Fight Bladder Cancer

from the charity

09

fight MAGAZINE

AWARENESS MONTH

ACTIVITIES IN MAY TO RAISE AWARENESS OF BLADDER CANCER

MORE KINDNESS

SUPPORTING EACH OTHER AT WORK

BLADDER CANCER & THE WORKPLACE

WHAT YOU CAN DO

GMB PARTNERSHIP GETTING TOGETHER TO SPOTLIGHT OCCUPATIONAL CANCER

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

THIS MONTH'S CONTRIBUTORS

Prof James Catto
NIHR Research Professor; Professor of Urology, University of Sheffield; Editor in Chief European Urology; Fight Bladder Cancer Trustee

Dr Simon Crabb
Associate Professor in Medical Oncology, University of Southampton

Stewart and Denise Crowe
FBC fundraisers

Amanda Harcus
FBC forum member

John Hester
FBC Chair of Trustees

Emma Low
FBC Head of Fundraising and Development

Laura MacKenzie
FBC forum member

Dr Lydia Makaroff
FBC CEO

Penny Robinson
President, GMB London Region

Daniel Shears
GMB London Region

Barbara Wilson
Founder and Director, Working With Cancer

If you have an idea for an article, or have a topic you think needs discussion, please just drop us an email at **info@fightbladdercancer.co.uk**

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

Fight Bladder Cancer
51 High Street
Chinnor
Oxon OX39 4DJ

+44 (0)1844 351621

info@fightbladdercancer.co.uk
www.fightbladdercancer.co.uk

Editor
Wendy Hobson

Deputy editor
Sue Williams

Stock photography
iStock
PJM Photography

Print
Cambrian Printers

Advertising
Contact **info@fightbladdercancer.co.uk** to find out about our advertising rates

Subscriptions
Visit **fightbladdercancer.co.uk/our-shop** to order a print copy or digital download of this magazine

Working to Fight Bladder Cancer

Welcome to the 9th edition of our *FIGHT* magazine.

This edition is dedicated to bladder cancer and the workplace.

The month of May is Bladder Cancer Awareness Month, and our theme this year is 'Working to Fight Bladder Cancer'. We have articles on the increased risk of bladder cancer for people working in certain professions, guidance on how to reach out for a second opinion, and tips for returning to work successfully after treatment.

In this edition of the magazine, we will be sharing our plans to make this year's Bladder Cancer Awareness Month the biggest ever. If you would like to raise awareness in your workplace, please contact us at **getinvolved@fightbladdercancer.co.uk**.

This Bladder Cancer Awareness Month we are partnering with the GMB workers' union to shine a light on bladder cancer, and to hold a Big Care Conversation to tell the story of care in the UK.

FIGHT is also filled with inspirational stories from people affected by cancer, along with some insights into the amazing fundraising and campaigning activity that continues throughout the year for Fight Bladder Cancer.

You can also read a valuable summary of all the major clinical trials that are currently recruiting bladder cancer patients in the United Kingdom.

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

COVID 19

COVID-19 is a new illness that can affect your lungs and airways; it is caused by a virus called coronavirus. As we go to press, the situation is constantly changing, so to keep up with the latest advice, visit **nhs.uk/conditions/coronavirus-covid-19** and follow the relevant links.

To reassure cancer patients and their carers, the One Cancer Voice group of charities – of which **Fight Bladder Cancer** is a member – has developed some advice to answer questions specific to cancer patients. You will find the link – along with other useful information – on our website at **fightbladdercancer.co.uk/get-help/covid**.

Everyone should follow the NHS advice on reducing the risk of infections by:

- washing your hands frequently and thoroughly with soap and warm water
- maintaining a 2m social distance
- staying at home when possible
- minimising face-to-face interactions
- avoiding non-essential travel
- self-isolating if in high-risk groups
- self-isolating if showing symptoms

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

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

FightBladderCancer BladderCancerUK

fight bladder CANCER
Registered charity 1157763

Contents

If you find a word or abbreviation you don't understand use our FBC glossary on page 13

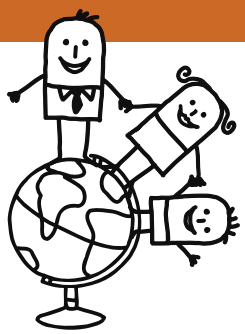
SPECIAL FEATURE – CANCER IN THE WORKPLACE

In this special section we highlight issues of bladder cancer and the workplace. We look at the increased risk of bladder cancer for people working in certain professions, tips for returning to work successfully after cancer treatment and we are joining forces with the GMB union to shine a light on bladder cancer.

FEATURES

REGULARS

FBC round up



Find out what has been happening at Fight Bladder Cancer both here at home and around the world.

SUPPORT

ONLINE FORUM

Our private online forum now has 4,791 members. In the past month, we have had over 514 posts and over 30,000 comments and reactions. Currently our most popular time for interaction is Friday evening. The forum is monitored by admin and moderators 24 hours a day, 7 days a week.

TELEPHONE AND EMAIL SUPPORT

Our telephone support line is available from 9.30am to 4.30pm Monday to Friday on **01844 351621**. 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 5 minutes.

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

SUPPORT GROUPS

We now work with support groups throughout the country, including **London**, **Glasgow**, **Glan Clwyd**, **Newcastle** and **Southampton**.

It is often helpful to know that there are others going through a similar experience, it makes the journey seem less lonely. There is also plenty of opportunity to ask questions and pick up information in a welcoming and friendly environment.

For a list of our upcoming support groups, please go to: www.facebook.com/pg/BladderCancerUK/events/

We recently visited support groups in Oxford and Southampton, where we shared news about the charity and the ways it can provide support to patients and carers. If you are a member of a local support group that might want to join our network, please do get in touch with us at **getinvolved@fightbladdercancer.co.uk**.

Join our online support group at: **www.facebook.com/groups/bladdercanceruk/**

BLADDER BUDDIES

We are always looking for patients and carers to join us as Bladder Buddies across the UK. Bladder Buddies are people who are happy to be put in touch with someone who has recently been affected by bladder cancer, or simply would like someone to talk directly to.

This isn't about giving medical advice but, having experienced it yourself, being happy to lend an ear and be someone to talk to. We all know how a bladder cancer diagnosis can make you feel very alone, and having a buddy can make all the difference.

To find out more about becoming a Bladder Buddy, please email us at **support@fightbladdercancer.co.uk** for further information and to find out how we would support you in this role.

FIGHT MAGAZINE

Over 2,100 *Fight* Magazines are shipped to all the major urology centres around the UK. If you don't see a copy in your local waiting room, please contact us at **info@fightmagazine.co.uk**.

CONTACT CARDS

We have been producing tailored nurse contact cards and sending them to Clinical Nurse Specialists across the UK. As part of our pilot delivery of this project, we have already delivered 13,250 individual contact cards to 46 nurses. This work is supported by a generous grant from the charity Making a Difference Locally, the charity arm of NISA Retail Ltd.

SCOTLAND

Fight Bladder Cancer was thrilled to host a group of patients, carers, voluntary organisations and clinicians in Edinburgh in February. The gathering of these individuals marked the formation of our first Scottish Steering Group and the development of a new strategy and programme of work for Fight Bladder Cancer in Scotland. The charity was generously donated a meeting room by the charity Foundation Scotland.

AWARENESS

UNIVERSITY HOSPITAL SOUTHAMPTON

Fight Bladder Cancer was present at the launch of a new £2.2 million urology centre at University Hospital Southampton. The urology department at UHS sees patients from across southern England and the Channel Islands for a range of issues including benign and malignant prostate, bladder, kidney and testicular disorders, renal stones, reconstructive surgery and complex urinary incontinence. Clare Tull, Senior Sister in Urology, thanked Fight Bladder Cancer for its partnership and ongoing support of bladder cancer patients at the hospital.

BRITISH ASSOCIATION OF UROLOGICAL NURSES

We were happy to return to Liverpool for the British Association of Urological Nurses annual conference. We were delighted to speak at the conference, as well as meet with old friends who visited our stand, along with new visitors who came to talk and gather information for their patients.

EUROPEAN MULTIDISCIPLINARY CONGRESS ON UROLOGICAL CANCERS

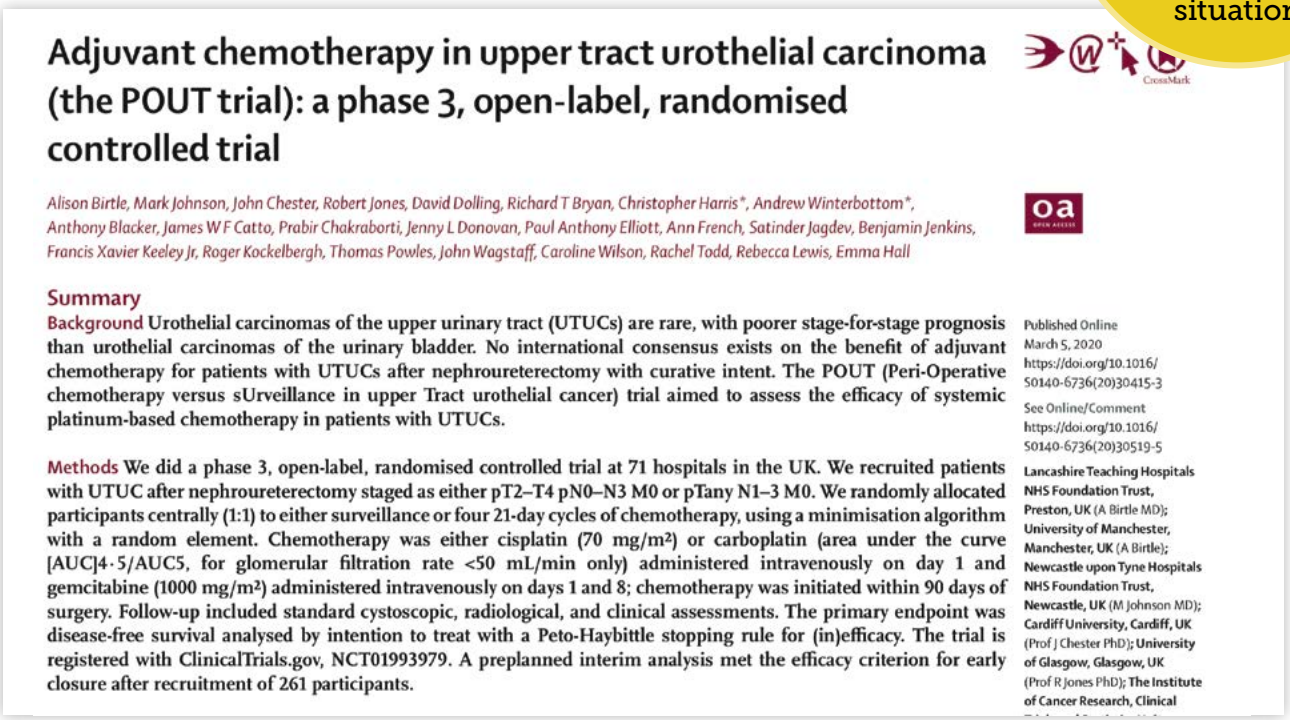
Fight Bladder Cancer was represented at the European Multidisciplinary Congress on Urological Cancers. We attended a productive meeting of the European Association of Urology Patient Advisory Group, and also presented advice on managing metastatic disease in daily practice.

RESEARCH

THE POUT TRIAL

Fight Bladder Cancer was part of the POUT study that showed that gemcitabine–platinum combination chemotherapy initiated within 90 days after nephroureterectomy significantly improved disease-free survival in patients with locally advanced urothelial carcinomas of the upper urinary tract. This research was recently published in *The Lancet*.

At the time of going to press Fight Bladder Cancer is adjusting its work to reflect the COVID 19 situation



Adjuvant chemotherapy in upper tract urothelial carcinoma (the POUT trial): a phase 3, open-label, randomised controlled trial

Alison Birtle, Mark Johnson, John Chester, Robert Jones, David Dolling, Richard T Bryan, Christopher Harris, Andrew Winterbottom*, Anthony Blacker, James W F Catto, Prabir Chakraborti, Jenny L Donovan, Paul Anthony Elliott, Ann French, Satinder Jagdev, Benjamin Jenkins, Francis Xavier Keeley Jr, Roger Kockelbergh, Thomas Powles, John Wagstaff, Caroline Wilson, Rachel Todd, Rebecca Lewis, Emma Hall*

Summary

Background Urothelial carcinomas of the upper urinary tract (UTUCs) are rare, with poorer stage-for-stage prognosis than urothelial carcinomas of the urinary bladder. No international consensus exists on the benefit of adjuvant chemotherapy for patients with UTUCs after nephroureterectomy with curative intent. The POUT (Peri-Operative chemotherapy versus sUrveillance in upper Tract urothelial cancer) trial aimed to assess the efficacy of systemic platinum-based chemotherapy in patients with UTUCs.

