

fight

MAGAZINE

**FOCUS ON
RADICAL
CYSTECTOMY**
EXPLORES
BOTH PHYSICAL &
MENTAL ASPECTS OF
BLADDER REMOVAL



**10 THINGS
I WISH I HAD
KNOWN**
ADVICE FROM
PATIENTS



**FEATURES
BY PATIENTS,
NURSES &
SURGEONS**



**LIVING
WELL WITH
A STOMA OR
NEOBLADDER
DON'T STOP
ME NOW!**

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magazine

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Cancer, registered charity number 1198773.

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is for information only and, as far as we
are aware, correct at time of going to press.
Fight Bladder Cancer cannot accept any
responsibility for errors or inaccuracies in
such information.

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 pass on this magazine if 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.*

Living well with Bladder Cancer

Welcome to the 14th edition of our *FIGHT* magazine.

This edition is dedicated to living well after bladder cancer surgery. We have some fantastic articles on TURBT, radical cystectomy, stomas, neobladders, packing for the hospital, staying on an even keel as well as help for carers.

We also have plenty of ideas for Bladder Cancer Awareness Month and how you can get involved. We are delighted to be able to share with you some amazing fundraising and campaigning activity 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.

We are so thankful to all the patients, carers, scientists and healthcare professionals who have shared their wisdom with us.

Please remember that you are not alone on this journey. There is a whole Wee Family with you. Fight Bladder Cancer is here to help you every step of the way. We offer free individual telephone, email and Facebook Messenger support. Our Bladder Buddy service can match you with someone going through a similar experience. Our private online support forum is open 24 hours a day, 7 days a week. Our monthly Zoom support groups mean that you can hear the stories of other patients and carers, wherever you are.

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

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



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

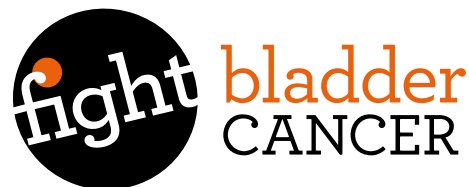
We take great care to provide up to date, unbiased and accurate facts about bladder cancer.



FightBladderCancer



BladderCancerUK



fightbladdercancer.co.uk

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If you find a word or abbreviation you don't understand use our FBC glossary at

[fightbladdercancer.co.uk/
get-help/glossary](https://fightbladdercancer.co.uk/get-help/glossary)
or scan the QR code.





From the CEO

OPINION
DR LYDIA MAKAROFF
FBC Chief Executive

It is with great sadness that I introduce this edition of *Fight* magazine without my colleague John.

In this issue, we show some love to the bladder cancer survivors and their families, reveal insights from specialists on how to live well after bladder cancer surgery, and share ideas on how you can get involved in Bladder Cancer Awareness Month in May.

With spring comes a renewed sense of optimism. Our gardens are in bloom and the sun is out, enticing us to venture out into the world again. However, an accumulation of challenging life events can still result in us feeling emotionally drained. So, let's acknowledge our shared experience, support one another, and take steps to maintain our wellbeing.

Ways we can do this include:

- reaching out to loved ones
- getting enough sleep
- getting out into nature
- exercising
- switching off from social media and the news
- making art
- reading
- seeking professional help if we need it

Until next time, please take care of yourself and those around you, and stay safe.

Dedicated Chair of Fight Bladder Cancer John Hester dies aged 76



John Hester, Chair of the charity Fight Bladder Cancer, died suddenly at his home in Powys, Wales, on Saturday 11 February 2023.

Diagnosed with bladder cancer at age 67, while working as a financial controller for a family group of companies in Wales, John initially helped Fight Bladder Cancer at conferences, attending the British Association of Urological Surgeons conference several times before becoming the charity's Welsh Regional Co-ordinator. He joined the Fight Bladder Cancer Board of Trustees as Treasurer in 2017 and was elected as Chair the following year.

After his retirement in 2019, John worked in close partnership with local county councils raising awareness of bladder cancer and supporting community projects. He promoted the NHS Blood in Pee campaign in Wales, and he led Fight Bladder Cancer's UK-wide campaign to ensure that as many accessible toilets as possible display a 'Not All Disabilities Are Visible' sign. He also volunteered as a Bladder Buddy, helping newly diagnosed patients one-to-one throughout their treatment.

One of the highlights of John's volunteer work for Fight Bladder Cancer in Wales was meeting with the mayors of Welshpool, Oswestry and Shrewsbury to spread the word about bladder cancer. The mayors were amazed when they found out how common it is, and they subsequently displayed Fight Bladder Cancer awareness posters in their home towns.



Tracy Staskevich, a co-founder of the charity Fight Bladder Cancer, said:

'John was passionate about making real change for bladder cancer patients both in Wales and across the UK. He believed in the good of people and was a wonderful, warm, empathetic and intelligent man – always full of ideas. We will all miss his reassuring presence, encouragement and steadfast support. Sending deepest condolences to his family and friends.'

Melanie Costin, bladder cancer patient and Support Services Manager at Fight Bladder Cancer, said:

'Our deepest sympathy goes to his wife Valerie, and all of John's family. He will be profoundly missed by everyone who knew him, as well as all the people he helped in the bladder cancer community. Funny, chatty, and fantastic John – he always tried to look after us. It's a huge loss.'

John is survived by his wife Valerie, his three children, and his many grandchildren and great-grandchildren. Deborah Major has stepped up as Interim Chair of the Fight Bladder Cancer Trustees. Diagnosed with bladder cancer in 2012, she has been a Trustee and the Vice-Chair of the charity since 2015. She said:

'It is with profound sorrow and a heavy heart that we mourn the passing of our colleague and friend. I deeply appreciated the strong values that John brought to the Board. Our future work at Fight Bladder Cancer will be his legacy.'



Today Fight Bladder Cancer is a national organisation actively involved in awareness, support, policy change and research.

More about Bladder Cancer

- Bladder cancer is not a rare cancer, even though it is hardly ever talked about.
- Over 21,000 people are diagnosed with invasive and non-invasive bladder cancer each year in the UK (Kockelbergh, et al. 2017. J Clin Urol, 10(1S) 3–8)
- Most people diagnosed with bladder cancer are over 60 years old, but increasingly people of all ages, from children to teenagers, young adults to the middle-aged can be diagnosed with bladder cancer.
- Despite this high occurrence, it receives less than 1% of the funding for cancer research.
- It is the only cancer today where the prognosis is getting worse.

The symptoms

The main things to look for are

- Blood in your urine, no matter how much or how many times
- A need to urinate more often or with a sudden urgency
- Urinary infections that don't clear up



About



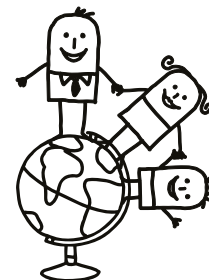
bladder
CANCER

When Andrew Winterbottom had his bladder cancer diagnosis in 2009, he and his wife Tracy Staskevich were shocked to discover there was no patient-specific support focused on bladder cancer. They made it their mission to ensure that no one in their position should ever feel alone.

Today Fight Bladder Cancer is a national organisation operating from its headquarters in Chinnor, Oxfordshire. It is involved in support, awareness, advocacy and research. Fight Bladder Cancer actively supports 7,250 patients and family members every year. The charity's materials are patient-focused and are used by many leading urologists, oncologists, specialist nurses and researchers nationally and internationally. Its website currently receives over 42,000 unique visitors a year.

FBC round up

Find out what has been happening at Fight Bladder Cancer



SUPPORT

PATIENT INFORMATION BOOKLETS

Fight Bladder Cancer has sent folders containing the complete set of ten PIBs to 281 health professionals and has posted out 8,074 individual booklets to patients and carers. In addition, 15,039 people have downloaded information booklets and leaflets from our website.

'Many general urologists are unaware of the patient information booklets. So I sit my patients down with all my master copies of the booklets, and then they go to the website and download their own copies. We need to get that message across.'

Professor Alison Birtle



All patient information booklets are free for download from the Fight Bladder Cancer website at fightbladdercancer.co.uk/downloads

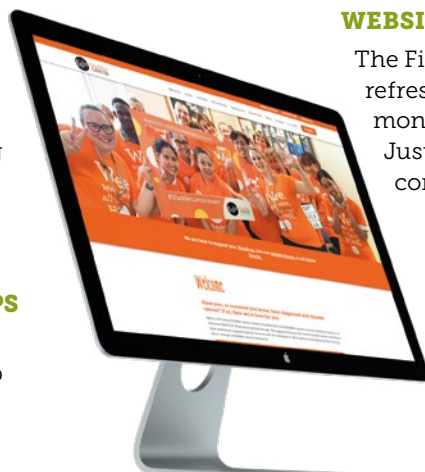
FORUM & ZOOM SUPPORT GROUPS

Fight Bladder Cancer manages the private forum, which now has 5,562 members. We are also hosting monthly Zoom support groups. You can register at fightbladdercancer.co.uk/zoom

FACE-TO-FACE SUPPORT GROUPS

Southampton: Deb Major (Trustee) hosted a face-to-face support group on 7 September

Scotland: Dorothy and Danielle (Trustees) hosted a virtual women's Scottish support group on 20 September.



WEBSITE

The Fight Bladder Cancer website has been completely refreshed. **38,389** people visited it in the past 12 months. The most popular pages are Downloads, Just Diagnosed, and Getting Support. We will continue updating the website over the next year.

EMAIL & TELEPHONE SUPPORT

Fight Bladder Cancer has supported 529 carers and 1,709 patients via email and telephone over the past 12 months. We have sent 796 support emails, made 812 phone calls and received 592 calls.

Fight MAGAZINE

Fight Bladder Cancer has organised the posting of 1,574 copies of *Fight* magazine #12 to 630 addresses, and it was emailed to another 521 households.

Fight Bladder Cancer has organised the posting of 1,935 copies of *Fight* magazine #13 to 817 addresses, and emailed it to another 662 households.



POLICY

NEW TREATMENTS

NHS England has approved nivolumab to treat people who have had their bladders removed but are still at high risk of recurrence. The Scottish Medicines Consortium is currently reviewing nivolumab. They have not yet asked Fight Bladder Cancer for comment.



NICE National Institute for Health and Care Excellence

Lydia Makaroff (CEO) and Alison Birtle (Trustee) successfully submitted an appeal against NICE's decision not to fund avelumab for the maintenance treatment of advanced bladder cancer. It is now available in England and Wales, in addition to Scotland. Lydia Makaroff is advocating for NHS England and Scotland to pay for nivolumab to treat people who have had their bladders removed but are still at high risk of recurrence. The first meeting with NICE was held on 26 May 2022.

PATIENT ADVOCATES

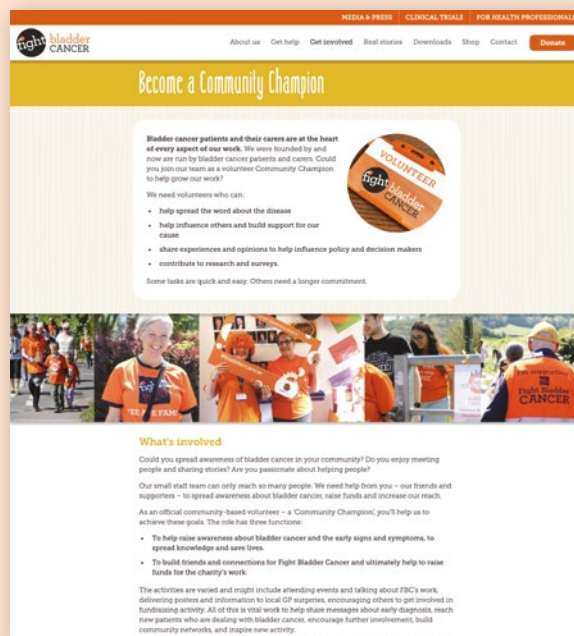
Sana Gilfillan (Policy Manager) will support volunteer patients Susan Mullerworth, Tom Gamble and Julia Macleod to host regular Patient Advocate meetings and engage with their parliamentary representatives.



If any trustees and observers want to become a Patient Advocate, please email sana@fightbladdercancer.co.uk

AWARENESS

Amy Jacob (Supporter Care Officer) and Vicky Sales (Communications Assistant) have created a new webpage about becoming a Community Champion: fightbladdercancer.co.uk/get-involved/volunteer/become-community-champion



They have ordered printed copies of two NHS awareness posters co-branded with the Fight Bladder Cancer logo and you can also find digital version of them on the website at: fightbladdercancer.co.uk/downloads



FBC IN THE NEWS

Fight Bladder Cancer was mentioned in the news:



ALL-PARTY PARLIAMENTARY GROUPS

Alison Birtle (Trustee) spoke at the Cancer and Immunodeficiency event for the All-Party Parliamentary Group for Vulnerable Groups to Pandemics and said, 'patient groups demonstrated clear communicative value through the pandemic.'

