

10

MAGAZINE

WITH YOU EVERY STEP

DISCOVER OUR GROUND-BREAKING NEW RANGE OF PATIENT INFORMATION BOOKLETS

MAKING IT THROUGH

HOW NURSES & PATIENTS HAVE MANAGED THE PRESSURES OF COVID-19

A VIRTUAL AWARENESS MONTH

REACHING OUT – BUT KEEPING OUR DISTANCE!

WE FOCUS ON MENTAL HEALTH: BEING KIND TO YOURSELF & STAYING STRONG



MY DIAGNOSIS COUNTS

TRACKING THE IMPACT OF BLADDER CANCER IN THE UK

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The UK has now left the EU, but detailed discussions on new arrangements are continuing. There have been media reports about potential problems with the supply of vital medications. If you are concerned, you should consult your medical team for the latest information.

Please recycle this magazine when it is no longer required, via your Urology/GPs waiting room! Many thanks.

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



Fight Magazine

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Working to Fight Bladder Cancer

Welcome to the 10th edition of our *FIGHT* magazine.

Fight magazine is a ground-breaking magazine for the whole bladder cancer community – from those directly affected by a bladder cancer diagnosis, to those working to help us fight.

In this special section, we examine the mental health implications of living with bladder cancer and offer advice and guidance. We are so thankful to all the patients, carers, scientists and healthcare professionals who have shared their experience and knowledge with us.

The threat of Covid-19 plus dealing with bladder cancer makes a horrible combination, adding additional stress to an already challenging time of our lives. Please remember that you are not alone on this journey. There is a whole Wee Family walking with you, and we are travelling a similar path.

Fight Bladder Cancer is here to help you every step of the way. Our Support Services Manager offers free individual telephone, email and Messenger support. Our Bladder Buddy service can match you with someone going through a similar experience. Our private online support forum is open 24 hours a day, 7 days a week. Our regular support groups and Fight Clubs (currently online due to Covid-19) means that you can hear the stories of other patients and family members, and contribute your own.

Cancer changes our lives. We learn what's important, we learn to prioritise and we learn not to waste our time. In this edition we have inspirational stories from bladder cancer patients around the country. They have shared their tips for finding hope and happiness in these challenging times.

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 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)



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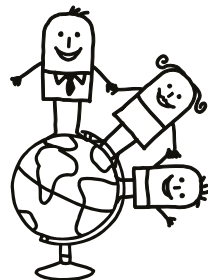
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Find out what has been happening at Fight Bladder Cancer



SUPPORT

ONLINE FORUM

Our online private forum now has 4,884 members, and is supervised by admin and 10 moderators from around the globe 24 hours a day, seven days a week. In the past month we have had over 406 posts and over 29,600 comments and reactions. Currently the most popular time for interaction on our forum is early evening on Thursdays.

'This forum was a great support to me when I was diagnosed. What a truly wonderful bunch of people you all are.'
Sandra

TELEPHONE AND EMAIL SUPPORT

Our telephone support line is available from 9.30am to 4.30pm Monday to Friday on **01844 351621**.

As many of our staff are now working from home, this number is redirected to one of our mobiles if there is no one in the office. There is a voicemail for messages outside these hours or when we are very busy. In the past month, we averaged 6 calls a day, with an average handling time of 6 minutes.

For more information about our email support service, please contact us at info@fightbladdercancer.co.uk



FIGHT MAGAZINE

As many urology centres have now removed reading materials from their waiting rooms due to the risk of COVID-19 transmission, we are now offering a digital version, as well as free posting of this magazine directly to patients, carers and health professionals. To sign up for your free digital or physical copy, please visit: fightbladdercancer.co.uk/contact-preferences



Sign up for your free copy of Fight!

EUROPEAN ASSOCIATION OF UROLOGY

We joined a multi-disciplinary team of experts to find the best answers to patients' COVID-19 urology-related questions. The questions and answers on the EAU FAQ page was updated as experts examined how COVID-19 was affecting people with bladder cancer worldwide. Visit uroweb.org/eau/patient-information-COVID-19-call-for-action



COVID-19

Fight Bladder Cancer continued its support of patients and carers during lockdown with its private online members' forum and online support groups. Chats and support continued online during the lockdown.

Understandably the amount of support and the kind of information we needed to provide gave us a considerably larger workload, particularly when reassuring patients and keeping abreast of news and developments.

We added COVID-19 news and updates to our forum as well as creating an informative page for our website; we held online support groups where people could discuss any worries and hear news from FBC as well as hear the results of a survey which we helped create along with Cancer52; and we hosted an informal support chat open for patients, healthcare professionals and family members. The support team attended regular meetings by NHS England and Cancer52, and sat on a European

Association of Urology COVID-19 multi-disciplinary team panel.

In the main 60 days leading up to and during the peak of the virus, our online private forum posts went up 16% overall with 29,200 posts, comments and reactions. We received 170 emails, 182 phone calls and 483 messages, which required detailed and personalised responses.

'I found the online support group very informative and great to see so many people joining in. Keep fighting everybody.' David

'I thought the online support group was very informative and lovely to put faces to names. I would certainly join in another.'
Alison

RESEARCH



THE POUT TRIAL

FBC was part of the POUT study that showed that gemcitabine-platinum combination chemotherapy initiated within 90 days after nephroureterectomy (a surgical procedure to remove the renal pelvis, kidney, ureter and bladder cuff) significantly improved disease-free survival in patients with locally advanced urothelial carcinomas of the upper urinary tract.

The results show that chemotherapy given in this way reduces the chance of cancer returning by about half. These results were published in The Lancet and suggest that adjuvant platinum-based chemotherapy should be recommended as a new standard of care for all patients with this type of cancer in whom there are no definitive contraindications to chemotherapy.

Andrew Winterbottom, founder of Fight Bladder Cancer, joined the NCRI Bladder Group as a consumer member and contributed to the progress of the trial until it closed. Andrew supported the trial's patient engagement activities and helped disseminate the trial among FBC members.



'No trial can or should ever begin without asking patients what the best design should be and POUT was a trial that had patient input from conception to completion. Thanks to Andrew Winterbottom's input we made this trial a success.'

Dr Alison Birtle, Former Chair of the NCRI Bladder Group and POUT trial Chief Investigator, FBC Trustee

COVID-19 SURVEY

We are a proud member of Cancer52 – an umbrella organisation linking almost 100 charities supporting people with less common cancers – and co-created a survey about cancer patient experiences during the COVID-19 crisis. We found that:



- 74% of patients had their outpatient appointments delayed or cancelled during the peak of the pandemic
- many patients reported a loss of face-to-face contact with clinicians
- there was a lack of information on delays
- patients were not able to take anyone with them for support at consultations and during treatment
- patients found that video links with their healthcare team were very helpful, and in some cases better than waiting for hours in the hospital.

The information will be used in discussions with the government, NHS and industry to push for the best possible care and treatment.

EXEMPLAR RESEARCH PROJECT

FBC is currently interviewing people with bladder cancer and carers for research interviews to collect the views and experience of people affected by bladder cancer.



These interviews form part of Fight Bladder Cancer's Exemplar Research project, which is a study aiming to help define what exceptional services for people affected by bladder cancer would look like. If you would like to know more about this project, please contact research@fightbladdercancer.co.uk

POLICY

NICE National Institute for Health and Care Excellence

Fight Bladder Cancer shared stories of the hopes and experiences of people living with terminal bladder cancer at the recent NICE appeal of immunotherapy for treating locally advanced or metastatic urothelial carcinoma after platinum-containing chemotherapy.

EARLY DIAGNOSIS RESEARCH CHARITIES COALITION

Fight Bladder Cancer is an active member of Cancer Research UK's Early Diagnosis Research Charities Coalition. We are working with other charities to plan how to optimise communications between patients and their GPs in order to give people the right words to describe their symptoms and improve follow-up.



SCOTLAND

The Fight Bladder Cancer Scottish Steering Group worked with Member of Scottish Parliament, Miles Briggs, on a motion on bladder cancer. The motion noted that:

- late diagnosis, especially in women, leads to poorer outcomes
- there have been no significant improvements in survival rates in the last 10 years
- research funding is low compared to other cancers
- the website fightbladdercancer.co.uk was to be commended

It was supported by Brian Whittle, Alexander Stewart, Jackson Carlaw, Peter Chapman, Mark McDonald, Jeremy Balfour, Annie Wells, Donald Cameron, Margaret Mitchell, Alex Cole-Hamilton, Willie Rennie, Liam Kerr, Michelle Ballantyne, Alexander Burnett, Iain Gray, Oliver Mundell, Bill Bowman, John Scott, Gordon Lindhurst, Alison Harris, Liz Smith, Claudia Beamish, Elaine Smith, Edward Mountain, Monica Lennon, Liam McArthur, Angela Constance and Johann Lamont.

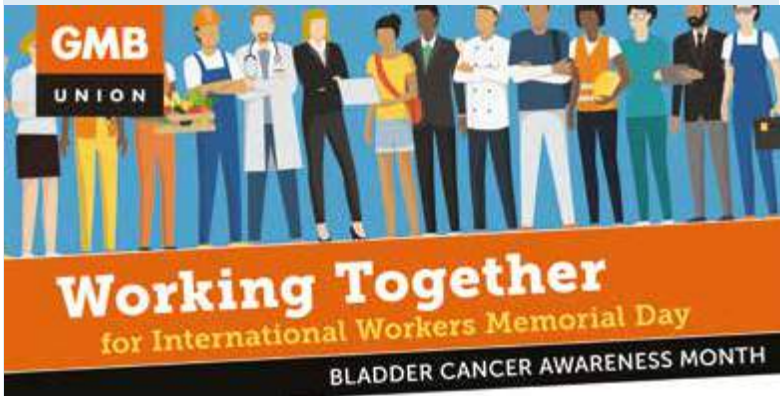


GMB WORKERS' UNION

Fight Bladder Cancer is proud to be collaborating with the GMB Workers' Union to raise the awareness of the importance of bladder cancer in the workplace. Earlier this year, FBC attended a GMB campaign planning meeting. FBC showed support on International Workers' Memorial Day, and the GBM published a statement on World Cancer Day to shine a spotlight on bladder cancer, calling for this generation to be the last generation to have to live with a disease that needs to be talked about and tackled.



'My Mum was lucky that her symptoms were picked up quickly and she was treated. This is not often the case, and a big problem is that the cancer isn't diagnosed until it's having a serious effect. It's why I'm working with the charity Fight Bladder Cancer.'
Penny Robinson, President, GMB London Region



IMPROVING CANCER LITERACY

FBC were co-authors on a paper on calling for a strategic framework to improve cancer literacy in Europe. We said that improved personal cancer literacy, combined with health literate organisations and systems can potentially improve the quality of care and health outcomes among patients with cancer. National Cancer Control Plans and Europe's *Beating Cancer Plan* can be used to strengthen cancer literacy.



CANCER AND AGEING

We contributed to an independent briefing paper written by the Economist Intelligence Unit called *Cancer and ageing: Policy responses to meeting the needs of older people*. The paper examined the challenge of an ageing population and rising incidence of cancer to better understand how countries could provide more customised service provision to older people living with cancer. The paper found that multi-disciplinary teams are vital to improving outcomes, and that patient support services are of great help to those with cancer and their carers.



ALL.CAN UK PSYCHOLOGICAL WELL-BEING

We are a member of All.Can UK, and worked with them to conduct an international patient survey which asked 4,000 patients and carers where they identified inefficiencies in their cancer care. A key finding of the UK survey results was around the need for psychological support during and after care and the issues patients faced in accessing these types of service. As a result, the All.Can Working Group decided to focus on the value of psychological and emotional well-being for people with cancer in 2019 and beyond.

In order to gain a deeper understanding of the link between mental health and cancer, and the psychological support offered to people in the UK, Fight Bladder Cancer is working with All.Can to develop a report, *Placing the psychological well-being of people with cancer on equal footing to physical health*, which is due to be published at the end of 2020.

WORLD BLADDER CANCER PATIENT COALITION

We worked with the World Bladder Cancer Patient Coalition's *Start-up guide for bladder cancer patient groups*, which is designed to promote the establishment of bladder cancer patient groups in different countries. It also provides pre-made resources and shares best-practice examples for getting started. FBC was featured in a case study on our online support forum for people affected by bladder cancer.



AWARENESS



WORLD CANCER DAY

Fight Bladder Cancer supported World Cancer Day on 4 February. On World Cancer Day, we recognised that our commitment to act will lead to powerful progress in reducing the global impact of cancer. 2020 marked the midway point of the three-year 'I Am and I Will' campaign. 'I Am and I Will' is an empowering call-to-action urging for personal commitment and represents the power of individual action taken now to impact the future.

MAY – BLADDER CANCER AWARENESS MONTH

During the month of May, Fight Bladder Cancer led the British activities for Bladder Cancer Awareness Month. We also worked with the European Cancer Patient Coalition and the World Bladder Cancer Patient Coalition on global activities. Worldwide, Fight Bladder Cancer was the most active Twitter account related to #BladderCancerAware, and had the most mentions. During the campaign period, followship increased by 23% on LinkedIn. We reached 207,300 people on Twitter, and 301,630 people on Facebook. See page 42 for more details!

From the Chair

OPINION

JOHN HESTER,
FBC Chair of Trustees



COVID-19 has caused many changes for most organisations and more so for people. Fight Bladder Cancer is no exception. With our office in Chinnor closed following lockdown, our amazing staff, working from home, have continued the charity's important work, for which I must commend them. So many patients have been adversely affected by cancelled appointments and treatments, and the additional anxiety that can create, that the continued support of FBC has been of immense value.

The last few months have also seen an immense commitment from the whole FBC team to create our new series of patient information booklets. I am sure that both patients and healthcare professionals will find them a hugely valuable resource.

The Wee Bookshop and Café is open again and ownership has now transferred to Vicky, who has agreed to maintain its association with Fight Bladder Cancer. I would like to assure everyone that the books donated for re-sale will continue to benefit the charity.

My best wishes to all in these challenging times.

OPINION

DR LYDIA MAKAROFF,
FBC Chief Executive

Note from the CEO

To say these past six months have been extremely challenging for all of us is a bit of an understatement. Not only have we had to cope with the practicalities of living in lockdown, but also with being separated from our loved ones, financial and employment uncertainties and many facing the additional challenges of shielding.

In our particular community, anxiety about COVID-19 has combined with the constant anxiety about cancer, making things harder still. In this edition of *Fight* magazine, we decided to focus on the particular challenges of mental health.

Here at FBC, we closed the office in Chinnor during lockdown. The whole team worked from home, with phone lines diverted to our mobiles and much use made of video conferencing to keep things running smoothly. We continue to 'meet' regularly with the NHS so that we can share information with you about the constantly changing situation.

It was wonderful to stay connected to all of you with our online support groups, by reading your stories on our private forum, and talking to you on our helpline.



Throughout the pandemic and as we ease back into some semblance of normality, please remember, you are not alone – the Fight Bladder Cancer Wee Family is here to walk with you on your journey.

Introducing a ground-breaking range of **Patient Information Booklets** for bladder cancer patients



Covering the entire bladder cancer pathway!

Read more about the titles on offer and why we embarked on this ambitious project overleaf ...

Knowledge that puts patients in control

As we begin to launch our new series of Patient Information Booklets, we look back at why we embarked on this project and look forward as we near completion.

ARTICLE
WENDY HOBSON
Fight magazine editor

While the information highway on high-profile cancers, like breast and lung cancer, speeds along delivering high-quality intelligence to anyone who needs it, it seemed to many of the patients who discovered Fight Bladder Cancer’s private online forum that they were resigned to chugging down the B road of bladder cancer, trying to negotiate the potholes and obstacles strewn along the way.

‘I didn’t know there was such a thing as bladder cancer’, ‘I couldn’t seem to find answers to all my questions’, ‘I felt so isolated – as though no-one knew what I was going through’

were the sort of comments we heard over and over again. Bladder cancer, it seemed, was the Cinderella cancer that no one really wanted to talk about.

Since its inception in 2009 by Andrew Winterbottom and Tracy Staskevich, Fight Bladder Cancer has existed to fulfil four key objectives:

- to support anyone affected by bladder cancer
- to raise awareness of the disease
- to back research
- to change policy at the highest level

One of the key ways of achieving these objectives is through the supply of high-quality information to the people who need it most: the patients themselves. Both through our *Fight* magazine, the Fight Bladder Cancer website and the private online forum, we provide a stream of targeted, clear and straightforward information to patients, and also their carers and loved ones.

Over the years, we amassed a store of crucial knowledge, not only on the physical facts of the disease and the details of possible treatments, but also personal stories of people’s real-life experiences – what precisely happened to them, how it affected them, how they felt about it and what helped them get through tough times.

It was all too valuable to be kept to ourselves. So we started to think about the best way to give everyone who needed it access to this treasure trove of information. It was there on the website, of course, but – especially for new patients – it is difficult to find the answers you need when you have no idea which are the right questions to ask.

What we needed was a way of providing patients with knowledge that:

- 1 was clear and straightforward – explaining the medical vocabulary patients might encounter but presenting it in a language and design that made it easy to understand and refer to
- 2 contained just the guidance and advice that was crucial at that point on their cancer journey so they did not have to sift out what was not relevant to them
- 3 was fully backed not only by patients but by experienced medical professionals
- 4 could be easily distributed to as many patients as possible

It was clear from the start that one booklet was not enough; it would be too overwhelming. So gradually we formulated a plan so that each booklet represented a block of information needed at a critical point in the patients’ cancer pathway.



We identified the best people to contribute to the booklets so that they would represent an accurate picture of the whole experience, and enjoined some of the finest oncologists, doctors and specialist nurses as well as patients themselves. Many months went into creating the initial drafts, followed by reviews by staff, patients and contributors.

