

fight

MAGAZINE



HOPES & DREAMS

OUR FOUNDER OUTLINES HIS PLANS FOR FBC FOLLOWING A TERMINAL DIAGNOSIS

QUALITY OF LIFE

JIM CATTO & SAMANTHA MASON DISCUSS THEIR CURRENT RESEARCH STUDY

STORIES

PATIENTS SHARE THEIR BLADDER CANCER EXPERIENCES

BCAM 2018

WE REVIEW LAST YEAR'S BIG AWARENESS CAMPAIGN

MEET THE TEAM

WE INTRODUCE OUR EXPANDED TEAM AT FBC HEADQUARTERS

WE ASK YOU TO STEP FORWARD & HELP SUPPORT ANDREW'S VISION

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Looking to a new future

Welcome to the 6th edition of our FIGHT magazine.

This is a special edition of our FIGHT magazine in that we are bringing everyone up to date with the news that our founder, Andrew Winterbottom, has recently been given a terminal diagnosis and is currently having treatment that we all hope will be life-extending.

As the founder of Fight Bladder Cancer, Andrew remains passionate about the charity and consequently has launched a very personal campaign to help ensure the longevity of the organisation.

In this Step Forward campaign, Andrew is asking everyone to Step Forward to support people affected by bladder cancer throughout the United Kingdom by making a monthly gift to Fight Bladder Cancer, with his clear statement that you can't save his life but you can help save his dream.

This edition explains Andrew's forward vision for the charity and highlights the many new research and policy initiatives that FBC is planning for the near future.

It is also filled with inspirational stories from people affected by cancer, along with some insights into the amazing fundraising and campaigning activity that continues throughout the year for Fight Bladder Cancer. Bladder Cancer Awareness Month last year was our biggest ever campaign and we'll share some of the highlights of what you all achieved last year for our biggest ever Awareness Month. We also bring you a summary of our 2018 Impact Report.

There is some encouraging new research on potential new non-invasive tests for bladder cancer, details of the new World Bladder Cancer Patient Coalition, and a resumé of all the major clinical trials that are currently recruiting bladder cancer patients in the UK.

Andrew has a clear vision for the future of Fight Bladder Cancer which, supported by our trustees, will allow our new CEO, Dr Lydia Makaroff, to lead our fantastic team onto greater things to the benefit of bladder cancer patients and their families from across the UK and beyond.

Team FBC

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

SUPPORT

Supporting all those affected by bladder cancer

AWARENESS

Raising awareness of the disease so it can be caught early

RESEARCH

Campaigning for and supporting research into this much-ignored disease

CHANGE

Affecting policy at the highest levels to bring about change

fightbladdercancer.co.uk

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)



Registered charity 1157763

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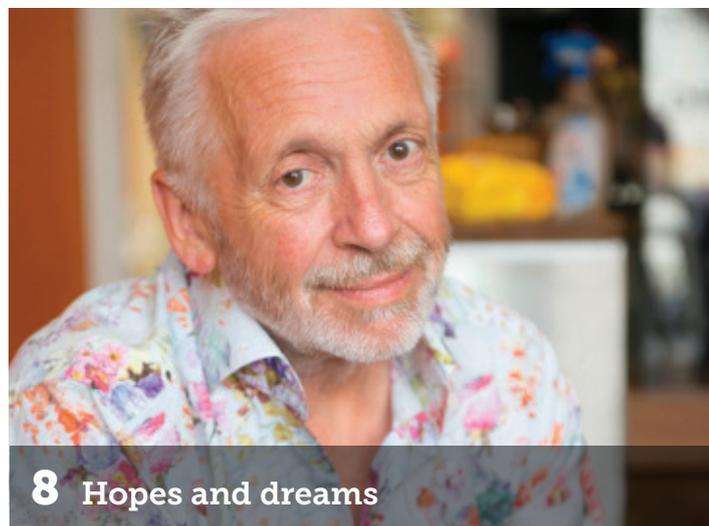
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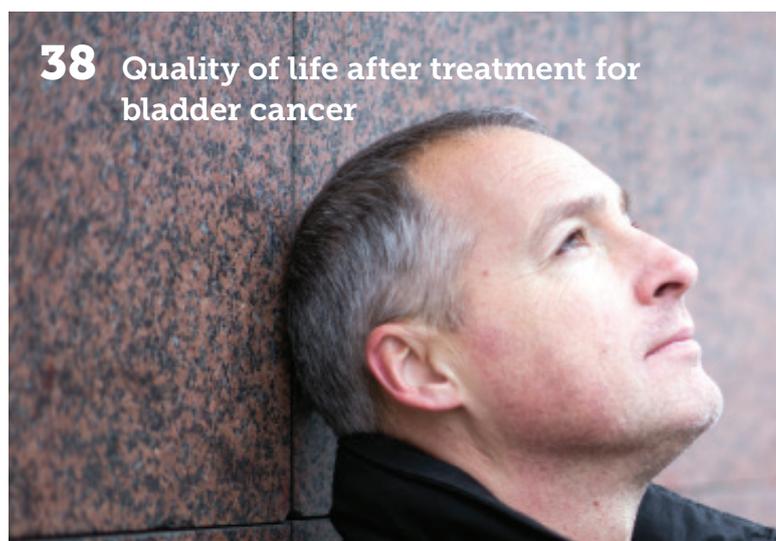
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FBC round up

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

SUPPORT

ONLINE FORUM

FBC's confidential online forum now has 4,295 members and is supervised around the clock by a team of ten dedicated moderators 24 hours a day, seven days a week.

BECOME A BLADDER BUDDY

As Fight Bladder Cancer continues to grow, we are now looking to recruit more people to join us as Bladder Buddies across the UK. Bladder Buddies can be patients or carers who are happy to be put in touch with someone who has recently been affected by bladder cancer in some way. They may be patients, carers, relations or simply friends who just need someone to talk to. Being a Bladder Buddy is not about giving medical advice; in fact, it is much more about listening than talking. With your personal experience of bladder cancer, you can lend a sympathetic and, above all, understanding ear to someone who needs to share their raw experience. 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 out more about becoming a Bladder Buddy, please email us at info@fightbladdercancer.co.uk and we will send you details of the application process and how we would support you in this role.



LOCAL FIGHT CLUBS

We now have support groups throughout the country, including Fight Clubs based in London, Canterbury, Denbighshire, Glasgow, Newmarket, Southampton and Stockport.

Fight Bladder Cancer is also supporting other local groups across the country that are run by hospitals, by providing speakers as well as printed materials. If you are a member of a local support group that might want to join our network, please do get in touch with us at sophie@fightbladdercancer.co.uk.

AWARENESS

FIGHT BLADDER CANCER ON THE RADIO AND IN THE NEWSPAPERS

We are constantly working to raise the profile of bladder cancer by making sure the activities of the bladder cancer community – patients, doctors, carers, fundraisers or researchers – are featured in the media. In the past year, Fight Bladder Cancer has been featured in the Chronicle Live, Daily Record, HuffPost UK, Kent Online, Oxford Mail, PharmaTimes, Portsmouth News, Redditch & Alcester Advertiser, Thame Gazette and the Herald Scotland.

Radio stations are a crucial way of reaching a wider audience and we have regular spots on both BBC Radio Oxford and Red Kite Radio.



WORKING WITH THE NHS

Fight Bladder Cancer worked with the NHS on their 'Blood in Pee' campaign, designed to ensure that the general public became more aware of the importance of going to see their GP if they had any sign of blood in their pee, even if it only occurred once. This symptom can have a number of causes, but it is essential to have it checked immediately as – if it does turn out to be something serious – early diagnosis is vital in improving the potential outcome.

TELEPHONE AND EMAIL SUPPORT

Our telephone support line is available 9.30am–4.30pm Monday to Friday on 01844 351621. There is a voicemail for messages outside these hours or when we are very busy. For more information about our email support service, please contact us at info@fightbladdercancer.co.uk.



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

media@fightbladdercancer.co.uk

NICE AND THE SCOTTISH MEDICINES CONSORTIUM

Fight Bladder Cancer has helped NICE and the Scottish Medicines Consortium review new medicines for bladder cancer during Health Technology Assessment meetings. We were able to ensure that the outcomes that are most important to patients – such as good quality of life – were given the right priority.

BRITISH ASSOCIATION OF UROLOGY SURGEONS

Our founder, Andrew Winterbottom, gave a presentation at the British Association of Urology Surgeons' meeting in Liverpool in June 2018, and at the British Association of Urology Surgeons' oncology meeting in York in December 2018. He discussed research questions in bladder cancer, as well as the importance of signposting bladder cancer patients to peer support groups.

BRITISH ASSOCIATION OF UROLOGY NURSES



Fight Bladder Cancer had a booth at the British Association of Urology Nurses' conference in Bournemouth in November 2018. We were able to extend our contacts among urology nurses, who are always pleased to see us for a chat and a catch-up.

TALK HEALTH PARTNERSHIP

During Bladder Cancer Awareness Month in May 2018, Fight Bladder Cancer hosted an online Ask the Expert Clinic, offering the opportunity to speak directly to bladder cancer experts online. Members of the public posted their questions about bladder cancer and received immediate answers from a panel of professionals.

RESEARCH

SUCCESS IN THE POUT TRIALS

Fight Bladder Cancer is an active member of the National Cancer Research Institute's Bladder and Renal Cancer Clinical Studies Group, and a partner in its POUT trial of chemotherapy versus surveillance in people with a type of cancer called upper tract transitional cell carcinoma, who have had their bladder and kidneys surgically removed. The study showed a 17% benefit in disease-free survival after two years for those who have added chemotherapy. At the American Society of Clinical Oncology Genitourinary Cancers Symposium, POUT was declared the most practice-changing study; it also won first prize for oncology at the European Association of Urology Congress.

BLADDER CANCER AWARENESS MONTH – MAY 2019

Take a look at what we got up to in the 2018 Bladder Cancer Awareness Month (page 14). For 2019, we have many more awareness activities planned, including awareness walks. We REALLY hope you'll join us. If you would like to find out how to get involved in Bladder Cancer Awareness Month, please contact us at getinvolved@fightbladdercancer.co.uk.

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

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 Facebook 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.

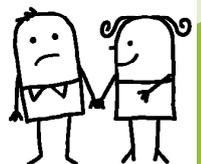
BLADDER BUDDIES

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

NO DECISION ABOUT ME, WITHOUT ME

The National Cancer Research Institute's Bladder and Renal Cancer Clinical Studies Group also promoted the 'No decision about me, without me' and 'Ok to ask' campaigns. Both of these campaigns focus on ensuring a patient-centred service, so the group promotes studies that patients want to be involved in, and looks at what the key questions are for patients, not just for the researchers, to ensure that trials can recruit successfully and deliver useful outcomes. The current consumer members of the CSG are internationally known advocates for bladder and renal cancer, and will be offering a vital cross-over period of mentoring to the incoming consumer members. Within these campaigns, Fight Bladder Cancer has empowered patients to challenge clinicians where studies are not available locally and ask for cross referral.

FURTHER RESEARCH

Fight Bladder Cancer gave feedback on the design of the iROC clinical study to compare robot-assisted surgery with traditional surgery for bladder removal. For more information about this and other clinical trials, see page 52.

Fight Bladder Cancer is currently conducting structured interviews as part of their Exemplar study with health professionals and bladder cancer patients in order to understand the major challenges in British bladder cancer care pathway. We will report on this research in the next edition.

POLICY

Fight Bladder Cancer has been very active in ensuring that the patient voice is heard in British and European policy discussions. Since its creation in June 2010, the Fight Bladder Cancer twitter account @bladdercancerUK has published over 11,900 tweets, and now has over 3,700 followers. Fight Bladder Cancer is also an active member of the Cancer52 neglected cancers network, the All.Can UK initiative to improve efficiency in cancer care, and is on the Board of the European Cancer Patient Coalition.

Fight Bladder Cancer was an author of the European Association of Urology's Update of Recommendations on the Appropriate Use of Social Media. We helped to develop ten practical recommendations for the responsible, ethical and constructive use of social media communication technologies. These recommendations include exercising professionalism, never undermining patients' privacy, and using disease-specific hashtags for structured online communication.

Fight Bladder Cancer was very active at the European Cancer Patient Coalition's annual congress in June 2018. In addition to chairing the working group on bladder cancer, and sessions on communication, immuno-oncology and molecular testing, we gave a presentation on what life was like as a carer of someone affected by bladder cancer. Fight Bladder Cancer will also lead the 2019 Bladder Cancer Awareness Month activities of the European Cancer Patient Coalition.

The Wee Bookshop & Café

'Such a lovely atmosphere, friendly staff and a fantastic charity. The children love spending their money on the books here and I particularly love the cakes!'
Hayley

The Wee Bookshop and Café is a magical place full of great books – both new and preloved – which also sells wonderful food and fabulous hot and cold drinks. They will be celebrating their third birthday in April 2019.

Every time you visit the Wee Bookshop and Café, you are supporting people affected by bladder cancer.

In 2018, the Wee Bookshop and Café launched many exciting initiatives, including a breakfast menu and occasional evening dinner club, in addition to its delicious lunches and cakes. They held numerous events, including children's story time, cupcake decorating, pottery painting and quiz nights. Still number one locally on TripAdvisor, the staff team have a real passion for excellence in great-value, home-produced food.

'Lovely food and friendly atmosphere. You can get a snack or a cooked meal or just coffee and cake. Great kids' corner for book reading too.'
Alex

The Wee Bookshop and Café is open 9am–5pm Monday to Saturday, 10am–4pm Sunday, serving breakfast, brunch, lunch (11.30am–2pm) and afternoon tea.



The Fight Bladder Cancer Shop

One of our fundraising forays is into the field of retail, and we have a whole range of products that you can buy to support your fundraising and to support our cause. You won't be surprised that there is a preponderance of orange on the shelves! Nor that we only sell good-quality products – we like to maintain our high standards across the board.

Of course, if you wear FBC clothing, badges or visible logos, you are spreading the word about bladder cancer and fulfilling one of our main objectives. Secondly, FBC takes a small profit from items sold to help to expand the help and support we offer to more patients and carers.



T-Shirts



Sportswear



Wristbands



Pin Badges



Tabards



Fundraising Products



FIGHT Magazine



Awareness Month Products

Visit: fightbladdercancer.co.uk/our-shop

ARTICLE
LYDIA MAKAROFF
FBC CEO

LET OUR VOICE BE HEARD!

Until now, there has been no organisation to speak as the global voice of people affected by bladder cancer. FBC CEO Lydia Makaroff champions the introduction of the World Bladder Cancer Patient Coalition.

Fight Bladder Cancer has been working with Bladder Cancer Canada and the Bladder Cancer Advocacy Network USA to found a new organisation: the World Bladder Cancer Patient Coalition. The concept has already been endorsed by many other patient organisations, including Bladder Cancer Australia and the European Cancer Patient Coalition.

This new initiative will be a milestone for bladder cancer patients and all healthcare professional with an interest in bladder cancer. A change for global initiatives on bladder cancer and a strengthening of the global bladder cancer patient voice.

This organisation is governed by a board of trustees, made up of people diagnosed with bladder cancer, carers of people with bladder cancer, or those engaged with bladder cancer organisations.

The first World Bladder Cancer Patient Coalition meeting will be held on Monday 18 March 2019 in Barcelona, Spain. It will be a global gathering organised by and for people affected by bladder cancer, bringing together bladder cancer patients' organisations from around the world.

We will be reporting on this landmark event in the next edition of our FIGHT magazine.

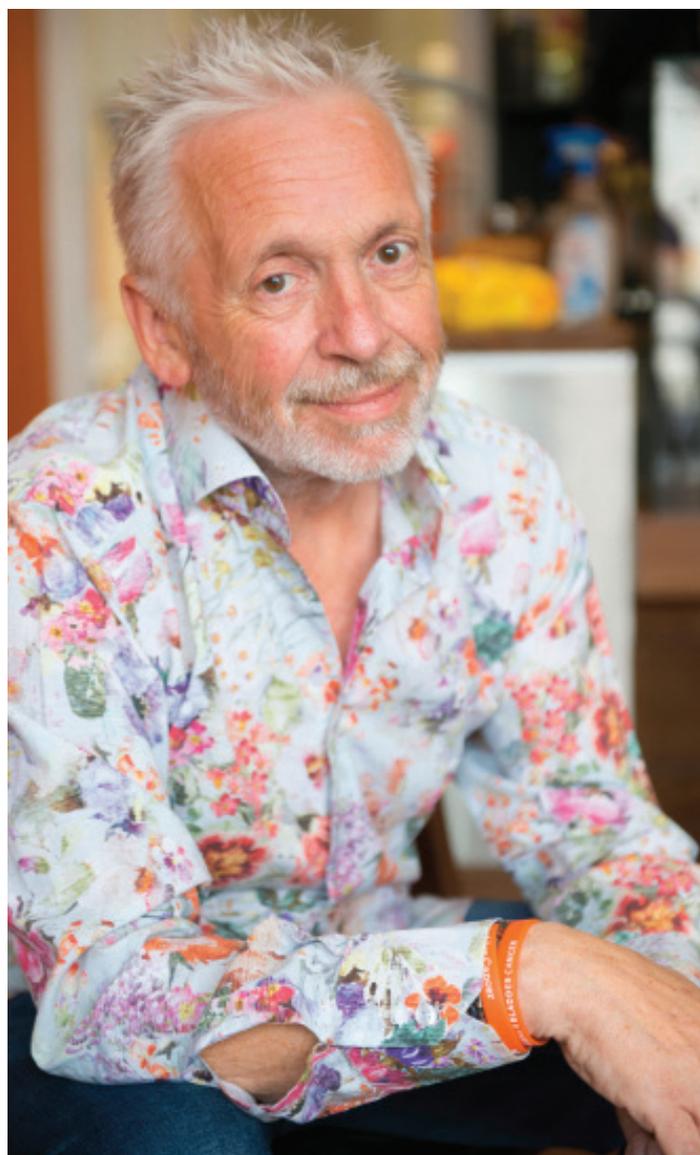
The mission of this organisation is to:

- foster an international community of people affected by bladder cancer;
- advocate for access to the best possible bladder cancer information, support and care;
- build alliances with health professionals, policy-makers, academics, researchers and industry.