Methods We did a phase 3, open-label, randomised controlled trial at 71 hospitals in the UK. We recruited patients with UTUC after nephroureterectomy staged as either pT2–T4 pN0–N3 M0 or pTany N1–3 M0. We randomly allocated participants centrally (1:1) to either surveillance or four 21-day cycles of chemotherapy, using a minimisation algorithm with a random element. Chemotherapy was either cisplatin (70 mg/m²) or carboplatin (area under the curve [AUC]4·5/AUC5, for glomerular filtration rate <50 mL/min only) administered intravenously on day 1 and gemcitabine (1000 mg/m²) administered intravenously on days 1 and 8; chemotherapy was initiated within 90 days of surgery. Follow-up included standard cystoscopic, radiological, and clinical assessments. The primary endpoint was disease-free survival analysed by intention to treat with a Peto-Haybittle stopping rule for (in)efficacy. The trial is registered with ClinicalTrials.gov, NCT01993979. A preplanned interim analysis met the efficacy criterion for early closure after recruitment of 261 participants.

Published Online March 5, 2020 https://doi.org/10.1016/S0140-6736(20)30415-3

See Online/Comment https://doi.org/10.1016/S0140-6736(20)30519-5

Lancashire Teaching Hospitals NHS Foundation Trust, Preston, UK (A Birtle MD); **University of Manchester, Manchester, UK** (A Birtle); **Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle, UK** (M Johnson MD); **Cardiff University, Cardiff, UK** (Prof J Chester PhD); **University of Glasgow, Glasgow, UK** (Prof R Jones PhD); **The Institute of Cancer Research, Clinical**

EXEMPLAR RESEARCH PROJECT

Fight Bladder Cancer 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**.

TRANSITIONAL ONCOLOGY AND UROLOGY RESEARCH

Fight Bladder Cancer visited Guy's and St Thomas' NHS Foundation Trust for a focus group with patients and the TOUR (Transitional Oncology and Urology Research) team. During this meeting, we helped to develop interventions to improve mental and sexual health for people affected by bladder cancer. The charity also contributed to a review of delay in radical cystectomy and the effect on survival in bladder cancer patients, and a review on the role for physical activity interventions in the treatment pathway of bladder cancer.

NATIONAL CANCER RESEARCH INSTITUTE

Fight Bladder Cancer is an active member of the National Cancer Research Institute's Bladder and Renal Cancer Clinical Studies Group. We launched a survey on patient priorities for bladder cancer, which will guide future research. The results from this survey were presented at the Second Bladder Translational Research Meeting in Birmingham.

EVOLVE

Fight Bladder Cancer is an active member of EVOLVE: A study to develop a model of meaningful patient engagement within guideline development. This study aims to determine the priority topics to be considered for patient and public involvement within clinical practice guideline development and implementation for prostate cancer, testicular cancer, bladder cancer and kidney cancer. The study is run by the Academic Urology Unit at the University of Aberdeen.

CHANGE

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. To learn more about the link between certain occupations and bladder cancer, read our article on page 16.

DYING FOR DIGNITY

Fight Bladder Cancer collaborated with Dignity in Dying to design and distribute a YouGov survey of 502 people with terminal diseases. Over half of people with advanced or terminal illness disagreed that death and dying was a taboo subject for them. This research showed that there are improvements to be made to existing end-of-life care, particularly around communication and advance care planning.

WAITING TIMES

Fight Bladder Cancer joined representatives from the British Uro-oncology Group, the Urology Foundation, British Association of Urological Nurses, Action Bladder Cancer UK, and British Association of

'I have found the Fight Bladder Cancer forum page such a comfort to be able to ask anything that is concerning me. Thank you for taking it on and for your care.'
Lindsey

Urological Surgeons to advocate for changes to the Waiting Times Standards. At the moment, the TURBT (Transurethral Resection of Bladder Tumour) can sometimes be classified as a definitive treatment rather than a diagnostic test. This misclassification can artificially stop the clock, and can result in a delay in treatment, because the hospitals are not pushed to reduce the gap between referral and treatment.

NICE

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

SCOTTISH MEDICINE CONSORTIUM

A patient representative from Fight Bladder Cancer attended a meeting with the Scottish Medicine Consortium with its patient group partners. In this meeting we discussed access to new medicines in Scotland, engaging with under-represented groups, and the importance of group patient submissions from Scottish patients.

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.

WORLD BLADDER CANCER PATIENT COALITION

Fight Bladder Cancer is a founding member of the World Bladder Cancer Patient Coalition. A representative from Fight Bladder Cancer travelled to Brussels to meet with the Executive Director and President of the World Bladder Cancer Patient Coalition, to ensure that bladder cancer is high on the global health agenda.

WAR ON CANCER

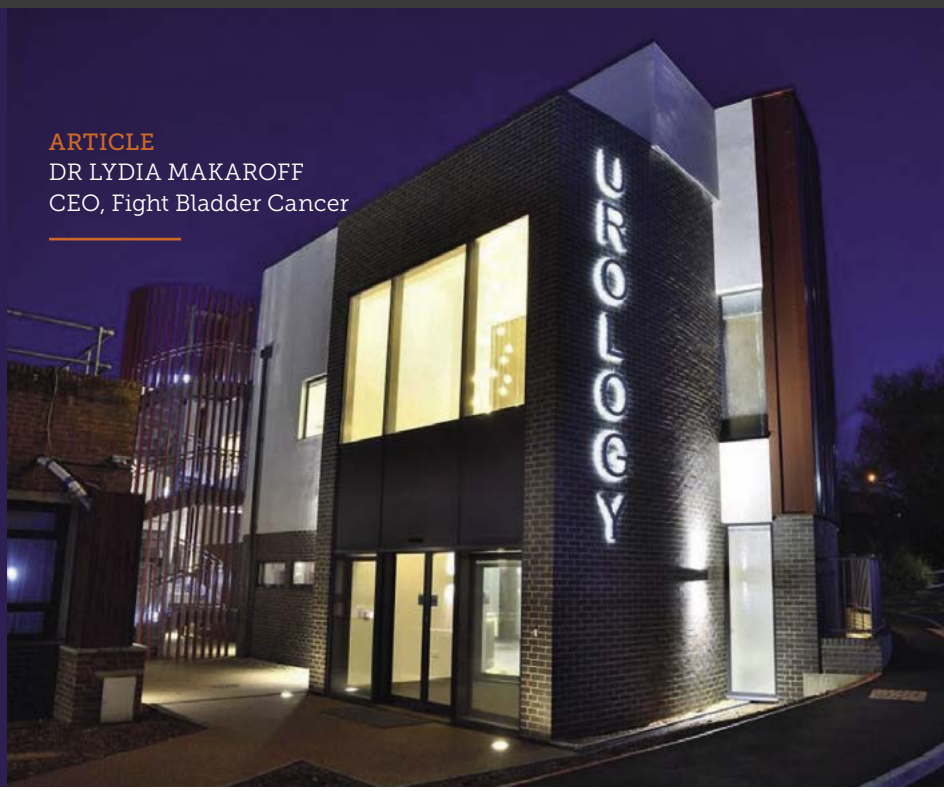
A representative from Fight Bladder Cancer spoke at the Economist's War on Cancer event in London. A panel discussion with other stakeholders explored how patient groups have influenced policy, improved in health technology assessment, and co-developed cancer-control policy.

ARTICLE

DR LYDIA MAKAROFF
CEO, Fight Bladder Cancer

Getting a second opinion

State-of-the-art facilities for urological cancer patients



The Stokes Centre for Urology is a brand new, £6m state-of-the-art Urology Centre opened by HRH The Duke of Kent in 2019. It allows the urological team to provide the very best care, diagnosis and treatment of people with urological ailments. Based at the Royal Surrey County Hospital, on the fringe of Guildford, the department is internationally renowned in the treatment of prostate and bladder cancer.

Thursday mornings are completely dedicated to helping patients with non-muscle-invasive bladder cancer, with one urologist (Mr Hugh Mostafid) and two nurses. Mr Mostafid is an expert advisor to NICE on bladder cancer, a member of the European Association of Urology Bladder Cancer guidelines panel and a faculty member of the European School of Urology.

The bladder cancer unit specialises in:

- **difficult and complex cases**
- **talking about pros and cons of treatments**
- **BCG failures**
- **deciding whether or not to get a bladder removal (radical cystectomy)**

If you have non-muscle-invasive bladder cancer, and if want to get a second opinion from this team, then simply ask your urologist or GP for a referral.

This second opinion is FREE under the NHS.

For more information, go to:
www.royalsurrey.nhs.uk/urology-

Left: Jo Walters, Centre: Hugh Mostafid and Right: Bronagh Lindsey

Other urology centres that are also available to give a second opinion include:

London
University College Hospital at Westmoreland Street
16-18 Westmoreland Street, London W1G 8PH
www.uclh.nhs.uk/OurServices/ServiceA-Z/UROL

Sheffield
Royal Hallamshire Hospital, Glossop Rd, Broomhall, Sheffield S10 2JF
www.sth.nhs.uk/services/a-z-of-services?id=256

Lancashire
Royal Preston Hospital, Sharoe Green Lane North, Fulwood, Preston, Lancashire PR2 9HT
www.lancsteachinghospitals.nhs.uk/urology

Aberdeen
Aberdeen Royal Infirmary, Foresterhill, Aberdeen AB25 2ZN
www.ucanaberdeen.com/ucan-centre/

Edinburgh
Western General Hospital, Edinburgh, Crewe Road South, Edinburgh EH4 2XU
www.waht.nhs.uk/en-GB/Our-Services1/Departments/Cancer-Services/Urology-MDT/

BLADDER CANCER awareness month

May is Bladder Cancer Awareness Month.

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.

May is Bladder Cancer Awareness Month, not just in the UK but across Europe and the rest of the world, too. And, together, we will be focusing attention on bladder cancer as part of our long battle to raise its profile so we no longer need to describe it as a forgotten cancer.

The theme for Bladder Cancer Awarness Month 2020 is Bladder Cancer & the Workplace

Bladder cancer can affect working life in many, sometimes unexpected, ways. And by focusing on work-related topics, we will:

- help patients, families, healthcare professionals & employers
- look at occupational risks and how we can improve working practices
- offer tips from survivors on returning to work
- encourage best working practices

COVID 19

In light of the Coronavirus (Covid-19) pandemic, this year's BCAM needs a new look – but it will still be orange!

As we go to press, we are constantly reviewing our original plans for campaign activities.

And we have loads of **new activities** that focus on **raising awareness via technology**. Take a look at some of our ideas on the next page – and we are sure you'll come up with more.

For more information on COVID-19 see **fightbladdercancer.co.uk/get-help/covid**

REMEMBER OUR CONTACT DETAILS:

Twitter: Follow us on **@bladdercanceruk**

Facebook: Follow us on **www.facebook.com/BladderCancerUK**

Website: Visit us at **fightbladdercancer.co.uk/**

Email: You can email us on **getinvolved@fightbladdercancer.co.uk**

You can phone us on **01844 351621**

You can write to us at 51 High Street, Chinnor, Oxfordshire, OX39 4DJ

How can YOU help us raise awareness?

During this time of reduced social gatherings and physical contact, FBC will be relying on social media, technology and its website to achieve its fundraising and awareness goals.

Whether you're **a patient**, **a carer**, **a researcher** or **a medical professional**, we hope you already follow us on **Facebook**, **Twitter** and **visit our website** but why not increase your online presence?

Make posts highlighting FBC, share messages of support for patients, nurses, and doctors.

What if I don't do email or websites?

If you prefer to phone or write, that's fine, too. Don't hesitate to call us – we LOVE to chat and hear your awareness month ideas. We have an answerphone if our lines are busy or if we aren't available to take your call. Similarly we really do like getting your letters, postcards and pictures. Please do write to us – if you are happy to share your address then we will add you to our postal communication list.

31 Days of Bladder Cancer Awareness!

Instead of the usual coffee mornings and bake sales at work, this year will need special 'at home' creative feel. Look out for our **Bladder Cancer Awareness Activity Calendar**. Ideas cover all 31 days of May and will range from wearing a Fight Bladder Cancer wrist-band, completing online surveys, displaying a car window-sticker, and wearing orange socks! We really hope these innovative ideas will keep everyone safe safe while demonstrating support for bladder cancer awareness. For more details see the link on our website **www.fightbladdercancer.co.uk**, or our daily social media updates.

Make a pledge!

We may not be able to participate in mass fundraising events like runs; sky-dives and cycle-rides at the moment, but you could always **make a pledge** do take up a fundraising or sporting challenge later in the year.

If you decide to pledge an activity, email us and we can help you by making an announcement via social media and shouting out your idea!