Then – just as we were about to embark on the final expert reviews by the clinicians – COVID-19 raised its ugly head and the world focused in on COVID, almost to the exclusion of all else. Consultants, nurses and Fight Bladder Cancer staff all went into overdrive, doing their utmost to support the immediate needs of their patients in this unprecedented pandemic. Clearly the booklets had to take a back seat.

But now the panic is subsiding and cancer treatments beginning to be normalised, so we are able to look forward to launching the series. We are confident that the booklets will be well received and serve an important role in informing patients at just the right level and putting them in control of their cancer choices.

We are hugely grateful for the support of the British Association of Urological Surgeons (BAUS), the British Association of Urological Nurses (BAUN) and the British Uro-Oncology Group in the production of this series.

‘Fight Bladder Cancer explained what the various procedures might entail. They also found me some great people to talk to who had already been where I had. It was such a relief to talk to people who understood!’

The series of booklets includes:

- Tests & investigations
- What is a TURBT?
- Low-risk & intermediate-risk, non-muscle-invasive bladder cancer
- High-risk, non-muscle-invasive bladder cancer
- Muscle-invasive bladder cancer
- Living with a stoma
- Living with a neobladder
- Advanced bladder cancer
- Surviving bladder cancer
- Diet & nutrition for bladder cancer patients

The titles will be available in pdf or printed format. For more information please contact sophie@fightbladdercancer.co.uk or call us on 01844 351621.

Surviving LOCKDOWN



ARTICLE
NNEKA SMITH
Diagnostic Radiographer

Hi, my name's Nneka. I'm 36, from Cambridgeshire and, like many of you, I am shielding for 12 weeks as a result of the Coronavirus pandemic.

I'm a diagnostic radiographer, so I use x-rays to help in various procedures. I work all around the hospital, in A&E, x-ray, dental clinics and surgical theatres, and anywhere else I am needed.

As I write, radiographers are on the frontline in the fight against COVID-19, giving chest x-rays to patients who are suspected of suffering from the coronavirus. At the outset, I was helping other frontline staff tackle this pandemic. However, due to a blood disorder that raises my risk of serious side-effects from coronavirus, I was told to shield.

COPING WITH ISOLATION

As a people person, I find the idea of isolation daunting and difficult; it makes me anxious and worried about my mental health. I am a person who recharges by spending time in the company of good friends, having dinner, chilling out and just doing nothing or having the rare night out. So, I've been trying out a few methods to keep my mental health in a good place and to allow me to feel connected to my communities.

1. Forgotten tasks

I have finally had time to complete tasks that I have wanted to do and haven't had an opportunity to. The most satisfying so far is the mindfulness colouring-in book I bought for myself three years ago (I'm terrible at taking time for myself, as a working mother of a six-year-old). I have found it incredibly cathartic and it has helped me focus on the present. I have used it to take a little bit of time out each day for myself to keep good mental health practices going.

2. Self-care

I have also signed up for an online self-care sharing group where we share an emotion that has been particularly challenging for us that week and describe how we coped, and then we have 30 minutes of guided meditation. I found this exceptionally useful. Usually I struggle with meditation/mindfulness activities, but this was so relaxing and engaging. We each had an opportunity to share and support each other and just talk about things that many of us have not been able to share with anyone. I have already signed up for next week's session.

Painting and drawing are things I used to do a lot to relax and reconnect, but these were some of the first tasks that were side-lined when I had my son, started new jobs and went back to studying. I have also picked these up again.

3. Social platforms

I have attended online dinners, brunches, birthdays and video calls with my nearest and dearest, so it feels like we still have our regular catch-up time. This has been great as I get to see people and not just read messages all day. You can appreciate the facial expressions your loved ones pull that make you laugh uncontrollably (usually at the most inappropriate times).

4. Exercise

I used to be very active and was a regional netball player until I needed hip surgery last June. So, I find exercising difficult, especially as I am not allowed to run or jump (the home trampoline does not count, right?). Still, I can be more active than I have been in previous months.

Usually I would be walking around the hospital, lifting and manoeuvring equipment and patients in addition to heading back to the gym, but neither is possible right now. Instead, I have been using my aerobic stepper and attempting some online yoga/workout videos. I still haven't found the best activity for me yet, but I am not giving up! Even when I was not allowed to walk (post operation), exercise remained crucial and was a guaranteed way to boost my mood.

Exercise remained crucial and was always a guaranteed way to boost my mood.

5. Daily walks

Apart from in my garden, I have not been out much over the last few weeks, but I am going to go on two or three walks a week around my village. I need to reconnect with nature and the outside world. When I have gone for walks, I have gone during quieter times in the day and seeing other people's faces and smiling from a distance and saying hi has been amazingly uplifting. I took walking around for granted and really need to start engaging with it more.

6. Cooking and baking

I love food and – along with hordes of others on social media – I have made banana bread! I have baked other things, too: rhubarb and apple crumble, apple and sultana cake. I have had more time to cook the recipes that you tend not to make at the end of a long day at work, plus I have been batch cooking and finding new ways to store fruit and veg to make them last – food waste is the last thing we should have at a time like this.

I used to love cooking and having dinner parties but cooking for one adult and a child means I've tended to stick to the basics and not had the joy of cooking more adventurous dishes.

Over the next few weeks, we are going to make and decorate biscuits, bake more banana bread and try some more new and exciting recipes.

It is a hard time for everyone right now but I think that makes it a better time than ever to take a step back and work on ways we can keep good mental health strategies and techniques going to keep us positive and ready for the return to life outside.



Getting through THE PANDEMIC



How the resilience of bladder cancer patient organisations is keeping support alive

The global pandemic has challenged patient organisations worldwide like never before. Still, bladder cancer patient organisations remain resilient, striving to provide the best support and information in the face of increasing pressures.

COVID-19 has undoubtedly created significant challenges for millions of bladder cancer patients around the world. Some countries are coming out of what appeared to be the most challenging period of the pandemic. Others are bearing the brunt right now, and the risk remains of consequent waves of the pandemic in the future. Delays in diagnosis and accessing treatment are only some of the challenges experienced by many bladder cancer patients, which has led patients to seek support and advice from the support groups and patient organisations such as Fight Bladder Cancer.



A worldwide survey

A group of global cancer coalitions and alliances has been working together to share COVID-19 experiences. Our survey – **'The Impact of COVID-19 on Cancer Patient Organisations'** – was a collaborative effort of the World Bladder Cancer Patient Coalition, the World Pancreatic Cancer Coalition, the Lymphoma Coalition, the Advanced Breast Cancer Global Alliance, and the work was led by the World Ovarian Cancer Coalition. A survey we conducted of 157 cancer patient organisations from 56 countries showed a collapse of their finances, coupled with a huge increase in demand for their services that is unsustainable.

From a global point of view, all the patient organisations had to deal with the impact of COVID-19 suddenly.

Increased demand for support also led to increased demand for information, which the organisations had to develop. It ranged from patient information pages to digital leaflets and resources, even many web-based meetings. Around 89% of organisations reported that they had to change their services for patients with cancer in some way, but were experiencing an increase in calls and requests for assistance from patients with cancer. Many had to move activities online, incurring additional costs, whilst already facing financial challenges.

What is the reality for bladder cancer patient organisations?

The survey has uncovered insights into the direct experiences of patient organisations offering support and services to bladder cancer patients.

Around 89% of organisations reported that they were experiencing an increase in calls and requests for assistance from patients with cancer.

These bladder cancer patient organisations, who are members of the World Bladder Cancer Patient Coalition, are directly in touch with over 140,000 bladder cancer patients each year.

There was no doubt that the pandemic has impacted all of the organisations to a varying degree. Thankfully, all of the responding organisations were able to maintain at least some services during the pandemic. Their breath-taking



ARTICLE
ALEX FILICEVAS
World Bladder Cancer
Patient Coalition

flexibility and resilience underscore their commitment to the patients they serve. Despite overwhelming circumstances, they are keen to learn, share and collaborate.

We have asked the World Bladder Cancer Patient Coalition member organisations if they have seen a change in a number of queries from patients and caregivers. **Over half (56%) of the respondents saw an increase in calls and emails.**

Unsurprisingly, around one-third of these queries were about COVID-19-related issues. Some of the most common questions raised by patients were about the information on the pandemic's impact on treatment, as well as the associated risks that COVID-19 presents.

Some of the most common questions relating to these queries were:

- How will COVID-19 impact me – am I more at risk of infection?
- How will the delay in diagnosis affect me?
- How likely is my cancer to recur/spread whilst my treatment is suspended?
- Should I be in the extremely vulnerable category, and should I be shielding?

However, there were also many questions on more technical issues as well as about the impact COVID-19 may have on access to bladder cancer treatments immediately and in the longer term.

- Will there be issues with supplies of medications and treatments?
- Is it safe to put off certain procedures?
- How can I access services at home?
- Advice on consideration of bladder replacement over the therapy.

Bladder cancer patients have also experienced mental health and well-being challenges. 89% of organisations reported patients experiencing isolation, 78% facing stress, anxiety or even depression, whilst 78% had decreased access to healthcare teams.

Due to the rising concerns and increase in queries, 78% of bladder cancer patient organisations have produced COVID-19-related information for patients and carers. Another third of respondents have also developed new services to respond directly to changing needs.

The World Bladder Cancer Patient Coalition collected many of these resources. It made these available online to ensure that more people affected by bladder cancer around the world have access to this information, especially where it would not otherwise be readily available in their country.

Raising awareness amidst global pandemic

Globally, half the organisations who raise public awareness have had to alter their activities because of the pandemic. Many have had to cancel or postpone events because of social distancing and lockdowns. The impact was even more prominent for bladder cancer patient organisations. They had to radically alter their awareness-raising activities, health professional education and advocacy programmes. This year, the World Bladder Cancer Awareness Month in May happened to take place amidst the global pandemic. Whilst the severity of the situation in May was higher in some countries than others, most of the organisations have transformed their plans. Some decided to tone down their campaign and delay in order not to overload already overstretched health systems. Others, having initially paused activities to focus on COVID-19, they are now stepping up activity in response to the sharp fall in referrals

for suspected bladder cancer.

The World Bladder Cancer Patient Coalition and our member organisations focused on sharing support messages for the community and COVID-19 frontline and key workers. We also strongly focused on promoting the support available for those affected by bladder cancer in countries where our member organisations are based. Collectively, we have continued communication about bladder cancer globally and its impact on patients in a number of countries, helping the world become more **#BladderCancerAware**.

Research and advocacy remain a priority

Not all the organisations engage in bladder cancer research. However, those that do undertake research activities have seen no change (57%) or have paused their activities temporarily (14%). Positively, none of the research projects these organisations currently undertake, or fund have been reduced in scope or stopped altogether due to COVID-19.

57% of organisations expect to continue research after the pandemic. When it comes to advocacy, many are not sure about the advocacy impact, but recognise the importance of continuing to be an active voice for the bladder cancer community.

The impact on bladder cancer patients

The survey has also provided insight into some of the direct impacts of COVID-19 on bladder cancer patients. Patients seeking advice about worrying symptoms as well as diagnosis appears to have been significantly impacted in many countries.

A staggering 8 out of 9 organisations noticed a drop in the number of people seeking help about symptoms which could lead to cancer. A significant impact was observed on bladder cancer treatments in terms of surveillance routine, delays or alteration of treatments.

The impact during the March–May period of 2020 has varied across countries. There were some similarities to reported patient impact by patient organisations. Some 78% reported cancellations of routine surveillance of patients, and the same number reported alteration of treatment protocols. Falling levels of participation in clinical trials or changes to clinical trial treatment and testing plans were also reported by 44% of responding organisations.

Bladder cancer patients have also experienced mental health and well-being challenges. 89% of organisations reported patients experiencing isolation, 78% facing stress, anxiety or even depression, whilst 78% had decreased access to healthcare teams. These numbers represent the number of patient organisations who have reported having experienced or supported bladder cancer patients in these areas.

Patient organisations have been playing an important role in reassuring patients, carers and managing anxiety. Elderly patients were reported to be more significantly impacted, as they were less able to count on the support provided by families and loved ones. Carers themselves were increasingly anxious since they were not able to visit patients or even attend medical appointments due to distancing norms.

Fundraising challenges

There is no doubt that the financial impact of COVID-19 was felt by all patient organisations, and in the bladder cancer community, it was no different. Fundraising events and community fundraising have been most severely affected by the COVID-19 pandemic.



These findings point to an urgent need to support the very organisations that for so long have played such a critical role in supporting cancer patients, advocating for positive change in cancer policy and practices and raising funds for vital research. The societal and economic value of this contribution should not be under-estimated – its loss would be immeasurable.

More than 40% have concerns for fundraising and philanthropy in the post-pandemic world. The most significant impact was on fundraising events (78%) and community fundraising (67%), whilst other fundraising activities have been affected for over a third of members.

Almost 70% of bladder cancer patient organisations predict a drop in income in the next 12 months, which could have a potential impact on the ability to continue all organisational activities and support for bladder cancer patients. There is evidence of agility in our member organisations, who are stretching themselves to provide the support and information for those who need it most in our community.

Over two-thirds of organisations are trying to find new ways to raise money because of the pandemic, transforming personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from running a marathon at home or in the park to other ways of starting online fundraising events and activities. We are collectively looking to share and inspire to find ways to be together apart.

Read the full report at worldbladdercancer.org

My diagnosis COUNTS

20,000 a year – the number of incidences of bladder cancer in the UK

Every diagnosis of bladder cancer is personal and no one should feel like just a number. However, it is important to collect statistics on bladder cancer so we can understand it better and provide the best treatment and support for everyone.

Poor awareness about bladder cancer is a major barrier to early diagnosis, especially for those whose initial symptoms do not fit the typical profile. This affects long-term outcomes for patients and their families. However, if we understand more about the different symptoms that can present and the categories of diagnosis, we should improve treatment for ourselves and people we care about.

People affected by bladder cancer in our network have shared their own experience of diagnosis and why they think raising awareness is so important.

How many people are diagnosed with bladder cancer each year?

When a diagnosis of bladder cancer is recorded in a hospital, different codes are used in the computer system, depending on the type of bladder cancer. These codes are based on the Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10).

There are three relevant codes: C67, D09.0 and D41.4.

'At the age of 25, I became pregnant with my first child. Everything went smoothly up until I started having symptoms of urinary tract infections. I visited my GP, but even after several courses of antibiotics my symptoms still persisted. I discussed my growing concerns with her, who told me "Don't worry, some pregnant woman are just unlucky; you're too young for bladder cancer".'

Danielle

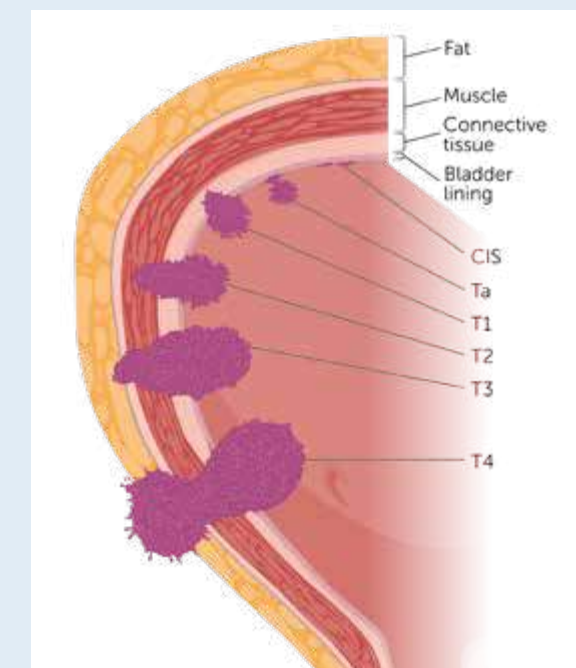


INTERVIEW

DR LYDIA MAKAROFF, FBC CEO

DR ROBERT PHILLIPS, FBC Medical Advisor

AMY RANDALL, FBC Research Lead



Invasive bladder cancer C67

C67 is what is usually referred to as 'bladder cancer' in statistical publications. It is defined as bladder cancer which has spread to the connective tissue that separates the lining of the bladder from the muscles beneath, or further into the muscle around the bladder.

Non-invasive bladder cancer D09.0 and D41.4

D09.0 Carcinoma in situ of bladder. Carcinoma in situ is a flat bladder cancer that is confined to the surface layer of the bladder and is more likely to lead to invasive bladder cancer.

D41.4 Neoplasm of uncertain behaviour of bladder. This is how most of the other bladder cancers are classified, including non-invasive papillary carcinoma – a growth which sticks out of the bladder wall.

Unfortunately, Cancer Research UK only counts invasive bladder cancer (C67), which means that if we use their statistics, we are not counting everyone.

We contacted the relevant departments in England, Scotland, Wales and Northern Ireland to see if we could get some more accurate statistics.

England

The National Cancer Registration and Analysis Service is part of Public Health England and records all cancers diagnosed in England.

The number of new cases of invasive bladder cancer (C67) has slightly decreased, from 8,900 in 2001 to 8,066 in 2016. Bladder cancer is more common in men than in women.

There are many more of these ‘non-invasive’ bladder cancers, and in total, for both invasive and non-invasive cancers, the number of new diagnoses each year is 4,500 for women and 13,500 for men, a total of 18,000 new diagnoses per year in 2016.

For more statistics visit www.cancerdata.nhs.uk/getdataout/bladder

There is a contrast between the incidence rates of invasive and non-invasive cancers, with the former falling and the latter increasing. This suggests that more cancers are being diagnosed when non-invasive. Once we have a longer set of data on cancer survival by stage, we might be able to see if this is true, which would be welcome news.

Scotland

For Scotland, we filed a Freedom of Information Request with the Scottish Cancer Registry, Public Health Scotland (PHS). In Scotland, in the year 2018 there were 882 diagnosed cases of non-invasive bladder cancer, and 809 diagnosed cases of invasive bladder cancer, for a total of 1,691 cases. There were 1,233 men diagnosed and 458 women diagnosed with bladder cancer.