Hopes, wishes, and dreams for FBC

After almost nine years following my first brush with cancer, learning that I now have terminal cancer came as a complete shock which has forced me to take a hard look at the future of FBC.



I am determined to use my remaining time to help secure the future of Fight Bladder Cancer and have launched the new Step Forward campaign (see page 11), which aims to encourage people to commit to monthly donations, an action that will help secure our financial stability as we grow and take on more activities.

It is absolutely crucial that everyone affected by bladder cancer – patients, carers, families and friends – have a reliable place to come to for support, information and advice. They need to know that someone is speaking up for them when key decisions are made about policy, care, treatment and research. That is not going to stop because I have to step back from leading the fight myself.

I began the charity from my garden shed, and through tireless effort by our small team it has become the voice for bladder cancer patients, helping over 200,000 patients and carers a year. The charity has grown year on year on a minimal budget, and is now in regular dialogue with major health and research bodies, national governments and the pharmaceutical industry, and is funding research into key issues on bladder cancer managed by our growing research team.

Fight Bladder Cancer has transformed the experience of patients and their families, at all stages of the disease, with support and advice. It has helped tens of thousands of patients as well as raising the profile of bladder cancer and giving a voice to patients in the NHS and research.

Top clinicians are now keen to work with Fight Bladder Cancer, and our funding support for academic-led research marked a milestone with the recognition of Fight Bladder Cancer as a non-commercial partner with the National Institute for Health Research (NIHR).

Despite the increasing work with clinicians and central policy-makers, Fight Bladder Cancer will not change its fundamental principle of being governed by patients. We will retain our patient focus and continue to be led by patients.

Every time you visit us, you're supporting people affected by bladder cancer.



Our Manifesto Commitment

The future work of the charity will be built upon the Fight Bladder Cancer Manifesto, made up of ten clear intentions.

- 1 Grow the patient voice.
- 2 Research into the causes of bladder cancer.
- 3 Support a non-invasive test for bladder cancer.
- 4 Obtain clarity on the impact of bladder cancer.
- 5 Eliminate the inequalities of the patient experience.
- 6 Address the under-resourcing of Clinical Nurse Specialists.
- 7 Develop impactful research for patient choice.
- 8 Improve the quality of life during and after treatment.
- 9 Improve communication.
- 10 Ensure all patients are signposted to the Fight Bladder Cancer charity.

As I prepare to hand over the reins of the organisation that I built from scratch, I have great trust in the team I will leave to run the charity day to day. I have spoken to a lot of other people who have started charities and discovered a thing called 'founder syndrome' where people don't understand that, at some point, they aren't going to be around. I always knew I would have to step back and hand my baby over to a team, so part of my job has been to create that team and I am confident that it is a great one.

We have already achieved a great deal. It's heart-warming what you can do in life if you put in the time and energy, and I feel very proud of what we've achieved. And I really want to say a big thank you to everyone who has been with me along the way, backing me and encouraging me so generously, most especially my co-founder, side-kick and awesome wife Tracy Staskevich.



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OPINION

JOHN HESTER, FBC chair of trustees

Let's STEP FORWARD together

Notes from our chair of trustees



As a bladder cancer patient myself, I am very proud that Fight Bladder Cancer is run by patients, for patients. The support that I received from Fight Bladder Cancer during and after my treatment was invaluable and inspired me to join the board of trustees.

I would also like to express my thanks to the many supporters and friends who have been busy raising money for the charity this year and volunteering in many of our activities across the country. Your energy and commitment are impressive and, quite frankly, we wouldn't be here without you.

Your energy and commitment are impressive and, quite frankly, we wouldn't be here without you.

The charity's roots are firmly fixed in being an organisation governed by bladder cancer patients and carers. With this built-in expertise, the charity continues to set strategic priorities based on a strong foundation and four pillars for success: offering support; building awareness; influencing and funding research; and shaping policy.

I would like to thank everyone who supports the charity, including our volunteers, staff, donors and my fellow trustees. The increase in activities and outputs over the years have been quite extraordinary and my congratulations go to Andrew Winterbottom, our founder and director, and his growing team of staff and volunteers based both in Oxfordshire, at the charity's central hub, as well as around the UK.

I wish Andrew all the best for his ongoing treatment, and I again thank him for all his work to establish and grow the charity.

John Leslie Hester



Here's how you can make the difference by making a monthly donation – as small or large as you are able – to FBC as part of Andrew's Step Forward vision:



Go online to www.fightbladdercancer.org.uk/stepforward and click the donate button.

If you would like to make a donation by doing your own fundraising for the Step Forward campaign, then you can call Emma or Sophie on **01844 351621**, or email fundraising@fightbladdercancer.co.uk.



STEP FORWARD... & HELP ME TO DELIVER MY VISION

I founded Fight Bladder Cancer to be a champion for every patient like me. Now I have a terminal diagnosis, and in my remaining time I want to secure the future of the charity so it can continue to be a powerful voice, advocate and, above all, a friend for everyone affected by bladder cancer.

THE FIGHT GOES ON

The future is clear. In my vision for that future, I am establishing the direction for Fight Bladder Cancer so it can continue to:

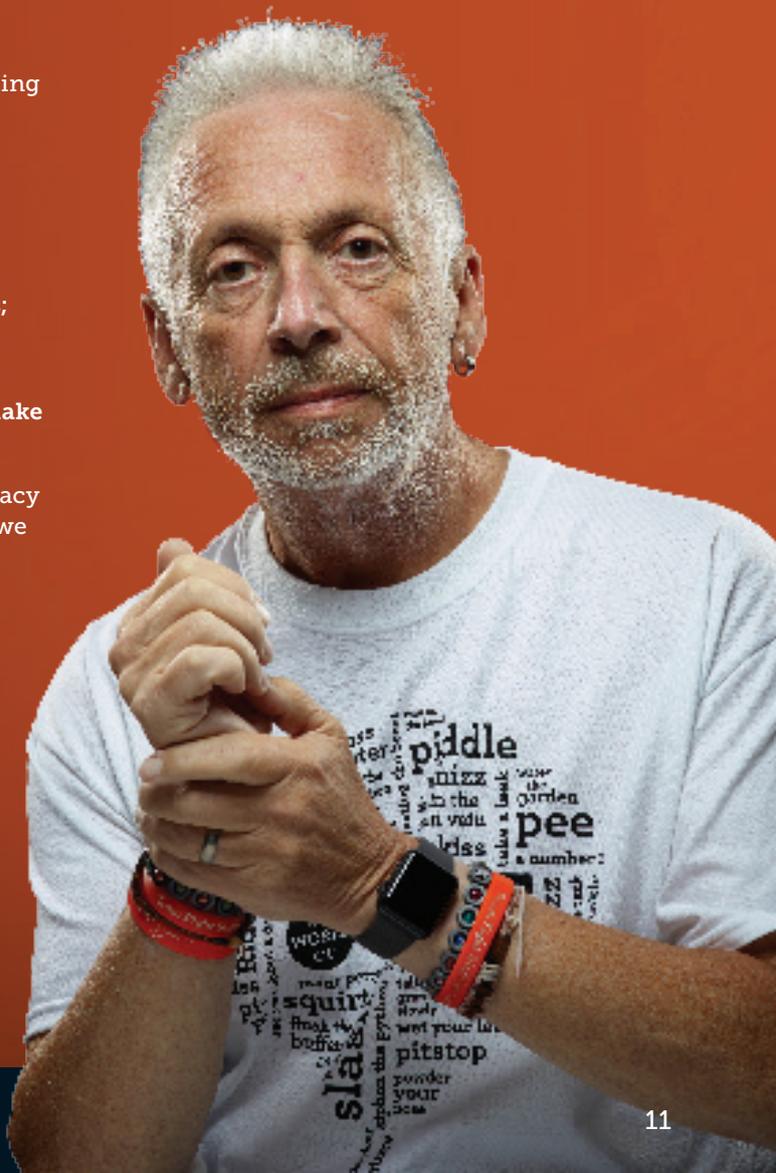
- provide good-quality support for everyone affected by bladder cancer;
- raise greater awareness of the disease and its symptoms;
- ensure quicker and earlier diagnosis and treatment;
- fund much-needed research to develop better treatments;
- strive to achieve the best outcomes and quality of life for patients;
- change core policy within the NHS and government to make this vision a reality.

I won't live to see it, but I hope you can help to deliver this legacy for me. After all, whether we are patients, families or friends, we are all stronger together.

Fight Bladder Cancer needs secure funding to continue its work. That is why we'd like you to **Step Forward** and help by giving a regular gift each month. This will make a huge difference to FBC and ensure that thousands more patients and their families get the help and support they need in the future.

Your generosity can touch the lives of so many people, and for that we are hugely grateful. Thank you.

I won't live to see it, but I hope you can help to deliver this legacy for me.



Cancer Nurse Specialist Laura spells out just how valuable FBC support for patients can be.

The value of Fight Bladder Cancer



As a Clinical Nurse Specialist working predominantly with bladder cancer patients, I have found Fight Bladder Cancer to be an amazing source of support to me and my patients.

Because there is so little in the way of support for bladder cancer patients from other sources, FBC makes a huge difference not just by being there for patients but by offering tailored support.

Fight Bladder Cancer have helped many of my patients through difficult times by providing just what they needed – whether that was personal support, someone on the end of a phone, or information and advice on their website or in their magazines and leaflets.

Patients often feel they don't understand what is going on and have little information about what is happening and likely to happen. Fight Bladder Cancer helps to bridge that gap by providing accurate, understandable information, given when it is needed. They also support us as nurses by enabling us to provide our patients with a source of information and support that we know we can trust. This can include allowing our patients to speak to other people in the FBC network who have been through similar

experiences. With bladder cancer having such a high recurrence rate and many patients having to undergo life-long surveillance and regular cystoscopies, patients live with the constant worry that their cancer will return.

But while nurses value the work of Fight Bladder Cancer and appreciate how quickly it has grown, it is still a small charity, which needs more support to help it grow and develop further. Then even more patients could be contacted and more work done to establish and run the Fight Clubs around the country that are valued so much by patients. Plus, they'd also be able to produce more FIGHT magazines, which the patients and staff find invaluable.

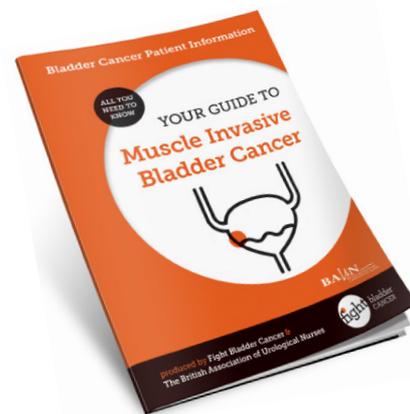
Working in partnership with Fight Bladder Cancer has been a crucial part of my role and seeing the positive outcomes from the patients confirms that I am referring them to the correct place. The charity is very patient-focused and is a great voice for patients and their needs, worries and concerns.

In the future, it would be great to see every bladder cancer patient – on diagnosis – being given contact cards for their Clinical Nurse Specialist together with information on Fight Bladder Cancer and how the charity can help them. That would enable FBC to develop events at which patients from around the UK could come together and share their experiences and coping strategies. That would be a great leap forward in their emotional care.

Working in partnership with Fight Bladder Cancer has been a crucial part of my role and seeing positive outcomes from the patients confirms that I am referring them to the correct place.

ARTICLE
LAURA NOBLE
Clinical Nurse Specialist

Fight Bladder Cancer patient information booklets



FBC announce a new series giving good-quality patient information

There are over 100,000 people living with bladder cancer in the UK, and over 18,000 people diagnosed annually in England alone, but the disease is a little known and poorly prioritised cancer.

Patients, carers, nurses, surgeons and consultants working in urology and oncology have all advised Fight Bladder Cancer that there is a significant need for a suite of good-quality patient information booklets for bladder cancer in the UK. Whilst the majority of patients are provided with some sort of literature at diagnosis, the quality and usefulness of this information is very varied depending on which hospital the patient is attending, the original source of the information, and their own diagnosis.

Good patient information is not currently available and Fight Bladder Cancer is working on a suite of booklets to fill this gap. The goal of the Fight Bladder Cancer patient information booklet project is to enhance patient care by providing a suite of complete, accurate and current information for bladder cancer patients and their carers at all stages of their disease. This suite of information booklets will directly enhance bladder cancer patient care, supporting patients and carers as well as the clinicians caring for them. These materials have been identified as a key need for bladder cancer patients.

We are working in conjunction with the British Association of Urological Nurses (BAUN), and the project has been supported by other key professional bodies, BAUS (British Association of Urological Surgeons) and BUG (British Uro-oncology Group), who have helped to develop these materials.

The booklets will cover all stages of bladder cancer, including treatment choices, and will be distributed to all Clinical Nurse Specialist (CNS) teams in the UK. With these booklets, bladder cancer patients will be provided with consistent, complete, accurate and appropriate information at all points along the care pathway.

Plans to launch, distribute and disseminate the materials in partnership with BAUN, will ensure that Clinical Nurse Specialists are aware of the booklets and provide them to their patients. Having a suite of booklets co-produced by patients, FBC and BAUN will give the booklets status and help to strengthen the bond between the whole CNS community, BAUN and FBC.

We are currently on plan to publish these booklets later this year with the intention, subject to funding, that they will be provided free of charge to all UK hospitals treating patients for bladder cancer.

These booklets will be a significant step forward in the provision of consistent and validated patient information across the whole pathway, a resource that we know patients and clinicians have been waiting for.

'It is our absolute pleasure to be working in partnership with Fight Bladder Cancer on these vital, and most overdue patient resources. Fight Bladder Cancer – given its deep patient insight – is in a perfect place to develop a strong suite of materials for patients and carers.'

Julia Taylor, President BAUN

'Alongside their deep patient insight, the support of their highly credible team of medical advisors and partners will doubtlessly ensure that Fight Bladder Cancer's new suite of materials will make a huge difference to care pathway of thousands of bladder cancer patients and their families.'

Jim Catto, Professor in Urological Surgery, University of Sheffield

'I felt alone and afraid. Thank goodness I came across Fight Bladder Cancer quickly and their fabulous website. I'm really backing their plans to get better materials into the hands of the hospital and nursing staff – it will make such a difference.'

Bladder Cancer Patient, Reading, 2018

Working titles for the booklets are:

- 1 Bladder cancer – initial tests for diagnosis
- 2 Low and intermediate-risk bladder cancer
- 3 High-risk bladder cancer (including carcinoma in situ (CIS) and treatment choices)
- 4 Muscle-invasive bladder cancer and treatment choices
- 5 Living with a stoma / Living with a neo-bladder
- 6 Advanced bladder cancer, including immunotherapy oncology (IO) treatments
- 7 Surviving bladder cancer, including the emotional side of diagnosis and treatment
- 8 Diet and nutrition advice for bladder cancer patients
- 9 Immunotherapy oncology for bladder cancer



BLADDER CANCER awareness month

ARTICLE

EMMA LOW,
FBC fundraising
lead

The month of May is internationally recognised as Bladder Cancer Awareness Month and in 2018 Fight Bladder Cancer set about delivering the biggest month of awareness, campaigning and fundraising possible. And with your help, we did it!

We shared facts, statistics, risk factors and symptoms. We organised events all over the country, and ran a multi-language social media campaign. And we supported patients and their families and healthcare professionals so they could carry out activities in their local communities.

Our overarching goal was to raise the profile of bladder cancer and better represent the bladder cancer community throughout the United Kingdom and beyond. We set out to raise awareness of bladder cancer by creating strong campaign materials to achieve widespread recognition and to launch a campaign that could grow year on year.

We were also delighted to collaborate with Bladder Cancer Canada, the Bladder Cancer Advocacy Network USA, and the European Cancer Patient Coalition, which ensured that we can continue to deliver a truly global service on bladder cancer awareness.

For maximum impact, we focused on themes within the campaign, such as:

- **Bubbles for Bladder Cancer**, in which we blew beautiful bubbles in memory of patients lost and in solidarity with those fighting;
- **Shining a Light on Bladder Cancer**, illuminating iconic buildings in orange lights;
- **Walking for Bladder Cancer**, FBC co-ordinating seven walks across the UK, some led by Clinical Nurse Specialists with their patients.

We also:

- Created campaign materials for partners to share;
- Used orange 'bubble zorbs' to raise awareness;
- Designed photo frames, posters and banners;
- Used a Twibbon and Thunderclap on social media;
- Shared many patient and carer stories.



We set out to raise awareness of bladder cancer by creating strong campaign materials to achieve widespread recognition and to launch a campaign that could grow year on year.



BLADDER CANCER

We came together across the world to show our support for all those affected by bladder cancer.