Let's stick together for **Bladder Cancer Awareness Month!**

Wee are family.

We are proud of our partnerships

Working with medical professionals

The NHS and other medical providers are important partners in Bladder Cancer Awareness Month. During May we will be sharing messages of support from patients and families via our social media. We will also amplify the bladder cancer-related guidance and advice of Clinical Nurse Specialists and urology teams.

New GMB worker's union partnership

We are excited to be launching a new relationship with the GMB, the trade union representing over 650,000 people in the UK. This collaboration will enable us to raise awareness and address work-related bladder cancer connections. If you're a union member and interested in getting your union involved, please email us: **getinvolved@fightbladdercancer.co.uk.**

Global partnerships

We are also delighted to continue to work with our sister organisations in Canada, Norway, USA, France, Italy, and Norway, as part of the World Bladder Cancer Patient Coalition, uniting to produce a global voice for bladder cancer awareness.

More activities for **Bladder Cancer Awareness Month**

(that can be done from home!)

Patient, family member, carer, employer or part of a healthcare team – we welcome you all! During these unprecedented times you can:

- **encourage** discussion on bladder cancer in your workplace
- **eat an orange fruit or vegetable** every day during May
- **take up a home-based fundraising challenge**, such as treadmill running, staircase walking or a sponsored skip
- **share** Fight Bladder Cancer social media messages
- **dress up in orange for a day** – or the month!
- **signpost patients or family members** to Fight Bladder Cancer

Make a donation via our website

We will spend your donations with care, adjusting our services and support programmes so that we can continue meeting the needs of the many people affected. You can visit our website, or send us a cheque in the post. Alternatively you can donate via this QR code by opening your smart phone camera and pointing directly at this image.

SCAN ME

THANK YOU!

You are the key to our success – particularly during these uncertain times – and we can't thank you enough for all your efforts. We appreciate every single person who has contributed to our Bladder Cancer Awareness Month in the past, and we really hope we can continue to work together this year.

P.S. Don't forget to send us your pictures and details of your orange activities!

#BladderCancerAware @BladderCancerUK

Bubbles for bladder cancer

In memory of patients who have lost their fight and in solidarity with those who are still fighting, we take a moment in May to blow beautiful bubbles. This year we encourage you to blow your bubbles on Sunday 31 May and post photos on social media with the tag #BubblesForBladderCancer. This year's event will be particularly poignant as it marks the first anniversary of the death of our inspirational founder, Andrew Winterbottom.

No Wee Walks for bladder cancer

We usually ask our supporters to take a Wee Walk during May to promote bladder cancer awareness. In light of Covid-19 we are sadly unable to encourage people to organise walking groups this year.

From the Chair

OPINION
JOHN HESTER,
FBC Chair of Trustees

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

Thanks must also be expressed to the many supporters and friends who have been busy raising money for the charity this year. Your energy and commitment are hugely impressive, and, quite frankly, we wouldn't be here without you.

I am delighted to be participating in another Bladder Cancer Awareness Month, especially as it has now gone global. Every year, I see greater awareness of this neglected cancer. I am proud that the theme this year is bladder cancer and the workplace.

Put up a poster

One area in every workplace that needs special attention is the toilet, and Fight Bladder Cancer has designed two posters specifically for this area.

We have produced a laminated sign for the outside of accessible toilets that states 'Not every disability is visible', and a laminated sign for the inside of all toilets highlighting the three most common symptoms of bladder cancer.

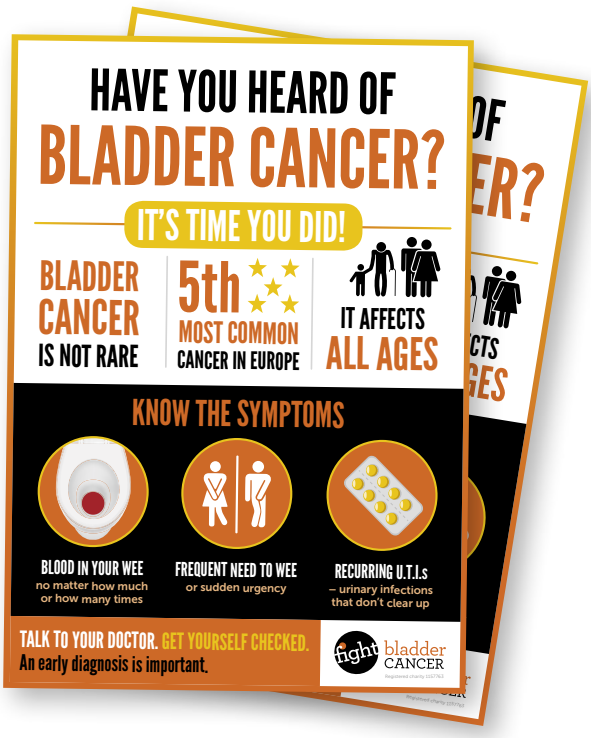
On a wider awareness theme, you might also consider approaching your local town or community council with a view to them displaying the signs in their public toilets.

An approach to village and local community halls and also sport centres can also be worthwhile. We have even been successful in getting our posters displayed in the toilets of our local watering holes (pubs!).

Please contact us at **getinvolved@fightbladdercancer.co.uk** if you would like us to send you laminated copies of these signs.

Additionally, I am particularly pleased that the World Bladder Cancer Patient Coalition is gradually gaining strength and that FBC is fully participating in its work. It took Andrew over eight years of lobbying and negotiation to bring the major national bladder cancer charities together to form this umbrella organisation. It is in some ways fitting that attending and speaking at the inaugural meeting on 18 March 2019 in Barcelona was Andrew's final major effort for the bladder cancer fight, before he sadly passed away on 31 May last.

We must remember that with all participants contributing, the national bladder cancer charities, but more especially patients worldwide, will benefit greatly in coming years.



The FBC Shop

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

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

T-Shirts

Sportswear

Wristbands

Pin Badges

Tabards

Fundraising Products

Window Stickers

Fight Magazine – Print & Digital

Thank You Notecards

Visit: fightbladdercancer.co.uk/our-shop

Introducing our section on BLADDER CANCER at work

What can you do?

See your GP if you have any of these symptoms:

- Blood in your wee
- Frequent need to wee
- Recurring UTIs

If you are working as a:

- tobacco/dye/leather/rubber/metal worker
- factory/chemical worker
- oil/petroleum worker
- hairdresser
- printer/painter
- leather worker
- nurse
- cleaner/domestic assistant
- gardener
- waiter
- electrician/mechanic
- seafarer

Then:

- Talk to your employer about the potential risks
- Ask your employer for a risk assessment
- Ask to use personal protection equipment
- Talk to your union

Find out more about Bladder Cancer at work on pages 13–23!

BLADDER CANCER at work

What are the risks?

Prevention of any major disease is always at the forefront of research. We have long known that smoking is the major cause of bladder cancer; here, Professor Catto looks at the evidence for work-related incidences of this cancer.

Bladder cancer is usually caused by exposure to chemical agents (carcinogens) that enter the circulation through inhalation, ingestion or skin contact. The agents reach the bladder lining when they are excreted through the urine.

Factory workers were 16 times more likely to be diagnosed with bladder cancer compared to people in other occupations, dye workers were 13 times more likely, and tobacco workers were 1.7 times more likely.

Smoking

The most common exposures to these carcinogens are from smoking tobacco, which accounts for around half of all bladder cancers. This includes smoking yourself (direct exposure) and inhaling secondhand smoke from someone else (indirect). Cancer risk varies with gender, smoking history (how many per day for how long) and the type of tobacco (blonde American or black Mediterranean). The exact carcinogenic agents are thought to be combustion products (that is, smoke and burnt cigarette) rather than nicotine. As such, electronic cigarettes may be less hazardous to the bladder.

Occupational hazards

The second most common exposure is through occupational tasks. In this case, fumes from the chemicals are typically inhaled or the chemicals come into contact with unprotected skin. Whilst the exact proportion of bladder cancers that arise from occupational chemicals is unknown, the Health and Safety Executive (HSE) estimates that it is 5–10%.

We conducted a study to determine which occupations were associated with bladder cancer and found that many chemicals were implicated, notably aromatic amines – found in tobacco and dyes – and polycyclic aromatic hydrocarbons. In both cases, workers were more likely to develop bladder cancer than workers in other occupations.

- **aromatic amines affect rubber workers, hairdressers, printers and leather workers.**
- **polycyclic aromatic hydrocarbons affect chimney sweeps, nurses, waiters, aluminum workers, seafarers, and oil or petroleum workers**

What is a carcinogen?

Carcinogens are substances that cause cancer. A common example of a carcinogen is tobacco smoke. Carcinogens come from both natural and man-made substances.

ARTICLE
PROFESSOR JAMES CATTO
NIHR Research Professor; Professor of Urology, University of Sheffield; Editor in Chief *European Urology*; FBC Trustee

Bladder cancer deaths

We also looked at what type of workers were more likely to die from bladder cancer. The highest rates occurred:

- in workers exposed to heavy metals and polycyclic aromatic hydrocarbons (metal workers, aluminum workers, electricians and mechanics)
- to those making diesel and combustion products (military and public safety workers)
- and those exposed to aromatic amines (domestic assistants and cleaners, rubber workers, painters and hairdressers)

What should be done?

Bladder cancer can be prevented by avoiding its causes, and one of those causes is carcinogens in the workplace, making bladder cancer an occupational health issue that puts many workers at increased risk. Despite improvements in working conditions, more effort is needed to reduce exposure to carcinogens, particularly in occupations that show an increased mortality risk.

References

Noon, AP, Martinsen, JI, Catto, JW, & Pukkala, E (2018). 'Occupation and bladder cancer phenotype: identification of workplace patterns that increase the risk of advanced disease beyond overall incidence'. *European urology focus*, 4(5), 725–730.

Chemical workers were 27 times more likely to die from bladder cancer compared to workers in other occupations, **metal workers** were 10 times more likely, and **gardeners** were 5 times more likely.

Success stories

Exposure to carcinogens has already been reduced through workplace health and safety regulations in most countries, such as the European Union directives (Council Directives 90/394/EEC7 and 98/24/EC8, for example) and the 2002 Control of Substances Hazardous to Health Regulations in the United Kingdom.

Success stories include the identification of the carcinogenicity of beta-naphthylamine in the dye industry, followed by reduction and substitution. Among hairdressers, the decrease in bladder cancer has been substantial, most likely because of restriction in the use in the 1970s of 4-aminodiphenyl (4-ABP), which used to be found in a lot of hair dyes.

Exposure to heavy metals (occurring, for example, among plumbers, welders, electrical workers, telephone installers and repairers, telephone linesmen and cable joiners) has decreased over time, but we haven't yet seen a corresponding decrease in bladder cancer incidence and death.

However, exposure to polycyclic aromatic hydrocarbons continues to cause bladder cancer, despite recent changes in industrial processes that reduce the possibility of exposure, such as changes in anode manufacture in the aluminium industry. Inhalation of diesel fumes still puts drivers, miners, marine workers and seamen at bladder cancer risk.

Occupations exposed to painting and dyes have shown limited reduction in risk compared with data from before 2009.

Moving forward

Workers around the world have the right to demand and get a safe and carcinogen-free workplace. Those people who are in an industry with known risks must receive workplace education and targeted screening.

Shining a spotlight on bladder cancer

ARTICLE
PENNY ROBINSON
President, GMB
London Region

How can we bring bladder cancer out of the shadows?

Every year, we celebrate World Cancer Day and use it to raise awareness of cancer and enjoin people in our fight to defeat it. And we all know where the focus of media attention will be: on breast cancer and lung cancer. What we are unlikely to see is any discussion about bladder cancer.

Why? Well, it usually affects older people and – let's be honest – we find it embarrassing. We don't often talk about issues with our pee, even to close family and friends.

But the shocking fact is that bladder cancer is the fourth most common cancer in men, and the fifth most common in women. There are an estimated 100,000 men and women living with bladder cancer in the UK and approximately 18,000 new cases are diagnosed annually. And when it touches your family, it is devastating.

My brush with bladder cancer

My Mum is in her 80s. She is still strong and vital, and to me she has always seemed indestructible. So it was a shock – a horrible, sickening shock – when she was diagnosed with bladder cancer.

We knew nothing about the condition, and soon found that it wasn't something you could easily find out about. One of the biggest problems is that there is so little to find. There is nowhere near enough dedicated research into bladder cancer, its causes, risks, prevention, detection or potential cure.

SPOTLIGHT BLADDER CANCER

There needs to be more research into bladder cancer.

Occupational hazard

One of the things we did discover was that Mum might well be suffering from an occupational disease. She had worked in the textile industry for many years, and clear links have now been established between cancer and workers who used chemicals in dyes and inks. Bladder cancer is also known to be what's called a long-latency disease, meaning that the symptoms only start to manifest many years after the exposure.

