and must be capable of being aggregated so that pathways of care can be described from a patient viewpoint.

## Building new purpose for PROs

So what is actually happening in the development of health-related quality of life (HrQoL) and PROs for use in cancer research? A review of the PROs scene reveals that activity across the whole of healthcare is growing and the use of HrQoL data to support policy development, regulatory decision-making, commissioning and treatment is happening. Patients sit on many of these panels and want to hear about the patient experience. There is also a growth in patient involvement in developing PROMs across a wide range of diseases. In cancer, there are a number of initiatives, some relatively small and some with patients actively involved.

For the UK, an important agent in all of this is the National Institute for Health and Care Excellence (NICE). They are working with Sheffield's School of Health and Related Research (SchHARR) to improve the methods by which they translate QoL data into the calculation of the incremental cost effectiveness ratio (ICER), which underpins the health economics in technology appraisals. There are other prominent UK groups working on QoL-related projects. The team in Leeds has been using information technology to gather data at the front line of healthcare in a number of very practical trials. In Oxford, the Quality and Outcomes of Person-centred Care Policy Research Unit (QORU) has a programme informing policy-makers and commissioners.

However, we need something more. We must gather evidence in each of the disparate cancers of treatments that offer benefit to patients, both directly through providing reliable information and advice, and indirectly through influencing regulatory decisions, access to treatments, funding and commissioning.

## The pathway concept

**Describing the patient pathway seems to me to be common sense; it could provide a vision which we all could work towards. By working together using the range of disparate skills at our disposal, it must be possible to unlock patient benefit and a lot more besides.** At the centre of any development of this kind must be the patients themselves. Only patients can provide the necessary input to that research to make it relevant.

We need to measure and describe the pathways experienced by patients in terms that patients understand. This would be done by bringing together quality-of-life data from a range of clinical and research sources,

aggregating and analysing it to describe stages in the disease pathway. Add the relevant medical and clinical information – along the patient journey – and you have a series of descriptions which can underpin the understanding of clinical care and treatment. Many of the developments noted in this commentary would fit into this concept with little or no modification. This concept provides a unifying purpose.

Clinical outcome measures may become secondary to quality-of-life outcomes in some cases. The way would be opened for longitudinal studies using PROs within a reference structure (the pathway), interpreted by patients rather than with more arbitrary researcher-defined outcomes. The existence of pathways would provide frameworks for developing new research ideas. Areas of clinical need would stand out and demand attention. As patients progress along a pathway, we would be able to inform them much more fully about the risks and benefits to expect when they consider a treatment, whether that is the standard therapy or a new intervention.

**A well-described evidence-based pathway is a good vehicle for identifying risks within a recognisable context.** If a risk is realised, a new pathway, or branch, would open up and consequences, mitigation interventions and





so on would be described and could be further researched.

The pathway will bring together disparate data and clarify situations which currently are open to variable subjective interpretation. It adds value in a patient-centred and patient-sensitive way to what we have now. The potential benefits are huge:

- better information for both patients and clinician;
- studies would no longer record outcomes in isolation;
- PROs could be the primary outcomes in research more easily;
- smaller effect sizes in studies would have context;
- smaller studies would be valid, creating huge savings in time and cost;
- we would see fewer 'look-alike' and 'new for the sake of it' drugs;
- it would be impossible to hide treatment side-effects;
- innovation would be encouraged; for example, the recent collaboration between a large pharma company and the NCRI consumer forum;

- regulators would trust data and could manage interim approvals more easily;
- ineffective treatments would be identified quickly.

This pathway approach may facilitate the appraisal of treatments defined as end-of-life. NICE currently utilises a higher ICER threshold for approving such treatments, even when there is only a small improvement in duration of life. A reliable pathway picture, demonstrating the QoL of patients, would help everybody involved.

**I believe such a collaboration to develop pathways of care and treatment underpinned through quality-of-life measures must be supported and enabled by effective patient engagement and involvement.**

### **Collaboration and co-ordination are the keys**

It might appear that elements for the pathway concept are falling into place but it is not in any integrated kind of way. The unifying vision is missing. The challenge is to get co-ordination and collaboration into place to create and sustain an integrated vision which drives standardisation of PROs and quality of life in a way which is relevant to patients. This move would add pressure for PROs to be adopted more usually as a primary outcome measure in cancer clinical research. I believe such a collaboration to develop pathways of care and treatment underpinned through quality-of-life measures must be supported and enabled by effective patient engagement and involvement. One of our roles as patients is to be the 'keeper of the vision', not to be technical authors. We can ensure directions are maintained, provide insights, and we can offer valid and useful input as the development progresses.

**This is a view being articulated by a patient. No-one I have spoken to thinks it is unreasonable, but is anyone prepared to respond and take the lead? At the very least we should have a debate. I believe the pathway concept needs effective patient influence if it is to happen, even patient leadership, but it also needs an independent organisation with influence to host it and there will be a requirement for investment. It will be interesting to see who steps forward.**





# It's time to take CONTROL

A review of what we CAN do to reduce the risk  
of bladder cancer

Although there are many causes of bladder cancer that are outside of our control – such as age, gender and even race (Scosyrev et al.; 2009) – the most up-to-date literature shows that there are also many environmental factors that can affect bladder cancer risk.

## 1 SMOKING

**Cigarette smoking is the primary cause of bladder cancer.**

### SMOKING: THE EVIDENCE

The National Institute of Health in America conducted a study involving 281,394 men and 186,134 women, aged 50 to 71 years old, to evaluate the association between tobacco smoking and bladder cancer (Freedman et al.; 2011). The study involved a lifestyle questionnaire, after which participants were followed up to determine whether or not they developed bladder cancer. Researchers found that former and current smokers both had much higher rates of incidence than people who had never smoked.

Those who had stopped smoking reduced their risk of bladder cancer compared to current smokers, but the risk was still elevated compared to never-smokers. Participants who quit 10 or more years before the start of the study had lower incidence rates of bladder cancer than those who quit only 1–4 years or 5–9 years before the start of the study. Current or previous pipe or cigar smokers were also at elevated risk compared to non-smokers.

The authors suggest that the rise in bladder cancer incidence in recent years, despite the decrease in smoking trends, could be due to changes in the composition of cigarettes.

Similarly, in a meta-analysis of 43 published case-control and cohort studies, Zeegers et al. (2000) found that cigarette smoking increased risk of bladder cancer threefold. **Zeegers et al. (2004) calculated that cigarette smoking causes 23% of all incidences of female bladder cancer and 50% of all male bladder cancer.**

### DOES THE TYPE OF SMOKING AFFECT RISK?

Pitard et al. (2001) found that the method of tobacco smoking did affect risk, so pure cigarette smokers were at higher risk than pure pipe smokers. Zeegers et al. (2004) suggest that this is because cigar and pipe smokers inhale less than cigarette smokers, which also helps to explain why cigar or pipe smokers have an increased cancer incidence in the head and neck, whilst cigarette smokers have a higher incidence of systemic cancers, including bladder cancer. Furthermore, smoking was also found to affect the severity of the cancer. In a study of 740 patients diagnosed over a 22-year period, heavy smokers (more than 30 years) were more likely to have a high-grade tumour and to have muscle-invasive disease at their original presentation than were non-smokers (Pietzak et al.; 2015).