We successfully reached new audiences through our networks in the pharmaceutical industry and other businesses, among clinicians and hospitals, in sports and social groups. In particular, the campaign had a strong impact because of our effective engagement with our network of healthcare organisations and individuals. We achieved broadcast coverage in APTN, BBC London and Sky News, as well as regional radio. Our social media thunderclap had a social reach of 91,660 people in 78 cities, and our patient video had over 3,000 views.

We created some powerful images and materials in support of our campaign.
AND IT'S ALL THANKS TO YOU!

We are grateful to all the patients, families, healthcare professionals and business partners who got behind us during the month – from sharing our messages to organising walks or events and actively campaigning with us.

Every single person who contributed is appreciated, and following this feature, you'll find stories about just some of those who got involved in the 2018 campaign. But we don't have room for everyone, so if you're not mentioned, please don't think we have forgotten you! We are truly grateful for EVERYONE'S support.

Together we managed to increase the awareness of bladder cancer in 2018, and we hope that you have been just as inspired as we have been to ensure that 2019's Bladder Cancer Awareness Month will be even bigger and better! Watch this space for our updates later in the year, and if you have any ideas for the 2019 campaign, please email us at getinvolved@fightbladdercancer.co.uk.



BLADDER CANCER

From small walks with family and friends to major regional walks with an army of supporters we walked together to promote awareness of this little talked about disease.



What some of our amazing supporters got up to for **BCAM 2018**

Walking, fundraising, blowing bubbles and a whole lot more – here's just some of the activities we enjoyed in Bladder Cancer Awareness Month 2018

Nurse and healthcare professional involvement

Fight Bladder Cancer was particularly thrilled about the number of Clinical Nurse Specialists and urology teams getting seriously into the spirit of the month and helping to spread awareness, including putting up posters; buying t-shirts; hosting information stands; and organising amazing fundraising activities. Support from nursing teams – such as those in the sample shown below – really made all the difference with spreading the word in 2018.



Nicola Lancaster, Uro-oncology Clinical Nurse Specialist, Darent Valley Hospital, Kent hosted an information stall and a 'guess how many tic tacs on the cake' game!

Jo Shingler, Consultant Nurse and Co-clinical Lead, Mid Essex Hospital was sponsored to cycle her normal working hours on a static bike in her urology centre.



Laura Noble, Sister, CNS Office, Freeman Hospital, Newcastle Upon Tyne Hospitals NHS Foundation Trust was busy raising awareness throughout the month. Activities included taking her colleagues, patients and supporters on a trip to the 'orange' Gateshead millennium bridge, and dressing her daughter in a Fight Bladder Cancer t-shirt for most of May!



Jenny Akins, Urology Advanced Nurse Practitioner, the Royal Wolverhampton NHS Trust, organised a walk on 20 May for their Bladder Cancer Support Group.



Walking to wake awareness

Led by determined patients, carers and healthcare professionals associated with the many FBC support groups and Fight Clubs around the UK, as well as our own Fight Clubs, both fundraising and awareness walks took place all over the country. Thank you all so much for getting up, getting active and getting involved! It's great to see you having such fun at the same time.

Brenda McCluskey-Mayes, Urology Sister, Kent and Canterbury Hospital organised a walk on 20 May for the Canterbury Fight Club and friends.

Dorothy Markham, our dynamic Scottish patient lead, organised a walk in the beautiful Falkland Estate in Fife. She was joined by almost 30 walkers including Stephen O'Neill, another bladder cancer patient, and his family who made the journey over from Cumbernauld!





Hazel McGhie from Glasgow, whose father was a patient and sadly died in 2016, kindly attended the Glasgow Fight Club walk, and you can see her above with the support group at the Glasgow Maggie's Centre where the group meets.



Deb and Paul Major and over 30 patients and carers got together for a walk for Bladder Cancer on Sunday 20 May to enjoy the sun, sea and sand of Bournemouth. The two-mile walk along the promenade finished at Branksome Chine where they had a well-deserved coffee break before heading back towards Bournemouth Pier for lunch!



Fight Bladder Cancer HQ also hosted a walk on Sunday 20 May back at our very own Headquarters in Chinnor, Oxfordshire, attended by well over 100 friends and supporters. We blew bubbles and thought about our friends sadly departed as well as those fighting hard. We then enjoyed a 5km walk onto the Chiltern

Ridgeway (as well as offering a shorter walk for those with wheelchairs and pushchairs) followed by some marvellous cakes and coffee at the Wee Café. The weather was simply glorious and a really good time was had by all!



Anita Brown, gregarious patient and activist, is always setting herself new challenges, and in 2018 she decided she would blow bubbles on one leg! Gathering friends and family members around her for maximum impact – she's the one with the can't-miss-it pink hair! – they adopted the monopod position to blow their bubbles for May's campaign.

Business partnerships

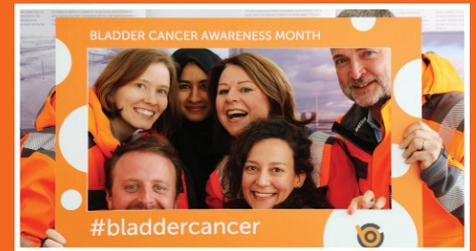
We were delighted that so many of Fight Bladder Cancer's corporate partners welcomed the opportunity to get involved during the month. This support included health diagnostic businesses and pharmaceutical firms – whose staff voted to fundraise, get walking, light up their offices and blow bubbles. We really were blown away and look forward to working with you again in May 2019. Thank you again for your kindness.



Staff from Janssen Pharmaceuticals really enjoyed getting stuck into coffee and cake at the Wee Café, after taking part in the Chinnor walk.

Lighting up to light the way

We were thrilled to have so many iconic buildings lit up with orange during the month, including the Kelpies in Falkirk Helix Park, the Spinnaker Tower in Portsmouth and the Gateshead Millennium Bridge. These came about through a combination of patients, carers, healthcare professionals all asking various contacts to help out and put in a good word!



Martin Knight of Knight Architects was one such good friend. Famous for their inspirational bridge designs and projects, Martin introduced FBC to Halton Borough Council and Mersey Gateways Crossings Board who kindly lit up their wonderful bridge (designed by Martin's team) for the campaign! Here's Martin, pictured far right with his team, and our very own Emma Low in the middle.



Larry Shelbourne, a patient and supporter, managed to get out to the Mersey Gateway bridge and take this marvellous selfie. Thanks Larry!

And finally ...

We hope that this summary of BCAM 2018 has provided a good showcase of the fun and energy people put into raising awareness of bladder cancer last May. We want to work with you in 2019 to make even more noise about bladder cancer so please get in touch with us soon to share your ideas and offer your support at fundraising@fightbladdercancer.co.uk.

Cancer? Well, at least I get cheap parking!



ARTICLE
MARY LOVETT,
FBC forum member

When cancer picked a fight with Mary Lovett, they picked the wrong person. Here she recalls her battle to be heard, her fight to get the treatment she wanted, and the strength she draws on to keep moving forward.

My name is Mary Lovett. I live with my husband in a village just outside Lincoln, where we moved last year from Bedfordshire to be near our daughter and son-in-law. I used to work for a university as a project support co-ordinator but took voluntary redundancy/early retirement in September 2014 and was looking forward to doing things I hadn't had the time to do while I was working, like gardening, baking and photography. Life was very good, especially as my husband had just been given the all-clear after having bowel cancer. He had been extremely ill and had spent a total of eight months in hospital but he claims that the combination of the excellent care he received from the NHS and me nagging him back to good health were the things that got him through.

Nine months later, however, in June 2015 at the age of 55, I was diagnosed with bladder cancer. So as my husband's cancer journey thankfully ended, mine began.

Early symptoms

I had been self-catheterising for years due to an inability to empty my bladder and this had contributed to infections, various problems and frequent urinary tract infections (UTIs), but I just accepted things and carried on as normally as possible. But in 2011, I noticed some blood when I was catheterising; not a great deal and it wasn't happening all the time, but I went to my GP who said it could be down the catheterising. I started to have more episodes of bleeding over the next few years accompanied by lower back pain. I just wasn't feeling right and kept returning to my GP

who would give me antibiotics for UTIs, yet still maintained that the blood in my pee was nothing to worry about. I wasn't happy and felt something wasn't right, but I stupidly assumed if it was a concern I would be referred.

In February 2015, I had a very heavy bleed, which went on all evening and through the night. By this time, I was fed up with being fobbed off, so I went to A&E as I was concerned that I'd lost so much blood. I saw a young doctor and explained everything that had been happening. He agreed with my concerns and said he would refer me to a urologist. This young doctor probably saved my life.

In April 2015, I saw a urologist who also said the bleeding was due to catheterising! But I'd had enough by this time and said I wanted it investigated. I had started researching causes of blood in your pee and although at that stage I didn't think it was cancer, I just wanted an answer to what was causing it. A week later I had a flexible cystoscopy (the main test used to diagnose bladder cancer). Another urologist said he could see red patches (for me that's

when alarm bells started to ring) but yet again he said they were probably due to catheterising! I felt that my symptoms were being dismissed and said I still wanted it investigated. I wasn't going to let go of the gut feeling I'd had all along that something wasn't right.

The following month I went in for a biopsy, or transurethral resection of bladder tumour (TURBT). However,

when I was signing the paperwork just before having the operation, the registrar explained that I might need a chemo-flush afterwards. I asked why and was told there was a 95% chance it was bladder cancer. That was the first time cancer had been mentioned – just what you want to hear before surgery. But I remained calm; I didn't see the point in worrying about it until it was confirmed.

Perhaps I was in denial. To this day I've never shed a tear over it – there's no right or wrong, I suppose, we all cope in our own way.

Diagnosis and treatments

So 16 June 2015 was the day my official cancer journey began – it's funny how everyone remembers the actual date. I went to the hospital with my husband to collect my results and I remember sitting in the waiting room and not feeling worried at all. I still didn't believe it could be cancer. When we went in, the consultant asked me if I had any idea what the problem was! He was faffing about and said he was waiting for a colleague to join us and he would just go and see where they were. I jokingly said to my husband, he's gone to get a Macmillan nurse – it must be bad news. Then he returned with a Macmillan nurse. I asked him to get straight to the point and tell me if it was cancer. I remember saying, 'Don't beat around the bush, tell it like it is. I can cope with it.' So he explained it was T1, G3 and CIS which meant the tumor had spread to the connective tissue beneath the bladder lining (T1); the cancer cells looked very abnormal and were more likely to grow quickly (G3); and it was likely that the tumour (carcinoma in situ or CIS) could not be completely removed with surgery because of its flat shape and its spread across the bladder lining, resulting in a high risk of progression to muscle-invasive disease.

He said that I would normally be offered six weeks of Bacille Calmette-Guérin immunotherapy (BCG) and then have a flexible cystoscopy to see if that had helped, but realistically if that didn't work my best chance was to have a radical cystectomy (RC – surgery to remove the bladder as well as nearby tissues and organs). As there was a national shortage of BCG at that time, I was offered mitomycin (chemotherapy). I was surprised to hear that the treatment was to start two days later.

The Macmillan nurse explained about the chemo treatments (administered via a catheter). She gave me a booklet to read about bladder cancer and told me that I would get free prescriptions for five years and cheap parking on treatment days. I remember saying, 'Well, it's not all bad news then!' She looked at me as if I had two heads! No other support was offered. Perhaps she

felt I didn't need it as I didn't break down.

It's true I still wasn't overly concerned by my diagnosis. Perhaps I was in denial. To this day I've never shed a tear over it – there's no right or wrong, I suppose, we all cope in our own way. In hindsight, I think having almost lost my husband to cancer because he was so ill, I thought mine isn't as bad and he got through it, so I can do the same.

As far as I was concerned, the six weeks of treatment would do the trick and that would be the end of it. However, by December 2015 I had a recurrence. I saw the original urologist – the one who had initially told me nothing was wrong – who now said that after a medical team meeting it had been decided the best thing for me was to have the RC as it was the best chance of being cancer free.

Before this appointment I had started reading up on bladder cancer and asked if I could have BCG treatment instead but he was against it. He said there was a 70% chance it wouldn't work; I said that means there's a 30% chance it would. He was not very happy with me and said I should have the RC and he said he would give me a few days to think about it. (My husband was with me, and couldn't believe how this man was pressurising me.) I told the consultant there and then that I was not having the RC and wanted to try the BCG. I know that many would opt for the RC in order to remove the cancer with the bladder, but it wasn't right for me; I wanted to preserve my bladder. Initially my husband wanted me to have the RC, as he said he didn't want to lose me, but he agreed to support any decision I made; my daughter said the same.

So the upshot was that I started the BCG programme three years ago and at first had six treatments a week, then went on to the maintenance programme, which is usually given as a course of three BCG treatments (one treatment a week for three weeks), repeated every six months for up to three years – normally a total of 27 treatments. I have just finished number 21, and will start again later this year.

Living with bladder cancer

Looking back over the past few years, for me living with bladder cancer has become the norm. The worst thing about it has been the side-effects of the treatment. BCG is harsh and has caused many side-effects: bladder spasms, joint pain, flu-like symptoms, tiredness and the much-increased frequency of needing the loo, especially through the night, which disrupts sleep. Some health professionals claim that BCG treatments only cause mild side-effects. This is so far from my experience that it really annoys me. BCG is not easy and can cause many complications, which can have a cumulative effect over the years.

I think people's perception of bladder cancer can be strange. Because my treatment hasn't really altered my appearance (in particular,

I haven't had any hair loss) they don't realise the seriousness of it and so assume that you are ok. I have actually had people say to me that I don't look like I have cancer! However, I have days when I feel really unwell, and get frustrated that it prevents me from doing things I want to. I try to carry on but it is not always easy. Perhaps I should cut myself a bit of slack at times.

I have known many people who have been diagnosed with other cancers and have undergone gruelling chemo/radiotherapy treatment, with visible changes to their appearance, and they have been inundated with offers of help – for example, shopping, housework or being accompanied to hospital appointments. Apart from my husband and daughter, who have been absolutely brilliant, I have

never been offered any physical help, not even by close friends or other family members. They have been supportive in other ways, by keeping in touch and asking how I am doing, and I know they genuinely care. My daughter has said I'm very good at pretending I'm okay, so maybe that's why it would appear that I do not need any support.

I am quite a strong person and may appear to have a flippant attitude to it all, but I do know how serious it is, that's just how I deal with it. I think every person who is diagnosed handles it differently. For me it's an inconvenience. Sometimes I feel a bit of a fraud. I'm having cancer treatment and I think I'm coping reasonably well – is it wrong that I'm not a blubbing wreck? I get fed up with being told how brave I am. I'm not brave, I'm just not afraid.

Advice to other people

If anyone notices symptoms of bladder cancer, act on it straight away, stand your ground if you feel you are not being listened to and insist on further testing. Once diagnosed, join an online support group – this is where my knowledge has come from, and it's good to be able to communicate with other people who understand exactly how you feel. Also it's your cancer, your body, don't let anyone try to persuade you to have surgery or treatments you are not happy with.

I have to say up front that I am so very grateful to the NHS for the treatment I've been given. There are a couple of improvements I could suggest. GPs and other medical staff could be given more training and be more proactive when a patient presents their symptoms. It would also help if they showed a little more empathy when patients report problems with treatments, as with me and the BCG. Just because the literature says some treatments only cause mild problems, that's not always the case. Everyone is different.

We need much more awareness concerning bladder cancer. Why is it that we hardly ever see anything in the media about it? Before I was diagnosed, I knew nothing about bladder cancer, I had never met anyone who had had it and, apart from the wonderful Fight Bladder Cancer support group I communicate with online, I still haven't

met anyone in person. I asked my CNS (Clinical Nurse Specialist) if there were any support groups in my area and she gave me details of a group that meets quarterly. Unfortunately I missed the first meeting, due to ill effects of my treatment, and the others are miles away. I asked if she treats many patients in my area and she said she does, so I think it would be great if there was a regular support group in my area. I would willingly take an active role. I think people who are newly diagnosed would benefit immensely.

Looking back to the start of my journey I would have liked the opportunity of sharing information with other bladder cancer patients. I've learned so much through my online support group, not just practical advice but we are also able to offer emotional support to each other when we are having a bad time. It helps the families of those affected, too, and I feel they are sometimes overlooked. When my husband was going through his cancer, I found it extremely hard and would have welcomed someone to talk to. Although, on reflection, I wonder if his determination to beat his cancer has somehow given me the strength to fight mine.

I'm a fighter and I remain positive. Cancer picked the wrong person to fight with when it picked me!

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Time to find a non-invasive test for bladder cancer

While it has a success rate of 80–97%, cystoscopy to test for bladder cancer is expensive and invasive. Bill Phillips looks at some alternative options.

Currently, cystoscopy is used to diagnose bladder cancer. A cystoscopy is a procedure to look inside the bladder using a thin camera called a cystoscope. A cystoscope is inserted into the urethra (the tube that carries wee out of the body) and passed into the bladder to allow a doctor or nurse to see inside. Cystoscopy detects bladder cancer in around 80–97% of people with the disease.

However, cystoscopy is an expensive, invasive procedure requiring clinic or hospital attendance. It also poses a small risk of infection as well as causing discomfort! There is a clear need to find a non-invasive alternative test that could be used to detect bladder cancer with similar diagnostic capability to cystoscopy.