Links between bladder cancer and workers in the print industry have been established for many years but, more recently, increased rates of bladder cancer have been identified in the gas industry, hairdressing, firefighting, food preparation workers and electronic assembly workers. There may also be increased risks for call-centre workers, drivers, and other workers who can't easily go to the toilet during their working time.

SPOTLIGHT BLADDER CANCER

We need to know more about the occupational links in order to change working practices.

The GMB (General, Municipal, Boilermakers and Allied Trades) union – which represents people working in the manufacturing industries – does an excellent job of raising awareness around mesothelioma – the cancer caused by asbestos. The correlation between mesothelioma and asbestos is similar to that between bladder cancer and industries using toxic chemicals.

GMB
LONDON REGION

Warren Kenny,
GMB Regional Secretary said:

'Occupational bladder cancer claims thousands of lives per year, and it is likely that official statistics are underestimated as there are many causes of the cancer, meaning the link to work is often not made.

'Due to the long latency before symptoms manifest, it is often perceived to be an older person's condition. As such, there has been little campaigning for preventative approaches and such an approach is long overdue.

'By working together with Fight Bladder Cancer we can provide a much-needed focus on this overlooked cancer and help to provide access to decision-makers in industry and government who can help address the shortage of research funding and poor prioritisation of bladder cancer.'

Mistaking the symptoms

Common bladder cancer symptoms include:

- needing to pee a lot
- weight loss
- tiredness
- lower back and/or abdominal pain
- incontinence

But most people associate such symptoms with old age or perhaps other less serious problems. It's only when someone notices blood in their urine that alarm bells ring and they go to their GP. Naturally enough, the sooner you get treatment, the better the potential outcome. My Mum was lucky that her symptoms were picked up quickly and therefore she was treated early. This is often not the case. Too many cancers are left to grow undiagnosed, making treatment that much more difficult once they are detected.

SPOTLIGHT BLADDER CANCER

We need to raise awareness so we can encourage early detection and treatment.

Let's make an issue of it

My personal experience is the reason why I was proud to help get a motion passed at the GMB Congress in 2019 on raising awareness of bladder cancer – the GMB is committed to raising this as an issue.

One of the things GMB will do is work to get a picture of how many members – in particular, retired members – have experience of bladder cancer, and their work histories. We think there are a lot of people like Mum, who may have been exposed without realising it, and may have symptoms beginning to develop. We also think there may be lots more cases of work-related bladder cancer than are currently recorded.

It is also why I'm working with the charity Fight Bladder Cancer, and with Lynsey Mann and Daniel Shears in the National Health and Safety department to get a campaign going across the whole of GMB.

And this article is the start of this new campaign to bring bladder cancer into the spotlight, so that workers like my Mum are the last generation to have to live with a disease that needs to be talked about and tackled.

SPOTLIGHT BLADDER CANCER

Support the GMB campaign to raise awareness.

Do your own research

For today, if you or anyone you know either has bladder cancer, or has any of the symptoms, do go and see your GP – it's always better to be safe than sorry.

You can also take a look at **fightbladdercancer.co.uk**. There's a lot of valuable information on the Fight Bladder Cancer website to help answer a whole range of questions and concerns.

SPOTLIGHT BLADDER CANCER

Support Fight Bladder Cancer and use their support.

I'm very lucky that Mum was treated and is still with us – not everyone is.

Mum fought off bladder cancer. We can all do our bit to fight it by educating ourselves, talking to our colleagues and friends, and campaigning to eradicate it once and for all.

@GMBLondonRegion
Press Office
07958 156846
press.office@gmb.org.uk

The hands-on care workforce is vitally important for the quality of life of hundreds of thousands of people in the UK, and is also vital to the future of the NHS.

References

Dr L Hayes, Dr E Johnson, A Tarrant, 'Professionalisation at work in adult social care', Report to the All-Party Parliamentary Group on Adult Social Care (July 2019)

The **BIG CARE** conversation

and why we need to grow the professional skills of our care workers

ARTICLE
DANIEL SHEARS
GMB Union

As the British population ages, care needs will change – in fact, they are already changing. We need to engage in some serious discussions now on what we will need in the future and how we can ensure that we can provide the type of care that properly reflects the needs of the elderly.

Care workers are professionals who offer support of all kinds both to older people – either in residential care homes or living independently – and also to vulnerable adults with illnesses, or young people who have been taken into local authority care. The landscape of care provision has changed in response to:

- the ageing of the British population
- narrower eligibility criteria for accessing care services
- increased complexity of service-users' needs
- a drive towards joined-up working between health and social care

All these factors are placing pressure on care workers to develop specialist skills and knowledge.

New skills for a new care package

The role of the care worker is increasingly mirroring health-related occupations, such as nursing, health or medical-related skills. Knowledge of complex conditions is more often seen as a requirement for hands-on care workers. Activities undertaken by homecare workers, for example, include identifying vital signs and undertaking stoma care.

Across care settings, workers are commonly expected to administer medications or prompt service users to take medications, and to possess the ability to provide sensitive end-of-life care. End-of-life care combines physical and emotional tasks that are usually focused on reducing the pain of the dying individual, maintaining their personal hygiene, making sure that they are safe and comfortable, and providing them with social and psychological support. The skills of care workers in respect of end-of-life care are often overlooked in accounts of their professionalism.

The hands-on care workforce is vitally important for the quality of life of hundreds of thousands of people in the UK, and is also vital to the future of the NHS.

The GMB

The GMB is the biggest union and the only in social care. They campaign for:

- **improved pay, terms and conditions**
- **the workforce to be professionalised**
- **a fully funded social care sector**

Care matters to everyone, and the GMB union wants to tell the story of care in the UK. You may be able to help.

Do you:

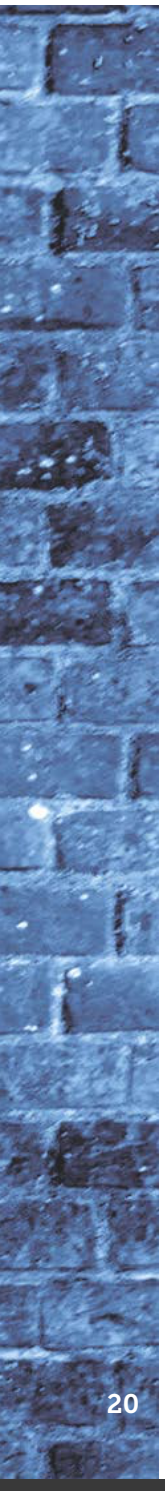
- **work in care?**
- **care for a family member**
- **need carers yourself**
- **used to work in care**
- **know someone who works in or needs care**

Then please take their survey at:
https://www.gmb.org.uk/campaign/big-care-conversation

Working with Cancer

Founded in June 2014, Working With Cancer® is a Social Enterprise which advises employers, employees with cancer, and working carers about returning to work, remaining in work or finding employment at any stage during or after cancer treatment.

ARTICLE
BARBARA WILSON
Founder and Director, Working With Cancer®



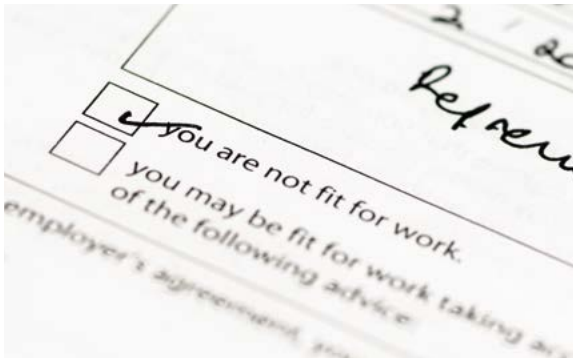
In the UK, 120,000 people of working age are diagnosed with cancer each year. Although survival rates for patients with cancer vary significantly depending on the type and stage of their cancer, with the increasing effectiveness of cancer treatments and a steady improvement in survival rates, returning to work has become increasingly important for patients and for society as a whole.

Not surprisingly for those of working age, the majority want to continue to lead full lives and, if at all possible, return to work. However, although many are able to continue working, the average return to work rate is only 64% after 18 months, and those surviving cancer are 1.4 times more likely to be unemployed, and three times more likely to receive disability benefits.

Working With Cancer® has created four guides that have been tailored to meet the needs of four different audiences:

- **line managers**
- **employees diagnosed with cancer**
- **employees who are working carers**
- **colleagues**

For more information about managing work and cancer please read on or visit the Working With Cancer® website: **www.workingwithcancer.co.uk**



Being realistic

Continuing to work during treatment and/or returning afterwards is important for our social and financial well-being. However, uncertainty surrounding the impact of the physical and psychological side-effects brings many challenges, and may lead you and your colleagues to make a number of uninformed assumptions about how long it will take to recover from treatment.

Although cancer can make you feel as if you have lost control of your life, there is, in fact, much you can influence, change and take the lead on, whilst still remaining in the driving seat in managing your career.

SIX KEY MESSAGES

If you are undergoing cancer treatment, there are six key messages on how to look after yourself.

1. **Be kind to yourself.**
2. **Engage your line manager.**
3. **Talk to work colleagues about your cancer experience.**
4. **Be prepared for setbacks.**
5. **Ask for support.**
6. **Focus on your future.**

'My world was crazy. In a few short weeks from feeling fit and well I had been diagnosed with cancer, undergone treatment including surgery and returned to work, whilst waiting for a second operation. Just hearing the word "cancer" changes everything.'

Cancer survivor

How cancer affects your working life

For some people, getting a cancer diagnosis means stopping work whilst having treatment, others feel able to keep working in some capacity. How it affects our work life will depend on several things:

- the type of cancer and its stage (if it has spread)
- the treatment and side-effects
- your finances
- practical support from family, friends and work colleagues

Many physical side-effects are 'invisible' and people may wrongly assume that if you look well, you must therefore be well enough to do your normal work.

Understanding the physical side-effects of cancer treatment is important, with the most common side-effects being:

- fatigue – extreme tiredness
- pain or limited movement
- risk of infection
- changes in appearance
- neuropathy – numbness or tingling of the hands and/or the feet, caused by some chemotherapy drugs
- lymphoedema – a long-term condition that causes swelling in the body's tissues
- risk of bleeding
- needing to eat little and/or often
- using the toilet more often

The emotional impact

It is common for people to experience the emotional impact of cancer, particularly after treatment has finished. This emotional processing of a cancer experience often happens at the same time you are considering returning to work. Internal struggles and shifts in priorities often make it difficult to make decisions about work. This may result in some hesitation to move forward with returning to work, and may be interpreted by others as a loss of interest in working.

On the outside, the emotional impact of cancer isn't always visible to others and, as with the physical impact, the assumption that the person 'looks OK and therefore must be OK' is easily made.

Understanding the emotional and psychological impact of cancer treatment is important, with the most common side-effects being:

- living with uncertainty
- loss of confidence
- cognitive problems
- depression
- a shift in priorities

'Like many I was so eager to "get back to normal" and a large part of that was to get back to work. It wasn't nearly as easy as I thought it was going to be, but my manager and colleagues really helped me through a difficult time.'

Cancer survivor

Questions you may want to ask

The following are some of the questions you may want to discuss with your employer and/ or family members and/or an independent financial advisor:

- How long will I continue to receive full pay and what is the sick pay provision?
- How will my pension be impacted by my cancer and possible periods of absence?
- What are my death benefits and provision for my dependants?
- What provisions are there for critical income protection, permanent health insurance and how will any private medical cover be impacted?
- What impact will my cancer diagnosis have on any personal/ family insurance policies, such as travel, car, private health insurance (PHI), mortgage or income protection?
- If I have long periods off work or working from home, how will this impact household bills and energy costs?
- What is the longer-term impact of my cancer on my financial affairs – wills, inheritance tax planning and providing for dependants and loved ones?

For some people, receiving a cancer diagnosis means they want to take a break from work and focus on getting well and having time with family and friends. In other cases, it might mean a reduction in working hours or taking unpaid leave. It is always a good idea to talk to your employer about the options and, before making any decisions, how any changes might impact your pay and benefits.

If you have to reduce your hours such that your income and benefits are impacted, you will find various sources of information and advice about managing your finances, accessing benefits and debt management, and about insurance on Working With Cancer's website.

Protection against discrimination

In the UK, everyone with a cancer diagnosis is classed as disabled under the Equality Act 2010 (or in Northern Ireland, the Disability Discrimination Act 1995 (DDA) (as amended) and protected against discrimination in the workplace because of cancer. The protection is lifelong regardless of whether treatment is continuing or completed, or whether you are in remission or not. This legislation covers all areas of employment including the pre-employment recruitment process and post-employment references. It also covers carers and in many cases people who are self-employed.