Wales

We reached out to the NHS Wales Informatics Service Information and Statistics. They informed us that in Wales in the year 2018, there were 170 diagnosed cases of non-invasive bladder cancer, and 499 diagnosed cases of invasive bladder cancer, for a total of 669 cases. The numbers for 2019 were very similar with a total of 672 cases.

Northern Ireland

The Business Services Organisation Information Unit in Northern Ireland provided local data. In Northern Ireland in the year 2018, there were 172 diagnosed cases of non-invasive bladder cancer, and 54 diagnosed cases of invasive bladder cancer, for a total of 226 cases.

Difference in bladder cancer rates between men and women

There are differences in rates of bladder cancer between men and women in all four nations, typically in the ratio of about 3:1. This is illustrated in the table below.

Nation	Men	Women	Total
England	13,500*	4,500*	18,000*
Scotland	1,233	458	1,691
Wales	512	157	669
N Ireland	158	68	226
Percent of Total	15,403 (75%)	5,183 (25%)	20,586* (100%)

**approximate numbers; for more precise data see below.*

Incidence rates per million population

This information compares the rates of bladder cancer per million population within the four nations. It is referred to as ‘crude incidence’ because it is not adjusted for factors that may influence the rates of bladder cancer, such as the age of the population, incidence of smoking or occupational activities. We have included the numbers of all types of bladder cancer, both invasive and non-invasive. Whilst England and Scotland appear to have very similar rates, it is not clear why Wales and Northern Ireland have lower crude rates. It is worth noting that historically when comparing the incidence of bladder cancer between countries, only the numbers of invasive bladder cancers (C67) have been used.

	Total number of bladder cancer cases	Population (millions)	Crude incidence per million population
England	17,921	56	320
Scotland	1,691	5.2	310
Wales	669	3.2	209
Northern Ireland	669	1.8	125

‘I’d never heard of bladder cancer before I was diagnosed. It wasn’t until I was having the flexi cystoscopy done and the doc said: “You’ve got bladder cancer.” ’

Clive



Bladder cancer incidents in the UK by type 2016–2018*

Bladder cancer type	England	Scotland	Wales	NI	Total
C67 Malignant neoplasm of bladder	8,066	809	499	56	9,428
D09.0 Carcinoma in situ of bladder & D41.4 Bladder neoplasm of uncertain or unknown behaviour, and other bladder cancer	9,855	882	170	5.2	11,079
Total	17,921	1,691	669	226	20,507

**Due to availability of data the statistics for England are for 2016 and statistics for the rest of the UK are for 2018.*

How to use the data

What are we to do with all these data? We think that they are a good prompt to start talking about important questions, such as the static survival rates in bladder cancer, and the disparity between men and women in outcomes. They can inform campaigns such as Be Clear on Cancer, and measure how effective they are. In a wider context, these data inform service planning and commissioning, such as funding for urology specialist nurses. Knowing the number of people affected by bladder cancer puts May’s Bladder Cancer Awareness Month into perspective, and it might be a surprise to many people how common this cancer is, especially in women.

CONCLUSION

This is the first publication of bladder cancer statistics from the four nations of the UK indicating that over 20,000 people are diagnosed with bladder cancer in the UK each year. We hope that this statistic is used by everyone passionate about bladder cancer to demonstrate that urgent action is required to address unmet needs for this group.

‘I went to the doctor and said “I’ve got problems with wanting to go to the toilet all the time” and they said “Well, you’ve probably got a bladder infection. We’ll give you antibiotics.” Two weeks later I go back and get different antibiotics and this went on five or six times and I knew then there was something wrong and I didn’t know what it was, but I knew it wasn’t right. I left it for two months because I thought I was being a nuisance at the doctor’s. GP surgeries need to be made more aware of what to look for, even if it’s somebody older.’

Barbara

Data sources

You can access the NHS England paper at <https://journals.sagepub.com/doi/full/10.1177/2051415816674103>

The data on cancer incidence and mortality are available at the NCRAS CancerData website: <https://www.cancerdata.nhs.uk/incidence> and <https://www.cancerdata.nhs.uk/mortality>

A paper on the number of cancers caused by external risk factors can be accessed here: <https://www.nature.com/articles/s41416-018-0029-6>

Cancer survival data are published by the Office for National Statistics: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/nationalestimatesforpatientsfollowedupto2017>

COVID vs. CANCER

– what a choice!

After a seven-year journey with cancer that took her along a rough road, Jean Banton found herself with even harsher decisions to make as the world was overtaken by the COVID-19 pandemic and hospital priorities were turned on their heads.

ARTICLE
JEAN BANTON
FBC Forum Member



My journey started exactly seven years ago and it has had a lot of ups and downs! Clear for three and a half years, I thought I had beaten the cancer – but then the recurrences began.

I found myself always waiting for either a check-up or an appointment to go in for a rigid cystoscopy to get rid of new growths. At more than one point I was almost ready to give up and let nature take its course, I was just so tired of the constant battle with the hospital to make sure I didn't get missed. Added to this, three years into my journey, my husband suffered a heart attack and two years later he was diagnosed with melanoma. What else could go wrong? I shouldn't have asked.

The pandemic hits

My last recurrence was 25 January 2020. It has always taken about three months to get an appointment so, although I was worried and stressed about what could be happening in my bladder, I didn't start chasing up my appointment until March 2020. By then, of course, the whole system was in the grip of COVID-19.

It was now almost impossible to get any positive information from the hospital at all, let alone an appointment. Bladder cancer – and any other cancer or long-term condition for that matter – was taking a back seat.

Plus there was the question of whether I even wanted to have the op in a hospital where there was COVID. Yes? No? Yes? It was a case of COVID versus cancer – what kind of choice is that?



An appointment at last

The phone call came on 28 April with a last-minute cancellation, but I had to go in that very afternoon for a COVID test and a pre-op, then the op would be the next day. I was terrified. I knew that there were lots of COVID patients in the hospital and only one theatre out of four was in use. Even if the operation itself went well, what were the risks that I would catch COVID? When the consultant told me he needed to see me in three months, all I could think was: right – you tell that to the appointments team!

Lockdown

Lockdown was hard. The simplest things, like grocery shopping, became a problem. Even with both of us being cancer patients, we were still not classed as vulnerable by the government and so entitled to support. We did eventually manage to get a delivery slot with a well-known freezer shop and that meant we weren't going to starve to death.

At first, we daren't even leave the house for a walk in case we caught the virus, but after a while we ventured out to a nearby park and managed to get some exercise. I even taught my husband to waltz – although even he would admit he has two left feet!

All the time, the strain of waiting for the phone to ring continued, but we tried to keep sane as best we could.

Looking forward

And so my journey continues – still struggling to cope but still hoping.

Throughout the seven years, I've never received any counselling and managed to avoid medication. To take my mind off things, I play online computer games, like Scrabble and Yahtzee; I also have an X-box and PS4 and enjoy playing Fortnite and RPG games .



And throughout the seven years, the Fight Bladder Cancer forum has been my lifeline and salvation; they are an amazing group of people to whom I will be eternally grateful.

Contact our online members' forum at
<https://www.facebook.com/BladderCancerUK/>

In the words of the old Beatles' song: 'I'm looking through you!'

Diagnostic radiographers are responsible for producing and processing images of body structures to support the diagnosis of disease and skeletal abnormalities due to trauma or disease. These images are also produced to support and guide direct interventional treatments and procedures. I currently work in the x-ray department and rotate round the hospital.

ARTICLE
NNEKA SMITH
Diagnostic Radiographer



Where do you find them?

Radiographers work throughout the hospital. We can be found on wards, intensive care, A&E, theatre, interventional radiology suites and in or outpatient x-ray rooms. You will usually find me in the outpatient department taking x-rays for patients who have been sent to us from their clinic appointments.

Before you come into the hospital for your appointment, make sure you read over your letter and follow any guidelines you are given. For example, sometimes you may be asked to drink water so that we see you with a full bladder.

Our x-ray rooms are equipped for all the necessary procedures. Once I have called in a patient and confirmed that the person in front of me matches the notes, I explain the procedure I have been told to undertake – such as an abdominal x-ray to visualise the kidneys and bladder etc. – and, while I am doing that, I can assess the patient's mobility and which technique would be most appropriate. I outline:

- how you need to sit, stand or lie down
- any breathing instructions
- and how long the procedure will take

I am also responsible for radiation protection, so while taking the scans, I'll adapt and control the amount of x-ray radiation produced using grids, shields or simply adjusting the energy values manually.

While I am doing all of this, I will treat you to some lovely storytelling about my day, find out how your day is going and generally keep things relaxed and chatty. Once it is all done, I make sure you know what to do next and where to go.

In other departments where you might meet me, I might:

- hold your hand if you are anxious
- go through the interventional procedure that is going to happen
- get your written consent for a procedure
- talk you through everything involved
- answer your questions and explain anything else you want to know

Recognising radiographers

Depending where you see us, we either wear scrubs or our uniform – mine is a white tunic with a burgundy stripe, but they vary between hospitals. Another give-away clue is if we are pushing our mobile x-ray machine between wards!



Pain-free procedures and pain control

Most of the procedures are painless, but if you are having an interventional procedure then we may offer you general or local anaesthetic or pain relief to ensure the procedure is as pain-free as possible. Where we can, we make sure one of the health professionals in the room talks you through what is happening (I have been known to sing or play music for service users who feel anxious or worried).

The all-important results

Occasionally, you may find out the result of the procedure once it is completed but more usually, you'll get the results within seven days at your next clinic or from your GP. In general, I will not be the one to tell you the result but I will let you know how and roughly when you will receive them.

Who else do radiographers work with?

Not only are we found throughout the hospital, we work with almost everyone within the hospital: orthopaedic surgeons, neurosurgeons, anaesthetists, nurses, physiotherapists, healthcare assistants and, most importantly, other radiologists. I love this aspect of my job. Working with other professionals ensures the best care for all our service users because we all bring our own specialities and understandings and work together as a multidisciplinary team.

Will YOU join the growing Wee Community who give monthly to Fight Bladder Cancer and help change lives for the better?

Monthly donations, however large or small, are the life-blood for any charity. Your support helps us to plan ahead, grow our services and reach more patients and families affected by bladder cancer. The charity's private forum, patient information service and campaigns to improve early diagnosis, treatments and research are ALL made possible with YOUR support.

If you would like to set up a regular donation to the charity – please visit the website fightbladdercancer.co.uk and click the DONATE button to choose your monthly option.

Any gift, whatever size, is welcome and YOU will be changing another patient's life today. You will also be joining other patients and families who support us monthly from all over the UK, such as Paul Michaels, from Buckinghamshire, who said;

"Repeat donations are the heartbeat of Fight Bladder Cancer. I stepped forward and made a monthly donation because the charity's support has made a big difference in my life. As a bladder cancer patient and a businessman, I understand the importance of regular and consistent cash flow for a small organisation."



THANK YOU

BLADDER CANCER AND MENTAL HEALTH

On the following pages we examine the mental health issues commonly associated with bladder cancer, with personal stories of how many patients have overcome such difficulties and gone on to live a happy and healthy life.

FBC offers all kinds of support just when you need it

- Private forum on Facebook
- FIGHT magazine
- Bladder Buddy scheme
- Online support groups
- Phone support on 01844 351621
- Email support at support@fightbladdercancer.co.uk
- Website at fightbladdercancer.co.uk
- Social media – Twitter @BladderCancerUK and Facebook @Fight Bladder Cancer
- Patient information booklets

10 STEPS to help improve your mental health

- 1 Do some exercise – it does not have to be much, just going for a short walk helps
- 2 Breathe some fresh air – whether for exercise or just being outside
- 3 Talk to a friend or family member
- 4 Message a friend or meet up
- 5 Do something you enjoy – watch a film, try an old or new hobby, dance to the radio
- 6 Eat well
- 7 Get enough sleep every night
- 8 Relax – with yoga, meditation, mindfulness or whatever suits you
- 9 Listen to some music
- 10 Look for support groups

Admitting your weaknesses can make you stronger

ARTICLE
WENDIE MORLEY
FBC forum member

As a community psychiatric nurse, Wendie spent a career helping others cope with problems such as anxiety, depression and stress. Strong and able to cope, she just got on with life, tending to appear calm and keep any doubts and uncertainties hidden away. When she faced her own cancer diagnosis, it changed her perspective.

My journey into bladder cancer started in 1999 when I had my first TURBT. I was informed that the tumour was low grade and superficial. The procedure was done every six months for the next 18 years and each time I was told I was one of the lucky ones and had a good mental attitude. I heard this so many times that I couldn't help but believe it and it helped me to sweep any self-doubt under the carpet. At that time, I didn't have access to the internet, Google or any other support system, so I just carried on with my life.

Following my TURBT in 2017 I received a call from the urologist to say that he would like to see me in clinic. Still I wasn't overly concerned as for 18 years nothing of any significance had changed.

Totally shocked

When I met my urologist, he told me that one of my kidneys was non-functioning and it would be advisable to remove it. By the look on his face I could tell there was more. He said that since the previous check six months ago, my diagnosis had become T2G3 with widespread CIS. I felt as though I had been punched in the stomach. The air seemed to have left my body, I felt hot and sweaty and was fighting back the tears. These feelings were totally alien to me. I can vividly remember that there was total silence in the room until the urologist said, 'I



am so very sorry and totally shocked at the rate of growth.' His advice was to remove my bladder and kidney as soon as possible.

I left the hospital shocked and numb. When I arrived home I just burst into tears and my husband was shocked as it was totally out of character for me. In 2006 when I was diagnosed with a brain tumour (fortunately benign) I remained fairly calm and never shed a tear, so the poor man couldn't quite grasp what was going on.

The next week of waiting seemed to be the longest week of my life. I was frightened that I had lost my coping skills; how I would cope with a bag was the biggest issue. Would I feel different from other people? How would my family cope, especially my husband? Would I feel less of a woman? Would I have to face death? I spent hours thinking about all these things. The surgery took place the following week. None of my fears transpired and life continued as normal. Fast forward just over three years and life for me is good and cancer free.

Learn to share your feelings

What I have learned from this experience is that I do not always

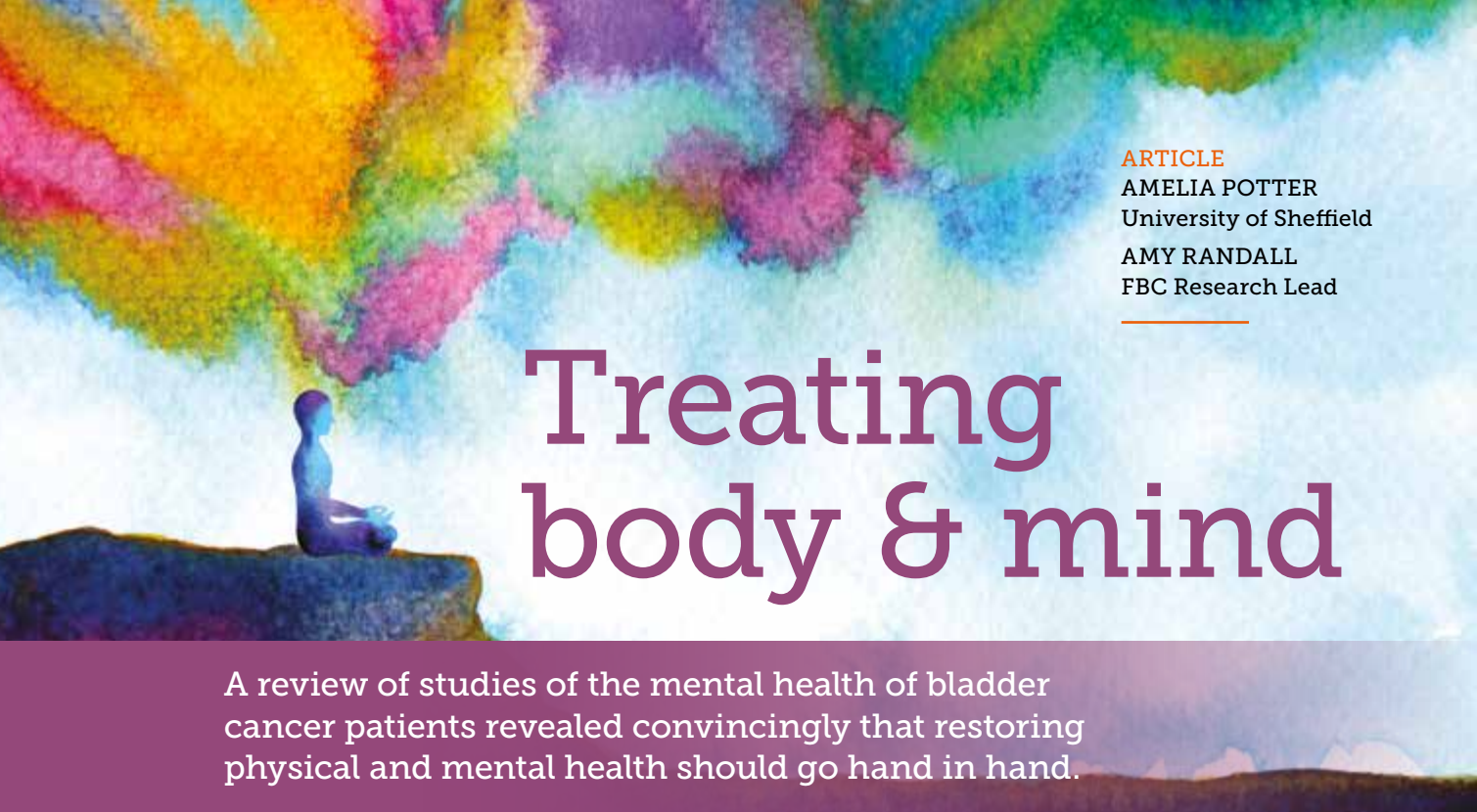
I am truly grateful for the emotional journey I have taken and that I can share some of the feelings I experienced when I was diagnosed with bladder cancer.

have to be emotionally strong and it is okay to talk about my feelings as nothing dreadful will happen. Reading the posts from the Fight Bladder Cancer forum has taught me that it is okay for me to feel a wide range of emotions and to share them. If I have a bad day I let one of my family know and tell myself that tomorrow is another day and things will be better, which they usually are. Lowering my guard has enabled me to be less harsh on myself and remember that I am human too. It has taken me a whole lifetime but the personal rewards are enormous.