'Fight Bladder Cancer has successfully changed the classification of TURBT as a diagnostic procedure rather than a definitive treatment. We need to develop an increasingly loud voice. At the British Association of Urological Surgeons congress, we asked many questions about how we could go forward with a national bladder cancer audit.'

Professor Alison Birtle

RESEARCH

We have updated our list of clinical trials currently recruiting bladder cancer patients in the UK at: fightbladdercancer.co.uk/research-trials

The paper 'Sexual Activity, Function and Dysfunction After a Diagnosis of Bladder Cancer' in *The Journal of Sexual Medicine* Volume 19, Issue 9, September 2022, Pages 1431–1441 was dedicated to Andrew Winterbottom (FBC Founder).

Alison Birtle (Trustee) is a co-author of 'Addition of nintedanib or placebo to neoadjuvant gemcitabine and cisplatin in locally advanced muscle-invasive bladder cancer (NEOBLADE): a double-blind, randomised, phase 2 trial' in *The Lancet Oncology* Volume 23, Issue 5, May 2022.

Melanie Costin (Support Services Manager) and Lydia Makaroff (CEO) presented at the European Association of Urology congress in July on 'Solutions for supporting deprived populations of patients and carers', 'Bladder cancer patients and health professionals co-creating patient information booklets', and 'Patient needs and worries when undergoing radical cystectomy'.



Lydia



Melanie

Hilary Baker (observer) is a co-author of 'Measuring Patient Compliance with Remote Monitoring Following Discharge From Hospital After Major Surgery (DREAMPath): Protocol for a Prospective Observational Study' in the Journal of Medical Internet Research Protocols 2022;11(4): e30638.



Vicky Sales (Communication Assistant) and Lydia Makaroff (CEO) spoke at the Bladder Cancer Translational Research Meeting on 31 March 2022 in London on 'The Patient and Family Experience of Non-Muscle Invasive Bladder Cancer'.

Lydia Makaroff (CEO) is a co-author of 'Key Messages from the European Association of Urology Virtual Patient Poster Session', *European Urology Today*, Volume 33, 12 January 2022.

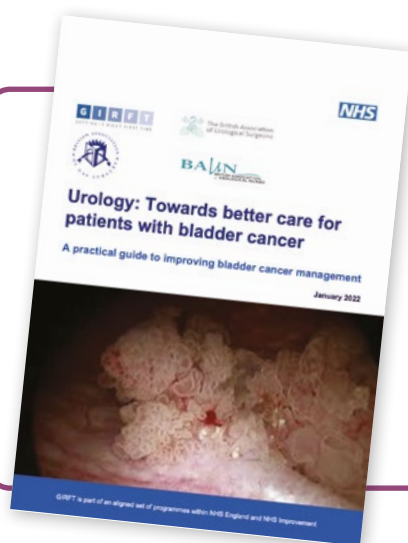


Alison Birtle (Trustee) is a co-author of 'Evidence or Prejudice? Critical Re-Analysis of Randomized Controlled Trials Comparing Overall Survival After Cisplatin Versus Carboplatin-Based

Regimens in Advanced Urothelial Carcinoma' *Clinical Genitourinary Cancer*, 27 December 2021.

RESEARCH ROUNDUP

- Melanie Costin has been the patient representative on the ATLANTIS clinical trial. This clinical trial found that targeted therapy (cabozantinib) without immunotherapy didn't show significant benefit compared to placebo as maintenance therapy in people with advanced bladder cancer who had responded to platinum-based chemotherapy. These results were presented at the American Society for Clinical Oncology GU meeting.
- The cisplatin versus carboplatin argument continues 22 years after these chemotherapy drugs were first in the clinic. Carboplatin is better than we ever thought. That is reassuring for patients.
- The POUT study [adjuvant chemotherapy in upper tract urothelial carcinoma] is ready to do an update on survival outcomes. Fight Bladder Cancer has been involved since the start of the trial.
- The BladderPath study has some data that will come out later in the year. This study examines how accurate MRI scans are at replacing TURBT for diagnosing invasive bladder.
- Param Mariappan presented some interesting data at the British Association of Urological Surgeons congress, showing that we could improve the pathway for patients in Scotland by removing cystoscopies at certain time points in the follow-up of people with low-risk bladder cancer. This seems to be a real step forward.
- Fight Bladder Cancer has financially supported the Q-ABC study (Quality of Life After Bladder Cancer (Q-ABC): A comparison of patient-related outcomes following radical surgery and radiotherapy). It has now completed its recruitment and analysis is ongoing for that.
- There isn't a urothelial cancer trial in the UK that we haven't been asked to provide a patient representative to advise on.



In January 2022, the NHS Getting It Right First Time team released a new report called: 'Urology: Towards better care for patients with bladder cancer: A practical guide to improving bladder cancer management'.

The work of Fight Bladder Cancer was highlighted as a best practice example of 'Developing powerful patient information materials'.

Without the input, candour and honesty of patients, family members and healthcare professionals, the information booklets wouldn't be the brilliant resource that they are. So many of you have told us how useful and informative you find the materials, and to receive this accolade from the NHS is the icing on the cake.

Let's spread a network across the UK!

**We need YOU to help
us raise awareness
for bladder cancer**

We need as
many volunteers
as possible to
fill in our map
of **Community
Champions**



As a small charity, we need help from our supporters to raise awareness for bladder cancer on a local level. Being a Champion would involve going out in your community to help raise essential funds and awareness for us. From organising stalls in local shopping centres to hosting quiz nights, our volunteer Community Champions are so important to help us to achieve these goals.

If you want to join in with the fun, please email champions@fightbladdercancer.co.uk and we'll send you a parcel full of our materials to help you get started!

Priorities for action 2022–23

At Fight Bladder Cancer, we believe that bladder cancer has been ignored for too long. Together, we can take action to change patients' lives for the better.

Over 21,000 people are diagnosed with bladder cancer every year¹

Bladder cancer is the 5th most common form of cancer in the UK, after breast, prostate, lung and bowel cancer.² Whereas outcomes for other cancers are improving,³ bladder cancer survival rates have remained flat or have fallen over the last three decades.⁴

There is an urgent need for action to improve the experiences and outcomes of people affected by bladder cancer

Bladder cancer care and treatment remains highly variable, with patients experiencing very different patterns of referral diagnosis, assessment and treatment across the UK.⁵

Fight Bladder Cancer has been actively working to better define where the greatest gaps in care are for patients across the United Kingdom

Between 2017–2022, we undertook the Exemplar Project – our largest research undertaking so far – to capture the views and experiences of bladder cancer patients, carers and healthcare professionals.⁶ We identified a range of actions which can be taken by governments, NHS bodies and others, to improve care and support for patients with bladder cancer.



ARTICLE
SHANNON
BOLDON
FBC Policy
Manager
(Maternity
Cover)

LYDIA
MAKAROFF
FBC CEO

Full details of our Exemplar Report can be found at fightbladdercancer.co.uk/roundtable

Based on these research findings, we are calling for four priority actions:

- 1 Develop and implement an exemplar pathway for bladder cancer**
- 2 Invest in the bladder cancer workforce**
- 3 Improve patient support and involvement in bladder cancer care**
- 4 Enhance the collection and publication of bladder cancer data**

We believe that these four actions will ultimately lead to better experiences and outcomes for bladder cancer patients.

Discover how we will tackle each of these priorities overleaf ...

Priority 1 Develop and implement an exemplar pathway

CALL TO ACTION:

Update key national guidelines for bladder cancer.

Establish best-practice pathways by 2025.

Service provision and patient experiences in bladder cancer are highly variable.⁷

This is primarily because, in contrast to other cancers, there is no standard pathway for diagnosis, assessment, treatment and follow up. Developing pathways appropriate to the national healthcare systems will reduce variability, spread best practice and improve continuity of care.

Developing exemplar pathways will reduce variability, spread best practice and improve continuity of care.

Priority 2

Invest in the bladder cancer workforce

CALL TO ACTION:

Invest in ongoing education of the existing bladder cancer workforce.

Expand the current bladder cancer workforce throughout.

Support from expert healthcare professionals can have a significant impact on the quality of individual experiences of care, as well as on patient outcomes.

We need to invest in the recruitment, training and professional development of staff across the range of services required in order that they can better support patients with bladder cancer.

However, there are serious challenges in the bladder cancer workforce. The UK already faces a shortfall of 189 consultant clinical oncologists (equating to 17% of the required total), which is expected to grow over the coming years.⁸ Additionally, one-fifth of patients report not having support from a urology Clinical Nurse Specialist (CNS),⁹ while non-specialist staff may lack appropriate training to support patients with bladder cancer.

Priority 3

Improve patient support and involvement in bladder cancer care

CALL TO ACTION:

Improve signposting to patient support services by 2023.

Create more personalised follow-up pathways by 2023.

Bladder cancer patients face treatments that may have lifelong implications for lifestyle, sex and quality of life

Supportive care and resources following treatment – depending on the needs of the individual – should be made available to all patients who may require them and should be backed by sufficient government funding to improve access. Personalised stratified follow up (PSFU) models should be implemented, which tailor ongoing support to individual needs, and ensure that patients with the greatest needs can access additional help.

Suitable signposting and access routes to services available from charities should be part of the process so that patients can fully explore the implications of their diagnosis and make informed decisions about their care.

Suitable signposting and access routes to services available from charities should be part of the process.

Priority 4

Improve the use of data to better understand bladder cancer and its impact on patients

CALL TO ACTION:

Make bladder cancer data publicly available.

Ensure data is published on all types of bladder cancer.

Data should include the two common forms of non-muscle-invasive bladder cancer currently excluded

This would more accurately demonstrate the prevalence of the disease, give value to the experiences of patients, and provide a more accurate picture to the health service in terms of required resources.

Insights from patients with bladder cancer are often not separated out from those of patients with other urological cancers in key datasets.

This can mean the distinctive voices and experiences of these patients are not heard or understood. All data should be made publicly available separately for bladder cancer, rather than having the results grouped with other urological cancers.

All data should be made publicly available separately for bladder cancer, rather than having the results grouped with other urological cancers.



Stuart McMillan MSP and Laura



Humza Yousaf MSP and Johnstone

Get Involved!

At Fight Bladder Cancer we are ambitious and know that there is much more work to do! Look at the resources we have to help you at

fightbladdercancer.co.uk/downloads

- Draft a letter to help you write to your parliamentary representative about bladder cancer: fightbladdercancer.co.uk/downloads/letter-and-email-elected-representatives
- Find out more information about becoming a patient or carer advocate: fightbladdercancer.co.uk/advocate
- Follow the template for holding a bladder cancer awareness event: fightbladdercancer.co.uk/downloads/awareness-event

¹ Fight Bladder Cancer, *What is bladder cancer* (2022), <https://fightbladdercancer.co.uk/get-help/what-bladder-cancer>

² Cancer Research UK, *Cancer Statistics for the UK*, <https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk>.

³ Cancer Research UK, *Cancer survival statistics for all cancers combined*, <https://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/all-cancers-combined#heading-One>.

⁴ Cancer Research UK, *Bladder Cancer Survival Statistics*, <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bladder-cancer/survival#heading-Two>.

⁵ Fight Bladder Cancer, *Exemplar Research Report* (2021), <https://www.fightbladdercancer.co.uk/sites/default/files/downloads/20210518-Fight-Bladder-Cancer-Exemplar.pdf>.

⁶ Fight Bladder Cancer, *Work for a better patient experience*, <https://www.fightbladdercancer.co.uk/get-involved/work-better-patient-experience>.

⁷ Fight Bladder Cancer, *Exemplar Research Report* (2021), <https://www.fightbladdercancer.co.uk/sites/default/files/downloads/20210518-Fight-Bladder-Cancer-Exemplar.pdf>.

⁸ Royal College of Radiologists, *Clinical oncology: UK workforce census report 2020* (July 2021), https://www.rcr.ac.uk/system/files/publication/field_publication_files/clinical-oncology-uk-workforce-census-2020-report.pdf.

⁹ Fight Bladder Cancer, *Exemplar Research Report* (2021), <https://www.fightbladdercancer.co.uk/sites/default/files/downloads/20210518-Fight-Bladder-Cancer-Exemplar.pdf>.