#### ARTICLE

JOSEPHINE ELLIOTT  
Oxford University  
Medical Student

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#### MECHANISM

The precise mechanism by which smoking causes bladder cancer is yet to be determined, but the etiology is probably related to the large number of carcinogenic chemicals present in cigarette smoke, particularly aromatic amines, including 2-naphthylamine and 4-aminobiphenyl (Letašiová et al.; 2012).

#### SECOND-HAND SMOKE

Jiang et al. (2007) conducted a study in Los Angeles County with 148 people with bladder cancer and 292 controls, all of whom were never-smokers. The researchers found that second-hand smoke was related to the development of bladder cancer in women. Women who lived with two or more smokers throughout childhood were three times more likely to develop bladder cancer than those without this childhood exposure. Women who had a domestic partner who smoked for 10 or more years were found to have a two-fold increased risk compared to those without this exposure. The authors did not find these associations in male never-smokers.

**TAKE-HOME MESSAGE:** To prevent bladder cancer, avoid smoking and second-hand smoking.



## 2 DRINKING WATER

**Chlorination is the most common method used for decontaminating drinking water and, at high levels, has been shown to be associated with an increased risk of bladder cancer.**

### CHLORINATION: THE EVIDENCE

In a meta-analysis of six case-controlled and two cohort studies with more than 6,000 bladder cancer cases and 10,000 controls, Villanueva et al. (2003) found that long-term consumption of chlorinated drinking water is associated with a significant increased risk of bladder cancer in men and a non-significant increase of risk in women. Many governments now set limits on the maximum level of chlorine and bromine permissible in drinking water (Daneshmand; 2018).

**TAKE-HOME MESSAGE:** Avoid high levels of chlorine in drinking water.

**Arsenic is a naturally occurring metalloid found in water, soil and air, that can be found in both an inorganic or organic form; only the inorganic form is known to be toxic (Letašiová et al.; 2012). Arsenic is found at higher concentrations in surface soil and ground water in certain countries, including Bangladesh, China, India and Hungary.**

### ARSENIC: THE EVIDENCE

Strong correlation has been found between bladder cancer and exposure to arsenic in drinking water at concentrations exceeding 300–500 µg/l (Meliker and Nriagu; 2007; Navarro, Silvera and Rohan; 2007). However, there is currently no evidence for concentrations below 200µg/l increasing risk (Mink et al.; 2008).

The exact mechanism by which arsenic can induce bladder cancer remains unclear, but Moore et al. (2002) suggest that it is probably by causing chromosomal alterations.

**TAKE-HOME MESSAGE:** Avoid drinking water in areas known to have high levels of arsenic in their water.

**Aristolochic acids are a family of carcinogenic, mutagenic and nephrotoxic phytochemicals, commonly found in birthwort plants. There has been some data to suggest that these acids are associated with an elevated bladder cancer risk.**

### ARISOLOCHIC ACIDS: THE EVIDENCE

In a population-based case-control study in Taiwan, Lai et al. (2010) found that consumption of Chinese herbs that contain aristolochic acid was associated with an increased risk of bladder cancer. Further studies will be required to confirm this association.

**TAKE-HOME MESSAGE:** Avoid consumption of aristolochic acids.





## 3 FLUID INTAKE

**There is evidence to suggest that increased fluid consumption can reduce bladder-cancer risk (Hemelt et al.; 2009).**

### FLUID INTAKE: THE EVIDENCE

Hemelt et al. (2009) conducted a retrospective case-control study with 381 bladder cancer patients and 371 control patients in four hospitals in South and East China to determine whether increased fluid intake, or consumption of certain drinks, reduces the risk of bladder cancer in a Chinese population. The researchers measured how much participants drank over the previous year of six non-alcoholic drinks: black tea, green tea, fruit juice, milk, water and soft drinks. Intake of three alcoholic drinks was also studied: beer, wine and spirits (including rice wine).

Results showed an increase in fluid intake was associated with a reduced risk of bladder cancer in men, however, due to the small number of female cases and controls in this study (69 and 88 respectively), the authors could not draw conclusion of the impact on women. This reflects the results of a previous follow-up study, involving almost 48,000 participants, by Michaud et al. (1999) over a period of 10 years. Michaud et al. (1999) found that total daily fluid intake (over 2.5 litres/4 pints compared to less than 1.3 litres/2 pints) was inversely related to bladder-cancer risk.

As found in other studies, milk was associated with a significantly decreased risk in bladder cancer (Hemelt et al.; 2009). Consumption of beer, wine and spirits was also associated with reduced risk, but tea consumption was not linked to bladder-cancer risk. However, another study found that consumption of large amounts of coffee (7 to 10 cups a day) may cause a slightly increased risk of bladder cancer (Zeegers et al.; 2001).

### MECHANISM

According to the urogenous contact hypothesis, an increase in total fluid intake causes a reduction in the concentration and time that carcinogens are in the bladder, therefore reducing bladder cancer risk. Potentially, increased frequency of urination also plays a role as a protective mechanism. This would also explain the small reduction in risk observed with alcohol consumption in this study (Hemelt et al.; 2009). Although the biological mechanism by which milk could have its protective effect is yet unknown, there are indications that some proteins and fat present in milk have anti-carcinogenic properties.

**TAKE-HOME MESSAGE:** Drink plenty of water (more than 2.5 litres/4 pints) and milk to reduce your risk of bladder cancer.

## 4 OCCUPATIONAL EXPOSURE

**Occupational exposure to aromatic amines, including 2-naphthylamine, 4-aminobiphenyl and benzidine has been shown to increase risk of bladder cancer.**

These compounds have been associated with products from the chemical, dye and rubber industries, and can be found in hair dyes, paints, fungicides, cigarette smoke, plastics, pollutant emissions from industrial installations, and metal and motor vehicle exhaust.

### AROMATIC AMINES: THE EVIDENCE

In a cohort study of over 11,000 English and Welsh workers in the rubber industry, Case and Hosker (1954) found a 200-fold increase in bladder cancer risk in workers exposed to 2-naphthylamine, compared to those who were not exposed to this chemical. The aromatic amine found to be most strongly linked to bladder cancer causation is benzidine, which is used in both the dye and rubber industries. In one of the most important industrial factories in Leverkusen (Germany), 92 of 331 workers who had been exposed to benzidine production before 1967 eventually developed bladder cancer (Golka et al.; 2004). For this reason, those who use hair dye, including barbers, hairdressers and individuals who dye their own hair, may be at a heightened risk of developing bladder cancer (Letašiová et al.; 2012). Due to the carcinogenic characteristics of these chemicals, occupational exposures are responsible for about 18% of bladder cancer cases (Letašiová et al.; 2012). As little as two years' exposure to one of these chemicals can be enough to increase risk, but one should be aware that the time between exposure and developing the cancer can take several decades (Letašiová et al.; 2012).

**TAKE-HOME MESSAGE:** Avoid long-term use of aromatic amines, such as found in the dye and rubber industries.



# 5 MEAT INTAKE

**Frequent bacon consumption may be associated with elevated risks of bladder cancer.**

## BACON: THE EVIDENCE

A prospective study pooling two US cohort studies analysed the link between meat consumption and risk of bladder cancer through multiple food-frequency questionnaires administered over time and statistical testing (Michaud et al.; 2006). Men and women with a high intake of bacon (more than five servings a week) were found to have an elevated risk of bladder cancer when compared to those who never ate bacon.



Never-smokers experienced a more than two-fold increase in risk when consuming one serving of bacon twice, or more, a week, compared with those who did not consume any bacon. The percentage of fat intake in diet was also higher, with a lower intake of multivitamins among consumers of greater amounts of processed meats or bacon.