Hindsight

Hindsight is a wonderful thing but I am convinced that my reactions would not have been so devastating at that time if I had the benefit of someone to talk to and to give me some emotional support. I was not aware of the kind of help that Fight Bladder Cancer now offers – in fact, little was available at the time. I just felt alone. None was offered to me until 2017 – 18 years from the original diagnosis – I was simply told I had a good, positive mental attitude, which really wasn't much help.





ARTICLE
AMELIA POTTER
University of Sheffield
AMY RANDALL
FBC Research Lead

Treating body & mind

A review of studies of the mental health of bladder cancer patients revealed convincingly that restoring physical and mental health should go hand in hand.

While there has been little research into the impact of a bladder cancer diagnosis on mental health, a 2019 review of studies concluded that poor mental health is negatively impacting bladder cancer patients.¹ And with the physical, emotional and economic demands of diagnosis, treatment and long-term follow-up, it is hardly surprising that bladder cancer patients can be prone to conditions such as depression, anxiety or even suicidal thoughts. Left untreated, distress can build up, so it is important to recognise and treat problems quickly.

This summary is based on a review of scientific articles that have researched mental health associated with the diagnosis, treatment and follow-up of both non-muscle-invasive and muscle-invasive bladder cancers. We combined our findings with the information from a series of interviews undertaken for our Exemplar study to identify the impact bladder cancer has had on patients' lives and relationships, along with the importance of accessing support. The patient quotes are from those interviews.

KEY MESSAGES

- Bladder cancer does affect many patients' mental health
- It is always okay to ask for help
- Take action and it can get better

Why bladder cancer patients are at risk

Cancer does not just affect your physical health. There are many factors that can lead mental health to deteriorate in bladder cancer patients, usually through a build up of stress and anxiety.

- the process of a bladder cancer diagnosis, invasive treatment and coping with the threat of recurrence can feel very long and lonely
- treatment can involve major surgery with its inherent risks and impact on the body
- patients may lose sexual and/or urinal function
- there are likely to be some significant physical changes, including perhaps having to learn to use a stoma and bag
- severe illness can impact relationships and you may also be worried about the people close to you
- it can be difficult to talk to others about what you are going through or you may live alone and have no one to support you

Interestingly, there was no evidence of a significant difference in mental health between individuals with non-muscle-invasive and muscle-invasive bladder cancer, suggesting the severity of the diagnosis may not have as much impact as might have been expected. Research also found no evidence of a significant difference between patients based on age, gender, race or disease stages¹.

Riding the roller coaster

The review highlighted that it is common for patients to experience a dip in mental health, with feelings of depression or anxiety, but that this often reverses as treatment progresses. For example, one study² of non-muscle-invasive bladder cancer patients found that although their mental health tended to decline after the first TURBT (an operation to remove an early tumour in the bladder), it improved after subsequent procedures, especially after the fourth operation.

Other studies 3 4 5 6 7 demonstrated that while mental health declined immediately following diagnosis, mental health then improved as time progressed, with one study showing it reverted back to normal after five years¹.

The effect on relationships

Particularly those who had been through radical surgery, which requires a long recovery and affects your sexual life, found that it affected their relationships. Several women who had had their bladder removed said that they felt they had not received adequate information but were very uncomfortable bringing up the subject of sex with their healthcare professionals. They wanted the opportunity to talk to other women who had been through the same surgery about their experience of sex following bladder removal.

WHAT SHOULD I SAY TO MY GP?

Patients often report that they find it difficult to talk about how they are feeling so mental health charity MIND has some suggestions to make it easier.

- be honest and open
- focus on how you feel
- try to explain your feelings
- don't think your problem is too small or unimportant

It can be useful before your appointment to have a think about how you would answer these questions:

- How have you been feeling lately?
- Has anything happened or changed in your life recently?
- Are you eating normally?
- How are you sleeping?

For more information you can head to mind.org.uk/findthewords or call MIND directly on 0300 123 3393.⁸

'A bit more emotional support when you are having those clinical meetings. I would have liked to have had a meeting with someone who tuned into how I was feeling emotionally.'

Finding the right solution

There are many ways to help improve mental health, whether patients are having problems after diagnosis or during or after treatment¹.

- **Cognitive behavioural therapy:** in early studies, this shows positive outcomes in treating psychological changes.
- **Pharmacotherapy:** therapy using drugs can be used to treat depression or anxiety in cancer patients.
- **Pre-habilitation programmes:** including physical therapy, counselling and addressing risk factors that can be changed. Pre-habilitation doesn't just provide mental support but also encompasses social support. This can be important because, following diagnosis and initial treatments, patients can find it difficult to work, complete jobs and socialise with others. These problems tend to improve as treatment continues.

Anyone being treated for bladder cancer will be making regular visits to their doctor or CNS. The professionals are well aware that the mental health of their patients is important, so they should be open to discussing and treating both mental and physical symptoms. Treating mental health is not only important for the patients' general well-being but it can also have an effect on how they cope with their treatment.

While some people said healthcare professionals in different areas of the UK were supportive, this was not the case for many people. Several people felt their treatment could have been improved if they had someone to talk to early on during their diagnosis and treatment.

Talking is good therapy

The ability to talk to people who have been through something similar was important to both patients and family carers. People have reported that the FBC online forum, Bladder Buddies peer mentoring and Fight Club support groups have provided a space for them to ask questions, share how they are feeling and gain understanding and emotional support.

For some, it was important to have a space to talk, separate from the people close to them.

'You need to have some sort of private way to talk, ask, process, without it becoming the central conversation in your house. If you have young children, you want things to be normal. You need to have something outside of your core living, to process and deal with it.'

SUICIDAL THOUGHTS

In some cases, severe depression and anxiety can lead to the patient having suicidal thoughts. Being aware in advance that this might happen should help patients to recognise whether deterioration in their mental health is becoming serious. If it does, they should call their GP or one of the helplines listed here to get immediate help.

Samaritans: 116 123 (for everyone)
Campaign Against Living Miserably (CALM): 0800 58 58 58 (for men)
Papyrus: 0800 068 41 41 (for under 35s)

More information

The availability of information leaflets for patients and their families was also an area which the patients said would have helped them. While some people did report receiving good information leaflets, many did not and it was reported that little is available for carers and family members which might help them talk to their family member with bladder cancer.

FBC are publishing a series of Patient Information Booklets on all aspects of bladder cancer (see page 9). Ask your CNS or visit fightbladdercancer.co.uk/booklets

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Advice and support

As well as *Fight* magazine, Fight Bladder Cancer has many supporting initiatives, including a private online forum, a Bladder Buddy service, an enewsletter, Fight Club support groups, a website, Facebook page and Twitter feed (see page 23). You can find out more at fightbladdercancer.co.uk
Everyone's experience and needs will be different, therefore we must improve on the range of services already available to provide support for people affected by bladder cancer and their families, such a signposting and accessibility so that patients and their families can access that support early on in their cancer journey. Such advances would have a positive impact on overall outcomes.

You could also approach a charity called Maggie's, which provides free online support during and after cancer. Maggie's staff include experienced specialist healthcare professionals who will listen to how you are feeling and answer any questions. They also offer support groups or private one-on-one or family sessions with a psychologist. There is a phone number and online community on the Maggie's website providing a space for people to share their experience and ask questions from home. maggies.org/ 0300 123 1801 enquiries@maggies.org

If you need help accessing any of the support or information mentioned, contact Fight Bladder Cancer support via the website at fightbladdercancer.co.uk on **01844 351621** or email support@fightbladdercancer.co.uk

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ARTICLE
MELANIE COSTIN
FBC Support Services
Manager

Scanxiety



Meaning: A word to describe the feeling you may have at the time leading up to a scan; or when you are waiting for an appointment for your scan results; or at any of those times when thinking about a procedure turns a mainly rational brain into a mess of doubts, worries, certainties that you have a pain here, an ache there, surely some anomaly somewhere on your body.
It's the time when every twinge means a recurrence, or for those of us still with our bladders, your need to sleepwalk to the toilet in the night for the eighth time must surely mean something new has grown.

What is anxiety?

Anxiety is really just a form of stress.
It is a feeling of fear that mainly relates to worry about what *might* happen, worrying about things going wrong, or feeling like you're in some kind of danger.
Everyone experiences feelings of anxiety from time to time when they encounter an unfamiliar or maybe nerve-wracking situation. The kind of anxiety that is triggered makes us think the 'what ifs':
● **What if** there is a lot of traffic and I miss my appointment?
● **What if** I can't find the urology department?
Once the worrying situation is over, you will start to calm down and feel better – often it's an immediate feeling.

When stress ceases to be motivating

Some degree of anxiety is perfectly normal and can even be motivating as it helps us stay alert, on our toes and ready to do our best, but if the worrying situation has gone and the feeling of fear is still there or gets worse, then it can affect your ability to actually get things done, and can stop you enjoying your daily life.
If you have a bladder cancer diagnosis, the feelings of anxiety can be difficult to control. With seemingly endless appointments and procedures, it can be difficult to relax our minds when there is likely to be another check-up on the horizon.
Most people do find themselves in a mentally better place when they get their full diagnosis and can start a treatment plan. Going for scans, operations, results, well, you would be in the company of many of us if you didn't feel at *least* a fluttering of anxiety trying to rear its head.

Understanding why it feels like it does

For some people, however, anxiety can be harder to deal with, sometimes because it triggers underlying issues. Getting a handle on why it feels like it does can help us win some control back over our fears.
Anxiety happens because a part of your brain thinks that there might be something it needs to protect you from. It then floods your body with a mix of things like oxygen, hormones and adrenaline, things that make you *stronger* and *faster*, more *alert* and *powerful*, so that basically you can fight for your life or make a run for it.
This is called the fight or flight response. It's normal and it's healthy and it's in everyone, but in people with anxiety, it can be a bit quicker to activate.

The part of the brain (the amygdala) that just wants to keep you safe is always having to be alert, waiting to fight whatever it needs to. However, it can't always tell the difference between something that might hurt you, and something that won't hurt you, and it doesn't care – all it wants to do is keep you safe.

When there is absolutely nothing to flee from or nothing to fight, there is nothing to burn off the chemical fuel that is surging through you, so the fuel just builds up. At this point things start to happen.

- **Your breathing changes** from normal, slow breaths to short, shallow breaths. This is because your brain is telling your body to conserve oxygen and send as much as possible to your muscles so that they can get ready to run or fight. You might feel a bit breathless, find yourself talking faster and your face may go red from the blood rushing to it.



ANXIETY CAN LOOK SOMETHING LIKE THIS

There are common signs of anxiety. If you experience some of these, it doesn't mean that anxiety is a problem for you. As bladder cancer patients or carers, all of us will experience some of them – it isn't a problem, it is quite usual. Something is *only* a problem if it is causing you a problem.

- **You might feel a bit dizzy or confused** because if you don't fight or flee, the oxygen builds up in your body and the carbon dioxide drops. Your heart races to get the oxygen around your body and can feel like it's literally beating out of your chest.
- **Your arms and legs might go tense or shaky** from the fuel rushing to them to help your flight or fight.
- **You might get a bit clammy or sweaty or have cold hands** when your body starts cooling itself down to stop it from overheating in case it has to fight or flee.
- **You may end up with butterflies or feel queasy and with a dry mouth or a dodgy tummy.** This is because anything happening in your body that isn't *absolutely* essential for your survival shuts down to conserve energy until the 'danger' is dealt with. Your digestive system is one of these.
- **You can feel really upset or even angry** because this same part of your brain also controls emotions, so when it's in fight or flight mode it's switched right up to high volume.

So, everything you feel when you have anxiety is to do with your body getting ready to fight or flee.

Thoughts

- **Negative thoughts – the what-ifs:** What if I get side effects, what if treatment doesn't work, the what-ifs that can be small thoughts that grow into huge worries
- **Over worrying about physical symptoms:** Could this pain mean a recurrence? What if an ache may be a sign of something more serious?

Symptoms should *always* be mentioned to your urology team. Thoughts, however, are just thoughts; they are NOT predictions. If they come, let them come, then try to let them go.

Remember you need the zzzz

If you are anxious, you may have difficulty sleeping, either falling asleep, or waking up and not being able to get back to sleep. When you are still and quiet and trying to relax, negative thoughts or worries will see it as an open invitation. They will basically get the party started in your head and sleeping will be almost impossible! Establish a relaxing bedtime routine and try the mindfulness or breathing exercises on the next pages.



Anxiety is so common

One in six people report experiencing a common mental health problem like anxiety and depression in any given week in England.¹ Without a doubt, someone you know or care about will also struggle with anxiety from time to time.

Anxiety has nothing to do with courage or strength

People with anxiety can be some of the strongest and bravest people you know.

Everyone experiences anxiety on some level

Anxiety exists on a scale, some people get it a lot and some people get it less, but we all experience anxiety on some level at some time in our lives.

Anxiety is a feeling, not a personality

Rest assured that, with the right care, you can overcome your anxiety.

¹ McManus S, Bebbington P, Jenkins R, Brugha T. (eds.) (2016). Mental health and wellbeing in England: Adult psychiatric morbidity survey 2014.

Feelings

- Fear, anxiety, feeling overwhelmed or out of control
- Dread
- Panic that seems to come from nowhere
- Feeling separate from your physical self or your surroundings
- Feeling as though you want to burst into tears
- Feeling angry

Physical reactions

- Racing heart
- Tightening in the chest
- Butterflies
- Stomach ache
- Tense muscles
- Shaking hands
- Feeling as though you are about to be sick
- Dizzy or light headed

If you experience a tummy ache, it is because we have hundreds of millions of neurons in the stomach – it is like having a brain in our stomach. Normally they are really good for our mental health, sending information

from our tummy to our brain, but when everything in there is out of balance, the messages sent back to the brain can stir anxiety. Try and cut back on the fizzy drinks and sugary foods!

Behaviours

- **You may avoid people or certain situations:** This isn't necessarily about wanting to avoid the people involved but more about wanting to avoid the anxiety that comes with it, such as a get-together or anything unfamiliar, the thought of having to answer questions or trying to avoid having to answer them
- **You may bite your nails, pull at your hair**
- **You may feel compelled to perform certain habits that don't seem to make any sense whatsoever,** such as grouping things together in even numbers, or having to touch the door handle a certain number of times before you leave the house, or checking the locks

People with anxiety tend to find all sorts of ways to make their anxiety feel smaller for a little while until it's under control.

HOW TO DEAL WITH ANXIETY

There are lots of ways to manage anxiety by strengthening the brain so it can protect you. The brain is like any other muscle in the body, it will get stronger with practice but it isn't always easy to start with.

Breathing

It's hard to believe that something as simple as breathing can help control anxiety, but actually strong, deep breathing starts the relaxation response that calms down the surge of chemicals that cause the horrible feelings of anxiety.

- It's an automatic response, so you don't need to believe it works, it just does – but you have to initiate it. Once you start slow, deep breathing, then your body will take over and do the rest.
- I was told to look at a rectangular shape, like a door, as you follow the side of the door breathe in, hold as you look across the top, then breathe out down the other side. It takes a bit of practice but it works.
- Sensations can be very helpful during anxiety, so you might try figure-of-eight breathing. Draw a figure of eight with your finger on the back of your hand. As you're drawing the first half of the eight, breathe in for three. When you get to the middle, hold your finger still for one. Then for the second half of the figure eight breathe out for three. Repeat this three or four times.
- One of my preferred methods is to imagine smelling a cup of hot chocolate. Breathe in the lovely chocolate smell for three, hold your breath for one, then blow it cool for three.

To make it easier for your brain to access the technique when you need it, practise a couple of times a day when you are feeling your calmest.

Anxiety doesn't define you. It's a feeling that will come, but it will always go.

Mindfulness

So, what is mindfulness exactly? It is about keeping our thoughts in the present and strengthening the part of the brain that calms emotions, watching your thoughts and feelings without hanging on to them for too long, because this is when we can magnify problems. Minds like to wander, especially anxious ones, and, let's face it, having a bladder cancer diagnosis to deal with will literally fill your head with thoughts, so staying in the present can take some practice.

Remember, that anxiety is driven by a brain that has been cast into the future – the 'what ifs' – and mindfulness helps to keep control of the brain, focus it on the present, and can stop it worrying about things it doesn't need to.

It can improve your concentration and help ease stress and depression. It can also stimulate the grey matter in our brain – and it's good to have more brain cells at times like these!

Some people like to reach a state of mindfulness with a breathing technique:

- Get comfortable and close your eyes
- Take notice of your breathing. How does the air feel as you breathe it in? Notice the sensation of the air, or your tummy rising and falling. Notice your heart beating

- Think about what you can hear and what you can feel outside your body. If your mind starts to wander, then focus on your breathing again

There are lots of brilliant apps that can guide you through, as well as guided meditations. Some include a map which shows you how many other people are doing it at the same time and can make you feel a little more connected. Have a search online or through your mobile App Store; there are many good free ones available.

You can also practise mindfulness, keeping your thoughts in the present, during a walk outside or even around the hospital.

- Notice the sensations, think about how the air feels on your face as you walk.
- Think about what sounds you can hear: the crunching on the path, leaves blowing.

All this may seem very small but it has a huge power to keep our thoughts in the present and stop them from wandering off into anxiety.