For over 80 years, cystoscopy has remained the best existing method for detecting tumours of the urinary bladder. Since bladder tumours have a tendency to recur and progress, many patients are subjected to repeated cystoscopies during long-term surveillance, with the procedure being both unpleasant for the patient and expensive for healthcare providers. This is one of the main reasons that there is such a huge cost for the diagnosis, treatment and management of bladder cancer, which is exacerbated by the fact that it has one of the highest recurrence rates of any cancer.

Establishing a new diagnostic technique would allow a reduction in the cost of diagnosis and check-ups, remove the invasive nature of the current technique and improve the speed of diagnosis. It would also improve quality of life for patients.

Active trials

There are currently several trials examining different tests to find a non-invasive way to use wee samples for diagnosis and follow-up of bladder cancer. Researchers are keen to find potential tests that have high sensitivity and specificity. A benchmark of 95% sensitivity and specificity has been suggested for potential tests.

There are many technologies in development and it is clearly an exciting time for non-invasive testing of bladder cancer. However, no tests are currently commercially available in the UK that meet the required sensitivity and specificity demands. There is therefore a pressing need for a conversation about the importance of non-invasive testing, and to find a test that works well for patients and clinicians. Ideally, this test would be available for use by GPs when their patients present with red flags, such as blood in wee and urinary tract infections that don't clear up after antibiotics.

More about sensitivity and specificity

Sensitivity can be considered as follows: how likely is the test to be positive in patients with the disease? Low sensitivity leads to high false negative tests.

Specificity can be considered as follows: if the test is positive, how likely is the patient to have the disease? Low specificity leads to high false positive tests.

A perfect test: this would therefore have 100% sensitivity and 100% specificity.

A useful example: screening for non-visible haematuria with test sticks. An individual with bladder cancer is very likely to test positive for haematuria (so high sensitivity) but a positive test can be caused by many other conditions (but low specificity).

Technology	Tests for	Useful for	Sensitivity/ Specificity**	Commercially available
Ampsecur	23 DNA Mutations	Diagnosis, treatment tailoring, follow up surveillance.	Likely to be >90%*	No – UK based
UroSEEK	11 DNA Mutations	Diagnosis, treatment tailoring, follow up surveillance.	Likely to be >90%	No – USA based
UroMark	150 DNA Methylation sites	Diagnosis, follow up surveillance.	Likely to be >90%*	No – UK based
AssureMDX Bladder Check	3 DNA Mutations + 3 DNA Methylation sites	Diagnosis, follow up surveillance	Likely to be >90%*	Yes but USA only
Cx Bladder Check	5 RNA molecules	Diagnosis, follow up surveillance	Useful to rule out disease	Yes but USA/Aus/ NZ only
OneRNA4Bladder (Genomic Expression)	Up to 20K RNA molecules	Diagnosis, follow up surveillance	N/K	No – USA based
Arcis	1 RNA molecule	Diagnosis, follow up surveillance	N/K	No – UK based
UroVysion**	Chromosome duplications/ loci deletions	Instead of cytology	Low sensitivity, reasonable specificity	Yes – inc UK
OdoReader	Volatile Organic Compounds	Diagnosis	Likely to be >90%*	No – UK based
ADX Bladder	MCM5 Protein	Diagnosis, follow up surveillance	Low sensitivity, reasonable specificity	Yes – inc UK
Mosaiques Diagnostiques	Up to 22K Peptides	Diagnosis, follow up surveillance	Low sensitivity, reasonable specificity	No – Germany based
NMP22	NMP22**	Instead of cytology	Low sensitivity, modest specificity	Yes – inc UK

Monetary costs of cystoscopies:

- Privately, between £800 and £4,000 – average about £1500. NHS estimated at £550 per cystoscopy.
- About 110,000 performed in UK per year for diagnostic purposes on new patients = £55 million.
- Similar number for follow up of established disease.
- Cost of non invasive tests approx £250-300 per test.

* based on current evidence; large scale trial in progress.

** Similar profiles are found for other commercially available tests introduced many years ago such as the bladder tumour antigen (BTA), and the cytokeratin based tests urinary bladder carcinoma antigen (UBC) and Cyfra 21-1. ImmunoCyt has modest sensitivity and specificity.

There is an opportunity for the bladder cancer community to support the current clinical trials to find a non-invasive test for bladder cancer. It is probable that any recommendations from current clinical trials are likely to take about five years to be clinically available to, and adopted by, clinicians.

A second opinion

Asking for a second opinion may not be a legal right, but most doctors and consultants will be happy to help you get one.

There are many good reasons why you might want to get a second opinion on a diagnosis or a suggested treatment.

'Sometimes people can get frustrated because it can take longer for their doctor to work out what is going on than they expected,' says Professor Steve Field, a GP and chairman of the Royal College of General Practitioners.

'People can lose faith in their specialist – they may feel they are being pushed towards an operation before they are ready. Or sometimes they feel as if their specialist is not dealing with them as if they were a whole person.'

GPs and consultants understand that people want second opinions either because they don't like the doctor they've seen, don't like what they've been told, or have more than one treatment option and need help deciding which to pursue.

You can change your GP simply by finding another one in your area. If you want a second opinion from a different consultant, however, you need to ask your GP. What happens next depends on the alternatives available. You may need to be referred to another hospital – your GP can also ask your consultant for clarification on this. Patients usually remember only 10% of what they are told, and their GP can help them to navigate through what is happening to them.

If you do need to see a second specialist, ask your GP who they would recommend. You can also search on Google Scholar to see who has published research in a field relevant to your case.

You don't have to tell your existing consultant who has been treating you if you're going to see someone else, but you may want to in order to copy your notes and test results to take with you. When you go for your second opinion, think about what you want to know, write it down and take a friend with you to help you remember what questions to ask and what the answers were! These can be stressful situations so it is quite normal not to remember everything you are told. Remember not to cancel any appointments with your old consultant before you get your second opinion, just in case you get the same advice about the best way forward.

In reality, though, there is sometimes little difference between the treatments offered to patients by different doctors. Sometimes going to another specialist for a second opinion can create more anxiety and stress.

Why people get a second opinion

People may want to see another doctor for different reasons, including:

- to confirm their diagnosis;
- to make sure they're having the best treatment;
- to support what they've already been told about their condition and treatment;
- because they don't feel that they can talk to their current doctor.

The benefits of seeing another doctor may include:

- feeling reassured that doctors agree on your diagnosis and treatment;
- having some different treatment choices to choose from if the second doctor offers a different treatment.

Seeing a different doctor is not always possible and may have disadvantages. These include:

- a possible delay in starting treatment;
- travelling some distance to another hospital – this could be difficult or even impossible;
- hearing your diagnosis again, which may be distressing.



It is very important for you to have confidence in your doctor and feel able to voice any concerns you may have.

It can take some time to arrange a second opinion. You will have already seen a doctor or specialist, so you won't be a priority. It is important to talk to your doctor about how long any delay is likely to be and whether a delay in starting treatment would be harmful.

Some people worry about offending or upsetting their doctor by asking to see someone else. This is unlikely to happen. In any case, doctors themselves often ask their colleagues about cases that are complicated or unusual.

Things to think about

Before you ask for another opinion, think carefully about exactly why you want one. This can avoid wasting time, effort (and possibly money) if you see another doctor privately. It may be because:

- you haven't fully taken in what the doctor has told you;
- you are not satisfied with the treatment suggested;
- you find it hard to talk to your doctor.

You haven't fully taken in what the doctor told you

If you have been unable to take it all in the first time round, it may help to ask your doctor to go over things with you again. Don't feel embarrassed about not understanding, or needing information repeated. Doctors realise how difficult it is for you to take in complicated medical information, especially if you are feeling shocked and upset.

If you have read up on your condition since you were first diagnosed, this could have raised questions or concerns. You may just need to talk through your treatment options with your specialist again. This will give you the chance to ask any questions that have come up since your first appointment.

You are not satisfied with the treatment suggested

Of course you are likely to meet other people with cancer at the hospital, or at a local support group, for example. It's natural to talk to each other about your illness and treatment. You will hear a lot about cancer through the media, on the news or in newspapers. You may hear about another type of treatment and wonder why you are not having it. This might make you feel less confident about the treatment you are going to be having. If you are feeling this way do talk to your doctor or specialist nurse.

There are many different types of cancer and the treatments will vary. Even if you have the same cancer type as someone else, your cancers may be at different stages. Not all treatments are suitable for everybody.

You find it hard to talk to your doctor

It can be difficult if you do not feel comfortable talking to your doctor. It is very important for you to have confidence in them and feel able to voice any concerns you may have. This can help to build trust and confidence in your relationship.

If you would prefer, try talking to another doctor in the consultant's team, such as the registrar. Or, if there is a specialist nurse in the team, you may find it helps to talk to them. They may be able to iron out any misunderstandings. If necessary, they may offer to talk to the doctor about your concerns. It can be useful to talk to your doctor and nurse together.

How to get a second opinion

After thinking everything through, if you still want to see another doctor, you can ask your specialist or GP to arrange it. They will refer you to another NHS doctor who specialises in treating your condition. You can ask for a second opinion from a private doctor, but obviously you will have to pay for this.

A relative can also ask for a second opinion, but only with the patient's consent.

Having a second opinion doesn't mean that the new doctor will automatically take over your care. If you decide you want the new doctor to treat you, both doctors have to agree and this has to be formally arranged between the doctors or hospitals.

Your current doctor or specialist should send the new doctor any relevant information, such as previous treatments, test results and information about the drugs you are taking. This will give them as clear a picture as possible about your case.

If you are having difficulty getting referred for a second opinion, the Patient Advice and Liaison Service in your hospital, or the local Citizens Advice Bureau may be able to offer advice.

Before your appointment

It may help to prepare for your second opinion by:

- thinking about what you want to get out of the appointment;
- making a note of your symptoms and any treatment you have already had;
- writing down questions you want to ask;
- asking someone to go with you for moral support and to help you take in the information given.

In the end, it is always you, the patient, who decides what treatment to have. Do make sure you are happy with what is happening. If you are in any doubt, ask more questions. And if that means a second opinion – go for it.

Q&A with Michael

– and why you never forget the date of your diagnosis

Melanie took time out to chat to Michael Sloane and discovered that a dogged determination and a sense of humour go a long way.

ARTICLE
MELANIE COSTIN
FBC support
services manager

One lunch time, at the Fight Bladder Cancer headquarters, I managed to pull Michael away from his computer, where he was busily typing away, to come and have a chat with me about his life and his bladder cancer diagnosis. He began with his first contact with FBC, as we grabbed a coffee.

I noticed a post on the forum which was looking for a volunteer to assist with the accounts. I thought, yes, I could come in sometimes and help out with those – it's what I do, I've always been a figures person.

Michael was diagnosed with Ta Grade 2 bladder cancer five years ago at the age of 58 and I asked him to tell me a bit about his life before he had the diagnosis.

I worked in accounts for a company that sorted out security and fire alarms for offices and companies and so on. We used to do a lot of work for the public service agency that ran all the government buildings.

So you hadn't done any work that put you into a high-risk category?

Well, when I was thinking about it, the office where I worked was two floors up and right next to a busy road junction and I always had the window open to let the fresh air into the office, even in winter. It was right next to the traffic lights so all the cars were waiting and revving their engines. I often wonder whether the car fumes, particularly the diesel, had any effect on me.

I grew up in Harrow. The first house we had was in West London, on a busy road. The house was a bit set back as we had a reasonable front garden but I can remember it often got a bit sooty in the hall so there must have been a lot of fumes from the vehicles. This got me thinking again whether this may have contributed to my diagnosis.

What made you leave London?

I've been married to my wife Linda for about 28 years now, although

I knew her for quite a few years before that. She was an occupational therapist. We were looking around for another house and we often used to come out to Marlow in Buckinghamshire at the weekends and we realised that we could get a fair bit more for our money there than we could in West London at that time, so we decided to move. I'm happy we came here. I do love the countryside and I like to go cycling when the weather is good. I suppose that one of the things that bladder cancer has made me realise is that I was maybe getting a bit unfit. I used to cycle a lot, now I have started again and I really enjoy it.

Tell me a bit about your diagnosis, how did it come about?

We were holidaying down in Dorset and we went to a place on the coast and down the front there they had an outdoor gym. I thought I would have a bit of a go, for fun really, a few crunches and so on. Afterwards

we went for a coffee and when I went to the loo it was the first time that I noticed my wee was all pink. I thought to myself: that's not very good. At first I thought maybe I overdid it in the gym as I hadn't been to one for years. The next time I had a wee it looked quite clear to me, so I thought it was just because I hadn't exercised for a long time. Everything seemed fine after that and we carried on enjoying our holiday.

When we came back home I came in for the toilet after washing my car and it was really red this time, so I thought I had better get this checked out. I was still in two minds about going to the doctors as it all started to look clear again but I went anyway. The doctor said that I still had microscopic blood in my urine – it was still there, I just wasn't able to see it – so he sent me off for a cystoscopy. The consultant put in the catheter with a camera and looked into my bladder, and there was a screen showing the inside of my bladder, then he took the camera out again. He could see the cancer straight away; it was really fast actually.

Although I kind of knew that it probably wasn't going to be good news, when he told me it was bladder cancer, it did stun me. I felt quite shocked. I've always had fairly good health and never had any hospital treatments since I was a kid. I should really have brought someone with me as I couldn't think what to say or what to ask. I had questions in my mind that I was going to ask but I found I couldn't really say anything.

The doctor said I would be having a TURBT, an operation to remove the tumour and see what stage it was. This would be done at Wycombe Hospital.

I came home and tried to find out some information about it – what the causes might be mainly. I found some general information,

for example if you smoked or had certain occupations the risk was higher, and also that men were more likely to get it than women.

I had my surgery done under a spinal anaesthetic rather than a general, so I was awake during the operation. I think this was the preference of the anaesthetist but I thought it was ok being awake, I didn't mind that. I couldn't feel anything as I was all numb. After the operation I saw the CNS, who told me my tumour was Ta grade 2, that I would need checks for the rest of my life but it probably wouldn't kill me. I thought, 'Ok, that's a relief!'

Michael didn't need any more treatment and went on to have a follow-up cystoscopy three months later which showed that he was clear of cancer.

I thought it was something that was behind me.

Six months later he went back in for his next check-up. It had come back. This time there were two tumours, not just the one as at his initial diagnosis.

It came as a shock. I could see that the tumours stood out quite a bit from the bladder wall and I thought it looked more serious than before and so was quite worried. They removed the tumours with another TURBT followed by a chemo-wash of mitomycin as they had done the first time, but this time under a general anaesthetic.

Luckily the tumours hadn't advanced in grade or type and at his next check-up everything was clear again. But at his following six-month check cystoscopy, the cancer was back again.

The second recurrence! This time things looked quite different, more like coral fingers, which didn't seem as bad. The first recurrence really stood out but this seemed to be

closer to the bladder wall. My surgery to remove it was very quick – I was in and out on the same day whereas previously I had been kept in overnight. I was told this time that it was only a Grade 1 tumour. I got a urinary tract infection (UTI) this time after surgery – that was painful! But it was sorted out with antibiotics and cleared up eventually.

I suppose, from my own experience, the first message I would give someone who has just been diagnosed would be that there is hope.

So how do things stand now?

Firstly I went on six-monthly checks, but as everything is looking good I'm now on annual checks. I feel a bit nervous about having that length of time between checks. It does seem like a long time and I do worry that the cancer has come back, but then I have my checks and see that everything is still all right. I suppose I'm hopeful if it has come back it will be a low grade and very treatable.

My wife is a strong support. The only time she broke down a little bit was when I had my first recurrence. The second time it came back we thought if this is something we have to live with for years, we will just have to live with it. We have just accepted things.

Had you heard of bladder cancer before your diagnosis?

I hadn't heard of anyone having it or ever come across it. Obviously I realise you can get cancer of anything, having had other people in my family die of different types. My dad died of prostate cancer so I knew about that one.

One thing I've noticed about bladder cancer patients is that it takes a lot to dent their sense of humour.



I asked Michael if he thought that having more knowledge about bladder cancer has made him feel more in control of things.

Definitely, yes! After the first operation, they told me about some online support groups. I noticed that Fight Bladder Cancer was based quite locally to where I live so that's how I came across you. Initially I looked on the website for information really and then I decided to join the confidential forum so that I could ask questions. Straight away people responded to my post, which was quite a nice feeling.

Michael is now able to give others information, too, and recently did a wonderful talk at Aylesbury Rotary Club.

They wanted someone who had experience of bladder cancer. I was a bit nervous doing my talk, but it was a pleasant evening in the end and I also enjoyed talking to the individuals afterwards.

Do you think that having a bladder cancer diagnosis has changed your life in any way. Has it made you think differently?

You are suddenly aware of your own mortality. Obviously you know you aren't going to live forever but suddenly you are facing the prospect that it might not be for very long at all.

I started to do things that I hadn't done for quite a while, such as taking overseas holidays. Many years ago I learnt to scuba dive; I did the course and then I never did any more after that. We never really went away anywhere I could do it, so I thought I would pick it up again. It had been quite a few years since I'd done the course and I wondered if I would still be able to do it. I was a bit nervous and not entirely confident I would

be able to remember what to do if anything went wrong. But once I was in the water it was great! It made me think of something Will Smith said: 'The best things in life are on the other side of terror; on the other side of your maximum fear are all of the best things in life.' Overcoming the fear gave me such a fantastic experience. I've been to Malta a few times now and done a bit of scuba diving out there.

Are there any messages that you would give to a friend or someone else who was worried about having bladder cancer?