Red meat intake was not significantly related to bladder cancer risk (Michaud et al.; 2006). However, the authors acknowledge that more studies are required to confirm these findings.

## MECHANISM

The theorised cause for this link between bacon and bladder cancer is that bacon contains high concentrations of nitrosamine, a known bladder carcinogen. Processed meats, although not found to be associated with increased bladder cancer risk in this study, also contain varying concentration of nitrites, which can be converted to nitrosamines and hence may also increase risk of bladder cancer (Michaud et al.; 2006). Further studies will be required to confirm this link and its possible mechanisms.

**TAKE-HOME MESSAGE:** Reduce your bacon intake.

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# 6 CHRONIC CYSTITIS

**Although often out of our control, chronic inflammation of the bladder has been shown to increase risk of bladder cancer.**

## CYSTITIS: THE EVIDENCE

Many studies have shown a positive correlation between individuals with recurrent or chronic bladder infections, or an ongoing source of bladder inflammation (such as gonorrhoea, prolonged indwelling catheters or neurogenic bladder) and bladder cancer (Groah et al.; 2002; Michaud et al.; 2007; Ho et al.; 2015). These conditions cause an increased risk of non-urothelial cancers, especially squamous cell carcinoma (Daneshmand; 2018).

## MECHANISM

There are many possible mechanisms for this association. Repeated chronic irritation can lead to metaplastic changes, then dysplastic changes, which can lead to carcinomas. Inflammatory cells, such as neutrophils, eosinophils and macrophages, are rich sources of reactive oxygen species. Chronic infection predisposes patients to obstructive uropathy, bacterial superinfection, and the production of nitrosamines in the acidic urine environment. Local infiltration of these cells into the bladder mucosa provides angiogenic and lymphangiogenic growth factors, such as cytokines, and proteases, which can enhance tumour progression (Daneshmand; 2018).

**TAKE-HOME MESSAGE:** Practise safe sex to reduce risks of infection.



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# A new lease of life

ARTICLE  
JOHN EDWARD  
PULLAN,  
FBC forum  
member

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John talks candidly about his journey with cancer and is thankful that it brought him many positive blessings

John is a retired Methodist minister, now 81 years old and living in Heysham, Lancashire with his second wife, Dorothy, who he married in 2003. Married to Dora for 40 years before her death from cancer in January 2000, he is a father and grandfather.

## Early signs

My journey with urinary problems began at about 60 years of age. I frequently had the urge to pass urine then waited ages, or at other times I could hardly get to the toilet fast enough. I was forever having to excuse myself in meetings and got to the stage of carrying a screw-capped bottle around in the car. I was diagnosed with an enlarged prostate and for about two years carried out self-catheterisation.

## The big bleed

On 2 May 2010, I was on an afternoon out with the church luncheon club to Windermere and we were having tea in Ambleside. I went to the toilet before leaving, when suddenly I had an outpouring of blood, which frightened me, I have to say; I didn't know what was happening. After it had abated somewhat, I packed myself round with paper towels and Dorothy drove me to A&E at Lancaster Royal Infirmary where I was kept in for three days while they ran a series of tests.

At the end of July I was admitted to LRI for a 'bladder scrape and pressure test' and a couple of weeks later, I was told I had bladder cancer. I was referred to the Oncology Department and prepared for a course of chemotherapy.

## Chemotherapy

Many thousands of people receive chemotherapy treatment for their cancer and cope well with it despite the side-effects – such as hair loss, nausea, and so on – so I do not want to speak against it. For me, however, a full body rash, vomiting, depression and having been stripped of most of my white blood cells meant I only completed two sessions. I was taken off it completely and received donated platelets in a six-day hospital stay.

The only alternative was surgery, which I underwent at Blackburn Infirmary where I had a cystectomy and also removal of my prostate, appendix, and 26 diseased lymph nodes, and, of course, a slice of my gut was taken out to form a stoma. I was in hospital for a total of 21 days and it took me six months to recover from the operation. But it opened up life to me again to live as normally as possible, with voluntary work in the community and busy with church life.

## Managing the urostomy bag

Suddenly having to copy with a bag brings a steep learning curve into your life. I had a bit of a head start as my first wife, Dora, had an ileostomy bag for 34 years following the removal of her large bowel at 26 years of age.

I have had a very supportive stoma nurse who retired in November 2017. For seven years now I have managed my stomach bag, leg bag and night bag well, which now just feel part of me.



## Other problems

Two years on from the operation, I developed a kidney infection and was prescribed Hiprex along with a high dose of ascorbic acid, which I was told I would have to take for life.

Two years after that, I developed a leak of bodily fluid from my redundant penis, which persisted in soiling clothing. I reported this at once but it took over two years with two failed attempts to examine my urethra fully. However, following an annual CT scan in October 2016, I was called back to be told that the cancer cell had been found in both lungs. This was a tremendous shock as I had been clear and healthy for some years. Following an EBUS test (bronchial and lung biopsy), it was revealed that these were bladder cancer cells, thus making a secondary cancer. The aforementioned leak was investigated under sedation and it was found that bladder cancer cells had formed a tumour in my urethra, which turned out to be the primary cause.

## Radiotherapy

The urethra problem was dealt with by 20 consecutive treatments of radiotherapy, which eradicated the tumour. What a relief for me and everyone looking after me.

## Treatment of lungs

It was initially suggested that I try chemotherapy again, substituting different ingredients to prevent a recurrence of my previous problem. However, a new breakthrough came when I was accepted on a two-year trial of a non-chemo drug called Pembrolizumab on an immunotherapy plan. So far I have had eight sessions of the drug and sailed through the treatment with only two minor side-effects. After seven months, the cancer has reduced by three-

quarters of its size and we look forward to being clear before long. Unfortunately, not everyone has had the same results so we cannot call it a wonder drug but I personally hope it is accepted by the NHS so that it can be used more widely and benefit a greater number of people. Again I feel I have a new lease of life for my age, being fit and mentally alert and having a real zest for life.

## Reflections

As I reflect on my journey with cancer, it affects not just the physical, but also the mental, emotional, practical and, for me, spiritual issues.

There are so many people in the three hospitals who have been involved with me in so many different roles – especially my oncologist, urologists, surgeons, radiologists, scientists, trials and specialist nurses and staff, plus transport and all who have supported me – to whom I am most grateful. So many in society are quick to point out the failings of the NHS but my experience is that of dedication, hard work, care and concern for those who are ill. You have to look at the general good of people's endeavours on your behalf. And finally to my family and wide circle of friends who have helped and supported in practical ways, despite their deep concerns for my well-being at various stages along the way, and for so many prayers which have meant so much to me personally.

**May those who read this article find hope and encouragement that cancer is not the end. I wish you the new lease of life that I discovered as you live with the big C.**





# Have they found the

When it comes to quitting smoking, the research lags behind the empirical and anecdotal information but the clear message from this CNS is: **GIVE UP!**

As a Clinical Nurse Specialist (CNS) a large part of my role is to support patients' complex care needs; including signposting to external services and psychological support. CNSs are well placed, throughout the patient's diagnosis, to assess risk and refer onward (NCAT, 2010). They also review patients throughout the treatment pathway, enabling discussions to take place regarding smoking habits and taking any opportunities to encourage interventions which could lead to the patient giving up smoking.