You can also do something creative, such as drawing. You don't have to be any good, just doing something creative can help focus your mind on the present and away from your worries and what may be upsetting you.

Exercise

The effects of exercise are amazing at helping to dispel anxiety. Our brain cells become very active and help us to think quickly, act quickly and to remember things, but sometimes they act a bit too quickly and it can set off feelings of anxiety. So, to stop these cells getting over-excited and causing us trouble, the brain has a chemical called GABA (gamma-aminobutyric acid); it's the brain's calm-down chemical. When the

levels of GABA in the brain are low, there's nothing to calm the brain cells down. Exercise is a brilliant way to bring the chemicals in your brain back up to the right levels. Once the brain chemicals are back to normal levels, the symptoms of anxiety tend to disappear into the sunset.

Any activity that gets your heart going counts as exercise, and it will be different for everyone. It doesn't mean that you have to go running until you are gasping for air – unless

you want to, of course – but many of us going through procedures aren't exactly able to exercise so vigorously. A brisk 20-minute walk or ten minutes of going up and down the stairs a couple of times a day will also do it. Do whatever you can manage. Try for something you can do at least five times a week. If you really are unable to do exercise, then calming things like yoga, where you will be concentrating on your breathing, can also help.

HELP ME NOW

If someone with you is struggling to control their anxiety, you can help them by doing this easy exercise to bring their brain into the 'now' by asking them to tell you:

- Five things that they can see
- Four things that they can hear
- Three things that they can feel
- Two things they can smell
- One thing they can taste

The order doesn't matter but by the time they have tried to do all of these, then things should have calmed down somewhat.

Another trick is counting backwards from 100, or asking them to spell a word backwards. They will be focused so much on this that their brain will not have the chance to wander off.

Talking

It's common to avoid talking about how you feel, especially as you may feel that others won't understand, or that you'll be judged or considered weak. Many people feel alone with their anxiety or that people don't understand them. At the risk of generalising, men have a tendency to be less likely to feel comfortable initiating a talk about their feelings.

But you are not alone.

More people will have been where you are than you think! Pick up the phone and ring us at Fight Bladder Cancer. We can just listen, or we can talk things through, point you in the right direction, or help you to join our private forum full of people who know how it feels.



You can take back control

We now understand so much about anxiety and there are many techniques that can help you deal with it. If things seem to be getting out of hand, there is no shame in asking for help. Everyone has mental health issues from time to time, and many of us need to ask for professional help during the course of our lives. If this is the time that you need to, then don't hesitate. Your GP will be able to discuss medications that can help you; they may only be needed for a short time.

Calming those tumultuous thoughts

When Teri was diagnosed with aggressive muscle-invasive bladder cancer in May 2016, it came as a massive shock. At 60 and only recently retired, she had always been blessed with good health, kept fit and been very active. Now she was on a steep learning curve and she had two amazing companions to help her through.

I've been lucky enough to have had ponies and horses all of my life. Over the years, they have brought me joy, love and companionship and have certainly taught me many a life lesson! So I suppose it was no surprise that they were to play a major role in helping me through the emotional and physical battering that comes with a cancer diagnosis. What was more of a surprise was just how much of a part that would be.

Being diagnosed with any type of cancer would have been a shock, but bladder cancer? I had never even heard of it, but I had to cope with it now, so it was on with the treatment plan, which was the fairly standard chemo and then RC. I had opted for a bag as it appeared to offer me the relatively simplest and quickest treatment option and I just wanted to get on with my life. Inevitably, there were a few hiccups on the way. First my chemo was stopped after only one cycle when an extreme reaction landed me in hospital. Then, following my RC in September 2016, I developed sepsis as a result of a bacterial infection. However, by mid October I was home and, although extremely weak, was on the road to recovery.

A racehorse and an Irish lass

At the time of my diagnosis, I had two horses. Karindi (Indi), a failed racehorse that had been with me for over 20 years, and Tanni, an Irish-bred lass I'd had for just two years. Indi had, from the start, made it very clear about her likes and dislikes and how she wanted to be treated. She was very unforgiving if things weren't to her liking, and in the early days had treated me to way more than a few white knuckle rides!

ARTICLE
TERI
MORGAN
FBC Forum
Member



Tanni had always been kinder and much happier to engage with people than Indi ever was. Unfortunately she had not had the best start in life and at the time of my diagnosis, it was evident that her various physical and behavioural problems would mean that she was unlikely ever to be able to be ridden.

I had stopped riding as soon as I had my diagnosis; I simply didn't feel comfortable doing so knowing that there were at least three large tumours in my bladder. However, I continued to spend many hours with both 'girls'; each in their own way was an enormous source of comfort to me throughout that time. Just being with them and doing everyday things, such as grooming or walking with them, was a taste of normality that soothed and helped to calm the tumultuous thoughts and emotions that were otherwise ever-present during that horrible time.

Indi astonishes everyone

After my RC, it was no surprise to anyone who knew me that seeing 'the girls' was top of my agenda, and it wasn't long before Ian, my lovely, amazing partner, was driving me the five miles along a mainly bumpy road to the stable yard. (All I can say is, thank goodness for cushions!)

It was so good to see them both and as I buried my face in each of their manes and smelt that familiar and oh-so-comforting horsey smell, I immediately felt some of the craziness, stress and anxiety of the last few months start to slip away. Over the next few weeks my visits gradually increased and by the time I was driving again, I was back to routine daily visits.

Indi was simply amazing. After momentarily being very suspicious of this feeble me, she quickly came around and from that moment she appeared to appoint herself as my carer. She astounded me (and everyone else who knew her!) just how gentle and considerate she was. In truth I had had no idea that she was even capable of it.

Back on board

Fast forward four months to one late afternoon in what was left of the winter sunshine. Indi was nibbling the grass verges as we wandered in from the field when I found myself looking longingly at her lovely, broad back. I became aware that she had stopped eating and was looking intently at me. As our eyes met, we both seemed to know that it was time for the next step and, before I knew it, I was standing on the mounting block with Indi alongside. She stood quietly and calmly while I somewhat hesitantly clambered onto her saddle-less back and then very slowly and

tentatively asked her to take a couple of steps. I was back on board – and boy did it feel good.

We continued, slowly but surely, building up my strength and confidence until, sadly, last September, she lost her life as a result of colic. I was with her to the end, and although deeply upsetting, it was the very least I could do for this incredible mare who had done so much to help me move on from such a traumatic time in my life.

As mischievous as ever

As for Tanni, well she, too, played a significant part in my recovery. Unlike Indi, she continued just being her own mischievous self. Despite the emotional and physical trauma she'd experienced previously in her short life, her enthusiasm and her delight with life continued to be a joy and she invariably lifted my spirits with her antics. (It took me weeks to convince her that the bag I now had tucked away in front of my right hip did NOT contain any treats!)

After my RC, she became my regular walking companion as I slowly built up my strength and stamina. As we gradually increased the distance, we both started to become stronger and the bond between us steadily grew.

Against all odds

I had no idea at the time that this was laying such a solid foundation, that against all the odds, she would eventually be able to be ridden. Whilst it has certainly not been plain sailing, and I continue to take things very slowly with her, she has continued to progress to the point that we now ride out regularly and do lots of other fun things together, such as horse agility. She has recently started going over some (very) small jumps, which she approaches with her usual enthusiasm and joie de vivre. She continues to be a real inspiration to me and there is no doubt in my mind that both she and Indi certainly helped me through some very difficult times.

After my RC, she became my regular walking companion as I slowly built up my strength and stamina. As we gradually increased the distance, we both started to become stronger and the bond between us steadily grew.

Screaming at the walls

A touching illustration of why carers need our support too

Few people volunteer to be a carer. When a partner or loved-one is ill, it is natural to do whatever you can to care for them but it can take a heavy toll, as Nancy found out when her husband was diagnosed with bladder cancer.

My husband, Barry, was rushed into hospital with a tumour blocking his bladder. He was suffering from sepsis and his kidneys were affected so he needed daily dialysis. He hated being in hospital plus the sepsis made him aggressive and difficult.

He only calmed down if I sat with him so I changed my working hours so that I could sit at his side all afternoon and till after midnight most nights. The night porters had to let me out, and often let me in again only a couple of hours later to calm him down.

On the rare occasions I wasn't there, the nurses would often phone in the middle of the night and I would talk to him, which would help.

For the first time in my life, I thought, 'I can't do this!' I would scream at my empty room, then feel guilty because I was okay and my husband was not.

Preparing for the big op

After 10 weeks, Barry came home to gain his strength for his big operation. He had a bag attached to each of his kidneys on his back.

For me, this was easier as Barry was much happier to be home and he slowly gained weight and strength and I continued part-time work so I could spend more time with him. We had several months with minor

hiccups of sepsis attacks when, if I managed to get him to hospital, he signed himself out hours later!

Talking to people in the middle of the night helped me regain the strength I felt was ebbing away.

The lowest ebb

Then one night Barry ripped the bags off his back in frustration and by the time I got him to hospital, sepsis was taking over.

The next day I was rushed into hospital as my retina had detached and I was blind in one eye. The doctor could not give me a general anaesthetic as my blood pressure was sky high so I consented to the operation while I was awake. I was back with Barry that night, although I was unable to move my head or lie down for a week.

I felt then that I had no choice. It was as though some other power had taken over and I could just sit day and night beside Barry without worrying about work or anyone else!

I didn't move from his bedside for seven days and nights. He knew I was there. Our favourite music played quietly in the background and I talked.

Carers need help too

There were times when I felt completely overwhelmed. But I found help then and now on the Fight Bladder Cancer forum. Talking



to people in the middle of the night helped me regain the strength I felt was ebbing away.

Somebody you love needs your help and you do whatever you can because they need you.

Life throws things at you and you just do what you have to do.

People say things like: 'Look after yourself' and 'Take a break'. But they don't tell you how. I now understand that when my husband was very ill with bladder cancer I should have looked after myself a bit better but, as a carer, that's not your priority.

Carers need help as much as patients do and I am thankful that I found help on the FBC forum.

Join our support forum at www.facebook.com/groups/BladderCancerUK

ARTICLE
NANCY CHANT
FBC Forum Member

AM I GOING BONKERS?!

Adapted with permission from an article originally published on BladderCancer.net

For cancer patient, Anita, mental health and cancer seemed to go hand in hand. Here, she chats about her experiences of the impact of cancer on mental health.

ARTICLE
ANITA BROWN
FBC Forum Member

You can't fight this evil disease without it impacting on your mental health – or at least I couldn't. To start with, the pressure to stay positive is unbelievable, and somehow we feel that we have failed when the darker days appear. I have felt that if I didn't stay positive, people would perceive me as being weak, and I didn't want to let anyone down, let alone myself.

Everyone has bad days

The truth is, we all need to have 'down' days, 'black' days and 'not so good days', and the reason is simple: to fully appreciate the 'fabulous' days! You know the ones. The ones where you are looking amazing and feel amazing; the ones where people compliment you on how well you are looking; the days where you get everything done that you wanted to, and more. These days are totally awesome but, just like a coin, there are two sides to it, so to have the fabulous days we do need the not so fabulous ones.

The dark days – or whatever you want to call them – suck! I got so low at times that I just kept thinking 'if only it were sunny...' or 'I will feel better tomorrow'. Slowly, I began to notice that I had lost interest in baking, which I love doing, and my old friend music wasn't much help either. My favorite TV shows couldn't hold my attention. I guess I knew then that something wasn't right!

My smile was a mask

So did I ask for help? NOPE! That would be far too easy. Instead, I tried to cover it up. I made sure that my family never saw me upset, and that I was always happy and smiling. I had made myself a mask, a face to cover my real face – and that was the face I showed to the world! Inside I was distraught. I was told that I was going to die, I was terminal, and yet here I was alive, and not wanting to seem ungrateful. I felt I had nothing left.

That last statement may surprise you, as I know it did me. You see, we had LIVED these last

few years, we had spent our savings on making the most of the time we had, and now we were struggling. I know my husband would never say it, or at least never admit to thinking it, but I wondered if he actually thought 'she should be dead by now' because I had! And I am pretty sure some of my friends had!

Thankful but lost

So here I am, grateful that I am alive, thankful for every new day, but totally lost. I had to give up my job because of the treatments I was having.

I worked as a home carer and I loved my job. I was always looking after others, and I thought that I would be satisfied looking after our home, my family and my fur babies. In truth, it bored the living daylights out of me!

I had lost my identity. All I was now was 'the lady with the pink hair who should have died by now'. I felt awful that I wasn't happier that I was still here. No, I felt guilty. Guilty for living the life that no one thought I was going to have. That's why we had an 80's Christmas Disco in June; that's why we had a winter ball; that's why we did everything in a rush because I am not meant to be here!





Can you see how all of this messes with your head? I should have reached out. There were people I could have called to help me, but instead, I carried on, hoping that the next day I would feel better.

I was tired

Weeks went by, a month perhaps, and I came down with a UTI – or at least I thought I had, it's sort of hard to tell with a bag! Anyway, I took my BOP (bottle of pee) to my GPs and, sure enough, I had a UTI, and they were going to send the sample to the laboratory. The following week, I was told there was a prescription for me at the chemist. It was for a certain antibiotic that doesn't work for me, hasn't worked for me for six or seven years. I called them up, and, to be honest, I was tired – tired of having to call them, to tell them, tired of always having to explain to them that I didn't have a bladder, so no I wasn't in pain, just tired.

I think after the last two years, my poor body has been through so much, and my mind was kept busy with treatments, making memories and living as much as I could. We literally tried to cram as many days out in between treatments as we could. Days at the fun fair, the beach, having meals out, spending time with friends, and now I had nothing to do, nothing to occupy my mind, which was very much alive.

So back to the tired bit ... I could feel tears running down my face, warm tears. I couldn't stop them from falling, and then I began to sob. I was crying down the phone to the GP, but she kept telling me that she knew 'what was best for me', and that's when I hung up!

I wanted to scream

I wanted to scream down the phone at her that she didn't know 'what was best for me' and if I left it to her then – there is no uncertainty in my eyes – she would still be giving me prescriptions for UTIs, just like she did when she didn't take me seriously about 'having something wrong' that wasn't a UTI but turned out to be terminal cancer!

I sat and cried and cried, and my wonderful chocolate lab, Sherlock (or Choppers McGraw) came over and sat by me, with his ears droopy and sad. I called Macmillan and asked to speak to someone, still crying. I hated how vulnerable I was feeling, I felt broken!

Blurting everything out to the nurse

My lovely Macmillan nurse called, and I blurted everything out. I was tired! Tired of all this rubbish, of fighting, of living and of putting on this happy face. I couldn't take it anymore. In the whole of my journey, I have never felt that low! I have had my moments, but not like this.

I woke up the next day feeling emotionally drained, delicate and sensitive, and yet I also felt a teeny weeny bit better underneath the cracked surface, deep, deep down, I could see a flickering of light at the end of the tunnel.

I don't have to put a face on anymore

That time seems months ago now, and yet I know it's not. I know that I don't have to put a face on to anyone anymore, especially not my loved ones. I have been assessed by a psychiatrist; they say I have PTSD and am having a 'depressive and anxious' episode.

I know that my family can cope. You see, once I was told I was going to die, I made a promise to myself that I would be really nice to everyone I loved so that when I did 'pop my clogs', so to speak, they all would have good memories of me and not ones where I'm snappy or crying or even feeling a little sorry for myself.

I didn't want them knowing how much it hurt to know that, one day, sooner than we all would like, I will not be here, and that thought is totally indescribable. I don't think that there is a measure of pain invented that could cover just how I feel when I think about that.

Now I was healing

My son, Ash, sat with me on my bed and held my hand, telling me that it was okay to feel like this and that I should just let it all out. My husband, Tim, held me so tight and so close he made me feel safe again.

I guess the good thing about hitting rock bottom is that the only way left is to go up, to gain your strength again, to take time to see the good in the world. I took pride in myself that I was coping positively and happily. I now realise that it is so unattainable and that you can't keep it up. You need to feel the emotions that you are so scared of in order to be a whole person, you cannot just take the good and forego the bad.



Start talking about your mental health

The moral of this long story? If you have been feeling how I was, just empty and nothing left to give, then you need to start talking, to anyone, to a professional, a friend, to your doctor. Get the help to help you understand what is going on in your mind.

Our mind is a wonderful thing, and we need to take care of it just as we would our physical body, so take time out, read a self-help book, watch a trashy movie, be kind to yourself.

Just know that this journey we know as cancer is a horrific journey at times, and we have to acknowledge these times, then let it go – it's okay to not feel positive and happy all the time.



TOO MUCH TO BEAR

What can we do to help someone on the brink of taking their own life?

As we begin to emerge from a pandemic that will continue to have a devastating impact on many people's mental health for years to come, Lydia Makaroff assesses our awareness of suicide risk and what we can do to help prevent anyone we love from taking their own life.

Having occasional suicidal thoughts – known as suicidal ideation – is not uncommon but in someone with serious mental health issues it can, of course, lead them to actually attempt suicide. About four times as many men as women are successful, although women make more suicide attempts.¹

How does that impact cancer patients?

Research shows that rates of mental illness for those with a chronic illness or medical condition are greater than those of the healthy population, and while individuals with chronic illness, including cancer, often discuss many aspects of their condition or treatment, suicide remains an important but often neglected subject.

If you or someone you know has a chronic health condition, it could therefore be valuable to know the warning signs that show they may be at risk.

ARTICLE

Adapted from a
bladdercancer.net article
by DR LYDIA MAKAROFF
FBC CEO

What are the risk factors?