I suppose, from my own experience, the first thing would be that there is hope. When you get a first diagnosis, it really hits you; I thought, 'Well, that's it, I probably won't see Christmas.' But here I am five years later. Plus, since I was diagnosed, there have been new treatments coming through all the time. I realise that it's not always such a positive outcome for everyone but I think things are getting better. The work that has been done by the charity Fight Bladder Cancer is starting to make the decision-makers more aware of it. Bladder cancer is a big cancer and many people are affected by it.'

One thing I've noticed about bladder cancer patients is that it takes a lot to dent their sense of humour. As we made our way back to work, Michael said,

I'll always remember the time I was diagnosed. It was 2013. I remember because I'd been watching the football. Chelsea won the Europa League Cup.

Are you a Chelsea fan then?

No! I'm a Tottenham fan! So it went badly all round that year.

Getting used to a new 'normal'

ARTICLE

CHRIS LUCAS

FBC forum member

Chris looks back at his experience of bladder cancer and highlights the importance of emotional as well as physical support.

Hi! I am Christopher, aged 70. I am a retired automotive computer-aided designer and enjoy trying to play a little guitar and make home recordings. I'll start my story in 2008 when I first noticed blood in my urine. Understandably freaked-out, I had all the normal checks and was diagnosed with benign prostatic hyperplasia (BPH) otherwise known as an enlarged prostate. My doctors started me on Finasteride and regular check-ups.

Over the next few years I continued to pass blood on occasion and also suffered with a low flow rate, at times finding it quite difficult to pass urine. During these years I had many visits to Broomfield Hospital in Chelmsford, Essex for cystoscopies and various biopsies (including a template biopsy in 2015), all of which showed no sign of cancer.

I believe that at this stage in my story I should note that that I had been overweight for many years up to October 2012 (at which time I weighed 112kg) and was diagnosed as pre-diabetic. At this time I decided to lose weight by changing my diet and increasing my exercise, mainly walking, (I am now 78kg). I think this was a massive help to me during the times to come.

One night in April 2018 while standing in the bathroom and having my normal difficulty passing urine, I decided to go back to the doctor to try to arrange a TURP (where prostate tissue is removed from around the urethra) to help with my condition. Once referred to the hospital, the very first ultrasound scan showed a growth in a diverticulum (small pocket) in the wall of my bladder. This turned out to be a non-muscle invasive tumour (T1G3) and was removed at Chelmsford in July 2018.

The subsequent recommendation from the multi-disciplinary teams from all the local centres (including Southend and Colchester Hospitals)

was that I should undergo a radical cysto-prostatectomy (removal of my bladder, prostate and local lymph nodes). This was based on the perceived high chance of my bladder containing undetected tumours. I was referred to Guy's Hospital, where this procedure was carried out at the end of October 2018 by robotically assisted keyhole surgery.

The post-surgery histology showed multiple tumours in my bladder (which fortunately had not invaded the outer walls) and no cancer present in my prostate or the 25 lymph nodes which were removed.

The doctors pronounced me cancer-free in November 2018 with follow-up tests recommended in a year's time.

This news was, of course, the very best I could have hoped for and I will be eternally grateful to the urology team at Guy's and to Professor Shamim Khan and his fellow surgeons for saving my life. I am now getting used to my new lifestyle with a stoma, treating it as just a normal part of my life, and am working on my physical and mental recovery, which I have been advised could take as long as a year. I particularly mention mental recovery as the impact that the surgery and treatment had on me was unexpected. I have accepted now that my emotional state is somewhat fragile and will take time to normalise.

Lastly I must thank my wife Sylvia for all her understanding, care and support, without which it would have been a rocky road indeed.





The FBC Exemplar Study

What is the real patient

The day-to-day issues of living with bladder cancer are sometimes surprising, but vital in considering treatment priorities. Dr Hayley Dash answers our questions about the FBC project to improve services to a consistent 'gold standard'.

What is the Exemplar Project?

Using insights and experiences from patients, carers and healthcare professionals, the project aims to do three things in the next few years:

- 1 Firstly we want to define what makes an 'Exemplar' UK bladder cancer service – in other words, what makes a service for bladder cancer patients fit for purpose and outstanding.
- 2 Then we want to identify the gaps and inconsistencies in current services. At the moment, some places in the UK provide a very good service, others less so.
- 3 And finally we want to create a set of recommendations for how bladder cancer services across the UK can be collectively improved and where and how Fight Bladder Cancer should be involved.

We really can learn a huge amount about what works best from the NHS staff who deliver the current service.

In June 2018 Fight Bladder Cancer appointed Dr Hayley Dash, a highly experienced medical researcher, to co-ordinate a national research project which would examine the reality of the bladder cancer pathway across the UK. For too long, the limited quantity of research into bladder cancer has been focused around searching for breakthrough treatments, frequently regardless of the experience of the patient or whether day-to-day quality of life is good or bad. Fight Bladder Cancer's Exemplar study is about tackling exactly this. It is exploring the lived experience of having bladder cancer in the UK and asking clinicians and patients what their day-to-day experiences are, what works well and what doesn't.

What research have you done so far?

Since I started, I have been busy carrying out a survey with the NHS workforce – in other words I've been chatting to many of the expert doctors and nurses who work with patients every day at the sharp end. We had an initial pool of 34 medical practitioners who we asked to take part in a telephone interview, of which 17 responded. I am now analysing the details of each discussion to draw out themes and recommendations. We really can learn a huge amount about what works best from the NHS staff who deliver the current service.

Can you draw any conclusions yet or is it still early?

Well, we really are only at the beginning of the study, but I can confirm that broadly, the themes and topics identified by the workforce match the themes identified in the NICE guidelines review of 2015. My next priority is to identify the different models of bladder cancer services being implemented across the UK and draw out their differences: what works well or less well.

ARTICLE
DR HAYLEY DASH
FBC medical researcher



experience?



Early results from the interviews with healthcare professionals demonstrate that we have a highly experienced and dedicated workforce. However, they are not always able to deliver the service they would like to deliver and the challenges around that are complex and diverse. What I can say is that, when asked, 100% of our participants felt that there should be much more focus of raising awareness of bladder cancer by the charity, not only for patients and carers but healthcare professionals too. In addition, two-thirds of our participants felt that Fight Bladder Cancer should be behind patient support groups and 100% felt that the charity should provide more education for patients, carers and their families as well as signposting for other services, such as financial matters, following a diagnosis.

When we follow up with our healthcare professionals in 12 months' time, we plan to ask the same questions and find out if their views and experiences have changed.

What work will be done next within this research project?

The next phase of the project will be a patient survey identifying personal experiences, followed by a survey of the carer and / or family. We anticipate interviewing 50 to 100 patients and a similar number of carers / family members. Our plan is to approach patients' carers and families who already have a relationship with Fight Bladder Cancer as well as reaching out to our NHS colleagues. We also plan to recruit through current bladder cancer trials.

All being well, we plan to start our patient interviews early in 2019.

Bladder Cancer PROMS

– where are we going?

The reality of the patient experience of treatments for bladder cancer are collected by the recording of what is called 'Patient Reported Outcome Measures' or PROMS.

These PROMS, hopefully, record the reality of treatments from the patient perspective and give us an idea of the quality of life during treatment and afterwards.

Quality of life research in cancer is invaluable as it gives the patients' perspective and can inform clinicians of common issues that occur during treatment and highlight good (and less good) practice. In addition, it provides information to allow patients to understand the possible outcomes of treatment related to quality of life, so they can make informed decisions about their own treatment.

Quality of life can be measured using questionnaires, known as patient reported outcome measures (PROMs). There are many different questionnaires, each asking about different issues. These issues are collected into symptoms reflecting a single process. For example, one may be asked about physical functioning (how far you can walk, how well you can look after yourself); one about fatigue; about urinary issues (how often you pass urine, incontinence); or the nature and persistence of pain₁.

How PROMs are developed

To progress quality of life research and produce good-quality outcome measures, work has been undertaken to standardise how such things are measured.

Organisations specialising in cancer and chronic illness research, such as Functional Assessment of Chronic Illness Therapy (FACIT: <http://www.facit.org/>) and the European Organisation for Research and Treatment of Cancer (EORTC: <http://groups.eortc.be/QOL/>) have developed standards and guidelines for creating and evaluating PROMs for use with patients. This process includes a number of phases which address various measurements (also known as psychometric) properties (see figure 1 for an overview).

PHASE 1

Item development: Generation of items through literature searching and interviews with patients and healthcare professionals

PHASE 2

Item refinement: The item pool is assessed for comprehension and patient and clinical relevance and items are refined, producing a final item list.

PHASE 3

Psychometric testing: Following data collection, testing of reliability, validity and sensitivity is undertaken to determine how 'fit for purpose' the PROM is.

Figure 1: Overview of Patient Reported Outcome Measures development and psychometric testing phases



Item (question) generation phase. QoL issues and potential questionnaire items are produced as a result of literature-searching and interviews with both patients and healthcare professionals. This phase also addresses whether items are relevant to the target population.

Item refinement phase. The initial pool of items is assessed for comprehension and clinical and patient relevance. This usually involves further testing with patients. This phase is complete when the final set of items has been produced.

Psychometric testing phase. In this phase, patients are asked to complete the questionnaire alongside other commonly validated quality-of-life measures. Psychometric testing is carried out to assess:

- **validity** (whether the PROM measures what it is meant to be measuring);
- **reliability** (whether the scores on the PROM are similar each time for patients whose circumstances have not changed);
- **sensitivity** (whether the PROM identifies real differences or changes).

This testing is undertaken during both pre-testing of the questionnaire and as part of wider testing of the PROM with larger and more diverse patient groups.

It has been argued that there are too many PROMs available to measure QoL in bladder cancer patients and no clarity on how PROM research leads to changes in clinical practice₂. To date, a number of PROMs have been developed – both by cancer and chronic illness organisations and by groups of researchers/clinicians – to measure quality of life in bladder cancer patients, with further PROMs in development. There is little information to assist researchers in choosing the most appropriate PROMs with bladder cancer patients as no single measure is promoted over another. There is also a lack of clarity about whether the current PROMs are accurate measures of QoL, or if new measures are required.

Compared to other cancers, bladder cancer treatment and survivorship quality of life data are lacking

Is the system working for bladder cancer patients?

Compared to other cancers, bladder cancer treatment and survivorship QoL data are lacking. This is especially pertinent for patients with non muscle invasive bladder cancer (NMIBC). In order to improve patient QoL, robust QoL data about bladder cancer is required. Generating this data would provide information and understanding of the issues patients experience during and after diagnosis and treatment for bladder cancer and identify where there are gaps in patient care and support, and barriers to change. This knowledge could then be utilised to better counsel patients about likely outcomes, improve QoL and shape clinical care delivery.



New research

In this research we undertook a systematic review of the PROMs used with bladder cancer patients. The aims of the review were:

- to assess whether the PROMs were fit for purpose;
- which PROMs were most appropriate to use with different bladder cancer populations, such as muscle-invasive or non-muscle invasive.

Evidence from the review will inform choice for future PROM data collection, thereby ensuring that robust data about patient experience is collected. This, in turn, will contribute to addressing the FBC manifesto pledges 7 – impactful research for patient choice – and 8 – improving QoL during and after treatment.

The most appropriate way to meet the review objectives was to review studies that report on psychometric properties of PROMs, as this enables the selection of the best PROM for a specific purpose₃. The consensus-based standards for the selection of health measurement instruments (COSMIN) checklist is a critical appraisal checklist to improve the selection of health measurement instruments. It provides clear assessment criteria and standards to evaluate the methodological quality of studies that report and evaluate the psychometric properties of PROMs, and further guidance to evaluate the quality of each PROM. Development of the checklist involved consensus on which measurement properties are pertinent when

considering if a PROM robustly measures QoL, and how this should be reported (both statistically and methodologically). The criteria were developed over a number of years and iterations by a multi-disciplinary team of researchers working in psychometrics, medicine, qualitative research and healthcare, with expertise in the development and evaluation of outcome measurement instruments (including PROMS).

There were 23 studies identified by the review that reported measurement properties of 15 PROMs used with bladder cancer patients over the last 27 years, which were made up of three types:

- **Generic PROMs.** These are used to measure QoL in a variety of populations (not exclusive to cancer patients) covering general issues and ailments (such as mobility and general pain).
- **Cancer-generic PROMs.** These measure QoL issues experienced generally by cancer patients, and the impact of cancer on a patient's daily life, emotional health and relationships. Information can be utilised to compare the QoL of bladder cancer patients with other cancer populations.
- **Bladder cancer specific PROMs.** The third group focuses on commonly reported bladder cancer problems such as with urinary, bowel and sexual function. Findings may inform treatment regimens, policy and patient support.

The three generic PROMs identified in the review are all widely used in QoL research, and are accepted as being robust measures that are valid (measuring what they are meant to be measuring), reliable (measuring it accurately), sensitive (able to pick up differences between groups with different problems or changes over time) and applicable to a wide range of health problems⁴. Despite this, detailed information about the psychometric properties of these generic PROMs, when completed by bladder cancer patients, was not reported in any of the studies. Due to the lack of information, little can be concluded about which generic PROM is the most appropriate to use in bladder cancer research. What is understood is that they may lack sensitivity in measuring issues specific to cancer and bladder cancer.

The review highlighted that there is a lack of studies reporting the psychometric properties of cancer-generic PROMs in bladder cancer patient populations. A surprising finding was that despite publishing reference data for a variety of cancer groups and its frequent inclusion in bladder cancer QoL research, EORTC QLQ-C30, one of the main cancer-generic PROMs used in QoL research, has not published normative values for bladder cancer patients⁵.

Bladder cancer specific PROMs

Bladder cancer specific PROMs identified by the review were of variable quality. Perhaps due to the differences between NMIBC and MIBC, in terms of treatment protocol, only two PROMs are currently available that can be used with both patient groups: Bladder Cancer Index (BCI) and FACT-BI.

The psychometric properties of the BCI were more frequently evaluated in research and the PROM scored more favourably using COSMIN. However, the BCI is not without flaw, as evidence has suggested that results can be difficult to interpret. For example, if urinary function and urinary bother scores highly differ on the PROMs, there is no guidance as to whether QoL should be determined by symptoms (function) or importance of symptoms to the

patient (bother)⁶. FACT-BI was evaluated on fewer psychometric qualities, due to a lack of reporting in studies, and scored poorly on the COSMIN checklist. Evidence strongly suggests that there is more information about the psychometric properties of this PROM than is presented in publications. A recent overview paper of bladder cancer Patient Reported Outcome Measures reported that each new FACIT scale undergoes psychometric assessment of test-retest reliability, responsiveness and convergent and divergent validity with 50 patients, which is in-line with the PROM development phases undertaken by FACIT (who produced FACT-BI). As these data are not publicly available, a full assessment of the psychometric properties of FACT-BI was not undertaken.

In stark contrast to FACT-BI, studies reporting on the FACIT bladder cancer module for cystectomy patients, FACT-VCI described more about the psychometric properties of the PROMs. This meant that FACT-VCI was evaluated on seven of the nine psychometric properties assessed by COSMIN. FACT-VCI also had the most positive COSMIN ratings. It is frequently used in quality of life studies comparing types of diversion, but cannot measure quality of life in conservative treatment patients. Comparatively, the EORTC MIBC module, EORTC QLQ-BLM30 was assessed for two measurement properties only, but can compare radical and conservative treatment related QoL.

When evaluating NMIBC PROMs, the EORTC NMIBC module, EORTC QLQ-NMIBC24 scored well on the COSMIN checklist. As with FACIT, it is understood that the EORTC bladder cancer specific modules have been developed and tested according to specific guidelines (though they have not been internationally tested and validated). Although there is an internal paper that reports the development, refinement and early testing of EORTC QLQ-BLM30 and EORTC QLQ-NMIBC24, this paper is not publicly available and therefore certain measurement properties could not be evaluated for the review despite these properties being evaluated during development of the EORTC bladder cancer PROMs.

The review highlighted two main issues. Firstly, there is a lack of research that details the psychometric properties of PROMs used with bladder cancer patients in QoL studies. The second issue is that even when there is evidence that psychometric work has been undertaken, it is not always publicly available.

This knowledge could then be utilised to better counsel patients about likely outcomes, improve QoL and shape clinical care delivery.

There is a lack of research that details the psychometric properties of PROMs used with bladder cancer patients in QoL studies. Even when there is evidence that psychometric work has been undertaken, it is not always publicly available.

This is reflected in the finding that compared to other cancer populations, the psychometric properties of generic and general cancer PROMs are less well understood in bladder cancer populations. This is an issue as it leaves little indication of how appropriate PROMs are in measuring QoL in bladder cancer patients.

Begin a new approach

To improve the QoL of bladder cancer patients, it has been stated that a single, consistent approach must be adopted. To begin this process, it is imperative that there is an understanding of the psychometric properties of PROMs used in bladder cancer research, so that the most appropriate ones are highlighted. This work will identify where there are gaps in the understanding of how well PROMs measure bladder cancer patient QoL, and allow for informative and useful data on patient experience to be gained from QoL research.

In order to work towards meeting this aim, there would be a benefit in pooling data from studies which have used generic, cancer generic and bladder cancer specific PROMs. This would facilitate more detailed psychometric analysis of how well each PROM measures QoL. Organisations such as EORTC could use this data to produce reference values for bladder cancer patients and provide research teams with more information when choosing PROMs for QoL research.