Don't go red. Go to a doctor.

ARTICLE
VICKY SALES
Communications
Assistant

We must break the stigma around 'embarrassing' bladder cancer symptoms to save lives!

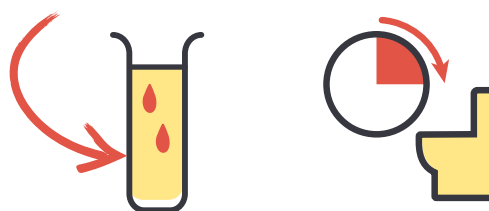
May is Bladder Cancer Awareness Month. In May 2022, we focused on breaking the stigma around symptoms deemed 'embarrassing' by patients to promote early diagnosis and save lives.

Incidence of bladder cancer

Globally every year, over 570,000 people are diagnosed with bladder cancer, and 1.7m people live with the condition. It is the 10th most diagnosed cancer and the 13th cause of death from cancer globally.

We need to talk about wee

The three most reported symptoms are visible blood in the urine, frequent need to urinate and pain or burning when urinating. See page 16 for other common symptoms.



Blood in urine

Frequent urination or pain when urinating

Many people delay going to the doctor because they feel embarrassed. It makes many people uncomfortable talking about symptoms such as finding blood in their wee and dreading an intimate examination; therefore, they don't seek a professional opinion. *The lack of awareness of the common disease – it is often called the 'forgotten' cancer – may also contribute to patients not coming forward early.*

Bladder cancer is the **5th most common cancer** in the Western world. **For men, it is the 4th most common.**

21,181 people are diagnosed with muscle-invasive and non-muscle-invasive bladder cancer in the UK every year. Yet bladder cancer currently receives **just 1% of cancer research funding in the UK**, despite the high number of people diagnosed. Raising awareness is part of the process of redressing that balance.

It is vital that people know bladder cancer symptoms and get to their GP as soon as they appear.





Don't go red; go to a doctor

We joined the global 'Don't go red. Go to a doctor' campaign from the World Bladder Cancer Patient Coalition to urge people to act on their symptoms.

We sparked conversations that drive awareness around the disease by homing in on the main symptoms and their problems. We must convey that people should not feel embarrassed to speak about their symptoms. Dialogue around bladder cancer and the issues that come with it make a world of difference!

Early diagnosis is crucial

A timely diagnosis significantly increases the chance of long-term survival and quality of life. By ensuring early diagnosis and seeking medical advice and care, the survival rate for bladder cancer can be up to 90%.

The 'Don't go red' campaign got people talking and raised awareness and funds so we can continue to support and make a difference for people affected by bladder cancer.

I PRETEND I AM A JEDI
WHEN WALKING THROUGH
AUTOMATIC DOORS



Colin takes a stand

After battling bladder cancer last year, which could only be treated with life-changing surgery, Colin O'Sullivan was left with two stomas. He is now determined to make a difference for other patients and break the stigma behind topics perceived by many as embarrassing.

Colin held a charity concert on 19 June 2022, which raised over £2,000 to help raise vital awareness for bladder cancer.

Colin's passion for raising awareness for bladder cancer comes from his self-confessed 'sheer lack of knowledge and the ignorance that comes from people's reluctance to discuss subjects like wee.



Colin

'We need people to know that bladder cancer is more common than people think and, in many cases, the first time they hear about it is when they get their diagnosis. Let's change that.'

INFORMATION BOOKLETS for Patients ...

In support of our efforts to better inform patients about bladder cancer and its treatment, we are delighted at the success of our series of **Patient Information Booklets**.

Well over 280 health professionals now have the professional edition folder containing reference copies of all ten booklets, and are ordering the appropriate copies for their patients, **8,074** print copies have been distributed and **27,878** copies have been downloaded by **14,402** people.

On 13 January 2022, the NHS Getting It Right First Time team released a new report called: 'Urology: Towards better care for patients with bladder cancer: A practical guide to improving bladder cancer management'.¹

The work of Fight Bladder Cancer was chosen as their best-practice example of 'Developing powerful patient information materials'.

The first 10 titles are:

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

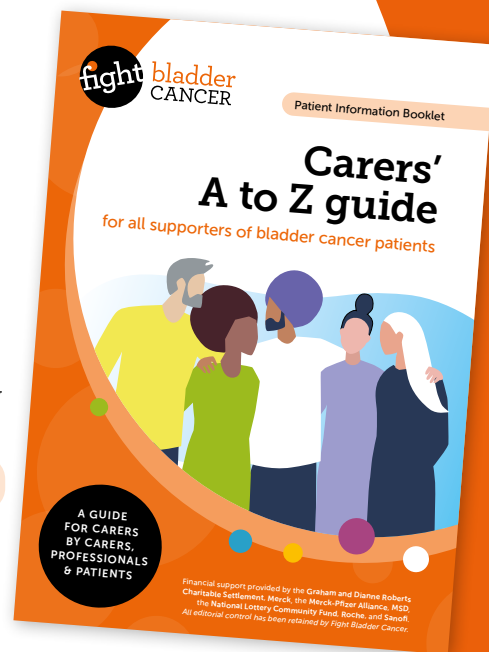
Ask your CNS to order a digital or print copy of the appropriate booklet for you. Go to fightbladdercancer.co.uk/downloads for a digital copy or go to fightbladdercancer.co.uk/patientinfo for a print copy.

... and now for Carers, too

Carers have always been at the heart of FBC, and now we have a designated booklet packed with information on how to be the best carer you can be. All the advice and helpful suggestions come direct from people who have been where you are now – so take advantage of their practical ideas to bypass problems or deal with them as quickly as possible.

- Carers' A to Z guide

Cited by the NHS as best practice in patient communication. Get your booklets now!



¹ https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/12/Urology_2021-12-10_Guidance_Bladder-cancer.pdf

SPECIAL FEATURE

Radical cystectomy

The theme of this edition of Fight magazine is anything related to radical cystectomy, and we have contributions from patients and carers, doctors and other healthcare professionals to try to give you a comprehensive view and guide you towards an assessment of what it might mean to your life.

Always remember that your cancer journey is yours and yours alone – no two sets of circumstance are the same – so always discuss options with your family and those closest to you, and with your healthcare team, before making decisions.

How Fight Bladder Cancer can support YOU

Fight Bladder Cancer is a UK-based charity that was founded and is led by bladder cancer patients and their families, so we know exactly what you are going through. Whether you are a carer or a patient and wherever you are on your cancer journey, the most important thing that you should know is **you are not alone**. We're here to support you and guide you to the people and resources you need.

Our strong support network includes:

- dedicated website at fightbladdercancer.co.uk with a wealth of information about bladder cancer, treatments and coping
- our private online Facebook forum at facebook.com/groups/BladderCancerUK
- our *Fight* magazine – sign up for your free digital or print copies at fightbladdercancer.co.uk/contact-preferences
- download back issues of *Fight* magazine from fightbladdercancer.co.uk/downloads
- Patient Information Booklets on all aspects of bladder cancer in digital or print format – talk to your CNS, go to fightbladdercancer.co.uk/downloads, phone the office on +44 (0)1844 351621 or email info@fightbladdercancer.co.uk
- support groups in many locations throughout the UK and a regular online group
- Bladder Buddy service which will team you up with a carer or patient who has similar experiences
- regular e-newsletter
- public Facebook page at facebook.com/BladderCancerUK
- Twitter feed @BladderCancerUK
- Instagram @BladderCancerUK



FACT FILE: Types of urinary diversion

If you have your bladder removed, the surgery will also involve making a new way for you to store and pass urine. This is called a urinary diversion.

A urinary diversion is either incontinent or continent. An incontinent diversion is where urine is collected in a bag on the outside of your abdomen. A continent diversion is where an internal pouch is made, which you then have control over emptying.

The three main types of diversion are:

- **Ileal conduit (urostomy):** This is the most common procedure. After surgery you will pass urine through a stoma on your abdomen into a collection bag outside of the body.
- **Neobladder:** This is when you have an internal pouch and pass urine through the urethra – or with the help of a catheter if needed – but with practice as you won't have a natural urge to go.
- **Indiana pouch (continent cutaneous pouch):** This procedure is less commonly performed. The urine is collected in a pouch inside the body, then you have control over when the urine comes out via a catheter into the stoma.

You may also hear of some more uncommon procedures, such as:

- **Mitrofanoff procedure:** This is sometimes used if, for example, your bladder cancer was in the urethra. There are different variations of how this diversion is done, but urine is drained directly from the bladder and through a catheter into a stoma usually near the belly button
- **Mainz II (Recto sigmoid pouch):** This is when your rectum is made into a pouch to collect the urine, you will then pass both urine and faeces out of your back passage.

Should I **get it checked?**

Early diagnosis of cancer is crucial in achieving the best outcome. This is the official list of symptoms from the World Bladder Cancer Coalition, ranked in terms of the most common.

- Visible blood in your urine
- Having to urinate more often than usual
- Pain or burning sensation when urinating
- Feeling as if you need to go right away, even if your bladder is not full
- Having trouble urinating or having a weak urine stream
- Being unable to urinate
- Having to get up to urinate many times during the night
- Lower back pain on one side
- Lower abdomen pain
- Loss of appetite and weight loss
- Feeling tired or weak
- Swelling in the feet
- Bone pain

These are additional symptoms that have been reported by other cancer patients.

- Recurrent and persistent urinary tract infections
- Metallic taste in the mouth
- Anaemia
- Loss of skin elasticity
- Post menopausal uterine bleeding
- A mass in the pelvic region



It is important to stress that everyone exhibits different symptoms in different combinations and varying severity. If you are concerned, contact your GP for further investigation.

Remember, however, that most people exhibiting these symptoms do NOT have bladder cancer.

You can find more details on what is involved in our Patient Information Booklets, *Tests & investigations* and *What is a TURBT?*, which can be downloaded from our website at fightbladdercancer.co.uk/downloads

Telephone the office on +44 (0)1844 351621 if you would prefer a printed copy.

Key investigations

If you have symptoms that are concerning you, visit your GP. Before you go, make some notes on the symptoms, when and how frequently they occur, whether there are any noticeable triggers, or anything else that will help the doctor diagnose the problem.

The doctor will undertake tests to rule out various conditions. These might include blood or urine tests, ultrasounds, X-rays, CT or MRI scans.

Flexible cystoscopy

One key investigative procedure is a **flexible cystoscopy**. A thin fibre-optic tube is inserted into the urethra and up into the bladder. The tiny camera on the end allows the urologist to examine the bladder in detail. It takes a few minutes and is done under a local anaesthetic.

Rigid cystoscopy

Better known as a **TURBT (Transurethral Resection of Bladder Tumour)**, the principle of this investigation is similar but the instrument is rigid, and the procedure is done under local, epidural or sometimes a general anaesthetic. During this procedure, the doctor may be able to remove the tumour or reduce its size. A biopsy will also be taken, removing some of the abnormal cells for investigation in a laboratory.

There is a less than 10% risk of infection or injury to the bladder during a TURBT, and both are easily correctable if they do occur.



Just pack the basics

Taking everything you need **but no more** will make your overnight stop much easier

Many procedures will be day cases, while others will require an overnight stop. For those with advanced bladder cancer, there is a possibility of emergency admission to hospital. If you have an overnight bag ready, it will avoid the stress of worrying whether you have everything you need.

Remember that if you do stay in overnight, you won't have much storage space so don't load up with things you won't use in 24 hours. Personalise this list to what you feel are essentials.

Information

Whether you load everything on your phone or you're a pen-and-paper person, have all your details to hand.

- **Yourself:** address, phone number, email
- **Carer:** address, phone number, email
- **GP:** name, surgery, phone number
- **NHS:** number
- **Hospital:** consultant's name, phone number, email
- **CNS:** name, phone number, email
- **Friends:** contact numbers for a chat
- **Car park:** online payment app (or some cash)

Medication

Some people carry a folder containing all their medical notes.

- Latest prescription
- Medications



Staying fresh

You won't spend a lot of time in the bathroom so you'll only need a few items to help you freshen up.

- Disposable face wipes
- Deodorant
- Soap
- Flannel
- Tissues
- Toothbrush
- Toothpaste
- Brush or comb

What to wear

It's quite likely that you'll change into a hospital gown and then back into your day clothes, so wear something comfortable and easy to get on and off. If you wear a couple of layers, then you can adapt to the room temperature.

- Pyjamas or nightdress
- Underwear
- Slippers

Leave it at home

You should arrive without make-up and won't need it during an overnight stop. Similarly, you are unlikely to have time for a shower, hair wash or shave. You should also remove any nail varnish before you go in.