Some of the most recognised risk factors for suicide include:²

- a family history of suicide
- previous suicide attempts
- isolation
- availability of firearms
- a chronic illness or medical condition
- substance abuse
- intoxication
- a personal history of abuse or trauma
- chronic stress
- recent loss

CHANGING BEHAVIOUR

In many cases, a person who is having suicidal thoughts may not verbalise how they are feeling, but there are clues in their behaviour, which include:³

- aggressive behaviour
- social withdrawal and isolation
- increase in risk taking, impulsive or reckless behaviour
- threats or comments like 'I wish I were dead,' that become more serious
- severe mood swings
- increased or new drug use
- talking or writing about death

SIGNS OF IMMINENT DANGER

If things become really serious, look out for these warning signs indicating imminent danger, including:⁴

- putting their affairs in order
- giving away possessions
- efforts to find needed instruments like toxins, weapons or firearms
- saying goodbye to friends and family
- a switch from highly emotional moods to calm (this could suggest they are no longer worried about their struggles due to a suicide plan)

WHAT CAN BE DONE TO HELP?

Many people who are considering suicide may not wish to attempt or complete it, yet see no other way out. Your intervention could be all that is needed to fend off disaster, so take signs or comments about suicide seriously.

If you are concerned about a loved one or friend – or if you yourself are struggling with thoughts and desires of suicide – do not ignore it. If they are not in imminent danger, consider straightforward, non-judgmental questions followed by listening with empathy and understanding. You may be the only one who has shown any concern, and your efforts could make a difference. Consider asking about the frequency and intensity of suicidal feelings, how long they have been surfacing, and if the person has a plan. Once you have reached out to them and made a connection, seek resources like lifelines and counselling services. There are many lifelines and online chat services that offer trained professionals to discuss what is going on and direct you to resources in your area.

If you or someone you know is in imminent danger, call 999 in the UK, or 112 anywhere in the world.

The Samaritans also offer a free telephone helpline on 116 123 at any time on any phone.



1. nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Suicide
2. Risk Factors taken from nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Suicide
3. Warning signs taken from nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Suicide
4. Imminent danger also taken from nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Suicide

A challenging year for BLADDER CANCER AWARENESS MONTH

EMMA LOW
FBC Head of Fundraising
and Development



Every year, throughout May, Fight Bladder Cancer collaborates with patients, carers, medical professionals, community groups and businesses across the UK and beyond to highlight the impact of bladder cancer, promote awareness of the symptoms and urge greater investment in research.

Awareness Month in 2020 was certainly a challenge in the midst of the Coronavirus pandemic. Our original plans for campaign activities had to be dramatically reviewed in light of the international health crisis. Our chosen theme and central topic for change had been 'tackling bladder cancer in the workplace' but with so many people furloughed, off work or working from home, we chose to put a pause on the campaign topic and instead focus on supporting our 'wee family' through social distancing, shielding and for many what has been a frightening and dramatic change to accessibility in healthcare and the systems for bladder cancer diagnosis and treatment.

Instead of the usual coffee mornings, bake sales at work and 'wee walks' – we created a special 'at home' feel by developing a Bladder Cancer Awareness Activity Calendar to cover the 31 days of May. Concepts included a range of ideas that kept people safe while demonstrating their support for bladder cancer awareness, such as:

- wearing a Fight Bladder Cancer wristband
- completing online surveys
- displaying a car window-sticker
- wearing orange socks!

We worked hard to maintain our usual activities and campaign messages, and we even added a few more – COVID-19 orientated ideas into the mix. These included:

- **wearing orange** – sharing orange selfies, doing Zoom calls in teams wearing orange fancy dress
- **sharing our social media posts** on LinkedIn, Twitter and Facebook
- **thanking NHS and medical professional carers** on 12 May – International Nurse and Midwife Day with a giant clap (in addition to the weekly 8pm clap)
- **taking up challenges** – as listed in the 31 Days of May Calendar
- **blowing bubbles** – we focused on bubble blowing on 31 May and remembered in particular the first anniversary of the death of our dear founder, Andrew Winterbottom

The range of participants, campaigners and fundraisers was once again vast. Here are just a few highlights:



Giving Tuesday now

As part of Giving Tuesday on 5 May, three friends and supporters – Liz Lewis, Ros Bruce and Deb Major (also a Fight Bladder Cancer Trustee) – created fabulous videos to share their reasons for supporting the charity. #GivingTuesdayNow was a new global day of giving and unity created as an emergency response to COVID-19, with the aim of creating a wave of generosity, citizen engagement and philanthropy amidst the pandemic.



Wee Quiz Night

On Wednesday 13 May, we hosted a gathering of minds via Zoom Wee Quiz Night. There were prizes, but most important was seeing friends and loved ones from our wee community and having some fun during the most difficult of times.



Craft and creativity

Throughout May we encouraged our friends and supporters to get creative during lockdown – everything with an orange theme, of course! Butterflies featured heavily in our design theme for 2020 – in particular we felt that their colour and beauty represented hope, optimism and warm energy – concepts that were much needed during the spring this year. Crafts shared with us at FBC HQ included jewellery making, baking, arrays of colourful butterflies, masses of orange bunting, and freshly sewn masks in all shades of orange! Last but not least, gardening images of multiple shades of orange and yellow from our supporters' gardens showed us just how much thought went into Bladder Cancer Awareness Month in 2020.





Bubbles for bladder cancer

On 31 May every year is a special day for the Fight Bladder Cancer wee community. We blow bubbles to remember all those affected by bladder cancer and those we have lost.

We were blown away by the number of people across the UK who took part in blowing bubbles with us this year. Plus we were particularly delighted to see our international friends in Canada, America, Australia and Europe all sharing their photos and messages. It was particularly moving, as well as stimulating and energising for us all, as we shared our memories of our dear founder Andrew Winterbottom on the first anniversary of his death. THANK YOU for joining with us.

Getting wordy with our corporate partners

We were thrilled that many corporate partners got behind Fight Bladder Cancer this year during May and shared our social media messages as well as engaging their staff in activities.

Our friends at **Great Bear Healthcare Ltd** – who have chosen FBC as their 2020 Charity of the Year – started fundraising and engaging in earnest during May. This included them interviewing one of our Scottish supporters, Dorothy Markham, and sharing her story with their customers and nurses as part of an awareness-raising activity.

Our friends from **Olympus Medical** once again came up with an original method of supporting Bladder Cancer Awareness Month. They invited people to complete an interactive word search, which featured lots of words relating to our campaign. In return they donated £5 per completed entry. The generous folks rounded up the donation to a total of £1,000 at the end of the month.



Support from medical professionals

We were so sad not to be able to run our Urology Department Fundraising Challenge this year, or to go on our usual tour of UK hospitals to host FBC information stands and visit you, our medical friends and partners. We were, however, delighted to continue our close friendship with the British Association of Urological Nurses (who had a Zoom team meeting wearing orange in solidarity with us).

We were also thrilled to be supported by bladder cancer Clinical Nurse Specialists all over the country who sent us emails, shared our social media messages and worked in partnership with us to reassure patients and support Awareness Month 'from a distance'.





Don't forget to get in touch with the Fight Bladder Cancer team if you have ideas for ways to raise awareness as well as urgently needed funds in May 2021. Please do call Emma or Sophie on **01844 351621** to share your ideas, or email fundraising@fightbladdercancer.co.uk. We love to chat with our friends and supporters and are keen to hear your stories and together – lay down some plans for next year's Awareness Month to make it even bigger and better.



Media spotlight during Awareness Month

Despite Coronavirus, the 2020 Bladder Cancer Awareness Month received a few significant mentions in the media. We were grateful to have the media and PR support of RPP Group UK who helped us engage the National Health Executive – sharing our press release on their website and social media. The pro-bona PR support also helped us to achieve local media stories in Scotland and the South West.

FBC social media responses and followers achieved the highest national engagement of all bladder cancer patient organisations around the world. (as analysed by the World Bladder Cancer Patient Coalition). Followers increased by **0.5%** on Twitter, **2.5%** on Facebook and **23%** on LinkedIn. We reached over **510,000** people on Facebook and during the month, Fight Bladder Cancer was mentioned **442** times by other stakeholders on Twitter.

THANK YOU

We remain humbled and grateful to each and every single patient, carer, family-member, friend, nurse, doctor, researcher, business partner and organisation that got behind Fight Bladder Cancer during May 2020 to participate in Bladder Cancer Awareness Month. Given the challenging times we were overwhelmed by the good wishes, support and energy that people gave to us. You can see a round up of many of our fundraisers on page 53. **THANK YOU ALL.**

Waiting, keeping busy, coping and waiting some more

In 2018 Mike Hill was diagnosed with stage 3 invasive bladder cancer. His wife, Alison, told us how her mental health was affected as she coped with the diagnosis, the support she has received and how – as part of her coping strategy – she nominated Fight Bladder Cancer for Charity of the Year with her employer InHealth.

The first sign that something wasn't right was back in 2016 when Mike had blood in his urine. The GP referred us to a urologist, who performed a cystoscopy. Although the results were clear, they thought Mike might have a blockage in the urethra so he had a stent put in; the pain was unbearable for several weeks.

Then in December 2017, there was another bout of pain and more blood in his urine. We didn't think much of it as Mike had already had the tests but after a few months of being in more pain we went round the loop again – appointment, tests, a CT scan and blood test. The blood tests came back fine and the scan seemed clear but the blood vessels in the scan didn't look right so he had a TURBT, which was sent off for a biopsy. After three weeks of waiting we got the results.

Mike had stage 3 muscle-invasive bladder cancer.

Mike was very quiet about it. He felt there was nothing we could do but get on with it, whereas I'm the sort of person who wants to talk through everything



I felt as though I had been knocked off my feet

Mike was very quiet about it. He felt there was nothing we could do but get on with it, whereas I'm the sort of person who wants to talk through everything. My daughter wasn't a talker either but was trying to be positive and upbeat about the situation. That was the worst thing for me – I'm so analytical – always 10 steps ahead and constantly worried. It didn't help that I had already been suffering with anxiety for a long time.

INTERVIEW
KATE MOORE
FBC Intern

EMMA LOW
FBC Head of Fundraising
and Development

The toughest part of it all was the waiting; it is so stressful and you're constantly going over it in your head and you have to force yourself to not search Google to try to find some answers. No matter how hard you try to keep busy, it never goes away. Fortunately, I had my work colleagues at InHealth who were very supportive and work was very busy, which kept me distracted.

Heartbreaking to watch

Mike chose to have radiotherapy and went to the Queen Elisabeth Hospital in Birmingham every day for four weeks. In the first and last week he also had chemo. The treatments really affected him as he wasn't able to work, was very tired and completely went off his food. I tried to give him sugary drinks and protein shakes just to make sure he had something. It was so heartbreaking to watch him go through treatment. I often thought 'I wish it was me rather than him'.

There is always that fear and anxiety that never goes away

People say that good things come in threes.

- Mike had another cystoscopy in July 2019 – clear.
- A CT scan in October – clear.
- More tests in January 2020 – clear.

The doctor said they won't have to do tests for another year. It was such great news. But, even so, for me there is always that fear and anxiety never goes away.



I'm so pleased I joined the private forum as I gained so much information and received a lot of support.

The FBC forum gave me hope

I first heard about FBC when I came across the website. I was searching online as I needed to know more about bladder cancer and wanted to know that I was not alone. You hear about many other types of cancers online but bladder cancer was not one I had heard of.

I noticed the charity had a forum so decided to join the group. I'm so pleased I did as I gained so much information and received a lot of support. You can post how you feel and ask questions day and night – there is always someone there to keep you going and give you the advice and the support you need. It was a big big help and I cannot thank the forum enough. I still go on there now and look to help others as I feel it's important to give back the support that I received.

The InHealth nomination was a no brainer

I wanted to do something for FBC as they had supported me so much and I knew that more awareness surrounding bladder cancer was urgently needed – so I decided to put forward FBC for nomination. Nominating the charity was also another fabulous way of keeping busy and distracting me from my worries.

I was so chuffed when Fight Bladder Cancer was chosen. And then I received a lovely email from one of my co-workers at InHealth thanking me for nominating the

charity, and bringing more awareness surrounding the disease to light. He had been diagnosed with bladder cancer himself and had been coping with it alone and was so relieved to hear about FBC. I felt so proud and pleased to have helped someone else.

It is so important to spread awareness

One of the best things to come out of the InHealth Charity of the Year nomination is spreading awareness. Bladder cancer is not widely known and not talked about enough. The more people who learn about it, the more GPs will listen and the higher the possibility that patients will be diagnosed and treated earlier and with a better outcome. InHealth employs over 2,000 staff nationally – and now they have all had the chance to hear about Fight Bladder Cancer and hopefully their families and loved-ones will be more aware.

It's also been fabulous to see all my InHealth colleagues getting behind the charity and raising over £3,000. I know what a difference it can make.

Can you help Fight Bladder Cancer by nominating us as your employer's Charity of the Year or by doing some fundraising in your workplace? If you think your company might enjoy supporting Fight Bladder Cancer then please email Emma Low our Head of Fundraising and Development on emma@fightbladdercancer.co.uk



The spotlight is on FBC:

InHealth Charity of the Year



To be chosen as their Charity of the Year by the UK's largest specialist provider of diagnostic and healthcare solutions is quite something. For the charity, it shines a spotlight on their activities and helps boost awareness – not to mention the chance to gain much-needed funds. For the company, it is a fantastic bonding opportunity for management and workforce to come together to fundraise and support a non-profit organisation.

So FBC was thrilled to begin its Charity of the Year status with InHealth at the start of 2019 and, after a successful year, we interviewed InHealth's Head of Brand and Communications, Zosia Hedges, to talk more about the Charity of the Year partnership, working with us and their year of fundraising events.



ARTICLE

KATE MOORE
FBC Intern

EMMA LOW
FBC Head of Fundraising
and Development

How did you first hear about FBC?

Every year, our staff nominate and select our Charity of the Year and, as a company, we encourage them to support smaller healthcare charities that are less well known but have a presence and an impact across the UK. We ourselves are based across the UK, so it's a great way to get lots of people involved and build relationships.

Fight Bladder Cancer was nominated by Alison Hill, a colleague who cares for her husband who has bladder cancer (see page 46). We selected it from all the nominations because we were so surprised by the statistic that it was the fifth most common cancer but that it receives such a small percentage of the national budget for research. Knowing this made us very keen to get involved and raise awareness of both the charity and the disease. Once the partnership was announced, we discovered that another colleague was a bladder cancer survivor but had not heard of the charity – all the more reason to help to raise awareness.

What type of challenges did you take on?

Where do I start? We ran a Valentine's Day breakfast, cake sales, a Halloween fancy dress sponsored walk, charity runs, knitted Christmas decorations and gifts. We also had a Christmas raffle at the end of the year where prizes were kindly donated from suppliers.

Tell us some of your favourite moments

I am sure everyone has their favourite, but mine was Halloween. After one of our colleagues noticed how the black and orange colours for Halloween matched perfectly to FBC, it was a natural fit! It was the first time we had tried a dressing-up event in the office before so I was a

bit nervous about what the response would be, but the whole team really went all out and there were some great costumes and props. It happened to be our Townhall event that day, too, so seeing our CEO present work-achievement recognition to skeletons, witches and mummies was brilliant! Everyone really enjoyed it and there was such a buzz in the office.

Aside from the fundraising, I also enjoyed Emma and Sophie coming to visit our offices to talk about the charity's story; one of our colleagues also told us of his journey surviving bladder cancer. Many colleagues have taken away these stories to share with others, which demonstrates perfectly how you can spread awareness not just within the company but on a wider scale, just like the ripples on a pond – that's quite special.

On the awareness front, we also shared stories and tweets throughout the year on various social media platforms, which was great not just for Fight Bladder Cancer but also for InHealth.

What did you enjoy most about working with FBC?

I would say the enthusiasm from the staff at Fight Bladder Cancer, as well as their continuous support throughout the year, was something that stood out for me. We had regular monthly calls to touch base and the staff helped us with setting up our personalised online fundraising page. I think the relationship we developed was really productive and they made the whole process so easy!

"Being charity of the year for InHealth during 2019 was extremely important to Fight Bladder Cancer. InHealth was the charity's first ever 'employee fundraising partner' and we really enjoyed working with them. We found them supportive, engaged and generous-hearted. The fact that we had been nominated by a staff member who is personally affected by bladder cancer meant the world to us. Thank you InHealth for smashing your target and raising over £3,000.

We really are so grateful."

Emma Low, Head of Fundraising
and Development

What have been the benefits for InHealth of collaborating with a charity like FBC?

The biggest benefit has been highlighting how important it is to raise awareness. Diseases like this can strike so close to home without our even being aware of them – as our two colleagues demonstrated. This just shows how much of a difference raising funds and raising awareness can make.

The fundraising brought everyone together from all over the company; even a subsidiary to InHealth, Preventicum, came together to show support and raised money by doing a 10k run in December, raising just under £1,000 of our £3,000 target. That was fantastic and helped develop our own relationship and their organisation.



Was the fundraising of benefit to your staff?

Absolutely! Teamwork was the biggest benefit. Charitable activities really do bring everyone together and, in our case, many different teams of people who wouldn't normally come together, worked alongside each other to fundraise. I believe all businesses should support a charity as this type of partnership is mutually beneficial – and above all it's a lot of fun!

Plus, having supported FBC and having had such a successful fundraising year, more people have come together to suggest charities for our next year's Charity of the Year, which shows the positive impact our collaboration has had!

Inspired by her uncle, inspiring to all of us

We shine the spotlight on just one of our many dedicated fundraisers, Grace Bentham, to show just how fortunate we are in the commitment and dedication of our members.

ARTICLE
SOPHIE MAGGS
FBC Supporter Care & Community
Engagement Manager

When I caught up with Grace last December, she was a student at Cambridge University, but her connection with Fight Bladder Cancer was already of long standing. In 2014, when Grace was 19, her uncle, Matt, had died from bladder cancer. Matt was brother to Grace's Mum, Rebecca, and Grace was his only niece, so they had a very special relationship.