## How it adds up

Bladder cancer is the seventh most common cancer in the world (Edmondson et al., 2017). 380,000 new cases are confirmed and 150,000 deaths occur each year, with an estimated male to female ratio of 3.8:1.0, (Witjes et al., 2015). In 2011, 10,399 people were diagnosed with bladder cancer in the United Kingdom (UK) and almost half of them (5,081) died from the disease (Cancer Research UK, 2014a; Office for National Statistics (ONS), 2015). Bladder cancer affects both males and females, young and old. However, age and smoking increase the risk, (National Institute for Health and Care Excellence (NICE), 2015a). Disadvantaged groups are most likely to smoke; those suffering mental illness are twice as likely to smoke, (McNeil et al., 2015).

## ARTICLE

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# smoking gun?

## How effective are treatments?

While treatments for bladder cancer have remained substantially unchanged over the last 30 years (NICE, 2015a), research and development in treatments for other cancers, notably breast cancer, have changed dramatically. Perhaps this is because bladder neoplasm is not as common as breast cancer (ONS, 2015). It is also impossible to predict which individuals will be cured, or even which will respond to specific treatments (Kamat et al., 2017), resulting in a large financial burden to the health service (NICE, 2015b).

Bladder cancer falls into one of two categories: non-muscle-invasive (NMIBC) and muscle-invasive (MIBC). Treatments for NMIBC are intra-vesical instillations of chemotherapy drugs such as Mitomycin C or immunotherapy Bacillus Calmette-Guerin (BCG). These treatments can affect quality of life (QoL) from extreme urinary frequency caused by chemical cystitis, to disruption of sexual relationships and / or psychological distress regarding treatment failure or recurrence (Anderson and Naish, 2008a). During weeks of intra-vesical instillations, there are also multiple endoscopic inspections. Due to the aggressive nature of the cancer and / or non-compliance to treatment and / or surveillance programmes, intra-vesical chemotherapy and immunotherapy is stated to have a 75% success rate (Kamat et al., 2017).

## Should patients give up smoking?

It is unclear whether smoking decreases the efficacy of intra-vesical chemotherapy; research has been inconclusive (Pietzak and Malkowicz, 2014; Ajili et al., 2013; Grotenhuis et al., 2015).

This uncertainty could be the reason that some healthcare professionals might not highlight smoking cessation to patients. However, patients who continue to smoke after a diagnosis of lung cancer have a higher risk of recurrence and more aggressive disease; therefore it is logical that bladder cancer patients are also at higher risk of recurrence (Bassett et al., 2012). Smoking has also been suggested to impair T- and B-cell responses and cytokine activity, and be the cause of other primary cancers (Rink et al., 2013). **Consequently, health professionals have a duty to discuss smoking cessation and risk of recurrence with patients.**

## Disease progression

Progressive disease or chemotherapy failure can lead to recurrent NMIBC or progression to MIBC (Burger et al., 2013; Ferris et al., 2013). Treatment of MIBC includes neoadjuvant chemotherapy followed either by radical surgery (cystoprostatectomy for males or anterior exenteration for females). An alternative is radical radiotherapy, which in some cases is given with concurrent chemotherapy. Survival at five years from either surgery or radical radiotherapy for NMIBC cases is 70–80%; for MIBC patients this falls to 50% (Margulis et al., 2008).

**Knowledge of the effects from smoking and the prognosis for MIBC patients is limited, with little research identified (Bostrom et al., 2011). However, empirical and anecdotal evidence highlights smoking as a preventable risk; therefore, cessation of smoking should be promoted to patients throughout their treatment pathways.**

Health professionals have a duty to discuss smoking cessation and risk of recurrence with patients.

## The gender gap

Masculinity issues are another crucial area for healthcare professionals to address, and they are working to raise public awareness and promote good health by picking up on opportunities to get their message across'. UK research has highlighted themes of fear, stoicism and lack of confidence in the NHS as reasons why men so often avoid reporting early symptoms. Patient interviews noted that some participants 'did not want to bother the GP', others stated 'cultural reasons' including the British 'stiff upper lip' (Whitaker et al., 2015).

**Interestingly, although females attend the GP surgery earlier than**

**men, delays in treating urinary tract infections caused delay in appropriate referrals, so women referred to urology teams tend to present with advanced disease, resulting in a worse prognosis (Henning et al., 2013). Clearly there is more work to do!**

Pietzak and Malkowicz (2014) found that cultural and societal changes have increased smoking rates for females. Until the 1920s, smoking was largely a male habit and the smoking rates were 50% for males and 33% for females. Manufactured cigarettes and advertising aimed at females changed this trend, and now the rates are similar for both sexes. During both the World Wars, female smoking

consumption rapidly increased (Hunt, Hannah and West, 2004). According to the Department of Health (1998), individuals from the least advantaged groups have barely decreased their smoking rates. Public Health England (2015) acknowledges individuals suffering from mental illness or those from disadvantaged backgrounds as being more likely to smoke.

**The UK government's smoking ban has changed some smoking behaviours. However, there is a professional duty for nurses, urologists, oncologists, general practitioners and CNSs to influence patients to change their habits and help them to stop smoking.**





There is a professional duty for nurses, urologists, oncologist, general practitioners and CNSs to influence patients to change their habits and help them to stop smoking.

### The role of the CNS

The role of the CNS is unique. Patients should be able to discuss anything they are concerned about without judgement. Specialist nurses work as advocates, promoting the patients' well-being by dealing with medical, social or quality-of-life issues that could affect healing or mental well-being. Most CNSs work Monday to Friday 9–5. If you have a non-urgent problem over the weekend, call your CNS and leave a message; they will phone you back on Monday. If it is an urgent issue, such as bleeding, you must go to a walk-in centre or A&E.

For other issues, contact Fight Bladder Cancer UK ([fightbladdercancer.co.uk](http://fightbladdercancer.co.uk)) to access their information, online forums and mutual support networks.

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# Robot-assisted surgery – and I was the first

How Jessie discovered an unexpected advantage to his choice of holiday destination – no baggage restrictions!