Storing things

- Glasses and glasses case
- Contact lenses and case or spares
- Hearing aid and container
- Dentures and container

Valuables

- Mobile phone, 3m phone charger & plug
- Tablet, 3m phone charger and plug
- Keys
- Small amount of cash
- Bank card

Leave it at home

Remember that the hospital cannot take responsibility for valuable items so leave them at home and keep those you do take safely. You should leave all jewellery at home, although, if necessary, they will tape over a wedding ring. Remove body piercings, if possible.

Snacks

- Refillable water bottle
- Mints
- Snack bars or fruit

Filling time

- Earphones
- Book, Kindle or tablet
- Notebook and pen
- Sketchbook and pencil
- Crossword or puzzle book
- Magazine
- Knitting, crochet or other craft
- Music or podcasts loaded on your phone



Staying on an even keel

How to steady your emotions

When you face a cancer diagnosis, your emotions can go all over the place! Melanie draws on her own experience and that of many cancer sufferers to give you some hints on how to cope.

ARTICLE
MELANIE COSTIN
FBC Support Services Manager



Finding yourself dealing with a cancer diagnosis will bring up a whole heap of emotions, no matter what your journey will entail. They won't always be the emotions that you would expect and others around you may feel rather confused if you laugh when something really isn't funny, or cry at something seemingly mundane. This may seem unusual – particularly if you are normally quite rational in your behaviour – but it really is perfectly okay to let your feelings come out in any way that they need to.

You are bound to experience a whole range of volatile emotions that will push you one way and then the next. You may describe yourself as being on a rocky road, a rollercoaster, a ship in a storm – choose your metaphor!

Get real – this is a tough call

Of course, you will feel negative at times; it would be unrealistic to think otherwise with all that you now have to think about. There are people who believe that having a positive mental attitude is the best way for them to get through – you may be one of them – and it certainly helps with your frame of mind. But don't beat yourself up if you are unable to keep up the PMA.

As much as I would love to be someone who can keep up a positive attitude all the time, I prefer to go at things in a neutral gear.

What does being in a neutral gear mean?

Simply that I am not expecting so much that a disappointment will be inevitable and yet come as a surprise and make things harder to deal with; on the other hand, neither am I constantly negative, which would make the whole situation feel much more difficult to get through. It is perfectly fine to have your down days, of course – it won't always be easy – but if you can aim to consciously maintain some kind of equilibrium, it is usually more helpful than swinging between the extremes. When I laugh when things get bad, people presume that I am strangely upbeat about everything, but it is my way of staying in a neutral gear and it works for me.

**Tip**

Trawling around online isn't always helpful, Dr Google can often be confusing and not relevant to your particular situation.

Choose your battles. Fit in what you can, and what you enjoy, without exhausting yourself. Try to find pleasure in the small things.

ISSUES THAT CAN PULL YOU DOWN

Many feelings are likely to hit you at one time or another.

Fear: The unknown of your cancer journey can be scary. You may not want to know and initially many people bury their heads in the sand. However, it is helpful to at least have a basic understanding of the terms being used so that you can follow what your medical team is saying to you. At FBC, we can help you with those confusing acronyms and descriptions. Ask for the appropriate FBC booklets, look on our website, talk to your CNS (Clinical Nurse Specialist). Please don't be afraid to ask.

Concern for the future: Getting a cancer diagnosis brings into sharp focus the fact that none of us knows what the future holds and it can help to remind yourself of that. The mountain to climb may seem so huge, but rather than taking the whole thing on in one go, tackling it in baby steps will make things more manageable. If you can try to focus on the present it is much better than dwelling on the unknown.

Pain: For some this can become rather overwhelming and push all other thoughts into the background. Please speak to your GP, CNS or consultant about pain relief; don't suffer in silence.

Loss: It is normal to feel a sense of loss, a loss of your old way of life, or that you are missing out on being able to do things that you might like to have done.



Grief: If you do feel overwhelmed with feelings of sadness, surround yourself with what matters to you, whether it is loved ones, friends, your pets or the simple things that give you joy in your life.

Panic: This is a common reaction to your circumstances. It may come and go, but remember to breathe, slowly and deeply, in and fully out until you begin to feel calmer. We can suggest techniques to help you if you find this hard to manage.

Overthinking: It is so easy for the mind to start spinning in circles. Try to drive in a wedge to slow things down. Meditation is often useful in stilling your thoughts.

Practising mindfulness or living in the moment can help you enjoy your time more, and stop some of those 'what ifs'.

Always remember that whatever you are feeling is normal – and that the team at Fight Bladder Cancer is here to help. YOU ARE NOT ALONE.

Making difficult choices

For some patients, there is only one treatment available, but many will be presented with a choice between different treatments. **There are no rights or wrongs; it is a question of deciding which one you feel is the right one for you.**

HERE ARE OUR SIX TOP TIPS TO MAKING THE RIGHT DECISION.

1 It's your life

Remind yourself at every stage that this is your decision. Take on board what other people feel but in the end, you have to have to make the decision and stick with it.

2 Consult your oncologist

Your oncologist will outline the options available to you. **Find out from them as much as you can about each option:** preparation; waiting times; what it involves; risks; likely outcome; recovery times.

3 Find reputable advice

Do your research. Talk to your CNS and any other health professionals involved in your care. Discuss the options with your family and those closest to you.

4 Second opinion

You can ask for a second opinion. Either ask your consultant or find a local specialist.

5 Be an APE, man!

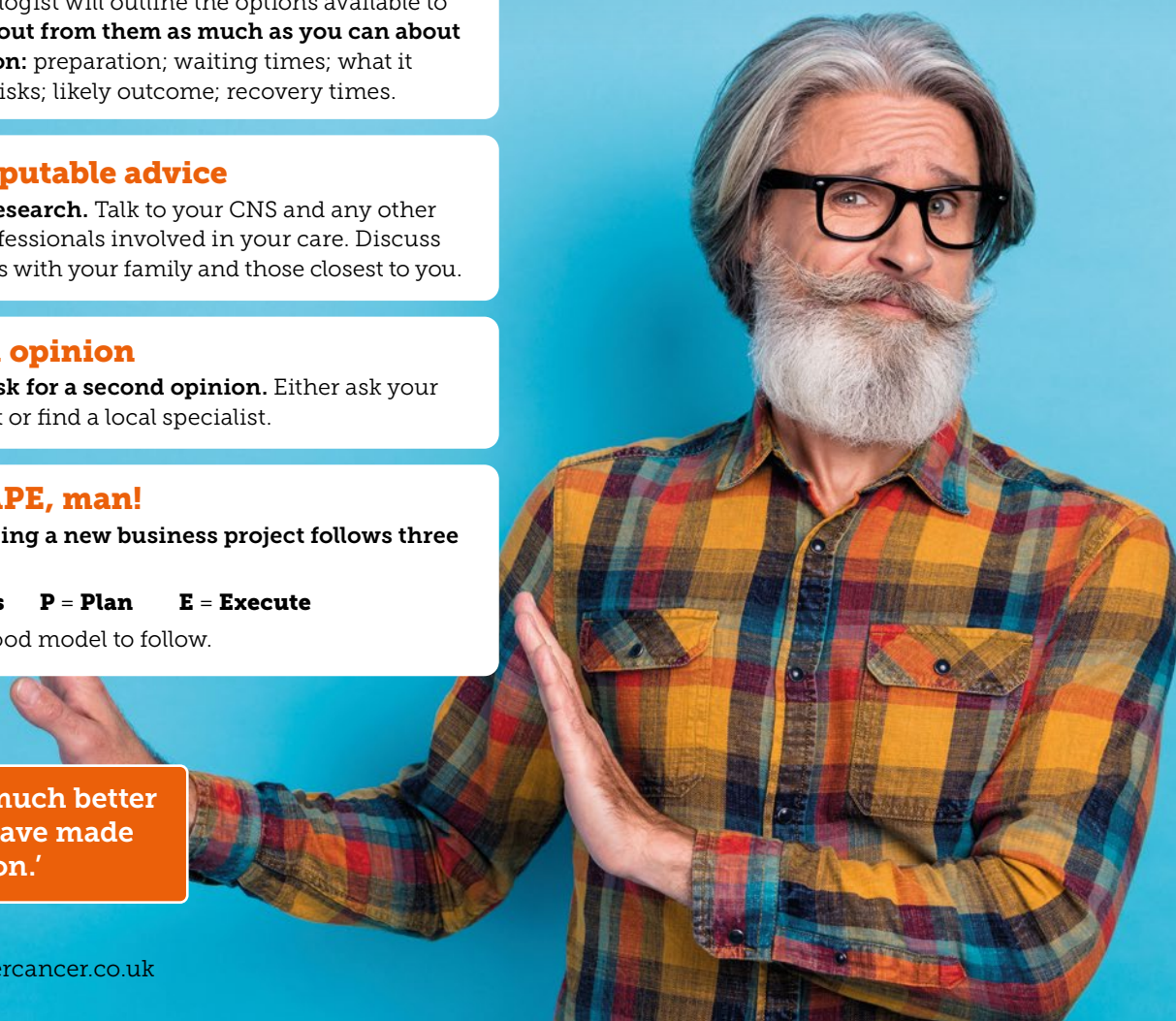
Investigating a new business project follows three stages:

A = Assess P = Plan E = Execute

That's a good model to follow.

6 Consider your supporters

Think about how your decision will impact those who are caring for you. In the final analysis, the choice has to be yours. Once you have made your decision, put all your will power into making it work for you.



'You'll feel much better when you have made your decision.'

The surgeon's perspective

ARTICLE

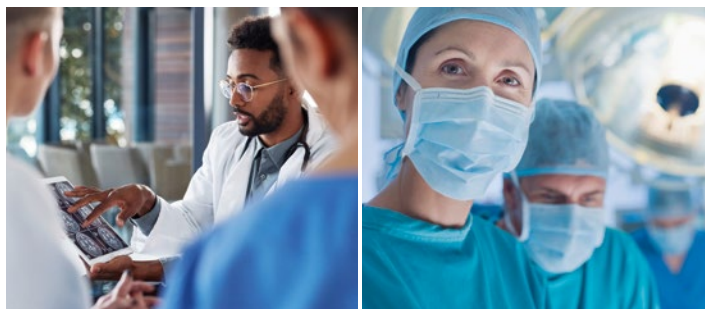
MR JAIMIN BHATT
Consultant Urological
& Robotic Surgeon,
Queen Elizabeth University
Hospital, Glasgow



What you need to know about radical cystectomy

As a consultant urological surgeon and the son of a bladder cancer survivor, Jaimin Bhatt has personal experience from both a professional and personal point of view. This dual perspective makes him extremely passionate about managing the best outcomes for his patients.

I work with an expert team of people who guide patients through the process of getting the best possible treatment given their individual circumstances. Once a patient is admitted into our care, the whole team is involved in the decisions about ongoing treatment, and each team member in turn is responsible for particular aspects of diagnosis and treatment.



The team – known as the multi-disciplinary team – includes urological surgeons, oncologists, radiologists, pathologists, CNSs and other experts. We meet weekly to discuss all our patients, the results of the various diagnostic tests and the best treatment options for each patient, based on disease factors and their general health, and using evidence-based guidelines. The test results and the decisions of the MDT are passed on to the patients.

For more details on all the procedures mentioned in this article, ask your CNS for the relevant copies of our Patient Information Booklets (see page 14) or download a digital copy from fightbladdercancer.co.uk/downloads



DIAGNOSTIC TESTS & TREATMENTS

Flexible cystoscopy

The first procedure is usually a **flexible cystoscopy**, performed by a clinical nurse specialists (CNS). This is a diagnostic procedure that only takes a few minutes. It involves inserting a camera into the bladder on the end of a flexible tube in order to examine the inside of the bladder.

CT scan

If a tumour is detected, the patient may then need a **CT scan** in order to gather further information about the tumour, its extent and position.

TURBT

A **Transurethral Resection of Bladder Tumour** is then performed, in which a bladder tumour is removed endoscopically under a general or spinal anaesthetic. Most patients are in hospital for a couple of days after the procedure. Sometimes, this is the only surgical intervention required; for other patients, we may only be able to take biopsies – small samples of tumour tissue – to be further investigated by the pathologist.

Medical treatments

For many patients, the recommended treatment, as well as regular checks, is to be given medications in the bladder via a catheter, such as **a full course of Mitomycin or BCG**, depending on the grade and stage of their cancer.

Some patients with more advanced disease will need **a radical cystectomy** or **external beam radiotherapy**; others may need **chemotherapy** or **immunotherapy**.