A mystery donor

The year before Matt died, Grace was still at school, in the last year of her A-levels. She had decided to take part in the South West Coast Path Walk in Exmoor to raise money for Fight Bladder Cancer while also raising awareness of the disease. Her uncle knew she was taking part and it motivated him to think positive as he went through treatment. FBC had supported Matt through his cancer journey, so he was very happy that Grace was giving something back to the charity, as a reflection of his confidence and gratitude for the support he had received from FBC founder, Andrew, and other members of the forum.

The walk raised an amazing £800, with the final total being reached by the contribution of an anonymous donor. Grace only discovered after Matt's death that it had been her uncle who had helped her reach her target.

Bubbles for bladder cancer

Moving on to university and in her first year at Durham, Grace was keen to build on her fundraising success. During that year's Bladder Cancer Awareness Month, she organised a bubble blowing event at her college, followed in her second year by a similar event at Durham Cathedral, where she also handed out leaflets. In her third year, the location shifted to Paris, and slowly her fundraising total notched up.

In her final year at Durham, Grace organised a day event at college and a day at the Cathedral, including a successful cake sale, where a great number of her friends lent her their support to raise awareness of bladder cancer and the help that the charity could offer. They raised around £200 for the charity.

Another change of location takes us to Cambridge, where Grace was studying for her Master's degree, but still supporting the charity during BCAM. During the May 2019 BCAM, a raffle, clothing swap, cake sale, walk and blowing bubbles not only raised awareness of the disease but raised a fantastic £243!

And there's more ...

In addition to all these wonderful events, Grace has also organised a Facebook fundraiser for her birthday, raising an additional £195 from donations given in lieu of birthday presents.

And there's more ...

When asked which were the most enjoyable events, she does not hesitate. While her Mum, Rebecca, has supported all her efforts, she was there in person for the events in Cambridge last year and the initial walk in 2014, making them extra special. Rebecca also organised a summer garden party in 2015 to celebrate Matt's life, which again raised money for FBC and awareness of the disease.

To support Bladder Cancer Awareness month in 2020, Grace and Rebecca joined forces, and each created a piece of wonderful art **each** day. Anyone donating to their page were included in a daily draw to win those two pieces. Then, at the end of May, everyone who had donated across the month was included in the Grand Draw and the winner was able to commission a piece of their choice as their prize. The fundraiser was supported by both Great Art and Rosemary & Co Artists Brushes who supplied some wonderful runner up prizes. This amazing challenge of 64 pieces of art took so much time but raised an incredible £2427!



Her inspiration is our inspiration

Grace's inspiration to get involved in supporting Fight Bladder Cancer was clearly her Uncle Matt. She shared with us that her commitment to the charity comes from the feeling that you can make a difference and that you're contributing to the cause. Being part of Bladder Cancer Awareness month allows Grace a chance to connect with Matt and his memory, and she feels honoured to share the message about bladder cancer.

Grace was incredibly positive about her experience with the charity. She knows her efforts are appreciated and she feels that she has a personal connection with the team. We'd be inclined to agree!



Grace and her Uncle Matt

And then there's Grandma...

Rebecca and Matt's Mum, Grace's Grandma, Jill Veasey is another talented member of the family as her folded books have adorned the shelves of the Wee Bookshop & Café.

When someone dies

Leaving a gift in memory of a loved one is an amazing way of celebrating their life. Asking family and friends to donate to Fight Bladder Cancer, instead of giving flowers, can offer comfort that each gift is going directly to support others affected by bladder cancer.

We can help you by creating a unique, personal donation page for

your loved one, which can include photos and even details of funeral arrangements. People donating can leave messages of remembrance, which can give comfort in the weeks and months to come. These pages allow you to see the total amount raised for Fight Bladder Cancer in memory of your loved one and know that it is making a real difference.

We can liaise directly with Funeral Directors to ensure they have our full details of where to send monies collected at services and can also provide donation envelopes which allow UK taxpayers to increase their donation by completing a Gift Aid declaration.



In memoriam

We are so grateful to those who choose to request donations to FBC in memory of their loved ones. Thank you.

LAURA WALKER



With typical selflessness, **Laura Walker** set herself the challenging target of raising the equivalent of the cost of her immunotherapy treatment. Thanks to her efforts and to generous family and friends, Laura's Just Giving page currently stands at an amazing £12,830. Sadly, Laura never knew just how successful she had been, as she died in February, but her positive spirit lives on. We send our thanks to Laura's husband, David, her mum, Jan and her brother, Martin, for their support.

Inspired by Laura, two of her close friends, Ali Sargent and Kate Griffin, took on their own endeavours to raise money for FBC. Ali, who signed up to do a tandem skydive, has raised more than £2,000 whilst donations from Kate keep rolling in, from the sale of her own specially crafted Laura's Gin. A HUGE thanks to you both from everyone here at FBC.

DONALD HAMPSON



Donald Hampson died from bladder cancer in March, following his diagnosis 13 years ago. Survived by his loving family: wife Pat, daughter Carole and sons, Jeff and David along with 11 grandchildren and nine great-grandchildren. We are incredibly grateful to Donald's family and friends who donated in his memory, raising more than £950 for Fight Bladder Cancer.

SALLY HURLEY



Sally Hurley, much-loved wife, mother, loving grandmother and friend to many, passed away in February, friends and family gave to Fight Bladder Cancer, raising a wonderful £650. This money will go directly to help support others affected by bladder cancer. Thank you.

KEVIN EYRE



We are incredibly grateful to Matthew and Sam who established a donation page in memory of their stepdad **Kevin Eyre**. Kev, much-loved husband of Sue, died on 4 August after a courageous and bravely fought battle with bladder cancer and we are honoured to have received donations given in his memory. Huge thanks to his family and friends who have given so generously; their fundraising page has reached nearly £2,000.

SARAH FOSTER



When **Sarah Foster** passed away in August, husband Neil knew immediately that Sarah would have wanted family and friends to give donations in her memory to Fight Bladder Cancer. We are so thankful to all those who have given in Sarah's memory.

Please do contact us if you would like help in co-ordinating donations in memory of someone who has died, we are here to help. Email sophie@fightbladdercancer.co.uk or call 07920 164706

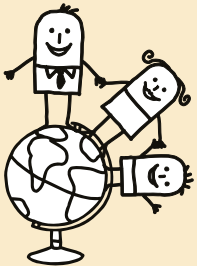


Scan this code to take you straight to our donations page.

Fundraising round up

Spring 2020 – Autumn 2020

Art fundraising In memory: Artist Rebecca and teacher Grace ran an awesome fundraiser throughout May (see an in-depth article about their activity on page 50). Rebecca and Grace were dedicated to raising awareness and funds during Bladder Cancer Awareness Month because Rebecca lost her brother Matt (Grace's Uncle) to Bladder Cancer in 2014 at the age of 42. They were grateful for the support he received and wanted to give something back. Unable to host a coffee and cake event, they decided to use their fabulous artistic skills and created TWO pieces of stunning art every day during May.



FUNDRAISING CHALLENGERS: THE BRAVE, THE WILD AND THE WHACKY

The generosity and spirit of patients and their families really shone through during May. Here we bring you the stories of Sarah, Amanda and Paul who helped make such a difference in May by fundraising for us.

Amanda Harcus was diagnosed in January 2020 with early stage bladder cancer and is now happy to report good health. She wanted to raise awareness and give back to our wee community and started doing ambitious fitness challenges to raise money – she challenged herself to 2 minutes of crunches and 2 minutes of planks as well as walking 10,000 steps a day in May! Amanda – you're amazing!



grew, Sandra upped her challenge and went for the 10k. Well done Sandra on raising an amazing £1,193 for Fight Bladder Cancer. What a great total and we are so grateful.

Supporting Fight Bladder Cancer – it's a husband and wife partnership in the Mullerworth Household!

Susan Mullerworth, a well-known patient ambassador for Fight Bladder Cancer, came up with yet another fabulous fundraising concept during Awareness Month this year – called 'Roll the Dice for Bladder Cancer'. She and her husband Matt created a series of videos to tell Susan's story as well as encourage people to raise funds and donate in a new and interesting way.

As if Susan's efforts weren't enough, husband Matt has also personally facilitated a fundraising opportunity through his friendship with Liverpool Football Club and with Jamie Carragher and the 23 Foundation in particular. Matt was able to secure the donation of a 2017/18 125th anniversary club shirt which was in a RARE orange. The top has been autographed by Jamie who also added 'You'll Never Wee Alone' in tribute



to those affected by bladder cancer. Raffle tickets were sold via an online platform and over £580 was raised for the charity. Thanks Matt and Susan for all your amazing efforts.



Paul and Brenda Michaels: Many of you will have previously read about our Fight Bladder Cancer friends from Buckinghamshire. Paul, a patient since 2017, is busy running an IT advisory company and married to Brenda who is a practice nurse. Despite the challenges of lockdown,

they once again set themselves a fundraising 'pick and mix' challenge for Awareness Month, from exploring new walks and cycle rides, through to baking for friends and continuing to raise awareness for FBC. We really are grateful to them for their fabulous efforts and energy!

Sandra Mooney set herself a challenge during Bladder Cancer Awareness Month in support of her dear friend, Viv Taylor, who is a patient. Together the friends enjoy singing in the Offerton Methodist Choir – who had chosen Fight Bladder Cancer as their Charity of the Year in 2020. The choir had planned on raising money for the charity during all their public concerns across the year. Sadly the Coronavirus pandemic meant all concerts had to be put on hold. Sandra felt very sad about this so she decided to organise a 5k walk for herself. As the sponsorship



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 of 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. They also LOVE hearing your ideas, catching up and also getting your feedback. If you'd like us to get in touch, feature your fundraising activity or send a big shout out to your supporters, please email fundraising@fightbladdercancer.co.uk



Sarah and Neil Foster got married on 11 July and kindly asked for donations to FBC, instead of gifts, raising in excess of £1,000 for the charity!



18-year-old Freya Sheldon chose to fundraise for Fight Bladder Cancer during her role as Royal International Miss UK. She raised £720 by abseiling down the Peel Tower and selling handmade knitted Christmas puddings, that contained chocolate oranges!



Huge thanks to Matt Mullerworth and Jamie Carragher's 23 Foundation for supplying a signed orange Liverpool FC shirt – this raised £580 in an online raffle, won by Ravi Ruparel and his daughter.



Lauren Cook completed a 30-day fitness challenge, in memory of her Mum and raised a fantastic £1,020 for FBC – thank you Lauren!

For her 2.6 challenge, Heidi Mason walked at least 5km a day for 26 days and raised just under £600 for FBC! Thank you!



We are so grateful to Ali Sargent for completing a tandem skydive for FBC. In memory of her good friend Laura Walker. Ali has raised over £2,600 for the charity and we want to say a MASSIVE thank you to her and her friends and family for supporting her efforts.

Lucy Thurlow, a very special lady

ARTICLE
SOPHIE MAGGS,
FBC Supporter Care &
Community Engagement
Manager

When long-term supporter of FBC, Jan Southwell, was announced as President of Potters Bar Bowls Club for 2020–2021, he confirmed that his charity of choice for the year would be Fight Bladder Cancer. Having lost his brother-in-law to the disease, Jan has consistently raised awareness of the disease and the charity itself, truly believing in the support it offers.

As a postman, Jan's job took him to many addresses and one of these areas was Whetstone in Barnet, north London. One of the many families that got to know Jan on his deliveries was the Thurlow family and it was pure chance that Sue Thurlow joined the local bowls club and recognised Jan from many years before.

One day, Sue mentioned that her daughter, Lucy, had been rather ill but would be visiting the club that afternoon. When Lucy arrived, it immediately was apparent that she had indeed been very poorly; Lucy had sustained permanent neurological damage following several severe epileptic fits in 2011 and was confined

to a wheelchair. This also affected her sight, and she had become completely blind. She moved into a wonderful rehabilitation care home after six months in hospital, and her new life meant being supported by one-to-one carers, 24 hours a day.

Jan was incredibly moved by the extent of Lucy's condition and started to visit her at the home and, with the support of her fantastic care team, Lucy began to be able to do more than before. Her amazing willpower and determination spurred her on and she was keen to undertake challenges to raise funds for charities close to her heart.

Earlier in 2020 Lucy announced to her Mum, Sue, that she wanted to help 'Jan's charity', Fight Bladder Cancer. In May, Lucy cycled 31 miles over five days on her static bike and raised a phenomenal £734 for Fight Bladder Cancer. Her amazing physio team – Carolina, Luciana, Elizabeth

In May, Lucy cycled 31 miles over five days on her static bike and raised a phenomenal £734 for Fight Bladder Cancer.



and Molly – all helped Lucy to achieve her goal, but it was Lucy's resolve that ensured she completed the challenge. Lucy celebrated her 48th birthday shortly after.

Raise some money & have some fun!

WE NEED YOUR SUPPORT

FBC is committed to:

- supporting all those affected by bladder cancer
- raising awareness of the disease so it can be diagnosed early
- campaigning for and supporting research
- affecting policy at the highest level to bring about change

Our services are in more demand than ever but 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.

We can help you fundraise!

Emma and Sophie will support and encourage you all the way, designing posters, flyers, sponsorship forms or pretty much anything that helps you to raise money. That includes telling you about Gift Aid, which makes every pound worth even more. Call on 01844 351621 or email at fundraising@fightbladdercancer.co.uk, emma@fightbladdercancer.co.uk or sophie@fightbladdercancer.co.uk.



The CALIBER trial

Investigating use of chemotherapy in the bladder to reduce the chance of low-risk non-muscle-invasive bladder cancer returning

Bladder cancer is the eleventh most common cancer in the UK, with around 10,000 people diagnosed each year.¹ Bladder cancer can be divided into two groups:

- non-muscle-invasive bladder cancer, where the cancer is confined to the lining of the bladder
- muscle-invasive bladder cancer, where the cancer has spread deeper to involve the muscle wall of the bladder and beyond; this is a life-threatening condition for which radical treatment is required

Patients with non-muscle-invasive bladder cancer are categorised as low-risk, intermediate-risk and high-risk depending on how likely their cancer will progress to the muscle-invasive stage.² Low-risk bladder cancer affects around 5,000 new people per year in the UK and accounts for about half of all bladder cancer diagnoses.³

People diagnosed with low-risk bladder cancer are unlikely to develop muscle-invasive bladder cancer in the short term but they are at risk of their cancer returning frequently. They are usually treated with surgery under general anaesthetic. Several small studies have shown promising results using chemotherapy inside the bladder (chemoablation) but the best chemotherapy schedule and the effectiveness of chemoablation in completely clearing all the cancer in the bladder is uncertain.

The aims of the CALIBER trial

The CALIBER trial was developed by UK researchers in collaboration with patient representatives. The trial aimed to establish the short-term effectiveness of chemoablation in the treatment of low-risk bladder cancer. CALIBER aimed to find out if at least six out of ten participants’ cancers could be removed by chemoablation. This was checked three months after people completed treatment. If the chemoablation was effective in the short term, a larger trial would be developed to assess longer-term benefits, with the aim of standardising low-risk bladder cancer management and potentially removing the need for over a thousand patients each year to undergo surgery.

Treatment groups

People with low-risk bladder cancer were invited to take part if their cancer returned after their first diagnosis. Those who agreed to join the trial were put into two treatment groups:

- surgery
- chemoablation

Participants in the surgery group received the same treatment they would have had if they had not joined the study. Patients in the chemoablation group received mitomycin C chemotherapy directly into their bladder once a week for four weeks and did not have surgery.

Between January 2015 and September 2017, 82 people joined CALIBER from 24 NHS hospitals; 28 people had surgery and 54 people had chemoablation. Participants were aged between 66 and 78 years, 77% were male and 23% were female.

Check-up schedule

The check-up schedule used in CALIBER was designed to match the schedule that would have been followed for people who did not join the trial. Three months after treatment, participants had a cystoscopy to check if there was any cancer remaining in their bladder. This was timed to match when low-risk bladder cancer patients would usually attend clinic to see if their cancer had returned. Both groups of patients attended regular clinic visits for 12 months after treatment and if their cancer did return, they received further treatment as agreed by them and their doctors.

Initial results

CALIBER found that three months after completing treatment:

- 20/54 (37%) of chemoablation patients were free of cancer
- 21/28 (81%) of surgery patients were free of cancer

ARTICLE

STEVEN PENEGAR
CALIBER Trial Manager

HUGH MOSTAFID
CALIBER Chief Investigator

There were no major differences between the two groups in the proportion of participants with cancers that returned over the next 12 months, however people who received surgery and still had disease at their three-month check-up were more likely to have further recurrences within the year after their initial treatment than those free of disease at their three-month check-up.

Side-effects

Very few side-effects were reported. The most common side-effect was needing to urinate more often than normal. Eight out of 28 people in the surgery group and nine out of 53 people in the chemoablation group reported this side-effect. No one in the study had severe side-effects as a result of their treatment. Patients in both groups reported similar experiences of quality of life and general well-being in the questionnaires they completed.