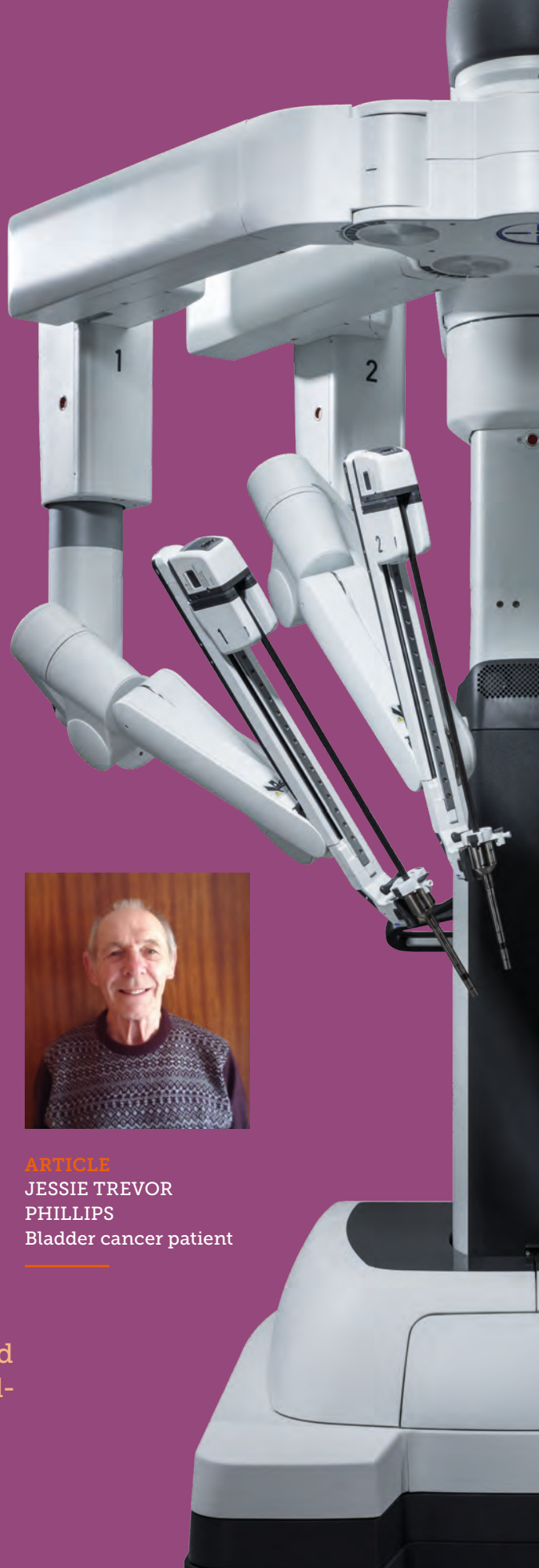
My name is Jessie and I am 70 years old. I live in Wombourne, in south Staffordshire. I am married with two children and I have three grandchildren and two step-grandchildren. I was the first patient in the West Midlands to have a Da Vinci robotic-assisted radical cystectomy.

After experiencing blood in my urine in March 2012, I attended Russells Hall Hospital in Dudley to undergo a flexible cystoscopy. This revealed a large tumour in the bladder, which was removed on 10 April. I returned home the following day with a catheter; it was not very comfortable and I was very pleased when it was removed a week later. I then saw the specialist at Corbett Hospital on 30 April, who informed me that some of the tumour was still in the bladder wall and I would need MRI and CT scan to see if it had spread anywhere else. I was told that I would need to have radiotherapy at New Cross Hospital in Wolverhampton.

When I saw Mr Peter Cooke at New Cross Hospital on 6 June 2012, he informed me that I had a very rare bladder cancer and advised me that the best course of action would be to have my bladder, prostate and lymph glands removed. I would then have a urostomy stoma and have to wear a bag for the collection of urine. I was totally shocked. I was only expecting to have radiotherapy.

Mr Cooke and Jenny Akins (the urology nurse) explained everything to me and my wife, and said I would be a prime candidate for the operation to be carried out by the use of the Da Vinci robot. It would be the first time that this operation had been carried out in the West Midlands so Mr Cooke gave me time to think about it and discuss it with my family. But I knew this was the best course of action so, although I was extremely nervous, I told Mr Cooke to go ahead and make all the arrangements.

On 21 June at New Cross Hospital, Mr Cooke and a specialist from Sweden carried out the ground-breaking operation using the Da Vinci robot.



**ARTICLE**  
JESSIE TREVOR  
PHILLIPS  
Bladder cancer patient



**I am so glad I was able to have my surgery with the use of the Da Vinci robot as I feel my recovery has been much quicker than it would have been with conventional surgery.**

### **A steep learning curve with help to lean on**

Within days, I was walking in the ward and after about a week, I was changing my stoma bag myself. I made a few mistakes but there was always someone on hand to help. All the nursing staff were excellent and very patient with me.

I came out of hospital on 2 July and for the next few weeks the nurse visited me at home to change my wound dressings. Although I was in some discomfort, it certainly wasn't as bad as I thought it would be. Some days were better than others.

I started doing gentle walks around the garden. Five weeks after the operation, my wife took me for a drive. My first big outing was six and half weeks after surgery when I went to see a live band at the Robin 2 in Bilston with my son-in-law driving. I started driving short distances after eight weeks and also managed to walk a little further each week.

### **I'd got my life back!**

On 15 August, I went back to see Mr Cooke, who gave me the wonderful news that all the cancer had been removed. What a relief! There was no need for chemotherapy or radiotherapy. I was over the moon – I had been given my life back.

I started to go out more to build up my confidence, but I found that because my stoma bag filled up so quickly I needed to wear a leg bag attached to my urostomy bag. But I have had no problems accessing toilets when I explain my situation, and people are always very helpful. I have also bought a radar key so that I can access disabled toilets. **Radar keys open over 9,000 disabled toilets in the UK and are available from outlets online.**

I had to make some adjustments. I changed my motor bike for a lighter one, but I was able to ride again in September. We decided to sell our touring caravan as I found it difficult to set up and manage the awning.

I am so glad I was able to have my surgery with the use of the Da Vinci robot as I feel my recovery has been much quicker than it would have been with conventional surgery. That has helped me to remained positive throughout and accept the changes in my life.

### **The care continues**

The aftercare from New Cross has been great. If I have any questions or concerns I can speak to Jenny or Helen, my local CNSs, who can both answer any queries.

In 2013, I did have a little scare when they found a shadow in my gall bladder. However, this was surgically removed and thankfully showed no cancer. I do have two very large hernias, which I cannot have any treatment for, but they are just uncomfortable. I am now more than five years post op and doing well. I do have off days and get very tired, but that could have more to do with my age!


I am a member of Wolverhampton Bladder Cancer Support Group and also attend a similar group in Dudley. Hopefully my experience will help others who are in the same position.

This year we are going abroad for the first time since my op, and have made the decision to go on a cruise to Norway. It is somewhere I have always wanted to go, but it's also a great choice as taking all my stoma bags and equipment will be no problem – there's no baggage restriction!



# Ask the experts about ...

# BCG treatment



In this edition – an in-depth look at Bacillus Calmette-Guérin treatment to help patients understand and cope with the procedure

For most people affected by bladder cancer, there are subjects that we just wish we could ask an expert. Well, with our wonderful Medical Advisory Panel behind us, FBC is now able to invite readers to send in questions on any subject that we might be able to help with. We can't guarantee that your question will be featured in *Fight* magazine, but all letters will be answered!

The question that we have selected to be answered in this edition has come in from Paul who wants to know more about BCG treatment, which he recently found out that he needs to help prevent his cancer coming back.

## What is BCG treatment?

Bacillus Calmette-Guérin (BCG) is used to treat higher-risk non-invasive bladder cancers. BCG treatment has the widest range of patient experiences from 'not a problem at all' through to 'that was hell on earth'.

BCG is a live vaccine used to vaccinate against TB (tuberculosis), but it is also used to treat bladder cancer. It is put into the bladder through a catheter to stop or slow down the re-growth of the cancer. When it is put into your bladder it triggers an immune response that causes inflammatory changes in the bladder.

BCG treatment is normally given once a week for six weeks and continues with a maintenance regime for three years.

## Are there any reasons why I should not have BCG?

BCG treatment is contraindicated if:

- you have a UTI;
- the initial operation to remove the cancer from your bladder (TURBT) was done less than 14 days earlier;
- you are taking immune-suppressive medication or are immune-compromised;
- you have a bleeding disorder;
- you have active TB and are receiving treatment;
- you are breast feeding;
- you are pregnant or trying to conceive;
- you have had a flu or shingles vaccine within the last six weeks.

## Is there anything I need to do before my treatment?

You should limit your fluids for six hours before treatment. One glass of fluid may be taken with breakfast, and you can eat normally.