Radical cystectomy

As a bladder cancer surgeon, I perform radical cystectomies on patients with high-grade or muscle-invasive bladder cancer.

A radical cystectomy is a major operation with multiple steps in which the patient's bladder with the cancer is removed, usually together with adjacent organs (prostate in men, womb and sometimes ovaries in women), as well as pelvic lymph nodes.

A urinary diversion is then performed. The most common is an ileal conduit using a segment of small bowel that is joined to the kidney tubes (ureters) and brought out of the abdominal wall as **a stoma**, with urine collecting in a bag. Another option is to use a longer segment of small bowel to create an internal sac, or **neobladder**, connected to the kidney tubes on one end and the urethra on the other.

The first consultation

Counselling patients going for radical surgery deserves and takes time in my clinic, and I always see patients twice and encourage them to bring a member of their family to make sure they understand all the information. In the first consultation, I give them a broad overview, and we focus on a programme that I have introduced in my hospital called **Getting Better Faster**.

I tell my patients that they are in the driver's seat throughout their journey and the only day off they have is the day of their operation, when my team and I take over.

The second consultation

Before the second appointment, we offer to order the free Patient Information Booklets from Fight Bladder Cancer, which are a truly fantastic and helpful resource. For anxious patients, I also arrange for them to speak to a few of my awesome patient ambassadors who have walked this journey in the same hospital before, as this gives a real perspective that no surgeon or nurse can give. I am eternally grateful to these amazing individuals for their time and empathy and delighted that this group is growing in numbers. I also provide my secretary's contact details.



Did you know?

Medical doctors are known as 'Dr' while surgeons are addressed as 'Mr' or 'Miss'. This is an anomaly resulting from the fact that surgeons were qualified by diploma rather than the degree that qualified physicians to be called 'Dr' prior to the mid-19th century. Some surgeons are looking to change this in line with modern qualifications.

After a couple of weeks we go through the finer details of the operation, including risks and complications, and the patient signs the consent forms. Thankfully, the frequent risks are not serious, and the serious ones are not frequent. Patients are encouraged to ask questions, especially about expectations of recovery and lifestyle modification after surgery.

Patients then attend a preoperative assessment and also meet the stoma nurse, who discusses living with a stoma (a bag for life).

The operation

On the day of the operation, my anaesthetist instantly puts them at ease (after all, it is their day off.) I gently remind my patients that they will be back in the driver's seat tomorrow, although we will start again with small steps, and they will call the shots.

The operating theatre is one of my favourite places, where I work with a wonderful team of theatre nurses, anaesthetists, operating department practitioners (ODPs) and my trainees, who assist me during the operation – we usually have some soothing background music playing.



Paula

Going home

After their operation, patients are looked after in the HDU for a day or two and then in the urology ward. The patient is surrounded by nurses, doctors, physiotherapists, stoma nurses and other team members who encourage them to get through the **ABC of Getting**

Better Faster until they are ready

for discharge, usually by five to seven days after their operation, sometimes a bit longer. Since the inception of **Getting Better Faster**, patients have been able to return home up to a week earlier than before.

As a wise person once said:

'To get through the hardest journey, we need to take only one step at a time, but we must keep on stepping.'



Rebecca

Getting Better Faster

Patients need to be as fit as they can for a radical cystectomy operation as we emphasise it's not unlike running a marathon or climbing a mountain. Like all high-performance athletes, the first ingredient of success is having the right attitude and mental stamina.



Colin

This requires self-motivation and positivity, which I have always found in abundance in all my patients. I have also found a great deal of satisfaction from patients with this strategy, as not only does this empowerment get them fitter for their operation, but suddenly their focus shifts from their cancer to something they feel they can control – their wellbeing.

KEY STEPS

Here are the key steps, or as I call them, the **ABC of Getting Better Faster**, and each one is discussed in detail with patients and their families. I often appoint family members as proxy coaches to encourage my patients during this 'prehabilitation' phase.

Before surgery ...

- A** = **A**ttitude (positive), **A**ction
- B** = **B**reathing exercise
- C** = **C**ease smoking, being in **C**ontrol
- D** = **D**ietary build-up
- E** = **E**xercise aiming for 1h or 10k steps/day
- F** = **F**ight Bladder Cancer booklets

Ours is a holistic, patient-centred pathway that empowers patients throughout their journey, starting from the minute they leave my clinic to after they have had their operation.

After surgery

- A** = **A**ttitude (positive)
- B** = **B**reathing exercise
- C** = **C**hewing gum*, **C**hanging stoma bag, **C**atheter flushes
- D** = **D**iet, **DVT** prevention, **D**ischarge planning
- E** = **E**nergy requirements, **E**xpected follow up
- F** = **F**ootsteps of recovery

*We encourage patients to chew gum after the operation as it speeds up recovery of bowel function, which is vital for nutrition needed for healing.

Living with a urostomy

Cristina Luchetta – a specialist CNS – explains exactly what is involved in creating a stoma, and gives some useful tips on how to care for it.



Cristina, Jo and Rachel

A urostomy – also known as an **ileal conduit** or **urinary stoma** – is surgically created to divert the urine when the bladder is removed.

What is a stoma?

The surgeon cuts a portion of the small intestine (bowel) to create the conduit to which the ureters – one from each kidney – are attached. The conduit is then pulled through the wall of the abdomen and sutured (stitched) to the abdomen, creating a stoma. It is normal that the stoma bulges out about 2 1/2 cm (1in), which makes the stoma like a spout, and protects the skin from being irritated.

The urine is then directed through the spouted stoma into a watertight stoma bag (pouch) applied over the stoma to collect the urine. The stoma bag has a sticky back, called a flange, which adheres to the

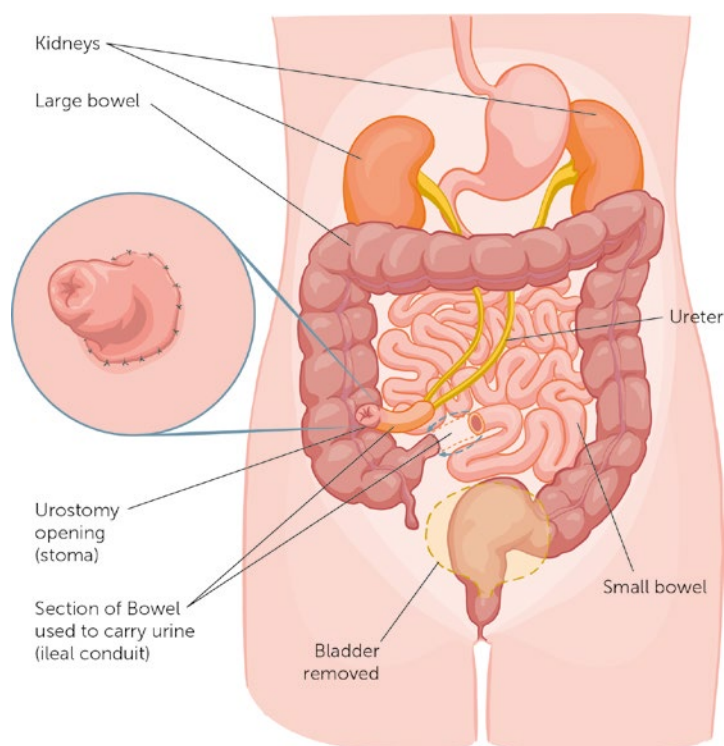
skin. The stoma will always drain urine and the quantity is in relation to the oral fluid intake. The stoma bag takes on the role of the bladder and it needs to be emptied when full. The bag itself will need to be changed every one to three days.

Positioning the stoma

Prior to the surgery, patients are supported by their stoma nurse to prepare them for the procedure both

physically and psychologically. The stoma nurse will assist in identifying the position of the stoma and mark it on the abdomen.

A urostomy is generally positioned on the right side of the abdomen lower than the umbilicus but there is some flexibility in the precise position. The nurse will aim to avoid any creases, scars and skin folds which may prevent the bag from sticking well to the skin.



Tip

We recommend that you empty the bag as soon as you wake in the morning. The reduced intake of fluid overnight decreases the urine output from the urostomy and possibly makes the change of the bag easier.

ARTICLE

CRISTINA LUCHETTA
CNS, Westmorland Hospital

In hospital

The hospital stay is about 10 to 14 days, during which time the stoma care nurse will teach the patient how to change the bag and guide them through essential support on caring for the stoma.

Changing the bag is a process of remembering some basic and simple steps which will be demonstrated several times. While in hospital, try to practise changing the appliance as often as you can so that you master the technique and feel confident before going home. You may want your supporter or carer to watch, too, in case they can help you.

Tip

There are also many videos on YouTube showing the whole bag-changing process.

The ability to learn these skills may be limited if a patient has any post-operative complaints – such as extreme tiredness, nausea or vomiting, constipation or diarrhoea. These are not uncommon consequences of the surgery, but should quickly settle down.

Caring for your stoma

A healthy stoma is pink, moist, warm and soft. The spout is not painful, although the skin surrounding the stoma (peristomal skin) is covered by nerve endings so treat it gently.

The stoma will naturally produce mucous. Immediately after surgery, there are two small, hollow tubes sticking out of the stoma (ureteric stents); their role is to protect the area where the ureters have been stitched to the small intestine. They are not painful and will be removed 10 to 14 days after surgery. Practice in changing the appliance will take those stents into consideration.

Following removal of the stoma bag, wash the stoma and peristomal skin with lukewarm water, dry the skin gently, then apply a fresh stoma bag.

Tip

Oily products may make the skin slippery, which can prevent the new stoma bag from firmly adhering to the skin. Chemical products or brisk removal of the old appliance may damage the skin, which will also prevent the bag sticking well.

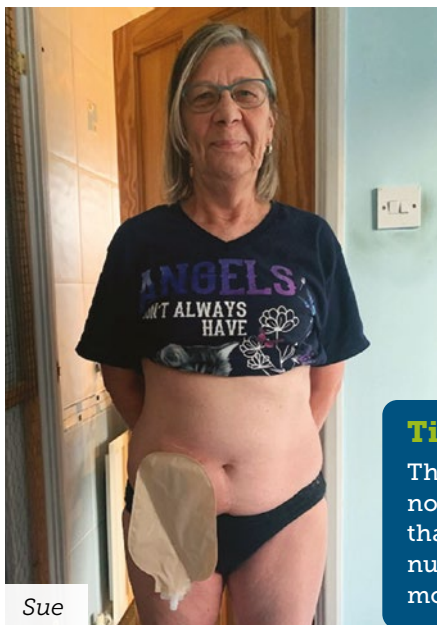
A stoma nurse can provide help and advise the best treatment if the stoma or surrounding skin feels sore or excoriated.

It is recommended any abdominal hair around the stoma is trimmed regularly to ensure the appliance adheres directly to the skin and has a good seal.

Choosing your equipment

There is a large variety of urostomy appliances available. The stoma nurse will suggest the most appropriate in relation to stoma size, abdominal contour, creases/folds, scars, dexterity, visual impairment and personal preference.

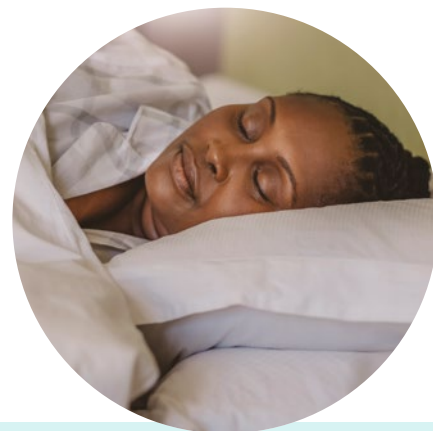
The hospital stoma nurse will explain how to obtain supplies of stoma bags, which are available on prescription and delivered directly to you.



Sue

Night drainage

Overnight the urostomy bag can be attached to a night drainage system allowing an uninterrupted night's sleep. The alternative is to get up in the night to empty the urostomy bag instead.



Going home

Before going home, the hospital stoma nurse will put you in touch with the community stoma nurse, who will be the main point of contact after the discharge.

However, the recovery from the surgery does not end with the discharge from hospital. Physical recovery from surgery may take a few months but psychological adaptation may take longer.

From the moment of the bladder cancer diagnosis to the time of surgery, it may feel like a rollercoaster experience. Some view the urostomy as a new beginning. Others may find this moment overwhelming and feel that it unleashes a range of emotions: from anxiety about how you will cope, to anger at losing control, fear of not feeling like a whole person any more or even that this is the end of your life.