Funding research to evaluate the psychometric properties of PROMs used in bladder cancer research would contribute towards achieving this aim. Psychometric evaluation of generic, cancer generic and bladder cancer specific PROMs should be reported and published, ideally using the COSMIN guidelines, so that it can be determined how useful these PROMs are with their intended bladder cancer populations using a rigorous methodology.



The Bladder Cancer PROMS research team: from left to right Professor Jim Catto, Samantha Mason, Dr Amy Downing, Dr Penny Wright, Sarah Bottomley and Professor Adam Glaser.



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Calling all patients in YORKSHIRE

ARTICLE
SAMANTHA MASON
Research assistant,
University of Leeds

The Life and Bladder Cancer study, funded by Yorkshire Cancer Research, is investigating the quality of life of bladder cancer patients living in Yorkshire, and aiming to identify the specific issues people face.

This study includes a cross-sectional survey that will evaluate quality of life (QoL) in different patient groups and highlight common issues that arise in the years following a bladder cancer diagnosis.

We are asking people diagnosed with bladder cancer between one and ten years ago in the Yorkshire, Humber, North Derbyshire and South Tees regions to take part in the study. Around 4,000 people will be invited to complete a one-off survey. The survey was sent to 400 people in November 2018 and a further 3,600 people will receive an invitation through the post in January 2019.

We anticipate that the survey will take around 30 minutes to complete and this can be done on paper, over the telephone or online. A freephone helpline will be available to answer any queries or concerns and to assist anyone wanting to complete the survey over the telephone. Contact details for Fight Bladder Cancer will also be provided so that people can contact the charity for support with any concerns about their diagnosis and treatment.

The survey contains a variety of questions covering a range of areas. Among other questions, people will be asked to answer questions about their urinary, bowel and sexual functioning, in addition to questions about how they feel physically, emotionally and socially. They will also be asked to answer questions about the wider impacts of bladder cancer on their everyday lives, such as the impact on finances, relationships and on their social life.

By taking part in this survey, patients will provide a wealth of information and valuable insight into life with bladder cancer from their perspective. It is important that we have good information about the problems that people living with and beyond bladder cancer experience, so that better support can be offered to patients in the future.

Results from the study will inform us about the patient journey following diagnosis and treatment of bladder cancer, what is important to patients and what factors impact on their physical and emotional well-being.

The findings of the study will identify the kinds of information and support that patients require from service providers and gaps or barriers in care giving. This information will then be used to evaluate hospital services and to inform future changes to these services.

If you live in Yorkshire and the hospital who provided your care has agreed to be involved, you may be invited to participate. Should you receive a survey, we would be very grateful if you would take the time to complete it. We hope to receive completed surveys from as many of the people invited to take part as possible.

This is your opportunity to tell us what matters to you and to have your views heard and listened to.

More information about the Life and Bladder Cancer project can be found on our website: www.lifeandbladdercancer.org

ARTICLE

JIM CATTO and SAMANTHA MASON
Professor of urological surgery and FBC trustee,
and research assistant, University of Leeds

Quality of life after treatment for bladder cancer

Joint authors of a research paper on the health-related quality of life after treatment for bladder cancer in England, Samantha Mason and Jim Catto offer this accessible resumé of the report.

Currently, we know little about quality of life after bladder cancer treatment. This is despite the fact that these treatments can affect urinary, sexual and bowel function, not to mention a person's self-esteem.

To understand quality of life and to help improve future care, the Department of Health (England) surveyed adults who had survived bladder cancer for one to five years after their diagnosis and initial treatment. These people were identified using the National Cancer Registration and Analysis Service and were sent a questionnaire in the post, with a cover letter from their treating cancer centre. Permission to approach patients was given by the Health Research Authority (ref ECC 5-02(FT7)/2012).

In total, 500 men and 173 women responded to the survey. Most (93%) respondents were white and 65% were in remission from bladder cancer. 80% of respondents had at least one other long-term condition. 60% had received endoscopic treatment, 15% had received radiotherapy (external beam or chemo-radiation), and 14% had had their bladders removed. 16% of respondents were using a stoma.

Overall, 65% of respondents reported at least one problem that was affecting their quality of life. 43% of respondents reported problems with common daily activities. Respondents aged 85 years or older were most likely to report some problems with mobility, self-care and usual daily activities.

Over 33% of people who had TURBT (with or without chemotherapy into the bladder) reported weeing 'quite a bit' or 'much' more frequently than usual. 44% of people treated with radiotherapy and 50% of people treated with chemo-radiation reported weeing 'quite a bit' or 'much' more frequently than usual.

We need to make sure that doctors and nurses are asking questions about these issues when they meet people with bladder cancer.

Despite all these challenges, it was encouraging to see that about 75% of respondents reported that they were 'quite a bit' or 'very much' content with the quality of their life right now.

Almost 75% of respondents reported that they were 'not at all' or 'a little' satisfied with how they were coping with their illness. Feeling nervous 'quite a bit' or 'very much' was reported by 10% of respondents; particularly by women, and those with three or more long-term conditions.

Of respondents younger than 55 years old, 50% reported problems with anxiety or depression, compared to between 31–44% of other age groups. People with three or more other long-term conditions also reported more problems with anxiety or depression.

Overall, 25% of people responded that they experienced a lack of energy 'quite a bit' or 'very much'. Pain was reported 'quite a bit' or 'very much' by 10% of respondents, and was higher in respondents with three or more other long-term conditions.

Just under 50% of respondents said that they didn't like their body appearance at all, or only liked it a little. People with a stoma were more likely to report not liking their body at all or only liking it a little.

Overall, 21% of people reported difficulties with everyday living. 41% of people with three or more other long-term conditions reported difficulties with everyday living. Around 33% of respondents answered that they were not able to work, or only work a little. 14% of people reported difficulties with money matters, and these difficulties were greater in people aged younger than 55 years of age.

About 33% of people reported difficulty with travelling or plans to take a holiday. Respondents with a stoma were more likely to report 'quite a bit' or 'very much' difficulty with travelling than those without a stoma.

About 66% of people reported some sort of issue with their sex life. Overall, 17% of men reported 'quite a bit' or 'very much' difficulty with sex, compared to 5% of women. Of the women, 50% reported that they were 'quite a bit' or 'very much' satisfied with their sex life, compared to 33% of men. 86% of women said they were 'not at all' or only 'a little' interested in sex, compared to 60% of men. Dissatisfaction with their sex life was more common in people



who had bladder removal surgery, compared to those who had other treatments. 96% of men with a stoma reported their ability to maintain an erection as 'not at all' or only 'a little'.

Despite all these challenges, it was encouraging to see that about 75% of respondents reported that they were 'quite a bit' or 'very much' content with the quality of their life right now.

These results highlight the need to support people with a new diagnosis of bladder cancer, especially related to issues of weeing more frequently, anxiety and depression, lack of energy, returning to work, travelling, and sex.

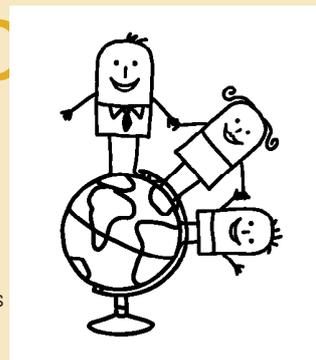
We need to make sure that doctors and nurses are asking questions about these issues when they meet people with bladder cancer. We also need to identify the people who are at greatest risk of experiencing these problems, so we can find them and help them sooner.

Finally, this work has led to the Yorkshire Cancer Research funded Life and Bladder Cancer survey. The first part will be run in early 2019 (<https://www.sheffield.ac.uk/oncology-metabolism/research/urology/research/labc>). We will mail out 4,000 surveys to all patients surviving Bladder Cancer in Yorkshire. If you receive one, please do take the time to complete and return the survey.

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Fundraising catch up



May – August 2018

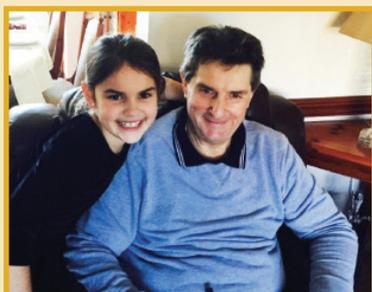
Personal donations and fundraising are the mainstays of the income here at Fight Bladder Cancer. We would not be able to do what we do to support people affected by bladder cancer – raise awareness, support research and campaign to get policy change at the highest level – without all your help.

We are SO grateful and absolutely love working with you. We like to use this spot to feature some of your stories – it's not possible to include them all – but we also do our best to promote your activity on our Facebook page and send you lovely messages of thanks and support. If you don't hear from us, please pick up the phone to Emma and Sophie, or send them an email at fundraising@fightbladdercancer.co.uk. They also LOVE hearing your ideas, catching up and also getting your feedback.

If you'd like us to feature your fundraising activity and send a big shout out to your supporters, please email fundraising@fightbladdercancer.co.uk.



Sian Rollings completed the Forest of Dean Trail Marathon in August and raised £430. This was her first marathon and she did amazingly well in 26°C heat!



Libby Nicol went without electronics for a whole two weeks and raised just over £410! She is Pete and Lin Ray's granddaughter, well done Libby!



Caroline Evason and daughter **Sophie** held a cake sale and a Facebook birthday fundraiser, generating just over £660 for Fight Bladder Cancer! Pictured here is Caroline's wonderful Dad, Eddie.



Aly, Kate and **Emma Metcalf** completed the Wirral Coastal Walk in June, helping to raise almost £100 for FBC.



Donna Anstead climbed Mount Snowdon in July, raising £380 for FBC! Here's Donna with her dad, Ray.



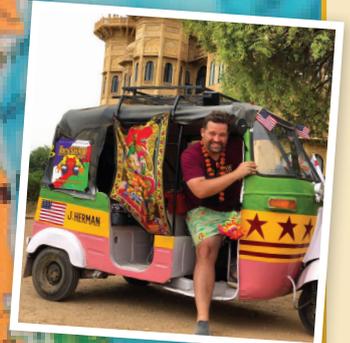
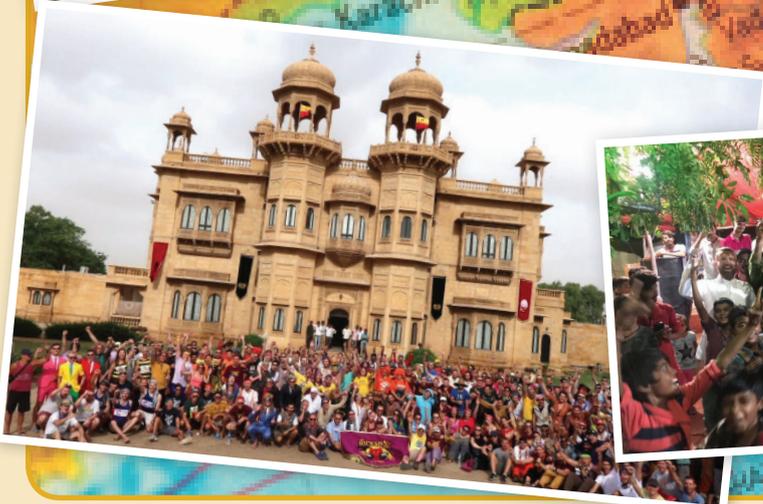
Emma and **Wendy** completed the Jurassic Coast Challenge in July raising just under £800 for the charity.



Dione, Lorraine, Martyn, Annabel, Sue, Kim, Aimee and Hayley from the Anglia Revenues Partnership, took part in the 36-mile Fen Rivers Walk in July in support of their colleague, **Jo**. They blew their initial target out of the water – raising nearly £5,100!

Take a look at pages 14-17, where we've rounded up some of the fundraising that went on as part of Bladder Cancer Awareness Month in May 2018.

Shirley and Mike Norris packed their bags and took part in the Rickshaw Challenge in India during August, raising almost £2,500 for the charity!



Raise some money & have some fun!

There are so many fun and easy ways you can raise money to support our work – try one of our tried-and-tested ideas or let your imagination run riot.

You can download our fundraising ideas booklets from our website

www.fightbladdercancer.co.uk/downloads



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.



Are you sporty?

To help raise awareness and funds, you could:

- run a marathon – or something shorter;
- jump out of a plane;
- climb a mountain;
- do a bike ride;
- join a sponsored walk;
- play in a charity match.

Fight Bladder Cancer has a partnership with an event company, RunforCharity, who help us to get entry to a host of sporting activities both in the UK and internationally. Take a look at <https://runforcharity.com/charity/fight-bladder-cancer> and you will see that you can join in any event, large or small, in the UK or abroad to raise money for Fight Bladder Cancer. Whatever you decide, why not wear the FBC logo and help spread the message at the same time?

Good at organising?

Alternatively, you could consider getting together with friends and arranging your own fundraising and social events in 2019. Not only is this great fun socially, but it helps build awareness of bladder cancer and can even bring people together to meet others who have been affected by bladder cancer.

We have supporters arranging quiz nights, curry evenings, golf days and darts evenings. These gatherings are great fundraisers, superb fun and a chance to meet up informally with people to share experiences.

FBC fundraising on Facebook

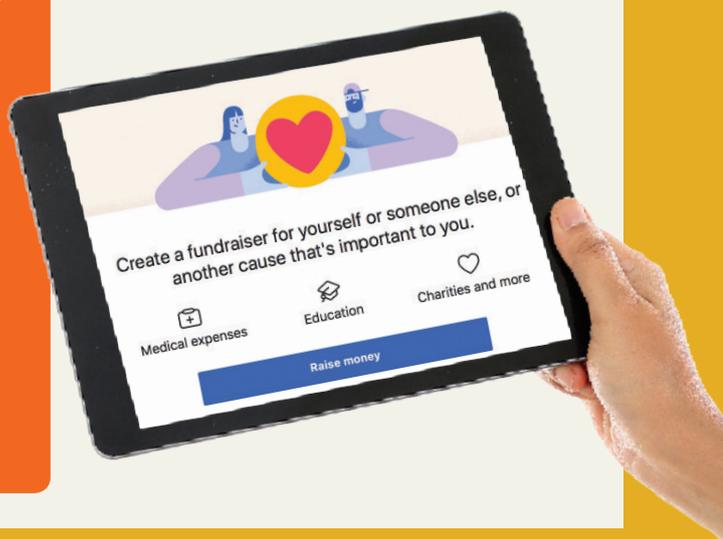
Facebook fundraising is a new initiative that was launched by the social media giants in December 2017. We have been delighted by the number of people that have chosen Fight Bladder Cancer as their charity for their fundraiser and we are so grateful for all the money that has been raised in this way. Unfortunately we don't always get notified by Facebook when a fundraiser has started up a campaign for us, so if you want to get involved and need some help, or would like to let us know you've set one up, please email sophie@fightbladdercancer.co.uk. We have been doing our best to catch up with fundraisers from 2018. All of you should receive a Certificate of Success which will be posted on your Facebook fundraising page, but if you've had a fundraiser for Fight Bladder Cancer that's ended more than a month ago, please let us know and we will send you one of these, which you can post up on your page to thank your pals!

We can help you fundraise!

As you will read in the team introductions on pages 44-48, Emma and Sophie are available to chat on **01844 351621**, or you can email them at fundraising@fightbladdercancer.co.uk or individually on emma@fightbladdercancer.co.uk and sophie@fightbladdercancer.co.uk. They both work part-time, but will endeavour to get back to you swiftly if they aren't around.

They will support you to deliver your fundraising dreams, encouraging you all the way and answering any tricky questions or concerns. Their support includes the design of posters and flyers and some other materials such as banners, sponsorship forms, posters, cake toppers and special thank you cards! You name it, they will consider developing it IF it helps you to raise money! Vivaly, we will also help you secure the most money for Fight Bladder Cancer by helping you and your supporters to claim Gift Aid (that's tax rebate which we can claim). So make sure you get in touch with the team, who will really ensure your fundraising gets off to a smooth start.

And finally, please be reassured that Fight Bladder Cancer will spend your hard-earned money with great care, giving you regular updates on the charity's progress. In 2019, the team are hoping to send monthly newsletters by email to supporters and friends. This newsletter will include punchy updates on projects and short insights to patients' and carers' stories. If you would like to receive this supporter newsletter, please let Emma know on emma@fightbladdercancer.co.uk.



Meet the FBC team!

We introduce you to the fabulous team in the orange corner!

As many of you will know from your calls and emails into the Fight Bladder Cancer office, and our fabulous dialogue with you all on Facebook and other social media, we have been thrilled to be able to invest in a few additional team members this year. We now have a growing and dynamic mix of volunteers and staff in the office, although we are ALL part-time – except for Lydia, our new CEO – so please bear with us. We do promise we WILL always get back to you! We thought that this edition of FIGHT magazine would be a great opportunity to introduce the team to you so you know who is at the receiving end of your communications!

LYDIA MAKAROFF

CEO



Lydia has over ten years' international experience in disease support, research and policy. She carried out medical research during her PhD at the Australian National University and as a senior post-doctoral fellow at the University of Washington. After working at a pharmaceutical company, she joined the International Diabetes Federation to lead

the Diabetes Atlas and other public health projects, and then took up the role of Managing Director at the European Cancer Patient Coalition. She has experience in supporting people affected by serious diseases, monitoring the government's commitments to health, writing papers, and working collaboratively with stakeholders to achieve change. Lydia holds a PhD in medical research and a Master's degree in Public Health.

When she's not with her friends, family or cats, Lydia likes to walk through green spaces or read a good book.