Types of discrimination

In respect of cancer survivors, there are three main forms of discrimination:

- **direct disability discrimination**
- **indirect disability discrimination**
- **discrimination arising from disability**

Other forms of discrimination are:

- **harassment**
- **victimisation**
- **the failure to make reasonable adjustments**

In Northern Ireland, the DDA does not cover discrimination arising from disability and only partially covers victimisation.

Direct disability discrimination

This applies when, because of a disability, an individual receives less favourable treatment than someone who does not have that disability.

Examples are: not recruiting or promoting or training someone because they have cancer.

Indirect disability discrimination

This applies when a rule or policy or practice which applies to everyone puts disabled people at a disadvantage compared with those who are not disabled, although this may not apply if it can be shown that it is meant to achieve an organisational objective and is fair and balanced in its application. Not knowing about a person's disability (that they have cancer, for example) is not an excuse for indirect discrimination.

Examples are: not being selected for a role or promotion or training because of a reason related to having cancer, such as having too many days of sick leave.

Discrimination arising from disability

This is when someone is treated unfavourably because of something arising as a consequence of their disability rather than the disability itself.

With this form of discrimination there is no need to compare the individual's treatment with someone else's but it cannot occur unless the employer knew (or should have known) that someone was disabled. However, this is not a licence for employers to ignore issues. The Equality and Human Rights Commission guidance states that 'an employer must do all they can reasonably be expected to do to find out if a worker has a disability'. As with indirect disability discrimination, this form of discrimination may not apply if it can be shown that it is meant to achieve an organisational objective and is fair and balanced in its application.

Examples are: needing to have regular rest or toilet breaks or having difficulties in using public transport or needing regular hospital appointments, which impact an individual's performance or work commitments and lead to unfavourable treatment at work.

Harassment

Harassment is when someone behaves in a way which offends another employee or makes them feel distressed or intimidated. This could be abusive comments or jokes, graffiti or insulting gestures.

Examples are: being teased about frequent trips to the toilet, about hair loss, or about forgetting things because of 'chemo-brain'.

Victimisation

If an individual believes they have been treated badly because they have complained about discrimination or harassment or because they have helped someone who has been discriminated against, this is called victimisation and is unlawful under the Equality Act.

This only partly applies in Northern Ireland where an employee would need to prove that they had been treated less favourably than someone who had not made a complaint. Employers can also be held vicariously liable for how their employees behave at work where this results in direct discrimination and harassment.

Workplace adjustments explained

Within the UK and Northern Ireland, employers have a legal duty to make 'reasonable adjustments' (also called 'workplace adjustments') to the workplace and working practices, so as not to place an individual at a 'substantial disadvantage' because they have or have had cancer. It is generally acknowledged that making adjustments is an essential part of securing an employee's successful return to work and that they should be offered to an employee from the point of their diagnosis but also be an integral part of any return to work plan.

There is no fixed description of what a 'reasonable workplace adjustment' is because what is reasonable for one individual or organisation may not be reasonable for others. It will depend on how practical it is to accommodate and the cost of the adjustment.

THIS IS MY STORY

ARTICLE
LAURA MACKENZIE
FBC forum member

Nov 2019 – On holiday and second long haul since surgery. Two stoma bags and still in a bikini!

It was late in August of 2017 that I noticed that my urine was much darker than usual. As alarming as this was, it turned out to be not nearly as frightening as the journey that lay ahead.

These symptoms got worse, and I went straight from a GP to a urologist and then to a colorectal surgeon. A CT scan and cystoscopy couldn't reveal much through all the foreign matter in my bladder, and I was told I had either Crohn's disease, diverticulitis or cancer. I went straight from A&E to a pre-surgery ward, where I had a blood transfusion and a sigmoidoscopy.

Sigmoidoscopy is a procedure by which the doctor can examine inside the colon using a flexible tube with a light at the end.

After the longest three days of my life, I went home. It was a long two weeks later when I was called in and told I had cancer.

After a couple of consultations with my lead consultant at the Glasgow Royal, an MRI scan and a PET scan, I found out I needed something called a total pelvic exenteration. I sat speechless as the consultants listed what would be removed: part of my bowel, my bladder, my ovaries, my womb, my cervix and part of my vagina. I would be left with an irreversible colostomy and a urostomy and would need to use two stoma bags for the rest of my life. I took the news of the treatment far worse than that of my illness. All I could imagine was becoming the stereotype of an old woman who can't pee or poo properly. And I was only 40 years old.

However, I found strength I never knew I had. With my husband, who was my rock throughout all of this, I managed to stay positive and started to work on how I was going to get through it. There was still so much I wanted to do and places I wanted to see. This couldn't be it, I told myself.

Preparing for major surgery

Apart from the cancer, I was a healthy person overall, with no other medical conditions. But I knew this would be a major operation and there was a chance I would not pull through. It was critical everything was in the best shape possible in preparation for what was to be major, complex invasive surgery lasting around 12 hours, so several things had to be done to achieve that.

At that stage, my kidneys were only functioning at 60% and I was told I had a blockage and needed a stent put in to ensure my kidneys were not damaged. I had the operation, but they weren't able to put the stent in because the blockage was too great.

I knew this was a possibility and so woke up with two nephrostomies instead. This wasn't pleasant, but it did the job, and my kidneys returned to full functionality.

A nephrostomy is an artificial opening from the kidney to the skin that allows urine to drain directly from the upper part of the urinary system.

I was still very ill, but already I started to look a bit better, and the consultant was surprised at what a difference it had made.

However, faeces were still passing through my urethra due to a fistula caused by the cancer and made me scream the house down in pain. Nothing helped.

My consultant insisted I had a second PET scan before he would do the operation, to see if the disease had spread to anywhere else in my body. If it had spread and the operation could not go ahead, palliative care would have been the only option. My consultant said he honestly wasn't sure what that would be, as I couldn't have radiotherapy – due to the type of cancer, it would have given me sepsis that would have almost certainly killed me – and chemotherapy was not very effective for the type of bladder cancer I had.

Fortunately, the PET scan showed there was no spread so I got the green light for the operation to go ahead. I was admitted to hospital on Halloween in 2017. That night was awful. To cap it all off, I had my period as well, and so I was bleeding from both sides. I had to call my husband to come and spend the night with me.

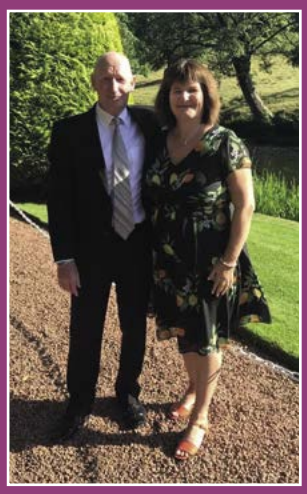
I spent just two days in ICU and then 15 days in enhanced recovery before going home.

Getting back to normal

I went back to work at the end of January 2018, initially part-time, but by the middle of February, I was back full-time. I work at home, so this definitely helped me to exceed my goal here. In fact, I smashed most of my pre-op goals, notably my February goal of going to the local pub. I made it there on 30 November 2018, the day I received the pathology results and got the all clear. I had stage 4 cancer, but all 40 lymph nodes taken during the operation came back clear. It was such a relief.

6 Jan 2018 – Two months since surgery, at my friend's 40th and first overnight away post surgery.

April 2018 – First in-person business meeting post surgery. Five months after op and three months after being back at work.



July 2019 – My parents' Golden Wedding.

September 2018 – Bridesmaid for my friend 10 months post surgery.

It is good to get back to doing things you like as soon as you are fit and it is medically safe to do so. This makes you realise that with stomas you can still do almost anything.

Lucky to be alive

As well as reaching out to other people through the Fight Bladder Cancer online support group when I am down, I also remind myself how lucky I am to be alive. I also play some of my favourite happy tunes, a particular favourite being 'It's 5 o'clock somewhere' by Alan Jackson – it takes me straight to a beach with a cocktail in my hand. I regularly remind myself how strong I have been and how far I have come.

I also consider myself very lucky, as I have gone back to a fairly normal life again, while many I know are not as fortunate. If all else fails, I cuddle my husband and don't let go.

Amanda takes the practical approach

ARTICLE
AMANDA HARCUS
FBC forum member

and concludes that kindness is a principle we should all embrace

I have to say, I feel a bit of a fraud. Everything that has happened was over so quickly and I have had the best possible outcome so far. But writing it down is cathartic and if it helps one other person realise something might not be quite right, then that has to be good – right?

My life was pretty perfect – well, to me anyway. I was doing a job I really enjoyed and was good at; I had a fabulous marriage; and I had celebrated reaching the milestone age of 50 – or forty ten as I like to say – with a big party with friends and family. I love a big party!

But milestones have a habit of making us think, and this one nudged me into taking a good look at myself. I'm not unhealthy – somewhat rounded from too much of the good life, yes; a little unfit compared to my 20s, maybe; peri menopausal, most definitely – but I knew I needed to take charge of my health.

In particular, during the previous year I seemed to gain weight immediately I even looked at food, and still gained weight even when I was eating really sensibly. Plus I was lethargic and felt – I don't know, that something wasn't right. My menstrual cycle was awful and painful. I had a nagging back pain all the time, and for at least a year always put it down to period pains or, later on, being peri menopausal.

So after my birthday, I saw my doctor to see if we could sort out all my womanly challenges and changes: night sweats, peeling feet, mood changes, fatigue, back ache and nasty periods! He referred me for a gynae scan at the beginning of December and that proved to be the beginning of my journey.

Feeling unwell

In November, we took a week's break to St Lucia as we were both exhausted from work and our last holiday was June 2019. I had picked up a cough before we went and it turned into bronchitis which was treated with antibiotics on holiday and more when we got back. We work flexibly in any case, so I did some work but I often didn't feel well enough – or couldn't stay awake long enough! I was back in the office the week before Christmas, but still with a bit of a cold and a cough, and still not back to full energy.

On 19 December, I got a call from my GP – that was most unusual so I knew instantly that something wasn't right. He was nervous and quickly

COMPASSION IN THE WORKPLACE

I am an HR director and I'd like to share my view of how people should be treated at work. It is really simple: treat people in the way you want to be treated, be kind and be compassionate.

At work, I reviewed our special leave policy so now everyone can take up to 10 days as they need to, for whatever reason, and managers have discretion as necessary. One member of my team was away for six months because of his own ill health. When he came back, we phased him back in and changed his role to ensure he continued to make a complete recovery. Another staff member took time off to care for a close relative, who was very ill and passed away. I made the situation very clear:

- **I did not expect to see him in the office**
- **he should be clear what he could do, and we amended his workload accordingly**
- **I did expect him to keep in touch and keep team colleagues up to date**
- **I gave him loads of assurance that he wouldn't lose his job, and even put that in writing**
- **and I made sure he knew we were there for him**

When someone is seriously ill, my view is that all employers should make the job work for them. My experience has shown me that some people will want to stay in work and work through if they are well enough, others will want to hibernate and emerge out the other side when they are good and ready. Either way, work is often the thing people hold on to and it becomes more important. Being compassionate and supportive always pays forward. Both my team members are loyal, work hard and know they can give the same support to others at work if they need to. A win, win outcome.

explained that the gynae scan was all clear. However, the scan had picked up a shadow in my bladder, which might not be anything (yeah right, I thought) but he was sufficiently concerned to have already done an urgent referral. I asked if there was a chance this could be cancer, but his answer was evasive: 'Let's rule out anything sinister. Have a happy Christmas!'

Practical mode

My response was to move into practical mode. For me, that is easier than dealing with and facing my emotions! I advised my immediate work team, my boss and chief exec that we might need to prepare for me not being in work in the new year or beyond that..

My husband and I chose not to tell our family – there was no point. We couldn't answer any questions and had no facts (I like facts!), so we kept it to ourselves.

On 21 December, I woke up with a nasty cold and full chest infection. Again, I saw the doctor, had more antibiotics and was signed off until 2 January. I spent Christmas and new year confined to home, getting well and more worried about not having an appointment within two weeks. But finally a letter dropped on the mat, confirming an appointment at one-stop urology for 2 January. That seemed a long way away.

Now it gets real

The GP wanted to check my chest so I also took the opportunity to ask about the scan report, which she printed off for me. It was this that finally made things stop being surreal and it hit me – this is really happening to me. Seeing the words 'gold alert, fast track potential cancerous find' hit me hard in the chest and made me cry.

But I wasn't having any of that! I had a stern word with myself; no point crying over something that isn't certain – get your big girl pants on! I found it irritating when anyone tried to reassure me that it could be nothing – perhaps scar tissue from a car accident years ago. That made me want to scream! I needed to get real, to get facts. They don't do referrals for nothing, and one in two of us will get cancer in our lifetime – looks like it's me.