Tip

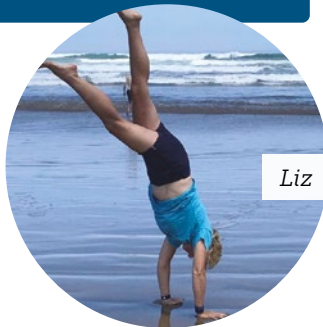
There is no appliance that fits all. It is normal to try a few before finding a bag that is right for you. Contact your stoma nurse if the appliance leaks twice or more in 24 hours.

Tip

Plan carefully before embarking on a new activity so that you are well prepared for your new routines, such as keeping an 'emergency' kit in the car and carrying plenty of supplies on holiday.

You may also have practical questions:

- Will I be able to go back to work?
- Can I go swimming?
- Can I wear my favourite clothes?
- What about sex?
- Will my partner still find me attractive?
- Will my bag show?



Liz

Emotions like anger, depression, feeling repulsed by the stoma or even feeling that you don't want to leave the house are not uncommon. The healing process takes time and everyone is different. Be patient with yourself and ask for help if you need it. Having a supporting network of people around is important during the recovery process. Long-term emotional issues may require input from experts.

Getting back to normal

While you will have to make some adjustments and give yourself a little recovery time, there's very little that you can't do with a urostomy routine that you could do without one! Gradually work your way back to activities you used to enjoy.



Ron



Johnstone

Tip

Talk, talk and talk. Contact Fight Bladder Cancer or other reputable associations which support ostomates all over the UK. Local stoma nurses, GP and delivery companies can provide valid support.



A second chance at life?

I grabbed it with both hands

The 'Don't go red' campaign has been stressing the importance of not feeling embarrassed about possible symptoms of bladder cancer. Bladder cancer patient and FBC Patient Advocate, Laura MacKenzie told us how she felt about going to her doctor.

Laura's story began in August 2017, when she passed what she thought was blood but turned out to be faeces in her urine. This was due to a fistula caused by late-stage bladder cancer.

Initially, she was told she had just weeks to live. Fast forward to 2022, and Laura is clear of cancer and now lives with two permanent stomas.

Laura explained:

'Bladder cancer is particularly emotionally and physically invasive. Don't get me wrong, all cancers are in their own way, but with bladder cancer – as symptoms relate to urine and intimate areas of our body – it is natural to feel reluctant to speak out. Maybe even a reluctance to tell a partner, close family member or friend. Telling a doctor, for many, seems an impossible next step.

'Believe me when I say whatever you tell your doctor or show them, they have seen it before many times. To them, it is not weird or embarrassing – it's their job. Remember they can only help you if you tell them what's going on. The sooner you speak out,

the sooner you can get any help or treatment you need. Leave it too long, and the available treatment options reduce in number.

'Blood in the urine is not always bladder cancer, but it shouldn't be there. It may be a matter of reassuring you and treating what it is. Bladder cancer is misdiagnosed as a UTI only too often, especially in women. Give your doctor and yourself a fighting chance.'

'My stomas are a small price to pay for a second chance at life'



'Now, 4.5 years on from my operation, I am clear of cancer. This is a remarkable feat, given that post-op, I found out I only had weeks to live at the time of operating.

Today, I live an everyday life working full time and doing all the things I loved before.'

PERSONAL STORY
LAURA MACKENZIE
FBC forum member

Read Laura's full story here:
fightbladdercancer.co.uk/small
or scan the QR code.



Stuart & Snakey

PERSONAL STORY
STUART MARTIN
Bladder cancer patient

Around the world with a neobladder and a pair of Speedos!



Stuart is an ex-pat living in Germany. He tells the story of his RC and neobladder construction in his own unique style. First, perhaps I should introduce you to 'Snakey', which is what he calls his penis.

A few years ago my dear wife, Christel, said to me, 'You really should go to the doctor. The problem you are having weeing is not right.' So I did as I was told and made an appointment with my German urologist.

I'm not an 'ill man'!

Waiting in the waiting room was not a nice thing – seeing all these 'ill men'. Surely that wasn't me! I was called in for my inspection with the pipe down Snakey. When that was all finished, I was sent back to the ill men in the waiting room. It seemed like a long

wait. A wee bit later, the doctor called me into his office and consulting room and showed me a tumour in my bladder. Hmmm – that's it then, I can now officially sit with the ill men.

After a few visits to hospital for TURBT operations, I was classed as (the dreaded word) cancer-free but booked in for check-ups every four months. I did this for three years and then my dear wife died. This threw me into turmoil and I started smoking again after 30 years of abstinence. I moved to Frankfurt after I was lucky enough to find another partner, Renate, who stands by me.

But then I had a check-up in 2021. Oh no! I was back in the ill men's club again. This time I was put on a course of BCG, which I absolutely hated. And what made it worse was that after a long ordeal with this BCG, at my next check-up I was sent to hospital for a TURBT, which found a tumour that was not going to go away. But my bladder was.

An RC for me

Early in 2021, I was put on a course of chemotherapy to try to reduce the tumour before they removed my bladder. I kept all my hair but it knocked me for six, I can tell you – I have never felt so weak in my life. I was so pleased when the last one was finished at the start of September and I literally dragged myself on holiday to Lake Constance to get myself ready mentally for my big op at the end of September, when they would remove my bladder and construct a neobladder.

My doctor was brilliant and sorted out lots of things for me. That included a room of my own. I forgot to tell you I am an MRSA carrier so I was in quarantine. It was quite good to have a room on my own but the

downside was I knew that I was not getting as well looked after as I should have been because the staff had to get all kitted up just to check on me.

I weighed in at 113kg (17st 11lb) when I went into hospital, although my doctor was not so worried and said I would lose weight during my visit. He was right! I left the hospital at 85kg (13st 5lb). I could not and would not eat. They actually tried to get me on THC (a cannabinoid), which worked a bit, but I am now back to 113kg. I still have a bottle of THC so I will keep it for other reasons (I am also allergic to most painkillers other than opioids).



Aftercare

Since leaving the hospital I have had zero aftercare, mainly due to my MRSA. I completely understand that I am not really wanted among freshly operated patients! When I go to my doctor I have to phone in and make a booking so I will be the last patient of the day (bell round the neck needed!)

The good news is that my neobladder worked perfectly. In fact, I could not believe how well I could control it.

Okay, sometimes it leaked but, wow, I was impressed. I came home and they warned me I would have to self-catheterise, but I have never done this. I wee very well – I would say just below 500ml (17fl oz) if I hold it. I have found that by holding it as long as I can I get rid of the build-up of gunk a lot better. At first, I used to go everywhere with a pad in my pants

just in case – I hated it! Then one day I said to myself, 'no!'. And from then on I haven't used a pad, not even in bed, and I can honestly say that my bed stays dry and my pants, too. Okay, sometimes a couple of drops escape when I am getting out of my car – which I started to drive 10 days after getting out of hospital, by the way.

I have a stent from kidney to neobladder which has to be changed every three months. They wanted to give me a local anaesthetic but I said, 'No way. Just stick that pipe in old Snakey and do a swap.' It works okay and is not very painful.



So after nine months I feel I am in a good place and don't need to queue with the ill men!

Round the world with Snakey

Stuart brought smiles to many faces with a photo of himself, overtanned and in extremely tight Speedos. Fellow FBC Forum Members took the photo with them on trips or holidays and took photos of themselves with Stuart's photo. It was like a world tour, raising awareness of bladder cancer by raising a laugh.



10 things

I wish I had known

FBC Support Services Manager, Melanie, posted a request on the Fight Bladder Cancer forum asking what RC patients wished they had known before their op. Thank you so much to Anne Wass, Gabriel Whiting, Liz Lindsay, Lynne Spryszak, Sandra Semple and Sue Gore, who were pretty much in agreement about their top ten tips.

I wish I had known ...

1

... the importance of enhanced recovery programs

Get yourself in as good a shape as you can before surgery, by exercising to build muscles and stamina. Some hospitals have an enhanced recovery, prehab or pre-op programme and give patients strengthening and cardio exercises to do at home and alongside a physiotherapist at a local gym. Increased fitness can really improve recovery times.

Follow a good diet, too. If you're elderly or underweight, try to put on maybe 5kg in the weeks before the operation. Eat high-calorie and protein-rich foods and have second portions, too, even when it seems unnecessary. A doctor weigh-in is good.

2

... how much support I'd need

It is important to have someone there with you in the hospital when doctors make rounds. As the patient, you may be awake and conversing but you won't remember anything. Ask to record conversations on your phone if you are not accompanied (but do make sure you get everyone's permission first).

Support at home is critical, too. Anybody who lives alone needs to make plans for either family or a good friend to come and stay for at least a week once they get out of hospital.

Have things in place for when you get home, like a waterproof mattress protector, somewhere to store your ostomy supplies, and perhaps some meals in the freezer.

3

... what is 'normal' to expect post op – and what is not

Things like how to identify a urinary infection; the symptoms of sepsis; how long it is likely to take to recover appetite and energy; what is the likelihood of infection when the stents are removed, and should you have an antibiotic prescription? It would be reassuring to know that it is okay to still need pads after the operation and the liquid that leaks out is nothing to worry about. If you do get complications, don't panic. Contact your doctor or CNS for help.

4

... that I could talk to someone who'd been through it before

Speaking with someone who is already living with a stoma helps patients have a better insight into what to expect. It also means they have someone to speak to after surgery, which is really helpful. No one can truly understand what it's like unless they've been through it themselves. Plus you can make lifelong friends in support groups.

If you don't find the right people to speak to, you'll rely on your imagination – or Google – which are bound to be worse than the reality.

5

... to eat little and often

You need to get your strength back post-op so you'll need a good diet, although you may find you have little appetite, especially if – as is the case with some elderly patients – you have been fed on IV for a time after the operation or the hospital food is not as appealing as it should be. At home, you can make sure you have a nutritious diet and regain any lost weight if necessary. Take a look at the *Diet & Nutrition* Patient Information Book (see page 10).

But don't worry if you can't or don't want to eat – little and often usually works well, and you can try high-cal, high-protein shakes until you are feeling more like eating. Just try to eat a little more each day.

6

... to get moving as soon as possible

Get moving soon as you can and keep moving. It's hard but the quicker you move the better – just a little every day. The physios will get you going but they won't be there all the time.

Once you get home, keep up with gentle exercise. Walking is best as you can do a little every day and try to do a little more each day. Remember, though, no lifting. Get a good support belt for when you restart activities like gardening, housework or sports.

7

... more about my bowels!

Bowels rule, okay! Firstly, they are the key to getting out of hospital! A low-residue diet and a suppository on day four does the trick for most people. Secondly, be aware that your bowels may take three months to fully settle down with a regular stool softener to help. A good diet and plenty of water should get things back to normal but there are plenty of safe and effective bowel remedies to have on hand, and don't wait to ask if you need a little help. Laxatives are only a last resort.

8

... some more practical things

If you opt for a stoma, try to get the hang of doing your own bag changes from the start – the quicker you adapt, the quicker you'll accept things and get your life back.

Try to get some training from a stoma nurse and gather information on the practicalities – keep asking questions and trying different products and you'll get into a routine much more easily. Common issues include more about the night bag to avoid the night 'surfing'; how to leave some urine in the day bag before attaching; which is the right day bag for you; and how to troubleshoot bag leaks, which saves trial and error.

Other practical tips include having a 24/7 phone number for emergencies; very long leads (3m) for your charger; using hospital gowns instead of your own nighties; bringing in your favourite drinks and toiletries; bringing a comfortable cushion (Covid allowing); and having plenty of data on your phone in case the hospital wifi is hopeless.

You can feel normal and proud of your body. It takes a while, but you CAN do it and you DO get there!

9

... how exhausted I would feel

Even if surgery goes well with no complications, be prepared to feel overwhelmed and emotional, and rather scared not to have the medical team on hand. Ordinary things are likely to take a lot longer and leave you feeling exhausted. Take your time. It's a marathon, not a sprint so keep this in mind for recovery post op.

10

... what I had to look forward to

You will have problems along the way – everyone does. Bag leaks, for example, are almost a rite of passage till you hit on what works for you. Once you do, you'll never look back. So, don't be disheartened if things don't work out straight away and try not to let mistakes dent your confidence. See the funny side of any mishaps, if you can, and you won't go far wrong.

It's not easy to go through bladder removal and recover but lots of people do it. You need a positive attitude, not to pay too much attention to the inevitable wobbles, and a willingness to accept a new way of doing things. Never forget this operation will probably save your life.