By drinking less, your kidneys will produce less wee. This will help prevent the BCG being diluted and will also make it easier for you to hold the BCG treatment in the bladder for two hours.

If you normally take water tablets (diuretics), either take them after your BCG treatment is completed or at least six hours before your treatment. This will reduce the amount of wee produced and will enable you to hold the BCG in the bladder.

## What happens during treatment?

You will be asked to wee to ensure your bladder is empty.

A catheter will be passed into the bladder through the urethra to drain any remaining wee and insert the BCG.

The catheter will then be removed. In some cases the catheter may be left in the bladder during the treatment. If this is so, the catheter will be clamped to keep the BCG in the bladder. You will be asked to try not to wee for the next two hours.



## How long will the treatment take?

The treatment takes two hours, after which you'll be able to go home. You should feel well enough to drive yourself home after the treatment.

After your first few treatments, if you live within easy reach of the hospital and have your own transport, you may be allowed to go home with the medication in your bladder and wee at home after two hours.

If you are elderly or infirm, you may wish to arrange for a friend or relative to accompany or collect you.

## What to do after your treatment

When the BCG has been in your bladder for two hours you will be asked to wee into the toilet (men should sit rather than stand to prevent splashing). If the catheter was left in the bladder during your treatment, the BCG will be drained back into a bag before the catheter is removed.

You should abstain from intercourse/oral sex for two to three days after each treatment. The use of condoms thereafter is advised, and should continue to be used for several weeks after your treatment has been completed.

**BCG treatment is normally given once a week for six weeks and continues with a maintenance regime for three years.**



The effects on pregnancy are unknown. If you are planning to have children you should discuss this with your doctor, as female patients of child-bearing age are advised to use birth control during treatments and to wait at least two years before conceiving (longer if on maintenance treatment). Breast feeding is not advised when having BCG treatment.

You will be able to carry out your normal activities after treatment. There are no restrictions on driving, work or other everyday activities.

### **Are there any special precautions I should take at home?**

All the wee you pass during the first six hours after treatment should be treated as contaminated. It is recommended that you pour two cups of household bleach into the toilet (bleach neutralises BCG) and leave it for 15 minutes before flushing. Ensure no one uses the toilet during this 15 minutes.

For several hours after your treatment, wash your hands and genital area with soap and water each time you wee.

### **Are there any possible side-effects from the treatment?**

Almost everyone will get side-effects from having BCG treatment to a greater or lesser extent.

### **Common side effects**

These symptoms can last for a few days or a few weeks and include:

- flu-like symptoms what can last for between one and three days;
- problems weeing;
- pain when weeing;
- feeling the need to wee more often than usual that can last for two to three days;
- bladder infection and discomfort;
- blood/scabs in the wee;
- fever (high temperature) which may last one or two days; this affects about 30% of patients.

### **Less common side-effects that require urgent medical attention**

You should contact your medical team immediately if you experience any of the following symptoms:

- shortness of breath;
- confusion;
- dizziness or lightheadedness.

If you can't contact your medical team for some reason, we would recommend that you go straight to A&E.

### **Less common side-effects that require non-urgent medical attention**

These are not an emergency, but you should contact your medical team within 24 hours of noticing any of the following:

- fever of 39.5°C / 103°F or higher within 24 hours;
- fever of 38.5°C / 101°F or higher after 48 hours;
- blood in the urine;
- extreme fatigue.

Remember that fever, chills, flu-like symptoms, increased fatigue or an increase in symptoms such as burning or pain when weeing are not uncommon. However, if these increase in severity or last more than 48 hours, let your medical team know.

The most important thing to remember is that BCG is very likely to give you a range of side-effects. Most of these are normal, sometimes quite painful, but usually not dangerous. However, if you have any doubt, do contact your specialist nurse for advice.

# POUT

## LEAD INVESTIGATOR

DR ALISON BIRTLE,

Consultant clinical oncologist & FBC trustee

# A treatment changing trial?



This practice-changing trial is now getting the recognition it deserves. Andrew Winterbottom, Founder and CEO of Fight Bladder Cancer, has been a patient representative on the POUT trial that was led by FBC trustee Dr Alison Birtle, consultant oncologist and trustee and medical advisor to FBC.

The trial has recently been stopped as it had clearly demonstrated that a new treatment regime was significantly better than the current standard of care.

We will be publishing a full report in the next edition of our *Fight*

magazine, but we wanted to bring you the wonderful news as soon as we could!

### So what was the POUT trial?

Upper tract urothelial cancer (of the ureter, the tube draining the kidney on each side, and of the renal pelvis, the bit of the tube that pushes into the kidney at the top end) looks very

similar to bladder cancer but is less common and has benefitted from far less research.

After an operation to remove the kidney and ureter for this type of cancer, we know that there is quite a high chance of recurrence but we have never known if giving treatment with chemotherapy within the first three months after this operation reduces the risk of the cancer returning.

The POUT trial presented results at a recent international meeting and showed that this UK-led and UK-delivered study has shown for the first time that we can do better for these patients. It is now likely that giving four cycles of chemotherapy within 90 days of surgery for these patients will be the new standard of care.

A full article will appear in the next issue of *Fight* but in the meantime check out on line Alison's interview with eCancer at [goo.gl/a4cBXZ](http://goo.gl/a4cBXZ)

Professor Rob Jones from Glasgow, who was also involved in the trial, commented: '261 patients took part in POUT and many more wanted to but, for one reason or another, were unable. As a result of their selfless "donation" of time and risk of side-effects, with no guarantee of benefit, these people have changed the way we treat this disease for the better in the future. As doctors, we are eternally grateful.'

**'As a result of their selfless "donation" of time and risk of side-effects, with no guarantee of benefit, these people have changed the way we treat this disease for the better in the future.'**



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

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

Following our failed attempts at heating the bladder with a chemotherapy agent, Mitomycin-C (MMC) at 65°C, and the experience of others with solutions of up to 80°C<sup>[1,2]</sup>, we pursued more feasible methods.

First clinical article following a feasibility study, shows selective damage to tumours, whereas healthy tissue remains unaffected<sup>[5]</sup>. Since then, over 40 articles demonstrate its clinical potential.

Long-term follow up (10 years) on the randomised patients of the 2003 trial, showed durable outcomes<sup>[7]</sup>.

1988

1989

1991

2003

2010

Radiofrequency (RF) found to be the reliable and controllable means to heat the bladder tissue, in combination with a constantly cooled MMC instillation<sup>[3]</sup>. This also bypasses problematic heating of the urethra, and further degradation of the drug when directly heated<sup>[4]</sup>.

Randomised trial results show that certain types of patient, stayed cancer-free substantially longer, compared with one year of MMC instillations without the RF. Side-effects reported were comparable; generally mild, transient and self-healing<sup>[6]</sup>.

### Your health is your most valuable asset!

Ask your doctor about all treatment options, as well as their risks, benefits and clinical evidence.

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

The above is intended only to supply patients with available information for enhancing patient-doctor dialogue.

**We shall continue to strive for better minimally invasive solutions for bladder cancer patients - this is our oath to you.**

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

Breakthrough proving RF is the predominant mechanism of action in most 'hyperthermic' treatments, with non-thermal effects selective to cancer cells <sup>[9,10]</sup>.

Randomised trial results show that certain types of patient remained cancer-free for a longer period of time, compared with one year of BCG instillations when given as a primary treatment <sup>[12]</sup>.