I needed to understand

When you might be facing cancer, your mind goes into overdrive and if you are anything like me, you play through all the possible scenarios – and in my case, they came thick and fast. But I didn't have facts – and I need facts. So I ventured into the world of Dr Google – not always the best plan – but I did my utmost to fulfil my need to understand more without scaring myself too much. I needed to cope with whatever lay ahead. I avoided the US websites, as know the UK health approaches and the language can be different.

It was with these searches, and those on social media, that I discovered Fight Bladder Cancer. I joined the group and then spent a while reading articles, stories and people's posts, and then said hello. It was so very humbling, reading people's journeys, their experiences, their laughter and their pain. And what a great support network.

Confirmation

January arrived and my husband and sister came with me to the consultant. I felt young compared to lots of others in the waiting area, and most were male.

The consultant showed me the shadow on the scan and told me it was probably cancer. I jumped at the chance of having it confirmed straight away, so I signed the consent form for a cystoscopy and was soon lying on a bed wearing a gown, listening to a lovely, friendly nurse explaining what was going to happen. After some local anaesthetic was applied to my urethra, a small camera was inserted into my bladder, which needed to be full. I felt a small sharp, pinch sensation, then an image appeared on the 52-in tv screen. It was incredible, and a bit weird, to know that I was looking at the inside of my own bladder! It looked like brain coral with some fan coral growing off it. The consultant confirmed my suspicions – it was cancer, but it was only small and localised, although he said there could be more near the opening of my left kidney, but he would only discover that in surgery.

In a way, I was relieved that I wasn't wasting anyone's time. But when I got off the bed, I got my first lesson. I couldn't hold on to a full bladder and I pee'd on the floor because I was too embarrassed to ask for a dish. Lesson learnt: that is the first and only time I will let pride get in the way!

Always the pragmatist

As the cancer had to come out quickly, we discussed treatment options and I asked if it could be done so we could still go on our holiday on 6 February. The consultant said he would do his best. He explained the TURBT procedure, giving me a pack of information to take away and digest, and put me on his next list for 8 January.

Meanwhile, in the office ...

Once again, I went into pragmatic mode. The doctor extended my fit note and I contacted work to explain what was happening. I spent the next two days talking to key colleagues and focusing on an efficient handover to ensure things continued smoothly in my absence.

My only weakness was I had to do all this from a distance. I knew I couldn't face anyone from work as I wasn't sure I would hold it together. They are so kind and caring and I hate being vulnerable. But my employer was brilliant and simply said, 'do what you need to and we'll see you when you are well – not before.' How brilliant is that?

Dealing with the emotions

Unfortunately I couldn't supress my emotions entirely. Once everything was sorted, the sea of emotions rolled in, some waves strong and crashing, others pulling me back and more taking me under. I felt like I was drowning. My fears were confirmed. I could see and sense how worried my husband was, and now those statistics I'd read were swimming round and round my head:

- **4,500 women a year are diagnosed out of 18,000 incidences**
- **80% of bladder cancer patients survive for at least five years**
- **it's the type of cancer likely to reoccur**
- **it's one of the most expensive to treat**
- **it will mean a lifetime of check-ups and potential treatments**

We wouldn't know the full prognosis until after the surgery and the histology results.

I cried – I mean, I fell apart. I was racked with deep, grieving sobs, letting the terror surface. This turned out to be a good thing because what surfaced with it was a fierce determination to face this head on. I'd read enough by this stage to know what might happen if the TURBT didn't clear the cancer, so I had already made my decision on the treatment I would go through once before pushing for a neobladder. I wanted to get on with my life and live it and not spend time in rounds and rounds of treatment.

The procedure

8 January arrived. I arrived early, as much curious as I was unsure, since everything was new and unfamiliar, and we went through the usual pre-op questions and paperwork. The worst bit for me was having the

catheter fitted – only this was no ordinary catheter! It had to be big enough to accommodate a camera and instruments. There was no anaesthetic when it was inserted and I yelped like a wounded dog. 'Oh, sorry,' the nurse said, 'I thought at your age, your nerves wouldn't be quite so sensitive.' My bladder was filled with blue dye which had to stay in for at least 40 minutes before surgery. I nearly swore! But the feeling of wanting to pee kept my mind fully occupied!

And then the walk to theatre! I'd never walked with a catheter in, plus my bladder was full, so I was doubled over and shuffled rather than walked, apologising for being slow, and trying not to laugh at how absurd I must look. I was almost crossing my legs as it felt like the catheter would drop out, or I'd pee myself. The nurse helpfully explained that when a catheter goes in, your brain sends a signal to pee ... knowing that kinda helped.

A team of four was working in the anaesthetic room, all with great humour – I swear trying to make me pee! They sent me into the wonderful world of sleep until I woke up in the recovery room with the bladder wash applied in the bladder. I asked if it had gone well, and just remember the nurse saying, 'yes, you going to be fine' before I went back to sleep. When I woke up again the chemo liquid was being drained. It was bright orange – I had well and truly been Tangoed!

Home at last

I was home by the evening, drinking what seemed like my bodyweight in water to try to assuage the pain of peeing – it was bright orange and burnt like hell! By the morning, though, it had calmed down to more like a pinch, although I did need to pee often and could not hold it at all! I rested and followed all post-op advice.

What I really wanted were the histology results. My feelings were all over the place, a mixture of relief and uncertainty. Our holiday travel pack was sitting unopened on the side – I didn't want to look at it until we knew for sure.

The final results

The consultant confirmed that they had found two tumours: the fan-like coral growth was benign; the smaller one that he'd seen my the opening of my left kidney was cancerous but was low grade, slow growing with only a 10% chance of recurrence. He also noted a narrowing of my left kidney tubes. He recommended cystoscopy checks at three, six and 12 months, with support from a clinical nurse specialist (CNS).

I was and remain joyful and full of gratitude to the NHS. There were 21 people involved in my case from referral to now and I am beyond grateful to them for saving my life. My first follow up is in April but I have decided to keep it quiet and not get too excited until January 2021. If I am still all clear then, I will confidently declare myself as cancer free.

Why me?

I have racked my brains as to what has caused this. I have never even tried a cigarette in my life and not worked with chemicals. When I thought about it, though, my Mum was a heavy smoker and I loved cuddles on her knee as a kid. I also worked part-time in pubs before smoking was banned, and I was treated for smoke inhalation following a fire when I was 18. I also flew for a year as cabin crew. These may all be small factors that have contributed to my cancer. But, through counselling, I have come to accept that this is no-one's fault. It has happened, it's a wake-up call.

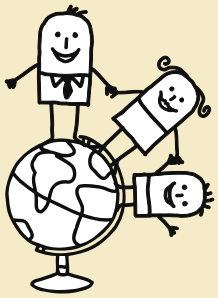
Giving something back

I know that, by the time we get to January 2021, my treatment will have cost around £12,000, so that is my target to raise for charity once I am fit enough and back to full health. I want to get more involved and raise awareness and continue to raise our survival rates.

When I reflect on the past 71 days, it's a whirlwind. Some days it feels as if it has all happened to someone else; other days it feels like a burden.

Writing about it has helped me to reflect on the lessons I have learned and how I am going to put them into practice. My life is still pretty perfect but I'm not going to take it for granted – ever. I am going to be more positive in looking after my heath. I have joined the gym and am giving myself the coming 12 months to shape up and lead a more active life. I have also talked to work about ensuring I put myself first, and manage my work-life balance and stress, making slow and small changes, and abandoning an all or nothing approach to health and exercise. I'm going to be more gentle, more consistent and more kind to me.

Fundraising round up



Autumn 2019 – Spring 2020

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 at **fundraising@fightbladdercancer.co.uk**. They also LOVE hearing your ideas, catching up and also getting your feedback.

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

Massive thanks go to **Andrea Taylor**, who ran the Edinburgh marathon in memory of her Dad and raised more than £700 for the charity!

In support of his Dad, **Gordon Alexander** ran the Glasgow half marathon and Loch Rannoch marathon for Fight Bladder Cancer and raised more than £2,160 for the charity – thank you so much!

Petula took part in the Escot Christmas marathon with her two sons. The event coincided with her retirement and she very kindly asked for donations to her fundraising instead of gifts – she smashed her target of £1,000, as her total fundraising reached a brilliant £1,270!

One of our wonderful trustees, **Hilary Baker**, organised a fundraising challenge at UCLH. Members of staff paid £20 each to undergo a CPET session and raised a fantastic £540 for FBC!

Helen Tabor ran the Amsterdam marathon, in memory of her Dad, in under 4 hours and raised a fantastic £450 for FBC – thank you, Helen!

Huge thanks to **Peter**, **Graham** and **Gary** from the Isle of Man who had full head and beard shaves and raised an amazing £1,470 for FBC.

Registered with FUNDRAISING REGULATOR

Robyn Bateman's boyfriend **George** kindly offered to have his head shaved for FBC, raising just under £2,400, in memory of Robyn's Dad, James. Thank you both for all your efforts!

Urology CNS **Heather James** took on the Deva Divas mini triathlon for FBC and raised a fantastic £400 – thank you for everything that you do!

Less than a year after her RC, **Karla Stevenson** ran the Great Scottish 10k for Fight Bladder Cancer, raising £245 – congratulations!

HUGE thanks to Consultant Urologist **John Keane** who completed the Deep River Rock half marathon in Belfast for FBC, raising just over £1,000!

In support of her Grandad, **Shannon Duggan** decided to ask people for donations to her fundraising page for Fight Bladder Cancer, when she had her hair cut off for the Princess Trust. Her fundraising total was nearly a whopping £300 – thank you so much, Shannon!

Huge thanks to **Johnny Guy** who raised a whopping £1,480 by cycling 160 miles across the North Yorkshire moors – the money being split equally between FBC and the mental health charity, Mind.

Huge thanks to **Richard Roberts**, who raised £257 braving the Polar Bear Boxing Day Challenge for FBC!

Thank you to **Alison Crellin** and her knitting and crocheting buddies for another fantastic raffle – this year's event has raised just over £500 for the charity!

Thank you to **Ria**, **Sheila** and **Danielle**, who completed the Tenby Boxing Day swim, in memory of Ria's Dad, raising both awareness and more than £600 for FBC!

John Verrall, Men's Captain 2019 Princes Risborough Golf Club

One of John Verrall's first tasks when he was voted in as Men's Captain at this great nine-hole course in Buckinghamshire, was to decide which charity he would fundraise for during his year's tenure. Knowing that he had been personally affected by bladder cancer, fellow golfer, Brian Fowler, talked to him about Fight Bladder Cancer, as it was based less than five miles away in Chinnor.

John's brother-in-law, Graham, passed away from bladder cancer in July 2016 and John was keen to help as he felt strongly that the disease wasn't one of the cancers that people knew about, let alone talked about.

'I hadn't realised that there was a charity supporting people with bladder cancer that was so close to the golf club, so when I heard about FBC, it was an easy decision to make. I wanted to support a charity that was focused on helping people who are affected by this disease.'

We met with John just before the start of his year as Men's Captain and worked through some of his amazing plans to raise both money and awareness of the condition. John was incredibly passionate about raising money for the charity and was especially keen to find a few new ways that hadn't been tried before! As well as money raised from the Captain's Drive, there was a collection tin on the bar for loose change donations and fines for hitting a ball into the bunker or the pond on the course. John also organised a well-attended Invitational Day at the start of June, which saw 11 teams of four players enjoy a full round of golf. This was followed by an enjoyable evening with an auction and Q&A session from ex-Chelsea FC players, Ron 'Chopper' Harris and Gary Chivers.

John found that the members of the club were incredibly supportive of his efforts and by the end of his year as Men's Captain he had raised a staggering £3,321 for Fight Bladder Cancer. Gary Tubb, Director of PRGC, was thrilled to confirm that this was the most successful year for a captain at the club.

'We are a club that has its roots firmly in the local community and it's great to know that John's year as captain has been so successful for Fight Bladder Cancer.'

It has been a delight to work with John and the club over the past year and to support their endeavours to raise the profile of the disease and raise valuable funds for Fight Bladder Cancer.

Are you a keen member of a sports or social club? Bowls? Golf? Rotary Club? Can you recommend fundraising and awareness raising for Fight Bladder Cancer?

We can help your sports or social club. Emma and Sophie are happy to arrange presentations, and have loads of ideas and top tips for ways to get your friends and club members involved!
Call us on 01844 351621 or email us on getinvolved@fightbladdercancer.co.uk

Raise some money & have some fun!

Registered with FUNDRAISING REGULATOR

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

You can download our fundraising ideas booklets from our website

www.fightbladdercancer.co.uk/downloads

WHY WE NEED YOUR SUPPORT

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

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

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

Our fundraising promise to you

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

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

We can help you fundraise!