The majority of patients are still here many years on – and still going strong, returning to work with plenty of energy and confidence. Bag changing will be part of a routine and done in minutes – and standing up to wee is such a bonus for women when out walking in the countryside!

For more information, help or support on any of these topics:

- talk to your CNS or GP
- call Fight Bladder Cancer on **+44(0)1844 351621**
- or email info@fightbladdercancer.co.uk and ask about our Bladder Buddy service
- join our online private forum at **facebook.com/groups/bladdercanceruk**
- go to **fightbladdercancer.co.uk/downloads** and download back numbers of Fight magazine, starting with *Fight* #13 on living well with bladder cancer
- you can also download copies of our Patient Information Booklets, including *Living with a Stoma* and *Living with a Neobladder*

The diary of a bag lady

– aged 66 ¹¹/₁₂ths!

What's it like to have a radical cystectomy?
Deb gives you some personal insights.

PERSONAL STORY

DEBORAH MAJOR

Bladder cancer patient
and FBC Trustee

Deb and her number one
cheerleader – husband, Paul



Setting the scene – I am not a neurotic

I was diagnosed in January 2012 with a low grade tumour, which was removed by TURBT. Unfortunately, at the third of my three-monthly checks, it returned as CIS so I was put on 18 doses of BCG treatment, then regular checks. Fast forward to April 2020 and I started to get constant UTI symptoms – sometimes the urine sample would show an infection but more often than not it wouldn't. At my flexi checks, I mentioned it but was told there was nothing to be seen and felt they thought I was being neurotic. It was a miserable time. A never-ending round of antibiotics which briefly took away the symptoms only for them to return.

October – now it gets scary

A flexible cystoscopy showed 'something' in my bladder. While not what I wanted, I did feel vindicated! I was quickly booked in for a rigid cystoscopy and, sure enough, the samples showed the CIS was back so I was booked in for a CT scan. I got the results over the phone one evening. They confirmed the CIS in the bladder but there were also tumours in the urethra and my left ureter where it joins the bladder. I remembered I had complained about the base of my bladder and urethra feeling uncomfortable, but nothing was seen during flexis. This was serious stuff now and I admit I was very scared.

November – the pace picks up

Within a few days I was discussing options with the urologist, whose opinion was we should 'get this out asap'. I agreed. I'd had enough by now. He explained that it would be a long operation performed by himself and a colleague. They would remove my bladder and urethra and try to save my ureter (and hence kidney) by taking frozen cuttings, working up from where it joins the bladder, and sending them straight to the path lab to check for CIS. Apparently there is slack in the ureter so they could still possibly save it and kidney if the CIS was not too far up.

I had three weeks before the op and because I was so fit (ha ha) I was put on an enhanced recovery programme, so I was to spend that time exercising as much as possible. I had visions of weights at the gym or something equally horrendous! No, just lots of fast walking, (maybe with a bit of jogging thrown in?) every day. He also mentioned stairs! Lots of stairs! I could do that surely? I did and I'm convinced it helped with my recovery. It also passed the time whilst waiting, which seemed like an eternity.

December – Eviction day

7am, Paul dropped me at the hospital and was given his marching orders. It was an emotional goodbye and I felt pretty low being on my own – Covid has a lot to answer for.

I struggled into the surgical stockings as they came up to my thighs not my knees, and donned the usual gown.

A long chat with the lovely anaesthetist, who was at pains to assure me that it was completely normal that my head would be swollen (from being at an angle, head down, for the op) when I woke up in recovery and I would think everyone was talking nonsense. But he would be there and I wasn't to worry; I wouldn't be sent to HDU (intensive care) until he was happy.

One of the surgeons arrived to go through the usual stuff. Then he hit me with, 'We're waiting to see if there is an HDU bed available as someone was brought in last night.' WHAT!?

I thought the 3 weeks dragged but it was nothing compared with that hour.

Who had taken my bed? The thought of having to get Paul to come back and collect me was just awful. An elderly lady sitting opposite, still in normal clothes for her minor eye op, complained loudly about her wait. I'm not sure how I kept myself from shouting at her!

Eventually they ushered me into the operating room. It's a good job things like that don't phase me. It was HUGE. So much equipment and so many people. No surgeons – they obviously make their appearance on stage once you're out! I laid on a sort of 'egg box' arrangement, ready for the table to be tilted once I was out. It didn't take long. I love that feeling when you're just going under ...

I don't remember waking up in recovery. The first thing I remember was being on a ward (not HDU in the end) and looking at a man in the bed opposite, still in a complete fog of anaesthetic and pain relief. (I was actually in a male bay for lack of beds.) I vaguely remember some people at the end of my bed talking to me but what they said or who they were, I have no idea! I slept. Poor Paul had to wait until 9.30 in the evening for a call to say how it went. Unfortunately, they couldn't save the kidney, but they told him the op went well and that my stomach looked like I'd been shot (I think they looked more like stab wounds!).

Day 2 – get up and get moving

The next morning, the 'physioterrorists' arrived to get me out of bed. WHAT? I said a few choice words, which they just laughed at. As I sat up, the world spun and I felt so sick. But they managed to get me into my slippers and dressing gown and off we went on the first step (literally) to recovery. Twice a day it happened and I hated it – I felt so dizzy. On the third day, stairs came into the mix.

The food didn't help – sorry, Southampton! I was on a high-protein, low-residue diet which was really awful. They gave me a menu, then said 'you can only choose that or that'!

Day 3 – brain fog

I was moved to a female bay but the torture of physio continued, as did the bad food! Not that I wanted to eat. I was still in a fog really as don't remember anyone changing my newly acquired bag or attaching a night bag. In fact, I don't remember being aware of anything much at all.

Day 4 – the joy of clean teeth

Progress! I made it all by myself to the bathroom.

I didn't think I could manage a shower on my own but just a wash at the sink and a teeth clean was lovely.

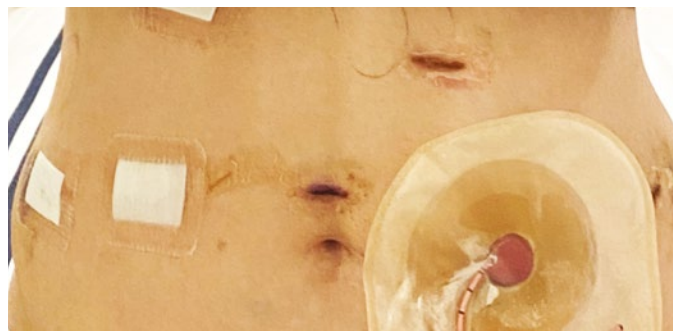
Back to bed to collapse. The stoma nurse arrived (had she been before?). She wanted to see me change my bag independently (had I even done it with assistance?!) and if she was happy I could go home. As much as I wanted to go home, that thought scared the life out of me. I didn't feel ready at all. Suddenly she was called away to an emergency – thank goodness! I got a reprieve.

Day 5 – time to go home

All part of the enhanced recovery program, the stoma nurse watched me change the bag, I hung around to collect my meds and by mid-afternoon I was in a wheelchair on my way to the great outdoors. Paul and the nurse got me into the car, with a cushion in front of me before the seat belt was put on!

It was so lovely to be out, but scary too.

Home to bed and recovery.



Roughly two weeks after op. Still have small catheter drain in to keep stoma open. Robotic operation, hence lots of cuts instead of one big one. Looks like a multiple stabbing! My left kidney was also removed.

Onwards towards Christmas

I slept in the spare room so Paul could get his sleep – I needed my carer to be firing on all cylinders! I use the word 'slept' but there wasn't much of that initially. The first few nights are quite scary, wondering if your bag and your night bag are securely in place, if you're going to have a leak, if your waterproof mattress cover really is waterproof, if the waterproof pad you're lying on (as extra protection) really is waterproof – and so on. It's a whole new and rather alien world.

I had music on my phone and some puzzle books to while away the time.

It was cold, so I went to bed with a hot water bottle, which I refilled from the hot tap in the wee small hours. One night I obviously didn't put the stopper back in properly and it leaked. I woke up cold, wet – and freaked! Still, I soon realised what had happened and was glad to test the system and find it worked.

When I finally got in the shower (maybe day two of being home) I suddenly felt very faint. I managed to have a brief shower then had to go back to bed. The next few days were spent either in bed or lying on the sofa wrapped in a cuddly blanket watching daytime TV or sleeping.

Eating was difficult. Still on high protein/low residue diet, Paul was delighted to be allowed white bread! I could only manage miniscule amounts. Toast, cornflakes, banana, Complan, stuff like that. I lost a lot of weight, which I had wanted to do for ages but not like that!

After two weeks, I started to feel a bit more normal. Paul dropped me off for my appointment with the stoma nurse (still couldn't come in because of Covid) and she said I was doing very well.

Christmas

I managed to eat a small Christmas dinner. The day was made extra special by my elder daughter and her fiancé getting engaged. But Covid kept my younger daughter, her partner and our grandson in quarantine.

January – on my own

At my second stoma-nurse appointment, she signed me off – SCARY! She booked a phone appointment in May but reassured me they were there for me if I needed them. Good job! Not long after, I started to have leaks and I couldn't work out why. I tried a convex bag (which apparently I shouldn't have had!) and it worked so I was switched over to convex bags and haven't looked back.

Onwards and upwards

I had a clear CT scan at five months, which was a relief. Unfortunately, I have a bowel prolapse that I'm waiting to have treated. It's uncomfortable but hopefully it'll be dealt with soon.

I think I've made good, steady progress over the last six months. It's a difficult thing to tell as it is a journey you take alone physically and we're all different.

I don't think I could have done it half as well without the support of the lovely people on the FBC forum who have been there before me.

There's always someone to answer the many worries you have. It's all about paying it forward as I'm now helping others following on behind.

I have returned to work, albeit on a very part time basis, helping out with exam invigilation. I still get very tired, especially in the evenings. I can usually be found lying on the sofa watching something on TV through my eyelids!



6 months after op. Incisions are a lot less visible now. Fading nicely.



A paddle at the beach and a hike around Exbury Gardens at five months post op.

Stoma myths EXPLORED

ARTICLE
LAURA MCKENZIE
FBC forum member

Don't believe everything you hear

From personal experience, Laura knows exactly what it is like to live with a stoma. Here she tells you the reality behind some of the fiction in circulation.

How much do you know about stomas? I will be honest, before I had my two stomas, I knew very little. Since having my stomas, I have heard lots of myths about how people perceive life with a stoma. Let's look at a few – and sort the fact from the fiction.

After having your bladder removed, you wet yourself all the time

FALSE

It is true you are technically incontinent as you have no control of how urine leaves your body, but that's what a stoma bag is for. A stoma is an opening in your stomach which, in the case of a urostomy, allows the urine to flow from your kidneys, through your ureter, which is connected to an ileal conduit. An ileal conduit is a piece which is taken from your bowel and used to transport the urine to your stoma bag. You empty your stoma bag when it fills up.

Only old people have stomas

FALSE

People get stomas for many different reasons. In my case it was due to late-stage bladder cancer, and I had an operation which included the removal of the bladder, so I needed an alternative method for urine to leave my body. Historically, bladder cancer was sometimes known as the 'old man's disease' and many people still think – particularly with a urinary diversion when due to bladder cancer – that it only affects old people. Not true. I was 41 when I got my stomas, although for some patients there are alternatives, such as neobladders and Indiana pouches (see page 28). Unfortunately, bladder cancer is affecting more young people and more women than previously.

You smell if you wear a stoma bag

FALSE

A lot of advancements have been made in the development and manufacture of stoma bags, especially in the last decade. The bags are made of odour-proof material and many also have a filter. There are also additional products available if needed to combat any odours.

Everyone can see you are wearing a stoma bag

FALSE

Most people can wear almost anything they wore before they had a stoma. It is not an issue if your bag can be seen but you can wear loose fitting clothing to help to make it less visible if you feel self-conscious about it. There is also a lot of support underwear available to help support the bag which in turn disguises it under clothes.

Your stoma will keep on changing shape

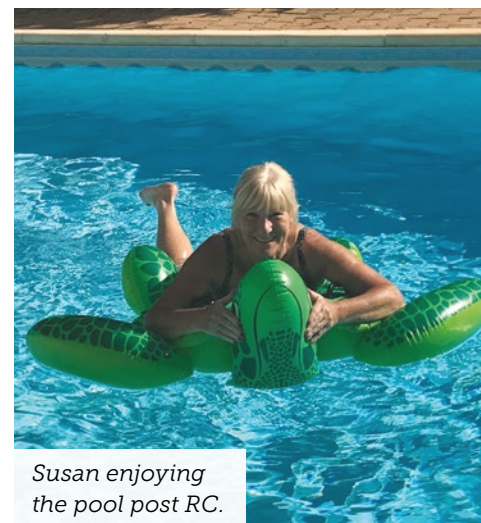
FALSE

In the first six weeks following your surgery, your stoma will reduce in size and will change shape and appearance. This is due to the swelling reducing internally and externally. Your stoma can also change shape or size if you put on or lose weight and your abdomen changes so you should keep an eye on it, but it won't constantly change daily or weekly.