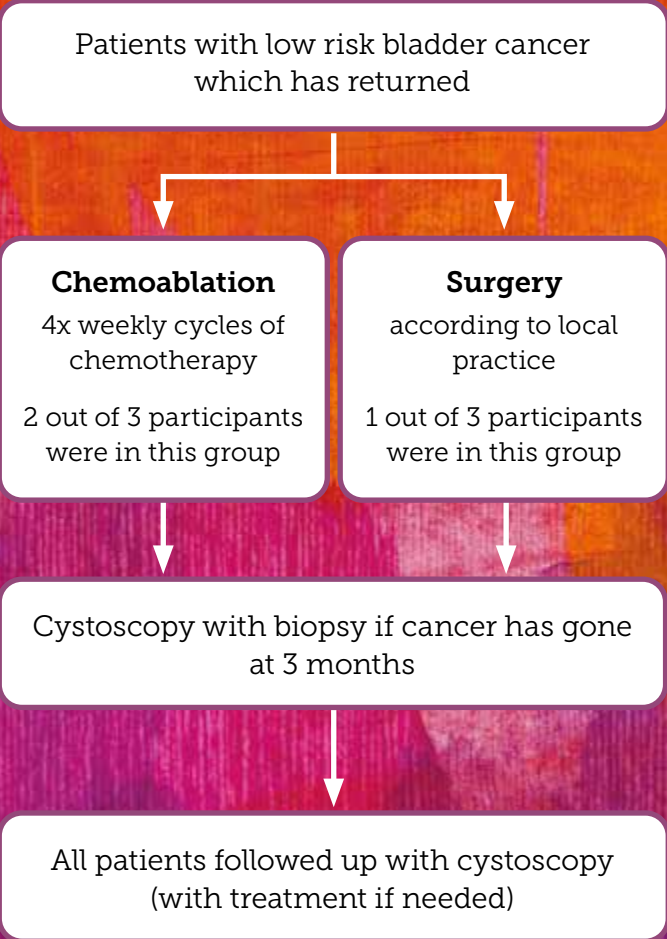
Results and conclusions

Our results show treatment of low-risk bladder cancer with chemoablation instead of surgery is feasible and safe, but the type of chemoablation treatment used in CALIBER does not work for enough people to suggest it could be a viable alternative to surgery for everyone with this type of cancer.

Nevertheless, there is a suggestion that chemoablation may delay the time it takes for cancer to return. This is an important scientific finding. Although the trial has not led directly to a new treatment that is better than surgery, this information was not known before. Further research is required to investigate the possible role of chemoablation as an alternative or additional treatment to surgery. For example, whether giving patients their chemotherapy before surgery (rather than after) has fewer side-effects, meaning more patients complete their treatment and therefore more people benefit.

The initial results of CALIBER were presented at conferences across the world in 2018 with updated results presented in 2019. Results were well received among the urological community. CALIBER results were published in a peer reviewed medical journal in 2020⁴ and future work is planned to use the biological samples donated by trial participants to find out more about this type of cancer.

CALIBER trial schema



Acknowledgements

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References:

1. UK Cancer Stats. 2017,
2. Sylvester RJ., et al, Eur Urol, 2006
3. BAUS Cancer Registry, 2009
4. Mostafid AH., et al, BJU Int, 2020

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.



Current open bladder cancer 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

UROX BIOMARKER

This trial will need a urine sample from participants who are under investigation for possible bladder cancer and are due to undergo a standard of care investigative cystoscopy and biopsy. This study is testing to see whether the UroX biomarker can be detected in urine samples and therefore be a way of diagnosing patients. Both healthy and bladder cancer participants are needed. ClinicalTrials.gov ID: NCT03973307

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

Non-invasive bladder cancer

KEYNOTE-676

This study is for people who have high-risk, non-muscle invasive bladder cancer that is persistent or recurrent following BCG induction. Patients will receive a drug called pembrolizumab along with BCG, or BCG without pembrolizumab. This is a study looking at how well pembrolizumab works together with BCG in people with bladder cancer. ClinicalTrials.gov ID: NCT03711032

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

CheckMate 9UT

This study is for people with non-muscle invasive bladder cancer. Patients will receive nivolumab treatment, with the possible addition of BCG, BMS-986205, or BMS-986205 + BCG. This is a study looking at how well these treatments work in people with non-muscle invasive bladder cancer. ClinicalTrials.gov ID: NCT03519256

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 for assessing treatments from the patients' perspective; help healthcare professionals make better informed treatment decisions, and provide a method to be able to effectively evaluate treatments for non-muscle invasive bladder cancer. ClinicalTrials.gov ID: NCT03091764

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

Advanced or metastatic bladder cancer

BladderPath

This study is to redesign the management pathway for patients with muscle-invasive bladder cancer by using an MRI scan rather than doing a transurethral resection of a bladder tumour (TURBT) to diagnose and more accurately and rapidly stage their cancer. We hypothesise this may improve outcomes for these patients by reducing

the time from diagnosis to definitive treatment. isrctn.com
International Standard Randomised Controlled Trial Number:
ISRCTN35296862

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

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

KEYNOTE-905

This study is for people who have muscle-invasive bladder cancer, and who are not eligible for chemotherapy. Patients will receive a drug called pembrolizumab along with radical cystectomy + pelvic lymph node dissection, or radical cystectomy + pelvic lymph node dissection without pembrolizumab. This is a study looking at how well pembrolizumab works together with surgery in people with bladder cancer. ClinicalTrials.gov ID: NCT03924895

KEYNOTE-866

This study is for people who have muscle-invasive bladder cancer. Patients will receive a drug called pembrolizumab along with chemotherapy and bladder removal, or chemotherapy and bladder removal without pembrolizumab. This is a study looking at how well pembrolizumab works together with chemotherapy and surgery in people with bladder cancer. ClinicalTrials.gov ID: NCT03924856

NCT03473743

This is a study for people with metastatic or inoperable bladder cancer who test positive for the FGFR (Fibroblast Growth Factor Receptor) alteration biomarker. This study will be used to test the ideal dose of two drugs called erdafitinib and cetrelimab, as well as to test their safety and how well they work. ClinicalTrials.gov ID: NCT03473743

NCT03390504

This is a study for people with advanced bladder cancer who test positive for the FGFR (Fibroblast Growth Factor Receptor) 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

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

FIDES-02

This is a study for people with advanced bladder cancer who test positive for the FGFR (Fibroblast Growth Factor Receptor) biomarker. Patients will receive either a drug called derazantinib, or both derazantinib and another drug called atezolizumab. This is a very early study looking at the safety and ideal dose of derazantinib. ClinicalTrials.gov ID: NCT04045613

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

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

NCT03523572

This study is for people who have advanced or metastatic bladder cancer, and who test positive for the HER2 biomarker. Patients will receive drugs called nivolumab and DS-8201a. This is an early study looking at the safety and ideal doses of the drugs. ClinicalTrials.gov ID: NCT03523572

LEAP-011

This study is for people who have advanced or metastatic bladder cancer, and who either test positive for the PD-L1 biomarker or who are not eligible for chemotherapy. Patients will receive a drug called pembrolizumab, and perhaps another drug called lenvatinib. This is a study looking at how well these drugs work together in people with bladder cancer. ClinicalTrials.gov ID: NCT03898180

NCT03782207

This study is for people who have advanced or metastatic bladder cancer, who have been previously treated with chemotherapy. Patients will receive a drug called atezolizumab. This is a study looking at how well this drug works in people with bladder cancer. ClinicalTrials.gov ID: NCT03782207

MORPHEUS mUC

For people who have advanced or metastatic bladder cancer, who have progressed during or following chemotherapy. Patients will receive a drug called atezolizumab, and perhaps one of the following drugs: enfortumab vedotin, niraparib, Hu5F9-G4, isatuximab, linagliptin, or tocilizumab. ClinicalTrials.gov ID: NCT03869190

NCT03096054

For people who have advanced or metastatic bladder cancer. Patients will receive a drug called LY3143921. This is an early study looking at the safety and ideal doses of the drug. ClinicalTrials.gov ID: NCT03096054

NCT03049410

Trial to compare robotically assisted radical cystectomy with open radical cystectomy. This is for people with non-muscle invasive bladder cancer or muscle invasive bladder cancer who will be having a radical cystectomy for treatment. This trial will compare robotically assisted radical cystectomy with open radical cystectomy. Patients will be randomised 1:1 to either have an robotically assisted radical cystectomy or open radical cystectomy and will be followed for 90 days following the treatment. ClinicalTrials.gov ID: NCT03049410

NCT03767348

This study is looking at the drug RP1 alone and then RP1 in combination with nivolumab. This trial needs participants with advanced and/or refractory solid tumours. The is a phase 1 and phase 2 trial and is being done to determine the maximum tolerated dose and recommended phase 2 dose of the drug. It is for a range of cancers but includes bladder cancer. ClinicalTrials.gov ID: NCT03767348

NCT03732677

This study is for people with muscle-invasive bladder cancer. Its aim is to determine the efficiency and safety of Durvalumab in combination with Gemcitabine/Cisplatin. It is a phase 3 clinical trial and will use the drugs durvalumab, cisplatin and gemcitabine. Patients must be planning to undergo a radical cystectomy to be eligible. ClinicalTrials.gov ID: NCT03732677

NCT03661320

This is for people with muscle invasive bladder cancer. This study is looking at the use of the drug nivolumab with chemotherapy or nivolumab and BMS-986205 (another drug) with chemotherapy followed by continued immune-oncology therapy and comparing it to just chemotherapy. It will look at the success of the addition of the drugs. ClinicalTrials.gov ID: NCT03661320

NCT04316689

This study will look at the safety and tolerability of the drug S-588210 in people with unresectable recurrent and/or metastatic solid tumours. This trial is for multiple different cancers, but includes bladder cancer. Participants will receive injections once a week for four weeks and then biweekly for eight weeks of the new drug. ClinicalTrials.gov ID: NCT04316689

NCT03934827

This study is looking at the safety and tolerability of the drug MRx0518 in people with solid tumours at 30 days post-surgery. It is a phase 1 clinical trial and the trial will look at the drugs' anti-cancer and immune system modulating properties. Patients will need to be amenable to surgical resection. ClinicalTrials.gov ID: NCT03934827

Main bladder cancer drugs

Generic drug names you are most likely to encounter, with some brand names. Some are only available in trials.

alprostadil Caverject®, Viridal®Duo, Vitaros®, MUSE®
atezolizumab Tecentriq®
avanafil Spedra®
avelumab Bavenicio®
AZD1775
AZD4547
AZD9150
BMS-986205
cabazitaxel Jevtana®
cabozantinib
carboplatin Paraplatin®
cetrelimab
cisplatin
derazantinib
docetaxel
doxorubicin Adriamycin®
DS-8201a
durvalumab Imfinzi®
enfortumab vedotin
erdafitinib Balversa®
evalumab
gemcitabine Gemzar®
Hu5F9-G4
Ibhibizone™
ipilimumab
isatuximab
JNJ-63723283
lenvatinib
linagliptin
LY3143921
MED14736

methotrexate Maxtrex®
minocycline
mitomycin Mitomycin medac, Mitomycin-C Kyowa®
NKTR-214
nintendanib
niraparib
nivolumab Opdivo®
olaparib Lynparza®
paclitaxel Taxol®
PD-0360324
pembrolizumab Keytruda®
pemigatinib
PF-04518600
PF-04518600,
PF-05082566
rifampin
RO7198457
rogaratinib
selumetinib
sildenafil Viagra®
SRA737
tadalafil Cialis®
tocilizumab
tremelimumab
varденаfil Levitra®
vedotin PPDCEV™
vinblastine Velbe®
vinflunine
vistusertib
vofatamab

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.

FBC glossary

ACC Advanced Cancer Coalition	confocal laser endomicroscopy an advanced imaging technique for diagnosis
adjuvant after initial treatment to prevent secondary tumours	CT computerised axial tomography, a scan that uses a series of x-ray images to create cross-sectional views of the body
angiogenesis the development of a blood supply to a tumour	cystectomy removal of the bladder
anterior exenteration surgical removal of a woman's bladder and reproductive organs	cystoprostatectomy surgical removal of the bladder and prostate
antiemetic a drug to counteract nausea and vomiting	cystoscopy a procedure to examine the inside of the bladder
B-cell response a natural immune response	cytokines cells that communicate an immune response
basal relating to the base	DAT device assisted therapy
baseline starting point for comparison	DNA deoxyribonucleic acid
BAUN British Association of Urological Nurses	durable response rate the length of time a response is observed
BAUS British Association of Urological Surgeons	DVT deep-vein thrombosis, a blood clot in a deep vein in the body
BC bladder cancer	dysplasia abnormal development
BCG Bacillus Calmette-Guerin, a treatment for early bladder cancer	dysuria painful or frequent urination
BCQS Bladder Cancer Quality Standards	EAU European Association of Urologists
biomarker something by which the disease can be identified	EBRT external beam radiotherapy
biopsy a sample of tissue taken for examination	EBUS endobronchial ultrasound test for lung cancer
BLC blue light cystoscopy	ECPC European Cancer Patients Coalition
BPH benign prostate hyperplasia	ED erectile dysfunction
cannula a thin tube inserted into a vein in the arm or hand	EMA European Medicines Agency, responsible for ensuring that all medicines within the EU are high quality, safe and effective
carcinogenic cancer-causing	endoscope a medical instrument that is made to see inside parts of a person's body
carcinoma malignant growth or tumour	enhanced recovery pathways methods of improving recovery times and experience
catheter a thin tube	eosinophils white blood cells that fight off certain parasites and infections
CCG clinical commissioning groups	ER enhanced recovery
checkpoint inhibitors drugs that prevent cancer cells from disabling protective T-cells	expressed active
chemoradiation combination treatment of drugs and x-rays	FDA Food and Drugs Administration (US)
chemotherapy treatment with chemicals toxic to the body's cells	FGFR fibroblast growth factor receptor
CIS carcinoma in situ or flat tumour	
CNS clinical nurse specialist	

FGFR test laboratory test to see if a cancer has a mutation in a gene that could potentially be treated with erdafitinib	lines [of treatment] treatment regimens
fMRI functional magnetic resonance imaging	luminal relating to the hollow inside an organ such as a blood vessel or an intestine
gene forms of DNA, a collection of chemical information that carries the instructions for making the proteins a cell will need; each gene contains a single set of instructions	lymph nodes contain white blood cells, and are found all through the body
GI gastrointestinal	lymphangiogenic originating in the lymphatic system
haematuria blood in the urine	macrophages white blood cells found within tissues
HCP healthcare professional	MDT multi-disciplinary team
Hickman line is a hollow tube inserted into a vein in the chest to deliver medication	metaplasia transformation of a tissue from one type of tissue to another type of tissue
histology the microscopic examination of cells	metastatic cancer that has spread from its original place to another part of the body
histopathological microscopic examination of tissue to identify disease	MIBC muscle-invasive bladder cancer
HNA Holistic Needs Assessment	MRI magnetic resonance imaging, a method of scanning using a magnet and radio waves
HrQoL health-related quality of life	muscle-invasive bladder cancer cancer that has spread to the muscles of the bladder
HSE Health and Safety Executive	mutagenic an agent that changes genetic material
ICER incremental cost effectiveness ratio	neoantigens newly formed proteins that have not been previously recognised by the immune system, often as a result of tumours.
ileal conduit see urostomy	NMIBC non-muscle-invasive bladder cancer
immune component part of the immune system	OCT optical coherence tomography, a medical imaging technique
immunotherapy also called immune oncology therapy, treatment that stimulates the body's white blood cells to fight cancer; these drugs can help keep cancer cells from hiding from the body's white blood cells	oncolytic cancer-killing
inhibitory pathway a situation in which defensive cells are prevented from attacking foreign cells	PALS Patient Advice and Liaison Service
intolerable toxicity the point at which the treatment becomes more harmful than the disease	PCT primary care trust
intra-vesicle installations treatments administered directly into the bladder via a catheter	PDD photodynamic diagnosis – a technique where a special liquid is placed in the bladder before operating, so the surgeon is able to distinguish tumour cells from normal cells
ITU intensive therapy unit	PDES inhibitors drugs that help erection with sexual stimulation, and are used in the treatment of erectile dysfunction. Viagra is a PDES inhibitor
KW key worker	PDL-1 inhibitor an antibody that helps T-cells recognise cancer cells

PD-L1 test laboratory test to see if the drugs atezolizumab or pembrolizumab are likely to work in people who are not able to have chemotherapy	sensitivity a measure of the percentage success rate of a test on patients with a disease
penile prosthesis/implant malleable or inflatable rods inserted within the erection chambers of the penis	specificity a measure of the percentage success rate of a test on patients who do not have a disease
PET positron emission tomography	squamous scaly
Peyronie's disease a disorder of the penis resulting in bent or painful erections	stoma an artificial opening on the abdomen that can be connected to either your digestive or urinary system to allow wee or poo to be diverted out of your body
PFS progression-free survival	surrogate markers a reliable substitute for the disease
photodynamic diagnosis BLC or blue light cytосcopy	T-cell a cell that can attack a cancer cell
PHR patient-held record	tachycardia abnormally fast heart rate
PICC line peripherally inserted central catheter, a hollow tube inserted into a vein in the arm to administer medication	targeted therapy drugs that block the growth of cancers by acting on specific proteins in cancer cells
platelets disc-shaped cell fragments in the blood responsible for clotting	TNM system (TNBM) tumour node metastasis, a way of defining the size, location and spread of a tumour
polyuria excessive urination – greater than 2.5 litres over 24 hours in adults	transitional cell cancer (TCC) most common urinary cancer
priapism a persistent penile erection not necessarily associated with sexual arousal	tumour abnormal masses of tissue that result when cells divide more than they should or do not die when they should; tumours can be benign (not cancer) or malignant (cancer)
primary endpoint answers to the primary questions posed by a trial	tumour microenvironment the cellular environment in which the tumour exists
PROMs patient-reported outcome measures	TURBT transurethral resection of bladder tumour – a surgical removal of part or all of a tumour
proteases enzymes that break down protein	urethra the tube connecting the bladder with the outside of the body
pyrexial having a body temperature above the normal range	uropathy a disease of the urinary tract
QoL quality of life	urostomy a surgical procedure to create a stoma
radical cystectomy (RC) surgical removal of the bladder and lymph nodes, as well as the prostate in men	urothelial of the urinary tract
radiotherapy treatment with radiation	UTI urinary tract infection
randomised trial a controlled trial in which people are randomly assign 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	visceral referring to the internal organs of the body, specifically those within the chest or abdomen
RCTs randomised control trials	WBCPC World Bladder Cancer Patient Coalition
refractory resistant	
resection surgical removal	

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

Darren Roberts, aged 50

Bladder cancer grading & staging

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

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

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

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

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

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

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

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

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

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