Emma and Sophie are available to chat on **01844 351621**, or you can email them at **fundraising@fightbladdercancer.co.uk** or individually on **emma@fightbladdercancer.co.uk** and **sophie@fightbladdercancer.co.uk**. They both work part-time, but will endeavour to get back to you as soon as they can.

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

And finally, please be reassured that Fight Bladder Cancer will spend your hard-earned money with great care, giving you regular updates on the charity's progress.

Make a gift in your Will today as part of your support for Bladder Cancer Awareness Month

Why we've made a GIFT FOR LIFE to Fight Bladder Cancer

Stewart Crowe describes himself as a 'boy-sailor' who spent 26 years in the military – in the Fleet Air-Arm. He was a keen swimmer and is now a keen cyclist and has worked as a swimming coach since 1987. He lives in Portsmouth with his wife Denise and was 72 years old when he was diagnosed with bladder cancer last May.

ARTICLE
STEWART AND DENISE CROWE
FBC fundraisers

ARTICLE
EMMA LOW
FBC Head of Fundraising and Development

Stewart and Denise have recently made a gift to Fight Bladder Cancer in their Will. Here Stewart tells us about his journey with bladder cancer so far and explains why 'paying it forward' through a gift in their Will matters so much to him.

I had been training hard for the London to Brighton cycle ride when on 1 March 2019 I passed blood in my urine for the first time. Hindsight is a great thing, because I reflect now that I had probably been visiting the toilet far more frequently, both during the daytime and especially at night.

As with the many stories you hear through our friends at Fight Bladder Cancer, I then went through a frustrating few months of antibiotics for a supposed urinary tract infection, as well as lots of worrying GP call-backs referring to raised prostate specific antigen levels and continuing discomfort and bleeding.

Eventually, my doctor gave me a referral to the Urology Unit at Queen Alexandria Hospital in Cosham just in case – to quote him – 'there was anything naughty going on down below'.

Sharing that 'unspoken reality'

I was fortunate to get a swift appointment and on 21 May 2019 the cystoscopy revealed a 5-centimetre tumour on the wall of my bladder, which was fortunately contained within the inner lining of the bladder. After the cystoscopy I had a CT scan to check for further concerns.

By this time, Denise and I started to discuss the probable outcome – although not in great detail because after nearly 50 years of marriage our mutual feelings have become fairly telepathic, so not much needed to be said.

What we did decide was that until we knew more, we weren't ready to tell our two daughters or their families. We just felt we needed all the facts before we shared news that would be bound to worry them. Later on, this really did annoy them, but we have no regrets – we simply wanted to know more ourselves before we worried them.

The waiting is the worst thing

After what seemed to take an age, I received confirmation that my tumour was cancer and surgery was scheduled for 18 June. I was to be seen in the 'morning batch' of surgeries and the last thing I saw was 11.45 on the clock, before waking later on with a dreadful burning sensation and an urgent desire to visit the toilet. I'd been given Mitomycin C and had to wait an hour for it to do its job.

Three weeks of waiting for my post-op appointment seemed an eternity. Tempers became frayed (well mine did); Denise just humoured me. Day-to-day tasks became more difficult to deal with and Dr Google was consulted many times – probably wrongly – to seek out the possible outcomes.

Finally we received the diagnosis. I had been treated for a non-muscle-invasive bladder cancer which was removed from the inner layer of the bladder lining. The tumour had been graded at level 2, which results in the cancerous cells looking less like normal cells and slightly faster growing.

Can I get back to cycling?

Eventually we were told about what lay in store in terms of treatment. I would require up to six further treatments with Mitomycin C being fed into the bladder to ensure that any remaining cancer cells were 'killed off'. After six weeks I would require another inspection of the bladder to ascertain what further treatment would be needed. Whatever the outcome, I would have to go for check-ups for the next five years to ensure that the cancer did not return.

A great sense of relief came over both Denise and me when the specialist said:

'You will now be in the care of one of our Urology Nursing Specialists and I will not need to see you again. Life can return to normal.'

I only had one question left: 'Can I start my cycle training again?' and his response was 'Why not?' Denise and I both shed a few tears but left the hospital a very relieved couple. I had the night off from training and celebrated with a takeaway and a couple of bottles of wine! We also had the job of telling the family, which was not easy but a vital stage of our journey.

The best of NHS care

I make an assumption that the support and information that I have received from the team at Queen Alexandra Hospital (Cosham) is also available at all urology units throughout the UK. If this is correct then the information and guidance can only be described as excellent. I really do hope that others in my situation receive the care and support that I have.

Brave is not a word I would use for myself – just get yourself checked out

I had my first of six Mitomycin C treatments on 7 August and was thrilled that just two days later I was back on my bicycle and was able to ride more than 16 miles. By the 15 September I was feeling well enough to cycle in the London-to-Brighton Cycle-Ride with my son-in-law and really was thrilled with my time of 4 hours, 8 minutes and 2 seconds.

After discussion with Denise we decided that we would publicise my case as far and wide as possible. We know of friends who have family members that did not contact their doctor when something 'was not quite right' and we wanted to give others encouragement and support.

As a result of 'spreading the word' I had many messages about being brave. I do not think of myself as brave but I do want to spread the word about seeking early advice and getting necessary treatment as soon as possible. That is where our support for Fight Bladder Cancer comes in. I first liaised with the team in August and was impressed to learn of their commitment and focus. I'm so pleased to get behind them and help add another shoulder to the wheel to raise awareness about bladder cancer. I really hope my blog might be of help to others too: **https://bladdercancerfollowmyjourney.blogspot.com**

What next? Living with the aftermath of bladder cancer

On 31 October I saw, via my post-treatment cystoscopy, where my bladder cancer had been. I have had some additional follow-up tests, appointments and long waits, and remain mindful that I will be kept under review for five years.

It hasn't been an easy year, but such great clinical care, the love of my wife and family and maintaining a positive approach has really helped. I'm also fortunate to be in touch with the team at Fight Bladder Cancer and to be supported by members of their fabulous online forum. My 'wee buddies' on the forum are a constant support and place for advice. I know that I can turn to them at any point. One of my daughters commented that 'I won the lottery' in terms of the support and care I have been given.

STEWART'S 5 TOP TIPS:

1. **Seek attention sooner than later.** Don't ignore symptoms.
2. **Prepare yourself emotionally.** I've been lucky to have Denise. You need friends around and people who love you.
3. **Speak to those near and dear to you** when you have the facts and the information. If you don't want to tell them before you know the facts, then don't.
4. **Raise awareness of bladder cancer.** People just don't know about it. Don't hide your illness – because you really can help to save other lives. Get behind Fight Bladder Cancer and work with them. I've shared it with my grandchildren and now they say 'how are things down below, Grandad?'
5. **Don't go on Google.** Use your own real-life healthcare professionals, call Fight Bladder Cancer or visit their website, or join the Fight Bladder Cancer Facebook Forum where other patients can guide you.

We have left a gift to Fight Bladder Cancer because we trust them

There are lots of cancer charities, but Fight Bladder Cancer is not generic. They are specialists. I feel that they are there for me, Denise and my family. Their good will and warmth make a real difference. The value of Fight Bladder Cancer is that they are focused and experienced. Their support is specific and personal.

Making a legacy donation is more than just fundraising, it's personal. I also like that they really are small yet achieve so much. Ultimately we trust that the charity will use our money in the future so they can best help most people. It's all about leaving a little bit of Denise and me behind to help achieve something good. I've spoken with Lydia and Emma and I know it's not a job for them – it's a vocation. The team at Fight Bladder Cancer are dedicated, committed, entirely professional and I know the charity will spend our gift with care.

How can people leave a gift to Fight Bladder Cancer in their Will?

- After you have decided what gifts you're giving your nearest and dearest, consider what sort of gift you want to leave Fight Bladder Cancer.
- Don't worry if you don't have much money – even the smallest of gifts can make a huge amount of difference for people affected by the disease.
- Then decide if you are making your gift by writing a new Will or writing a Will for the first time.
- If you already have a Will you can decide to add an amendment (which is called a Codicil).
- We strongly advise using a solicitor or a Will-writing service who will ensure your decisions are properly recorded.
- To find a local Will and probate solicitor in England and Wales, contact The Law Society on 0207 242 1222 or visit lawsociety.org.uk.
- In Scotland, contact The Law Society of Scotland on 0131 226 7411 or visit lawscot.org.uk.
- For extra support and step-by-step guidance visit the website rememberacharity.org.uk.
- Your Will MUST include Fight Bladder Cancer's Name, Address (51 High Street Chinnor, Oxfordshire, OX39 4DJ) and our Registered Charity Number 1157763.
- Fight Bladder Cancer will soon have some guidance on its website fightbladdercancer.co.uk but you can call Emma Low, Head of Fundraising and Development any time to discuss these matters on 01844 351621.

The THOR trial thunders ahead

Rising to the challenge of improving outcomes for advanced urothelial cancer

ARTICLE
SIMON CRABB
Associate Professor in Medical Oncology, University of Southampton

The THOR trial is looking at the possibility of delivering personalised medicine for advanced urothelial cancer, offering each patient treatment options based on their cancer's biological characteristics.

The commonest type of cancer affecting the urinary tract, urothelial cancer (also called transitional cell carcinoma) can occur anywhere through the outlet of the kidneys, the ureters, bladder and urethra. While it is often curable when diagnosed at an early stage, survival rates remain poor for people with advanced disease that has spread to distant sites. Some people with advanced urothelial cancer might only live for a year or two after diagnosis.

The story so far

For a number of decades, advanced disease has been treated with chemotherapy. Within the last few years, we have seen the introduction of immunotherapy treatment, which works by removing a 'brake' signal to our immune system, allowing it to attack the cancer. Patients are offered chemotherapy and immunotherapy either one after the other or both at the same time. Both have been show to extend average survival rates.

However, despite recent advances, some people with advanced urothelial cancer continue to have poor outcomes.

Not one disease but many

We believe a major challenge to improving outcomes for patients with advanced urothelial cancer is to understand the various sub-types of the disease and target them with different treatment options.

This is not actually a new concept. For example, in patients with breast cancer, we have known for some time that the disease can be divided into clinically important sub-types, based on differences in the underlying biology, and these sub-types are routinely defined at diagnosis. This allows oncologists who treat breast cancer to offer targeted therapy options to sub-sets of patients and the right combination of sub-type and therapy has been proven to be the most effective.

Understanding the genetics

The key to this approach is to understand the genetic basis of the disease. All cancers are caused by genetic changes that drive abnormal cell growth and survival. In urothelial cancer, we have seen very rapid advances in the last five years in our understanding of the key genes that are altered (or mutated) in a cancer's cells and these underlining genetics inform our appreciation of the disease sub-types. We now know that there are at least five distinct urothelial cancer sub-types, each with a different prognosis, and each responding in a different way to our current treatments. This knowledge opens up new avenues for testing experimental treatments.

Targeting mutant genes

Some urothelial cancers have been found to have a mutant form of one of two genes called fibroblast growth factor receptor 2 and 3 (shortened to FGFR2 and FGFR3). These genes produce proteins that transmit signals within our body's cells to influence how they function.

In normal cells, this is important for things like bone health. However, in some urothelial cancers, mutant FGFR2 or FGFR3 become a driving force to the cancer because the gene has become unregulated.

One of the most exciting areas of new research in urothelial cancer over the last couple of years has come from early clinical trials testing a new class of drugs that turns off FGFR2 and FGFR3 and related proteins. A particularly important finding was that the current data suggest identification of urothelial cancer sub-types will allow for therapeutic targeting of this approach, enabling us to treat only those who might be predicted to benefit. Equally important is the possibility that we might avoid treating anyone who is unlikely to benefit, relieving them of potentially negative side-effects. Already established in diseases like breast cancer, this patient-selection approach would be entirely new for urothelial cancer.

The THOR clinical trial

THOR is a large clinical trial involving over 600 patients in 315 centres across the globe taking part, currently including eight across the UK. The trial is testing a drug called erdafitinib, given as tablets, which blocks the function of FGFR2 and FGFR3 and similar proteins.

The trial is open to patients who have the sub-type of urothelial cancer that has a genetic mutation in FGFR2 or FGFR3. This is determined by first sending away a sample of the cancer (from a prior biopsy or surgery) for genetic analysis. If this analysis shows that these specific genes are mutated in the cancer, then the patient can be offered entry for treatment within the trial. Patients who have this sub-type of advanced urothelial cancer, and have had previous treatment with either immunotherapy or chemotherapy, are eligible to enter when they next need treatment.

Patients are randomly assigned to receive either experimental treatment with erdafitinib or conventional treatment with immunotherapy or chemotherapy (whichever they have not had before). It will test whether erdafitinib extends average survival compared to chemotherapy or immunotherapy. If the results are positive, then it is likely that this approach would become a standard treatment option. This would be the first step on the road to a precision-medicine approach for urothelial cancer, by establishing a specific treatment option for a biological sub-type of the disease.