ANDREW WINTERBOTTOM

Founder



Andrew, who with his wife Tracy, founded Fight Bladder Cancer in 2009 had a career in architecture that included designing hotels, shops, sports centres and visitor attractions across the world.

Diagnosed with a stage 4 bladder cancer in July 2009

and almost immediately after major surgery, started the process of setting up Fight Bladder Cancer as the first patient advocacy group in the UK for bladder cancer patients and their families. The charity, under Andrew's direction, has grown to be a significant voice

for bladder cancer across the UK and more recently across Europe, where he has helped to draft the European Cancer Patient Coalition's Bladder Cancer White Paper. Andrew is also a representative of the UK National Cancer Institute's Bladder Cancer Clinical Studies group and two specialist sub-groups for invasive and non-invasive bladder cancer. In addition, he has also been the patient specialist representative on the NICE panel, developing the latest UK Bladder Cancer Quality Standards, and a patient advisor to the Scottish Medicines Coalition and the European Medicines Agency.

Andrew is now working part-time for Fight Bladder Cancer to allow him to focus on his cancer treatment. In his spare time he loves to jump in puddles, look at art, listen to opera and have adventures.

EMMA LOW

Part-time Fundraising Lead



Emma has 24 years' work experience in the not-for-profit sector in marketing, fundraising and project development. Past roles have included head of fundraising at Crisis and executive director of marketing at Asthma UK. Emma has led

departments; achieved and exceeded ambitious fundraising targets; and given strategic input to a host of leadership teams and trustee boards.

After 15 years of freelance consultancy, Emma was so inspired by Andrew's vision, by the patients and families she met at Fight Bladder Cancer and the injustice of so little media and fundraising attention on bladder cancer that she agreed to join the staff team in 2018 to lead the charity's fundraising growth.

In her spare time, Emma is co-chair of the Chilterns' branch of the Institute of Fundraising, and a trustee of Youth Concern, Aylesbury, a local charity working with at risk and vulnerable young people. Emma enjoys spending time with her family (husband Chris, and children Lottie and Cameron); sipping gin and tonic; and walking with her friends and her Romanian rescue dog Olive.

MELANIE COSTIN

Part-time Support Services Manager



Melanie has been working for Fight Bladder Cancer for some time now, discovering the charity early on after her own bladder cancer diagnosis. Initially she helped to raise awareness and support various events, and she is now the

support services manager. The role has many facets, including helping those who have been recently diagnosed and providing information and support to them and their families along the way; talking at Fight Clubs and other support groups; raising awareness and providing information; running the Bladder Buddy service; and being an administrator on our very busy forum. When she gets invited to medical meetings, she definitely tries to get the patients' voice out there as much as possible! Her current job is a far cry from her pre-bladder cancer life, she originally trained as a technical draughtsperson, working on designs for the motor industry and in structural engineering.

Away from work, she runs an art class for dementia patients. She also loves to travel. She's a cemetery photographer – they can be monumental, Victorian or overgrown, she'll happily visit them all. She supposes she should say that she also loves cats and music.

SUE WILLIAMS

Part-time Office Manager



Having come from over 30 years in a book-keeping background in retail and then manufacturing, with some freelance work thrown in, Sue joined FBC in 2016 as an admin assistant to help Andrew to cope with his ever-increasing charity

workload, based initially at her kitchen table, then from a small room at the back of the Wee Bookshop and Café when it opened in 2016. The popularity of the café and its tempting smells of freshly baked cakes coincided with the growing size of FBC so more space was needed, and when the charity finally moved to

the current offices at 51 High Street, Chinnor, nearly two years ago. Sue's role is varied so no two days are the same. She answers telephones, deals with orders for charity goods and magazines, replies to enquiries from urology nurses for leaflets and posters, covers the admin tasks for the café and charity and pulls together the financial paperwork for entry into our accounting records. Together with a colleague, she occasionally loads her car with all things FBC and drives to a urology conference or health awareness day to set up our stand to raise awareness of FBC and offer support.

Away from the office, she enjoys various needlecrafts, drawing, beadwork, crosswords, Sudoku and reading. In the summer, she loves hunting for vintage crafts, fabrics and beads at car boot sales and vintage markets. She admits to being a crafting hoarder.

SOPHIE MAGGS

Part-time Supporter Care and Community Engagement Officer



Sophie started at FBC at the end of July 2018, joining Emma in the fundraising team, as the supporter care and community engagement officer. Sophie's whole career has always been within the customer delivery environment; from working for

large International companies, then, for the past nine years, with an interior design company.

Sophie has initiated and managed a number of large events, (including golf days, spa days and a masquerade ball) over the past six years to raise money for a local deaf children's group. Her own personal experience in fundraising gave her the push to join Fight Bladder Cancer.

Her spare time is spent looking after her two teenage children, Jackson and Millen, and their miniature schnauzer, Heston. She enjoys eating out, live music events, spending time with family and good friends, and she has a passion for anything creative!

ANNE MACDOWELL

Volunteer – Corporate Partnerships



Anne has nearly 40 years of experience working in the healthcare industry in both start-ups and well-established international

companies. She has lived and worked in the US, France, the UK and Switzerland and has been responsible for successful businesses extending as far as Japan. She has an undergraduate degree in music and an MBA from Harvard Business School.

Anne stopped paid work in 2017 and is currently working with a number of charities on a volunteer basis. Her role with Fight Bladder Cancer is to build mutually beneficial relationships between the charity and its corporate partners in order to drive the most successful outcomes possible for bladder cancer patients.

Anne has been married to her husband Martin for 30 years and they have two grown children, Katie and Charlie. In her spare time she enjoys travelling, learning, singing and participating in sports.

AMY RANDALL

Part-time Researcher



Amy is an experienced and highly motivated researcher with an MSc in Social Research Methods and a passion for research and social justice. She has a first class degree in Sociology from the University of Kent, and a Masters in Social Research Methods from the London School of Economics and Political

Science. She was motivated to apply for a position at Fight Bladder Cancer due to her interest in developing research studies to improve understanding of patient and carer experience. She is working to improve the understanding of patient and carer experience of bladder cancer services, identify needs, and informing Fight Bladder Cancer's work to support better outcomes and quality of life for those affected by bladder cancer.

JOSEPHINE ELLIOTT

Volunteer – Research



Josephine is a medical student at University College London, with an interest in medical education and global health. She is currently responsible for analysing the data from the Fight Bladder Cancer patient experience survey, and turning the results into a paper for publication in a scientific journal.

HAYLEY DASH

Part-time Researcher



Having spent a number of years in NHS pathology, Hayley went on to gain a PhD in Medical Diagnostics and Devices. She has been involved in the number of large-scale clinical trials in both the private and public sectors

in mental health, cardio-respiratory and oncology fields. Hayley has worked closely with a number pharmaceutical companies in clinical trial project management as well as engaging directly with NHS trial patients and their families. Hayley has a strong interest in NHS service evaluation and delivery, particularly from the patient and wider support network perspective.

MICHAEL SLOANE

Part-time Financial Assistant



Michael grew up in Harrow, went to university in Hull and after a period of time living in and around London, moved to Marlow Bottom in 1999. For over 29 years, Michael worked as an accountant for a

fire and security alarm company in Harrow. He came to volunteer at the charity in 2018, and assists with the accounting system, data entry and reporting. Michael was diagnosed with bladder cancer in 2013, and whilst he has had a couple of recurrences since, he has now been clear for the past three years.

Michael likes to cycle, and has cycled from west London to Brighton a couple times in the past. He has also enjoyed scuba diving in Australia and Malta. For more information about Michael's journey with bladder cancer, see his interview on page 26.

HELEN DRAYCOTT

Volunteer – Trusts & Grants



Helen is a former career prosecutor, now working as a criminal justice trainer and consultant. She is currently working on a project to strengthen the judicial system in Kosovo. She has extensive experience of a broad

range of cases as an advocate, prosecutor, manager and strategic lead, including violence against women and hate crime. She is working as a fundraising volunteer for Fight Bladder Cancer.

SUE MOORE

Volunteer

Sue is a radiographer with over 30 years in the NHS and she first met Andrew Winterbottom in her professional capacity. Their paths crossed again in Chinnor Village and she came to learn about the charity, which was then in its infancy. It was a change in Sue's father's health that resulted in her rethinking her working situation and a requirement to have more flexibility and time to support her parents. Her father's diagnosis of bladder cancer led her to leave her role in the NHS, take up other part-time work and free up some time to do some voluntary work with Fight Bladder Cancer.

Sue has counted stock, parcelled up magazines, learnt how to use e-Bay (just about) and put excess coffee supplies and donated items online, to sell for fundraising, and become an expert at folding T-Shirts and packaging them, in readiness for the lovely people who buy them online for their own fundraising events. Sue has even put together IKEA tables and bookshelves for the charity! She heads out to the Post Office whenever there are packages to send or funds to bank. Sue was also able to help input information and prices into the computerised till system for the Wee Book Shop and Café.

Our FBC trustees



JOHN HESTER

Chair

John is the financial controller at the Potters Group, which is the biggest privately owned waste management company in Wales. A bladder cancer patient, John became the chair of the trustees

after a period as our treasurer.



HILARY BAKER

Hilary trained as a Registered General Nurse at University College Hospital in 1983, and went on to have varied surgical experience, mainly in urology as a ward sister, and also a nurse manager in both the NHS and the private sector. In 1995 she

was appointed a urology Clinical Nurse Specialist at Central Middlesex Hospital when there was an increasing demand for nurses in specialist areas with knowledge and skills to support urology patients. In 2001, with funding from the NHS Plan, she was employed as uro-oncology CNS and team leader at Buckinghamshire NHS Trust. In September 2014, Hilary was appointed as lead CNS for uro-oncology. She has a BSc (Hons) in Cancer and Palliative Care and is registered as a specialist practitioner in adult nursing with the Nursing and Midwifery Council. She has recently completed her MSc in Cancer Studies at Oxford Brookes University.



DR ALISON BIRTLE, MB BS MRCP FRCR MD

Alison's general medical and specialist registrar oncology training was undertaken in London at Charing Cross and Westminster Hospitals. Her MD thesis was completed at the Institute of Urology,

University College London, and the Academic Urology Unit, the Royal Marsden Hospital. She is consultant clinical oncologist and honorary clinical senior lecturer for Lancashire Teaching Hospitals. She is chair of the NCRI Bladder and Renal Clinical Study Group. Her research interests are in systemic therapy in urological cancers, chemoradiation and radiotherapy advances in urological tumours, and survivorship.



PROFESSOR JAMES CATTO, MB CHB PHD FRCS (UROL)

Professor urological surgery at the University of Sheffield and honorary senior clinical research fellow at the University of Oxford, Jim qualified

from Leeds University in 1994 and trained in York and Sheffield, UK before a fellowship in Brisbane, Australia. He was appointed an honorary consultant urological surgeon in 2007 and specialises in uro-oncology. In 2014, James took over as editor-in-chief of European Urology. Jim has raised over £9.3 million in peer-reviewed funding and published more than 100 primary research manuscripts.



VALERIE HESTER

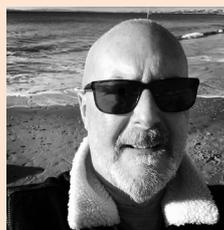
Valerie is the carer of a bladder cancer patient. She is currently the personal assistant to the financial controller at the Potters Group. In her long career as a nurse within the NHS, she attained the position

of lead maternity specialist in Wales.



DEBORAH MAJOR

Deborah is a bladder cancer patient, and a lecturer at Brockenhurst College, nationally recognised for excellence and innovation in further education based in the New Forest.



PAUL MAJOR

Paul is a carer of a bladder cancer patient. He is also a learning skills assistant at Brockenhurst College, a further education establishment in the New Forest which has been nationally recognised

for excellence and innovation.

What exactly are clinical trials?

We know trials are essential to increase our knowledge of bladder cancer but how do they work and what do they actually do?

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.

Why trials are essential for patients

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 the 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. You can find out information in the UK by going onto the website for the National Cancer Research Institute and clicking on the portfolio map for bladder cancer for an overview of current studies. <https://csg.ncri.org.uk/portfolio/portfolio-maps/>

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

How clinical trials work

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

Phase 1

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

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

Phase 2

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

Phase 3

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



ARTICLE

LYDIA MAKAROFF

FBC CEO and European Cancer Patient Coalition

New treatments for bladder cancer

The most recent scientific developments in bladder cancer were discussed at the recent European Society of Medical Oncology congress, and Lydia Makaroff outlines what she discovered.

The immuno-oncology therapies pembrolizumab, nivolumab and atezolizumab have been approved in Europe for locally advanced or metastatic bladder cancer following chemotherapy. pembrolizumab and atezolizumab are also approved as front-line therapy in patients who are ineligible for chemotherapy.

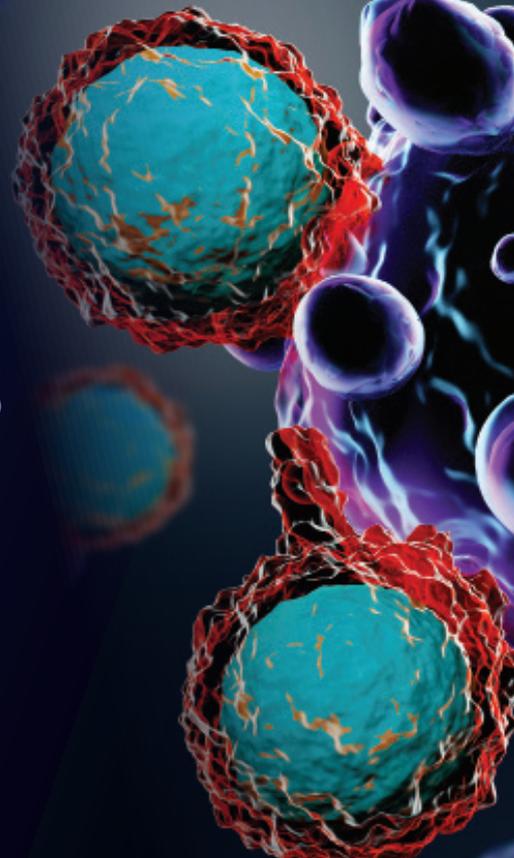
Currently, early data from two ongoing trials has led the European Medicines Agency to restrict the front-line use of pembrolizumab and atezolizumab to patients with tumours expressing high levels of the PD-L1 biomarker. However, new results from recently completed trials have challenged this restriction, and emphasised the need for an individualised approach to deciding whether or not someone should be treated with pembrolizumab and atezolizumab.

The combination of two immuno-oncology therapies – 6 + nivolumab plus ipilimumab – appeared to show an effect in some people with heavily pre-treated metastatic bladder cancer in the CheckMate-032 clinical trial. Overall, 38% of people (with both high and low levels of the PD-L1 biomarker) responded to the combination treatment. While 58% of people with tumours expressing high levels of the PD-L1 biomarker responded to the combination treatment. For all patients (with both high and low levels of the PD-L1 biomarker), the median (average) overall survival was 15.3 months.

The immuno-oncology therapy pembrolizumab showed durable anti-tumour responses in patients with high-risk non-muscle invasive bladder cancer. Around 39% of patients in the KEYNOTE-057 clinical trial responded to pembrolizumab.

The drug erdafitinib resulted in durable responses in patients with metastatic or surgically inoperable bladder cancer in the BLC2001 clinical trial. All these patients were positive for the FGFR biomarker. Around 40% of patients responded to the drug, and the median (average) overall survival was 13.8 months.

Exciting times for bladder cancer and the possibility of new treatments for advanced bladder cancer that are showing potential.



GLOSSARY

Atezolizumab: An immuno-oncology drug approved to treat some kinds of cancer.

Biomarker: a characteristic of the cancer that predicts how well a person is likely to respond to a particular treatment.

Combination treatment: two or more types of treatment given at the same time

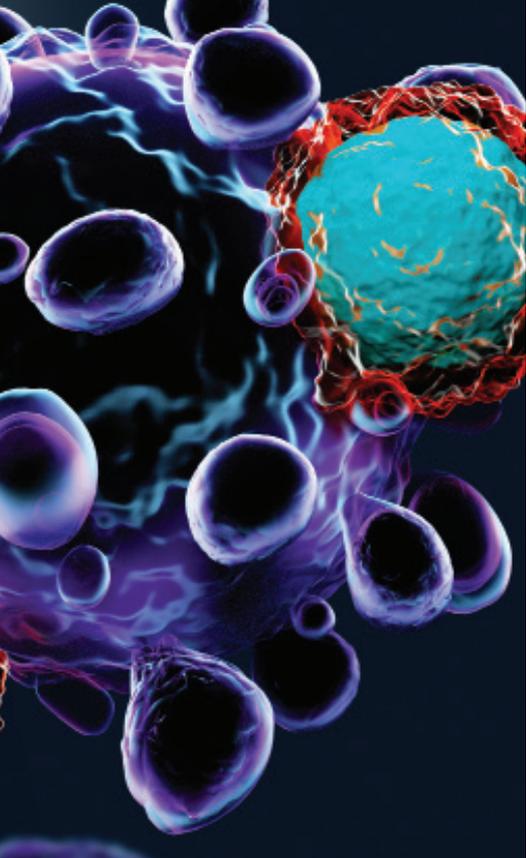
Durable response: a long-lasting good reaction to a cancer drug, usually lasting at least a year.