2014

2014

2015

2016

2017

Study shows that a variety of patients given RF treatments remained without bladder cancer (appearing anywhere in the body) for a longer period, compared with patients whose bladders were removed, with durable, long-term outcomes after 5 years <sup>[8]</sup>.

Discovery of RF harnessing the immune response, differentiating it from MMC instillations <sup>[11]</sup>.

The European Association of Urology (EAU) guidelines present RF-assisted chemotherapy instillations as the only proven efficacious technology for treating Non-Muscle Invasive Bladder Cancer <sup>[13]</sup>.

<sup>[1]</sup> England H.R. et al. *The Therapeutic Application of Hyperthermia in the Bladder*, BJU International. 1975;47(7):849-852. <sup>[2]</sup> Ludgate C.M. et al. *Hyperthermic irrigation of bladder in treatment of transitional cell carcinoma: its effectiveness in controlling persistent haematuria*, J R Soc Med. 1979;72(5):336-340. <sup>[3]</sup> Syrigos K.N., Skinner D.G. *Bladder Cancer: Biology, diagnosis and management*, Oxford Medical Publications. 1999;393-406. <sup>[4]</sup> Paroni R. et al. *Effect of local hyperthermia of the bladder on mitomycin C pharmacokinetics during intravesical chemotherapy for the treatment of superficial transitional cell carcinoma*, Br J Clin Pharmacol. 2001;52:273-278. <sup>[5]</sup> Rigatti R. et al. *Combined intravesical chemotherapy with mitomycin C and local bladder microwave-induced hyperthermia as a preoperative therapy for superficial bladder tumors - A preliminary clinical study*, Eur Urol. 1991;20:204-210. <sup>[6]</sup> Colombo R. et al. *Multicentric Study Comparing Intravesical Chemotherapy Alone and With Local Microwave Hyperthermia for Prophylaxis of Recurrence of Superficial Transitional Cell Carcinoma*, J Clin Oncol. 2003;21(23):4270-4276. <sup>[7]</sup> Colombo R. et al. *Long-term outcomes of a randomized controlled trial comparing thermochemotherapy with mitomycin-C alone as adjuvant treatment for non-muscle-invasive bladder cancer (NMIBC)*, BJU International. 2010;107:912-918. <sup>[8]</sup> Nair R. et al. *Challenging the gold standard: A comparison of long-term specific outcomes for high-risk non-muscle invasive bladder cancer treated with mitomycin hyperthermia and radical cystectomy*, Eur Urol. Supplements 2014;13(1):e1109. <sup>[9]</sup> Curley S. et al. *The Effects of Non-Invasive Radiofrequency Treatment and Hyperthermia on Malignant and Nonmalignant Cells*, Int J Environ Res Public Health. 2014;11:9142-9153. <sup>[10]</sup> Ware M.J. et al. *Radiofrequency treatment alters cancer cell phenotype*, Scientific Reports. 2015;5:12083. <sup>[11]</sup> Arends T.J.H. et al. *Urinary cytokines in patients treated with intravesical mitomycin-C with and without hyperthermia*, World J Urol. 2015;33(10):1411-1417. <sup>[12]</sup> Arends T.J.H. et al. *Results of a Randomised Controlled Trial Comparing Intravesical Chemohyperthermia with Mitomycin C Versus Bacillus Calmette-Guérin for Adjuvant Treatment of Patients with Intermediate- and High-risk Non-Muscle-invasive Bladder Cancer*, European Urology, 2016;69(6):1046-1052. <sup>[13]</sup> EAU Guidelines. Edn. presented at the EAU Annual Congress London 2017. ISBN 978-90-79754-91-5.

**MEDICAL  
ENTERPRISES**

**SYNERGO® RITE**  
FOR BLADDER CANCER



# Clinical trials

## Developing vital research for bladder cancer



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

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.

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

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

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

If you are interested in helping with our research work, please call 01844 351621 or email [research@fightbladdercancer.co.uk](mailto:research@fightbladdercancer.co.uk) for more details.



# Current open trials

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

## DETECT 1

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

## Non-invasive bladder cancer

### BRAVO

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

### CALIBER

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

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

### HIVEC II

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

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

### PHOTO

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

## Muscle-invasive bladder cancer

### BISCAY

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

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

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



## BRISTOL BLADDER TRIAL

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

Cisplatin is a chemotherapy drug often used to treat bladder cancer which is usually given together with another drug such as gemcitabine. This trial is testing the combination of cisplatin and a drug called cabazitaxel and how well this combination works for treating invasive transitional cell bladder cancer before surgery and more about the side-effects.

## IDEAL

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

## SPIRE

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

## ABACUS

ABACUS is a study for patients who are not able to receive neoadjuvant chemotherapy prior to cystectomy, usually because their kidney blood tests are not good enough to have cisplatin chemotherapy. In ABACUS, another drug

is given for 6 weeks or so before cystectomy to see if this improves the results of the surgery and to see if there are any side-effects that might make the surgery more difficult. The drug in ABACUS is MPDL3280A, a PDL-1 inhibitor.

## RAIDER

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

## Advanced muscle-invasive bladder cancer

## ATLANTIS

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

## MPDL 3280A

(The IMvigor Trial)

MPDL 3280A (IMvigor) is a study for patients who have

undergone a radical cystectomy for muscle-invasive bladder cancer and who have high-risk features on their surgical specimen, meaning that microscopic examination of the bladder, after removal, suggested that the cancer had a higher rate of coming back in the future. This study is looking at whether giving a new drug called atezolizumab, an anti-PDL-1 antibody, reduces the chance of the cancer coming back.

## PLUMMB

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

## Invasive upper tract urothelial carcinoma

### POUT

The POUT study has been discontinued and its recommendations accepted as the new standard of care. See article on page 57.