Other precision medicine trials for urothelial cancer

Genetic changes in the FGFR family of genes is actually more common in the earlier stages of urothelial cancer. There are a number of other clinical trials, both within the UK and globally, that are developing a targeted approach to treatment based on urothelial cancer sub-types, including those that are potentially curable.

The ATLANTIS trial, for example, which is recruiting in the UK, was described in detail in issue #04 of *FIGHT* magazine. This Cancer Research UK-funded trial involves analysis of a patient's tumour sample whilst they are undergoing chemotherapy for advanced urothelial cancer. This is used to allocate them to various experimental targeted treatments as 'maintenance therapy' following chemotherapy.

This move to a precision-based approach is exciting and challenging in equal measure. We believe it is the key to future improvements in treatment.

The clinical trials mentioned, and many others globally, will take some time to establish the optimal approach. However, we are convinced that providing the right treatment to the right patient is the way to deliver improved outcomes.

Please see the back of this magazine for a list of all clinical trials currently recruiting patients.

NEW TREATMENTS for bladder cancer

ARTICLE
DR LYDIA MAKAROFF, FBC CEO

A great deal of research is underway to develop knowledge in the fight against bladder cancer; new studies are being established, and new treatments are being offered. There are quite a few exciting scientific discussions and new clinical trials of immunotherapy and targeted therapy drugs.

Clinical trials usually go through three phases.

- Phase 1 studies are the first time that people receive the drug, and they look at the safety and side-effects.
- Phase 2 studies are the first to look at how well the drugs work.
- Phase 3 studies directly compare new drugs with existing treatments.

A drug cannot be made available on the NHS until the phase 3 results have been released, and it has been authorised by the European Medicines Agency.

Developments in immunotherapy treatments

Immunotherapy drugs are synthetic antibodies that effectively 'alert' our immune system to cancer. Some examples of immunotherapy drugs that are currently authorised or in clinical trials for advanced bladder cancer include: atezolizumab (Tecentriq®), pembrolizumab (Keytruda®), nivolumab (Opdivo®), durvalumab (Imfinzi®), and avelumab (Bavencio®).

Some of these drugs are authorised by the European Medicines Agency and funded by the NHS for the treatment of advanced cancer, and some are not.

- **atezolizumab** (Tecentriq®) and **pembrolizumab** (Keytruda®) are currently only allowed to be used in people with advanced bladder cancer after they have tried chemotherapy, or if they are not healthy enough to undergo chemotherapy
- **nivolumab** (Opdivo®) is approved in Europe for locally advanced or metastatic bladder cancer following prior chemotherapy, but is not available on the NHS

Developments in targeted therapies

Targeted therapies are drugs that block the growth of cancers by acting on specific proteins in cancer cells. Some examples of targeted therapies currently in clinical trials for advanced bladder cancer include: **erdafitinib** (Balversa®), **enfortumab vedotin** (PADCEV™), and **rogaratinib**. Currently, these targeted therapies available by participating in a clinical trial in the UK, but none of them is yet authorised by the European Medicines Agency or available on the NHS.

If you have advanced cancer, talk to your doctor and ask them if immunotherapy drugs and/or targeted therapies are available and suitable for you.

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

IDENTIFY

Hospitals often have a 'blanket' approach for investigating people with blood in their wee. IDENTIFY will collect data on people having these tests across the UK and internationally, looking at any trends with an aim to create a personalised diagnostic approach for each individual. The data will give patients the ability to make informed decisions, as well as reducing unnecessary and potentially harmful tests.
ClinicalTrials.gov ID: NCT03548688

Newly detected or recurrent bladder cancer

ANTICIPATE X

After being diagnosed with bladder cancer, patients will be asked to provide a urine sample. The urine samples will be used to develop better ways of diagnosing bladder cancer in the future.
ClinicalTrials.gov ID: NCT03664258

Non-invasive bladder cancer

PemBla

For people with non-muscle-invasive bladder cancer. Patients will receive a drug called pembrolizumab. This is an early study looking at the safety and ideal dose of this drug.
ClinicalTrials.gov ID: NCT03167151

KEYNOTE-676

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

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

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 of effectively evaluating treatments for non-muscle-invasive bladder cancer.
ClinicalTrials.gov ID: NCT03091764

iROC

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

PLUMMB

For people with invasive bladder cancer. Patients will receive a drug called pembrolizumab in combination with radiotherapy. This is an early study looking at the safety, tolerability and effectiveness of combining pembrolizumab with radiotherapy.
ClinicalTrials.gov ID: NCT02560636

BladderPath

This study is to redesign the pathway for patients with muscle-invasive bladder cancer by using an MRI scan rather than doing a 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

PIVOT-02

For people who have advanced or metastatic bladder cancer. Patients will receive drugs called nivolumab and NKTR-214, and perhaps another drug called ipilimumab. An early study looking at the safety and ideal doses of the drugs.
ClinicalTrials.gov ID: NCT02983045

NCT03170960

For people who have locally advanced or metastatic bladder cancer. Patients will receive a drug called atezolizumab with a new drug called cabozantinib. A very early study looking at the safety and ideal dose of cabozantinib.
ClinicalTrials.gov ID: NCT03170960

NCT03289962

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

RAIDER

For people with invasive bladder cancer who choose to have daily radiotherapy as treatment. Everyone taking part will have daily radiotherapy. People who take part will be in one of three treatment groups: standard radiotherapy, radiotherapy with the highest radiation dose focused on the tumour, or radiotherapy with a higher dose than normal focused on the tumour. RAIDER aims to confirm that this higher dose radiotherapy is safe and can be delivered at multiple hospitals within the NHS.
ClinicalTrials.gov ID: NCT02447549

KEYNOTE-905

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

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

NCT02599324

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

NCT03473743

For people with metastatic or inoperable bladder cancer who test positive for the FGFR (Fibroblast Growth Factor Receptor) 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

For people with advanced bladder cancer who test positive for the FGFR (Fibroblast Growth Factor Receptor) 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

For people with metastatic or inoperable bladder cancer who test positive for the FGFR (Fibroblast Growth Factor Receptor) biomarker. 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

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

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

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

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

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

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

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
adjuvant after initial treatment to prevent secondary tumours
angiogenesis the development of a blood supply to a tumour
anterior exenteration surgical removal of a woman's bladder and reproductive organs
antiemetic a drug to counteract nausea and vomiting
B-cell response a natural immune response
basal relating to the base
baseline starting point for comparison
BAUN British Association of Urological Nurses
BAUS British Association of Urological Surgeons
BC bladder cancer
BCG Bacillus Calmette-Guerin, a treatment for early bladder cancer
BCQS Bladder Cancer Quality Standards
biomarker something by which the disease can be identified
biopsy a sample of tissue taken for examination
BLC blue light cystoscopy
BPH benign prostate hyperplasia
cannula a thin tube inserted into a vein in the arm or hand
carcinogenic cancer-causing
carcinoma malignant growth or tumour
catheter a thin tube
CCG clinical commissioning groups
checkpoint inhibitors drugs that prevent cancer cells from disabling protective T-cells
chemoradiation combination treatment of drugs and x-rays
chemotherapy treatment with chemicals toxic to the body's cells
CIS carcinoma in situ or flat tumour
CNS clinical nurse specialist
confocal laser endomicroscopy an advanced imaging technique for diagnosis
CT computerised axial tomography, a scan that uses a series of x-ray images to create cross-sectional views of the body
cystectomy removal of the bladder
cystoprostatectomy surgical removal of the bladder and prostate
cystoscopy a procedure to examine the inside of the bladder
cytokines cells that communicate an immune response
DAT device assisted therapy
DNA deoxyribonucleic acid
durable response rate the length of time a response is observed
DVT deep-vein thrombosis, a blood clot in a deep vein in the body
dysplasia abnormal development
dysuria painful or frequent urination
EAU European Association of Urologists
EBRT external beam radiotherapy
EBUS endobronchial ultrasound test for lung cancer
ECPC European Cancer Patients Coalition
ED erectile dysfunction
EMA European Medicines Agency, responsible for ensuring that all medicines within the EU are high quality, safe and effective
endoscope a medical instrument that is made to see inside parts of a person's body
enhanced recovery pathways methods of improving recovery times and experience
eosinophils white blood cells that fight off certain parasites and infections
ER enhanced recovery
expressed active
FDA Food and Drugs Administration (US)
FGFR fibroblast growth factor receptor
FGFR test laboratory test to see if a cancer has a mutation in a gene that could potentially be treated with erdafitinib
fMRI functional magnetic resonance imaging
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
GI gastrointestinal
haematuria blood in the urine
HCP healthcare professional
Hickman line is a hollow tube inserted into a vein in the chest to deliver medication
histology the microscopic examination of cells
histopathological microscopic examination of tissue to identify disease
HNA Holistic Needs Assessment
HrQoL health-related quality of life
HSE Health and Safety Executive
ICER incremental cost effectiveness ratio
ileal conduit *see* urostomy
immune component part of the immune system
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
inhibitory pathway a situation in which defensive cells are prevented from attacking foreign cells
intolerable toxicity the point at which the treatment becomes more harmful than the disease
intra-vesicle installations treatments administered directly into the bladder via a catheter
ITU intensive therapy unit
KW key worker
lines [of treatment] treatment regimens
luminal relating to the hollow inside an organ such as a blood vessel or an intestine
lymph nodes contain white blood cells, and are found all through the body
lymphangiogenic originating in the lymphatic system
macrophages white blood cells found within tissues
MDT multi-disciplinary team
metaplasia transformation of a tissue from one type of tissue to another type of tissue
metastatic cancer that has spread from its original place to another part of the body
MIBC muscle-invasive bladder cancer
MRI magnetic resonance imaging, a method of scanning using a magnet and radio waves
muscle-invasive bladder cancer cancer that has spread to the muscles of the bladder
mutagenic an agent that changes genetic material
neoantigens newly formed proteins that have not been previously recognised by the immune system, often as a result of tumours.
NMIBC non-muscle-invasive bladder cancer
OCT optical coherence tomography, a medical imaging technique
oncolytic cancer-killing

PALS Patient Advice and Liaison Service

PCT primary care trust

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

PDE5 inhibitors drugs that help erection with sexual stimulation, and are used in the treatment of erectile dysfunction. Viagra is a PDE5 inhibitor

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

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

PET positron emission tomography

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

PFS progression-free survival

photodynamic diagnosis BLC or blue light cytoscopy

PHR patient-held record

PICC line peripherally inserted central catheter, a hollow tube inserted into a vein in the arm to administer medication

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

polyuria excessive urination – greater than 2.5 litres over 24 hours in adults

priapism a persistent penile erection not necessarily associated with sexual arousal

primary endpoint answers to the primary questions posed by a trial

PROMs patient-reported outcome measures

proteases enzymes that break down protein

pyrexial having a body temperature above the normal range

QoL quality of life

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

radiotherapy treatment with radiation

randomised trial a controlled trial in which people are randomly 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

RCTs randomised control trials

refractory resistant

resection surgical removal

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

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

squamous scaly

stoma an artificial opening 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

surrogate markers a reliable substitute for the disease

T-cell a cell that can attack a cancer cell

tachycardia abnormally fast heart rate

targeted therapy drugs that block the growth of cancers by acting on specific proteins in cancer cells

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

transitional cell cancer (TCC) most common urinary cancer

tumour 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)

tumour microenvironment the cellular environment in which the tumour exists

TURBT transurethral resection of bladder tumour – a surgical removal of part or all of a tumour

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

uropathy a disease of the urinary tract

urostomy a surgical procedure to create a stoma

urothelial of the urinary tract

UTI urinary tract infection

visceral referring to the internal organs of the body, specifically those within the chest or abdomen

WBCPC World Bladder Cancer Patient Coalition

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

selumetimib

sildenafil Viagra®

SRA737

tadalafil Cialis®

tocilizumab

tremelimumab

vardenafil Levitra®

vedotin PPDCEV™

vinblastine Velbe®

vinflunine

vistusertib

vofatamab

You can help us fight bladder cancer!

Call us on 01844 351621 or visit fightbladdercancer.co.uk/get-involved

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

Whether you are a medical professional or someone directly affected by a bladder cancer diagnosis, your help is invaluable. Working together we can make big changes and stop people dying of this disease. Email **info@fightbladdercancer.co.uk** to find out more.

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

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

Darren Roberts, aged 50

Bladder cancer grading & staging

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

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

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

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

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

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

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

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

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

INTUITIVE.

What's right for my fight?

Understand your options

If you and your doctor decide that surgery is right for you, be sure to ask about all of your options. Skilled robotic-assisted keyhole surgeons offer patients a minimally invasive surgical approach that may be right for your fight.

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

fightbladdercancer.co.uk