European Medicines Agency: The agency that is responsible for ensuring that all medicines within the European Union are high quality, safe, and effective

Front-line use: The first drug given to treat a cancer. Also called induction therapy, primary therapy, and primary treatment.

Muscle-invasive bladder cancer: Cancer that has spread from the lining to the muscles of the bladder.

Immuno-oncology treatment: drugs that increase the ability of our own body's white blood cells to fight cancer. Immuno-oncology drugs can help keep



The RAIDER clinical trial

Fine tuning radiotherapy for bladder cancer

Doctors can use radiotherapy to treat invasive bladder cancer (bladder cancer which has grown into the wall of the bladder). They carefully plan the treatment to make sure that the highest dose is directed at the cancer and as little as possible is directed at the surrounding healthy tissue.

The RAIDER study is looking at new techniques to try to improve radiotherapy treatment for bladder cancer. The principal investigator is Dr Robert Huddart, from the Institute of Cancer Research and the Royal Marsden NHS Foundation Trust.

The RAIDER study is for people with invasive bladder cancer who chose to have daily radiotherapy as treatment. Everyone taking part will have daily radiotherapy.

It is a randomised trial. The people taking part are put into one of three treatment groups by a computer. Neither the patient nor their doctor will be able to decide which group the people are put in.

If a patient receives adaptive radiotherapy, the doctor designs different treatment plans, and then chooses the one that best fits the patient on the day of treatment. This technique may mean that less healthy tissue is affected by the radiation, and people will hopefully have fewer side-effects.

The RAIDER trial aims to confirm that this higher-dose radiotherapy is safe, and patients can be treated at multiple hospitals within the NHS.

This is an international phase 2 clinical trial that started in September 2015, and is currently recruiting patients. The researchers need at least 180 people to join in the UK. The estimated primary completion date of this study is June 2020.

The aims of this trial are:

- to find out if adaptive radiotherapy can be carried out in the same way by different radiotherapy departments;
- to see if patients are willing to take part;
- to learn more about the side-effects of the different radiotherapy techniques.

The different treatment groups are:

- 1 standard radiotherapy using one scan and one treatment plan.
- 2 adaptive tumour-focused radiotherapy (radiotherapy with the highest radiation dose focused on the tumour).
- 3 adaptive tumour-boost radiotherapy (radiotherapy with a higher dose than normal focused on the tumour).

If this trial is successful, researchers hope to carry out a larger trial to find out if these new radiotherapy techniques are better at treating bladder cancer than standard treatment.

cancer cells from hiding from the body's white blood cells.

Ipilimumab: An immunology drug approved to treat some kinds of cancer.

Nivolumab: An immunology drug approved to treat some kinds of cancer.

PD-L1: An example of a biomarker. PD-L1 is a type of protein found on cells in your body. Some cancer cells have large amounts of the PD-L1 protein, which helps them hide from attack from the body's white blood cells.

Pembrolizumab: An immunology drug approved to treat some kinds of cancer.

Pre-treated: People who have already been given drugs to treat their cancer.

Response-rate: The percentage of patients whose cancer shrinks or disappears after treatment.

Tumours: Abnormal masses of tissue that result when cells divide more than they should or do not die when they should. Tumours may be benign (not cancer), or malignant (cancer).

Current UK bladder cancer clinical trials

For more information about all current bladder cancer trials head to Cancer Research UK's dedicated portal at www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/. There you will find further information about the studies and which hospitals are taking part.

Suspected bladder cancer

IDENTIFY

Hospitals often have a 'blanket' approach for investigating people with blood in their wee. IDENTIFY will collect data on people having these tests across the UK and internationally and look at any trends with the aim of creating a personalised diagnostic approach for each individual. The data will give patients the ability to make informed decisions, as well as reducing unnecessary and potentially harmful tests.

ClinicalTrials.gov ID: NCT03548688

Newly detected or recurrent bladder cancer

ANTICIPATE X

After being diagnosed with bladder cancer, patients will be asked to provide a urine sample. The urine samples will be used to develop better ways of diagnosing bladder cancer in the future.

ClinicalTrials.gov ID: NCT03664258

DETECT II

After being diagnosed with bladder cancer, patients will be asked to provide a urine sample. The urine samples will be used to develop better ways of diagnosing bladder cancer in the future.

ClinicalTrials.gov ID: NCT02781428

Non-invasive bladder cancer

CA209-9UT

This study is for patients with BCG-unresponsive non-muscle invasive bladder cancer. Patients will receive treatment with either nivolumab or nivolumab plus BMS-986205 and either with or without BCG. This is a study looking at how well these treatments work in people with BCG-Unresponsive non-muscle invasive bladder cancer. ClinicalTrials.gov ID: NCT03519256

iROC

This study is for people with non-muscle invasive bladder cancer or muscle invasive bladder cancer who are going to have their bladders removed. Patients will have either robotically assisted bladder removal surgery, or open bladder removal surgery. The study will look at which type of surgery has a better number of days out of hospital, recovery, and return to normal activities.

ClinicalTrials.gov ID: NCT03049410

NCT03091764

This project will develop and evaluate a patient-reported symptom index to assess the impact of treatment for non-muscle invasive bladder cancer on patient burden, toxicity, symptoms and side-effects. The symptom index will provide a method of assessing treatments from the patients' perspective; help healthcare professionals make better-informed treatment decisions, and provide a method of effectively evaluating treatments for non-muscle invasive bladder cancer.

ClinicalTrials.gov ID: NCT03091764

PemBla

This study is for people with non-muscle invasive bladder cancer. Patients will receive a drug called pembrolizumab. This is an early study looking at the safety and ideal dose of this drug.

ClinicalTrials.gov ID: NCT03167151

POTOMAC

This study is for people with non-muscle invasive bladder cancer. Patients will receive BCG treatment, with the possible addition of durvalumab. This is a study looking at how well durvalumab works in people with non-muscle invasive bladder cancer.

ClinicalTrials.gov ID: NCT03528694

Advanced or metastatic bladder cancer

BISCAY

This study is for people who have muscle-invasive bladder cancer. Patients will be tested for certain biomarkers and, depending on the results, will receive: AZD4547, durvalumab + AZD4547, durvalumab + olaparib, durvalumab + AZD1775, durvalumab, durvalumab + vistusertib, durvalumab + AZD9150, or MEDI4736 + selumetinib. This is an early study looking at the safety and ideal doses of the drugs. ClinicalTrials.gov ID: NCT02546661

CA209-274

This is a study for patients who have had their bladders removed after being diagnosed with cancer of the bladder, ureter or renal pelvis (urothelial cancer), and who have a high risk of the cancer returning. Patients receive standard follow-up care, with the possible addition of a drug called nivolumab. ClinicalTrials.gov ID: NCT02632409

CA209-901

This is a study for patients with previously untreated unresectable or metastatic bladder cancer (first line). Patients will receive either nivolumab combined with ipilimumab, or in combination with Standard of Care Chemotherapy, Versus Standard of Care Chemotherapy. ClinicalTrials.gov ID: NCT 03036098

CA017-078

This study is for patients with muscle-invasive bladder cancer. Patients will receive either neoadjuvant chemotherapy plus nivolumab or nivolumab plus BMS-986205, followed by continued post-surgery therapy with nivolumab or nivolumab plus BMS-986205 versus neoadjuvant chemotherapy alone followed by no post-surgery treatment. ClinicalTrials.gov ID: NCT03661320

EV-301

This study is for people who have locally advanced or metastatic bladder cancer. Patients will receive either chemotherapy (docetaxel, vinflunine or paclitaxel), or a new drug called enfortumab vedotin. This is a study looking at how well these drugs work in people with bladder cancer. ClinicalTrials.gov ID: NCT03474107

FIERCE-21

This study is for people who have locally advanced or metastatic bladder cancer, and who test positive for the FGFR3 biomarker. Patients will receive either chemotherapy (docetaxel), a new drug called vofatamab, or both chemotherapy (docetaxel) and vofatamab. This is a study looking at how well these drugs work in people with bladder cancer. ClinicalTrials.gov ID: NCT02401542

FIGHT-201

This is a study for people with metastatic or inoperable bladder cancer who test positive for one of the FGF/FGFR biomarkers. Patients will receive a drug called pemigatinib. This is a very early study looking at the safety and ideal dose of the drug. ClinicalTrials.gov ID: NCT02872714

FORT-1

This is a study for people with locally advanced or metastatic bladder cancer who test positive for the FGFR biomarker. This study compares chemotherapy (docetaxel, paclitaxel or vinflunine) with a new drug called rogaratinib. ClinicalTrials.gov ID: NCT03410693

JAVELIN Bladder 100

This is a study for people with locally advanced or metastatic bladder cancer. Patients receive the best supportive care, with the possible addition of a drug called avelumab. This is a study looking at how well avelumab works to treat people with bladder cancer. ClinicalTrials.gov ID: NCT02603432

JAVELIN Medley

This is a study for people with locally advanced or metastatic bladder cancer. Patients receive a drug called avelumab, with the possible addition of the drugs PF-04518600, PD-0360324, or PF-05082566 + PF-04518600. This is a study looking at how well these drugs work to treat people with bladder cancer. ClinicalTrials.gov ID: NCT02554812

NCT02365597

This is a study for people with metastatic or inoperable bladder cancer who test positive for the FGFR alteration biomarker. This study will be used to test the safety and ideal dose of a drug called JNJ-63723283, as well as to test how well it works. ClinicalTrials.gov ID: NCT02365597

NCT02516241

This study is for people who have inoperable advanced or metastatic bladder cancer. Patients will receive chemotherapy, with the possible addition of the drugs durvalumab and/or tremelimumab. This is a study looking at how well these drugs work in people with bladder cancer. ClinicalTrials.gov ID: NCT02516241

NCT02599324

This is a study for people with advanced bladder cancer. Patients will receive chemotherapy (paclitaxel), along with a new drug called pemigatinib. This is a very early study looking at the safety of the drug and what is the ideal dose.

ClinicalTrials.gov ID: NCT02599324

NCT02797977

This is a study for people with advanced bladder cancer. Patients will receive chemotherapy (gemcitabine) along with a new drug called SRA737. This is a very early study looking at the safety and ideal dose of the drug.

ClinicalTrials.gov ID: NCT02797977

NCT03170960

This study is for people who have locally advanced or metastatic bladder cancer. Patients will receive a drug called atezolizumab in combination with a new drug called cabozantinib. This is a very early study looking at the safety and ideal dose of cabozantinib.

ClinicalTrials.gov ID: NCT03170960

NCT03289962

This study is for people who have locally advanced or metastatic bladder cancer. Patients will receive a personalised cancer vaccine called RO7198457, with the possible addition of a drug called atezolizumab. This is an early study looking at the safety and ideal doses of the drugs.

ClinicalTrials.gov ID: NCT03289962

NCT03317496

This is a study for people with locally advanced or metastatic bladder cancer. Patients receive best supportive care with the addition of a drug called avelumab. This is a study looking at the safety of avelumab, as well as how well avelumab works to treat people with bladder cancer.

ClinicalTrials.gov ID: NCT03317496

NCT03390504

This is a study for people with advanced bladder cancer who test positive for the FGFR alteration biomarker. Patients will receive either chemotherapy, a drug called erdafitinib, or a drug called pembrolizumab. This study will test how well these drugs work in people with bladder cancer.

ClinicalTrials.gov ID: NCT03390504

NCT03473743

This is a study for people with metastatic or inoperable bladder cancer who test positive for the FGFR alteration biomarker. This study will be used to test the ideal dose of two drugs called erdafitinib and JNJ-63723283, as well as to test their safety and how well they work.

ClinicalTrials.gov ID: NCT03473743

PIVOT-10 (CA045-012)

This is a study for cisplatin ineligible patients with locally advanced or metastatic urothelial cancer with low PD-L1 expression. Patients receive either NKTR-214 in combination with nivolumab or a combination of gemcitabine and carboplatin.

ClinicalTrials.gov ID: NCT03785925

RAIDER

The RAIDER study is for people with invasive bladder cancer who choose to have daily radiotherapy as treatment. Everyone taking part will have daily radiotherapy. 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.

ClinicalTrials.gov ID: NCT0244754

FBC glossary

- adjuvant** after initial treatment to prevent secondary tumours
- angiogenesis** the development of a blood supply to a tumour
- anterior exenteration** surgical removal of a woman's bladder and reproductive organs
- antiemetic** a drug to counteract nausea and vomiting
- B-cell response** a natural immune response
- basal** relating to the base
- baseline** starting point for comparison
- BAUN** British Association of Urological Nurses
- BAUS** British Association of Urological Surgeons
- BC** bladder cancer
- BCG** Bacillus Calmette-Guerin, a treatment for early-stage bladder cancer
- BCQS** Bladder Cancer Quality Standards
- biomarker** something by which the disease can be identified
- biopsy** a sample of tissue taken for examination
- BLC** blue light cystoscopy
- BPH** benign prostate hyperplasia
- cannula** a thin tube inserted into a vein in the arm or hand
- carcinogenic** cancer-causing
- carcinoma** malignant growth or tumour
- catheter** a thin tube
- CCG** clinical commissioning groups
- checkpoint inhibitors** drugs that prevent cancer cells from disabling protective T-cells
- chemoradiation** combination treatment of drugs and x-rays
- chemotherapy** treatment with drugs
- CIS** carcinoma in situ or flat tumour
- CNS** clinical nurse specialist
- confocal laser endomicroscopy** an advanced imaging technique for diagnosis
- CT** computerised axial tomography
- cystectomy** removal of the bladder
- cystoprostatectomy** surgical removal of the bladder and prostate
- cystoscopy** a procedure to examine the inside of the bladder
- cytokines** cells that communicate an immune response
- DAT** device assisted therapy
- DNA** deoxyribonucleic acid
- durable response rate** the length of time a response is observed
- DVT** deep-vein thrombosis, a blood clot in a deep vein in the body
- dysplasia** abnormal development
- dysuria** painful or frequent urination
- EAU** European Association of Urologists
- EBRT** external beam radiotherapy
- EBUS** endobronchial ultrasound test for lung cancer
- ECPC** European Cancer Patients Coalition
- ED** erectile dysfunction
- EMA** European Medicines Agency
- endoscopic** an illuminated tubular device used to look inside the organs
- enhanced recovery pathways** methods of improving recovery times and experience
- eosinophils** a leukocyte or blood cell lacking haemoglobin
- ER** enhanced recovery
- expressed** active
- FBC** Fight Bladder Cancer
- FDA** Food and Drugs Administration (US)
- FGFR** fibroblast growth factor receptor
- fMRI** functional magnetic resonance imaging
- GI** gastrointestinal
- haematuria** blood in the urine
- HCP** health care professional
- histology** the microscopic examination of cells
- histopathological** microscopic examination of tissue to identify disease
- HNA** Holistic Needs Assessment
- HrQoL** health-related quality of life
- ICER** incremental cost effectiveness ratio
- immune component** part of the immune system
- immunotherapy** treatment using the body's immune responses, also called immune oncology therapy
- inhibitory pathway** a situation in which defensive cells are prevented from attacking foreign cells
- intolerable toxicity** the point at which the treatment becomes more painful than the disease
- intra-vesicle installations** treatments administered directly into the bladder via a catheter
- ITU** intensive therapy unit
- KW** key worker
- lines [of treatment]** treatment regimens
- luminal** relating to the hollow inside an organ such as the bladder
- lymph nodes** small glands that store the white blood cells that help to fight disease and infection in the body
- lymphangiogenic** originating in the lymphatic system
- macrophages** specialist cells in the blood vessel walls
- MDT** multi-disciplinary team
- metaplasia** conversion from normal to abnormal tissue
- metastatic** a cancer that has spread to an unrelated organ
- MIBC** muscle-invasive bladder cancer
- MRI** magnetic resonance imaging
- muscle-invasive bladder cancer** cancer that has spread from the lining to the muscles of the bladder
- mutagenic** an agent that changes genetic material
- 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
PDE5 inhibitors drugs that block the negative action of chemicals in the muscles that prevent blood flow
PDL-1 inhibitor an antibody that helps T-cells recognise cancer cells
penile prosthesis/implant malleable or inflatable rods inserted within the erection chambers of the penis
PET positron emission tomography
Peyronie's disease a disorder of the penis resulting in bent or painful erections
PFS progression-free survival
photodynamic diagnosis BLC or blue light 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
randomised trial a controlled trial in which people are randomly assigned to different groups to test a specific drug, treatment or intervention; neither the participants nor the healthcare professionals know to which group each patient belongs
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.

aprostadil Vitaros®
atezolizumab
avanafil Spedra®
avelumab
AZD1775
AZD4547
AZD9150
BMS-096205
cabazitaxel Jevtana®
cabozantinib
carboplatin Paraplatin®
cavaject
cisplatin

docetaxel
doxorubicin Adriamycin®
durvalumab
enfortumab vedotin
erdafitinib
evalumab
finasteride
gemcitabine Gemzar®
Ibhibizone™
ipilimumab
JNJ-63723283
MED14736
methotrexate Maxtrex®

minocycline
mitomycin Mitomycin C Kyowa®
NKTR-214
nintendanib
nivolumab
olaparib Lynparza®
paclitaxel Taxol®
PD-0360324
pembrolizumab
pemigatinib
PF-04518600
PF-04518600,
PF-05082566

rifampin
RO7198457
rogaratinib
selumetinib
sildenafil Viagra®
SRA737
tadalafil Cialis®
tremelimumab
varafenafil Levitra®
vinblastine Velbe®
vinflunine
vistusertib
vofatamab