# FBC glossary

<b>adjuvant</b> after initial treatment to prevent secondary tumours	<b>CT</b> computerised axial tomography	<b>histopathological</b> microscopic examination of tissue to identify disease
<b>angiogenesis</b> the development of a blood supply to a tumour	<b>cystectomy</b> removal of the bladder	<b>HNA</b> Holistic Needs Assessment
<b>anterior exenteration</b> surgical removal of a woman's bladder and reproductive organs	<b>cystoprostatectomy</b> surgical removal of the bladder and prostate	<b>HrQoL</b> health-related quality of life
<b>antiemetic</b> a drug to counteract nausea and vomiting	<b>cystoscopy</b> a procedure to examine the inside of the bladder	<b>ICER</b> incremental cost effectiveness ratio
<b>B-cell response</b> a natural immune response	<b>cytokines</b> cells that communicate an immune response	<b>immune component</b> part of the immune system
<b>basal</b> relating to the base	<b>DAT</b> device assisted therapy	<b>immunotherapy</b> treatment using the body's immune responses, also called immune oncology therapy
<b>baseline</b> starting point for comparison	<b>DNA</b> deoxyribonucleic acid	<b>inhibitory pathway</b> a situation in which defensive cells are preventing from attacking foreign cells
<b>BAUN</b> British Association of Urological Nurses	<b>durable response rate</b> the length of time a response is observed	<b>intolerable toxicity</b> the point at which the treatment becomes more painful than the disease
<b>BAUS</b> British Association of Urological Surgeons	<b>DVT</b> deep-vein thrombosis, a blood clot in a deep vein in the body	<b>intra-vesicle installations</b> treatments administered directly into the bladder via a catheter
<b>BC</b> bladder cancer	<b>dyplasia</b> abnormal development	<b>ITU</b> intensive therapy unit
<b>BCG</b> Bacillus Calmette-Guerin, a treatment for early-stage bladder cancer	<b>dysuria</b> painful or frequent urination	<b>KW</b> key worker
<b>BCQS</b> Bladder Cancer Quality Standards	<b>EAU</b> European Association of Urologists	<b>lines [of treatment]</b> treatment regimens
<b>biomarker</b> something by which the disease can be identified	<b>EBRT</b> external beam radiotherapy	<b>luminal</b> relating to the hollow inside an organ such as the bladder
<b>biopsy</b> a sample of tissue taken for examination	<b>EBUS</b> endobronchial ultrasound test for lung cancer	<b>lymph nodes</b> small glands that store the white blood cells that help to fight disease and infection in the body
<b>BLC</b> blue light cystoscopy	<b>ECPC</b> European Cancer Patients Coalition	<b>lymphangiogenic</b> originating in the lymphatic system
<b>cannula</b> a thin tube inserted into a vein in the arm or hand	<b>ED</b> erectile dysfunction	<b>macrophages</b> specialist cells in the blood vessel walls
<b>carcinogenic</b> cancer-causing	<b>EMA</b> European Medicines Agency	<b>MDT</b> multi-disciplinary team
<b>carcinoma</b> malignant growth or tumour	<b>endoscopic</b> an illuminated tubular device used to look inside the organs	<b>metaplasia</b> conversion from normal to abnormal tissue
<b>catheter</b> a thin tube	<b>enhanced recovery pathways</b> methods of improving recovery times and experience	<b>metastatic</b> a cancer that has spread to an unrelated organ
<b>CCG</b> clinical commissioning groups	<b>eosinophils</b> a leukocyte or blood cell lacking haemoglobin	<b>MIBC</b> muscle-invasive bladder cancer
<b>checkpoint inhibitors</b> drugs that prevent cancer cells from disabling protective T-cells	<b>ER</b> enhanced recovery	<b>MRI</b> magnetic resonance imaging
<b>chemoradiation</b> combination treatment of drugs and x-rays	<b>expressed</b> active	<b>muscle-invasive bladder cancer</b> cancer that has spread from the lining to the muscles of the bladder
<b>chemotherapy</b> treatment with drugs	<b>FBC</b> Fight Bladder Cancer	<b>mutagenic</b> an agent that changes genetic material
<b>CIS</b> carcinoma in situ or flat tumour	<b>FDA</b> Food and Drugs Administration (US)	
<b>CNS</b> clinical nurse specialist	<b>fMRI</b> functional magnetic resonance imaging	
<b>confocal laser endomicroscopy</b> an advanced imaging technique for diagnosis	<b>GI</b> gastrointestinal	
	<b>haematuria</b> blood in the urine	
	<b>HCP</b> health care professional	
	<b>histology</b> the microscopic examination of cells	



**MVAC** chemotherapy treatment involving methotrexate, vinblastin, doxorubicin and cisplatin

**narrow band imaging** imaging enhancement to aid diagnosis during a cystoscopy

**NCRAS** National Cancer Registration and Analysis Service

**NCRI** National Cancer Research Institute

**NED** no evidence of disease

**neoadjuvant chemotherapy** chemotherapy given before surgery

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

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

**neopeptides** newly formed cells

**neoplasm** tumour

**nephrotoxic** toxic to the kidneys

**neutrophils** a type of white blood cell

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

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

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

**PALS** Patient Advice and Liaison Service

**PCT** primary care trust

**PDD** photodynamic diagnosis

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

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

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

**PET** positron emission tomography

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

**PFS** progression-free survival

**photodynamic diagnosis** BLC or blue light cytology

**PHR** patient-held record

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

**polyuria** frequency of urination

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

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

**PROMs** patient-reported outcome measures

**proteases** enzymes that break down protein

**pyrexial** feverish

**QoL** quality of life

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

**radiotherapy** treatment with radiation

**RCTs** randomised control trials

**refractory** resistant

**resection** surgical removal

**sensitivity** a measure of the percentage success rate of a test on patients with a disease

**specificity** a measure of the percentage success rate of a test on patients who do not have a disease

**squamous** scaly

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

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

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

**tachycardia** abnormally fast heart rate

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

**transitional cell cancer (TCC)** most common urinary cancer

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

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

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

**uropathy** a disease of the urinary tract

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

**urothelial** of the urinary tract

**UTI** urinary tract infection

**visceral** of the nervous system

## Main bladder cancer drugs

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

**alprostadil** Vitaros®

**avanafil** Spedra®

**atezolizumab**

**cabazitaxel** Jevtana®

**cabozantinib**

**carboplatin** Paraplatin®

**cavaject**

**cisplatin**

**doxorubicin** Adriamycin®

**durvalumab**

**evalumab**

**gemcitabine** Gemzar®

**Ibhibizone™**

**methotrexate** Maxtrex®

**minocycline**

**mitomycin** Mitomycin C Kyowa®

**nivolumab**

**nintendanib**

**paclitaxel** Taxol®

**pembrolizumab**

**rifampin**

**sildenafil** Viagra®

**tadalafil** Cialis®

**varafenafil** Levitra®

**vinblastine** Velbe®

# You can help us fight bladder cancer!



Call us on  
**01844 351621**  
or visit **fightbladder  
cancer.co.uk/  
get-involved**

Every time you work with us, from giving a donation to helping distribute our posters and patient information booklets, you're helping make a big difference to everyone 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.

- **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**

**"I felt so alone with my cancer that I felt like giving up ... but finding Fight Bladder Cancer was my lifeline, they have been there for me at every step."**

Darren Roberts, aged 50

## Bladder cancer grading & staging

There are five broad categories of bladder cancer. Each person's cancer is defined by a code of numbers and letters according to how aggressive the cancer cells are, how far they have spread through the three layers of the bladder wall, and whether they have spread further into the body.

- Low risk non-muscle-invasive bladder cancer
- Intermediate risk non-muscle-invasive bladder cancer
- High risk non-muscle-invasive bladder cancer
- Muscle-invasive bladder cancer
- Advanced bladder cancer

Grades (1, 2, 3) indicate how aggressive the cancer is and therefore how likely to spread.

Tumour stages (T) indicate the spread of the tumour in the bladder.

- Ta = Papillary cancer is small growths on the bladder lining
- T1 = Cancers in the bladder lining
- T2 = Cancers that have grown into the bladder muscle
- T3 = Cancers that have grown through and beyond the bladder muscle and into the surrounding fat
- T4 = Cancers that have grown through the bladder wall into other muscles

Lymph node stages (N0, N1, N2, N3) indicate the spread of the cancer through the lymph nodes.

Metastasis (M0 or M1) indicates that the cancer has spread to other sites in the body.

Additional letters (CIS, p, c) supply further information.

- CIS = Carcinoma in situ is an aggressive form of cancer in which the cells grow flat on the bladder lining
- p = Diagnosis based on pathological or microscopic findings.
- c = Diagnosis based on clinical, usually imaging, findings.

# What's right for my fight?

## Understand your options

If you and your doctor decide that surgery is right for you, be sure to ask about all of your options.

Skilled robotic-assisted keyhole surgeons offer patients a minimally invasive surgical approach that may be right for your fight.



Intuitive recognizes the vital work of Fight Bladder Cancer in its aim to support and to achieve better outcomes and quality of life for all those affected by bladder cancer.

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