You can't go swimming

FALSE

Of course, you can go swimming. In fact, once your initial healing period is over, swimming is good light exercise for you. You can get special stoma swimwear, but most men go for normal high-waisted swim shorts and women a tankini or swimsuit with some supportive stretch.



Susan enjoying the pool post RC.

Choose your information sources carefully

If you are preparing for a radical cystectomy and you have chosen the stoma option, make sure you talk to the people who really know the facts: your medical team and the FBC forum members who have had the operation and are living successfully with their stomas.

Blood in pee

– why is it so important?

CNS, Jo, explains why it is crucial talk to your healthcare team about blood in your pee at any stage of your cancer journey.



ARTICLE
JO GALES-TODD
BAUN MEMBER AND
MACMILLAN UROLOGY
NURSE SPECIALIST

Most people who have a diagnosis of bladder cancer will have first sought medical advice because they noticed blood in their pee; in fact 80% of people diagnosed with it will have this as their first symptom.

- The blood may look pink, red or brown in colour.
- The quantity may be light, heavy, ongoing or just a one-off episode.
- It may be obvious or not visible to the naked eye (but detectable when a urine sample has been checked).

But it all needs to be checked out.

A camera examination (cystoscopy) may show the presence of a bladder cancer and the blood vessels which supply it are fragile and prone to bleeding. However, it is important to know why, following a diagnosis of bladder cancer, people can still experience blood in their pee, and what to do about it.

Following a TURBT

The first treatment is likely to be a cystoscopy (camera examination) followed by a TURBT (Transurethral Resection of Bladder Tumour), during which the surgeon may be able to remove a tumour, or may take biopsies. The surgeon will do what they can during the surgery to reduce the bleeding, but some bleeding will happen – after all you can't stick a plaster to the inside of your bladder! This often only lasts for a few days, although it can continue intermittently for a few weeks, and should resolve as your bladder heals.

You may find that up to three weeks following your surgery you start bleeding again. This can cause anxiety as it can happen just when people are starting to feel they are recovering, but it isn't necessarily something to worry about. This is sometimes called a 'secondary bleed' and is a part of the normal healing process. It should only last for a couple of days and should resolve of its own accord. If it is heavier, persistent or you feel unwell, then please discuss your symptoms with your CNS or medical team.

Side-effect of bladder washout treatments

Blood in pee can be a side-effect of the bladder washouts of BCG and Mitomycin-C. Both can cause inflammation of the bladder which can, in turn, cause bleeding. Usually this only lasts a day or two following the treatment, but it can occasionally go on for longer.

A catheter needs to be inserted in order to give these treatments and this can also cause soreness and bleeding. Additionally, both treatments increase the likelihood of getting urine infections, which can also cause blood in your pee.

The cause of the bleeding can be confusing and sometimes it can have a combination of reasons. You should always tell your CNS about it and seek advice.

This can be especially important if you are undergoing BCG therapy as your treatment cannot go ahead if you have had recent blood in your urine as that risks you getting a serious infection from the BCG itself, so your medical team will usually ensure this has completely resolved before continuing with treatment.



Muscle-invasive disease

Radiotherapy can be given as a course of treatment over a number of days to treat muscle-invasive bladder cancer, but a side-effect of this is that the treatment can damage the blood vessels in the bladder, making them weaker and more prone to bleeding.

If the cancer is invading into the muscle wall of the bladder and cannot be treated, then it can sometimes cause quite a lot of blood in pee. But even if the bladder cancer cannot be treated it doesn't mean that the bleeding can't be. Sometimes a cystoscopy (camera test) can be performed, areas of bleeding identified, and treated at the surgery using an electrical current or laser to seal the blood vessels. Sometimes a single dose of radiotherapy is given to the bladder to stop the bleeding.

Other causes

Even if you have a diagnosis of bladder cancer there can be other causes of blood in your pee. The most common is a urine infection, which is why your CNS or doctor will often ask for a specimen of urine to check for an infection before they do anything else.

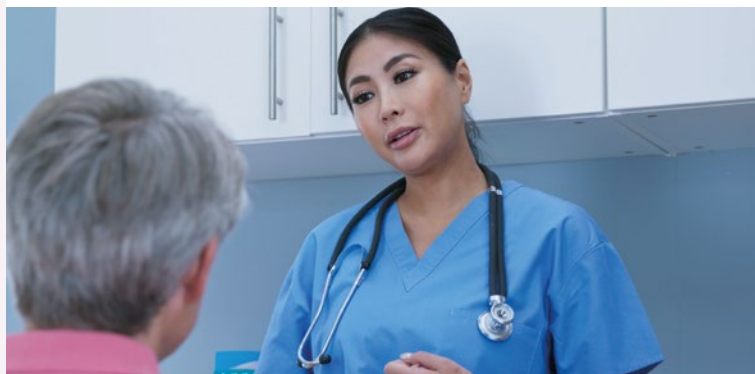
There can be other causes too: kidney or bladder stones; conditions where the blood doesn't clot properly; and other conditions involving organs such as the kidneys or the prostate. Urine can also turn a red colour due to certain medications, such as some antibiotics, or even certain food types, such as lots of beetroot! People who are on blood-thinning medications can be more likely to bleed, and it can take longer for this to stop, but it is important that the medication continues, unless advised by doctors, as there are usually very good reasons why it is required.

Is the cancer coming back?

This can be a source of a lot of anxiety and worry. Seeing blood in your pee can be scary, and a physical reminder of the diagnosis of bladder cancer. The volume can look a lot, but usually the blood is mixed with urine so it looks more than it really is. Unfortunately, the answer is not always clear, bleeding may be a sign of the cancer coming back, or it could be a side-effect of treatments, or even something completely unrelated to your bladder cancer diagnosis.

The only way to know is for it to be checked out, and the sooner the better.

If it isn't the cancer coming back, then getting reviewed quickly will help to give you some reassurance and hopefully some peace of mind. If, unfortunately, the cancer has returned, then the sooner it can be found, the better in terms of getting it treated.



What to do

If the bleeding is heavy, prolonged and/or has blood clots in it, or you feel unwell, it can put your health at risk so you need to be seen by a medical team. The blood loss can cause anaemia where you may feel tired, weak and short of breath, which may require treatment with iron tablets, or a blood transfusion. There is also the risk of clot retention, as if the blood collects in your bladder it can form a clot which could block your urethra (the pipe you pass urine down), making it difficult or painful to pass urine. This requires urgent medical attention, usually via A&E. If it is out of normal working hours, or at a weekend, please do not leave it until Monday to be assessed as you may need urgent treatment so please contact NHS 111 or attend A&E.

It is important to keep drinking adequate volumes of fluid (at least 2 litres (2.5 pints) a day as long as you have no other medical conditions which mean you should reduce this) to flush any blood out. Avoiding strenuous exercise, especially following bladder surgery, may also help to reduce this risk of bleeding.

But the most important message is to talk to your medical team – your CNS, keyworker or doctor. It can be embarrassing to talk about, after all peeing is usually a private function and not something that people tend to discuss in daily conversation! Some people might try to ignore it and 'hope it goes away' but it is really important not to do this.

Please always discuss it with your CNS or doctors. If they work with patients with bladder cancer, then blood in pee is something they will discuss a lot, so there is no need to worry about talking about it.

They'll be able to assess the cause of the bleeding, reassure you or check it out further.

Blood in pee is important – not just as the symptom that leads to bladder cancer being diagnosed; but throughout all the stages of treatment, so please talk about it.

PERSONAL STORY
DAVID RITCHIE
 Bladder cancer patient



I have a stoma – but I'm back in the running

While Covid put paid to the option of having a neobladder, David's can-do attitude meant he was back running a marathon two years after his surgery.

After a few years of symptoms and misdiagnosis, I was finally sent for a cystoscopy in October 2019. I was told that I had a tumour in my bladder and quite casually informed that I would probably have to have my bladder removed.

I still remember feeling numb and thinking,

'How am I going to cope with this, and how am I going to be able to tell my family that I have cancer?'

I was fearful for myself, but more because I did not want my wife and children to have to be worried about me.

I almost felt embarrassed and ashamed about what I had, and I would have preferred to keep it to myself. But, of course, that was not possible.

Once my family got over the initial shock, they seemed to accept it and rallied around me with fantastic support.

Why me?

As I was going through a 'why me?' phase, that support was just what I needed. I had always tried to look after myself – watching what I ate and staying active. I had run nine marathons, plus any number of shorter races. So why had this happened to me? This is an impossible question for anyone to answer. I don't waste any time thinking about that any more.

My treatment programme

My recommended treatment was a TURBT to take samples and remove the tumour, if possible. This confirmed that my tumour was muscle-invasive, which meant that the preferred course of action would be 12 weeks of neoadjuvant chemotherapy and then a radical cystectomy.

And this was all to happen just as we moved into the first Covid lockdown.

My goodness, my world was very different during that period. My chemo impacted me, especially after it, but I coped with this and tried to get on with life as usual. I elected to be assessed for a neobladder reconstruction and, following a further surgery, the doctors said I would be suitable for that.

My consultant put me in touch with a couple of his patients who had had a similar experience to mine, and I took great comfort in meeting with them and seeing that their post-op condition was pretty good. That gave me hope that I could also get through this.

Covid puts paid to my neobladder

My surgery was scheduled for early April but the lockdown limitations in the hospital meant that I would no longer be able to have the neobladder. Instead, I would have to have a stoma and urostomy. This was not my preference and I had plenty of moments wondering how I would cope.

However, I tried to remember that I was fortunate to be having any procedure at that time when things were so very restricted.

It was April Fool's Day 2020 when I had my op; I was hoping it was all an elaborate joke, but alas no.

Moving on

Five days in hospital after the op with no visitors seemed a long time before convincing the doctors to let me go home and see my family. That was wonderful. They were so supportive and helped me to build up my strength quickly.

Getting used to my new accessories (urostomy) took a few weeks; I bought a belt from eBay that holds my bag, and I wear it every day; it looks like a bum bag. I also got a hernia-type support strap which I wear when running; this is also very good.

Back on the run

My recovery was quick; I ran 10km just seven weeks after my surgery and realised that my running career was not over.

On 24 April 2022, I completed my tenth marathon in Blackpool to raise money for Fight Bladder Cancer. I am now signed up to run the Crete half marathon in October and am targeting to run 1000km in 2022.

Time for a holiday

During Easter this year, my wife, daughter and I spent a week in the Canaries. This was a key milestone for me as I have always loved travelling and holidaying with my family, but I was not sure how I would get on with it all.

In the end, our holiday was fantastic, the travelling was fine, and I swam in the pool and the sea most days. I am already looking forward to another holiday: two weeks in Portugal this summer.

After the initial shock of being diagnosed with bladder cancer, I was concerned about how my life would change. But I have found that, with a positive, can-do attitude, I have been able to return to a very acceptable lifestyle. Things are different now, and I need to adapt to many circumstances, but it is do-able and not as bad as I first thought.

If you are going through the initial stages of diagnosis, be assured that you can get through this trauma and develop a renewed lust for life, having been reminded of how precious it is.



The GP community's awareness of bladder cancer needs to be improved to ensure early diagnosis, as it is essential to treat this quickly to provide the best patient outcome. Fight Bladder Cancer plays a significant role in getting that message out there, for which I am very grateful.

Order a GP Awareness Pack for your surgery at www.tfaforms.com/4852487



Fundraising round up

Spring 2022 - Winter 2022

Without the amazing exploits of our wonderful supporters, we would not be able to provide our essential services. So, we would like to say a big THANK YOU to everyone who has contributed, run, baked, burst bubbles or otherwise helped us raise valuable funds.

Across the pond!

Thank you to **Helen Tabor** for running yet another marathon for us in memory of her dad who sadly passed away in 2017. Helen ran the Chicago marathon this year and not only raised an amazing £830, but also earned herself a new personal best! Absolutely brilliant!



Shan McCarney 'braved the shave' for Fight Bladder Cancer in memory of her mum who passed away in 2020. She went live on TikTok to her 230k followers and did a super job at raising awareness for the organisation. Donations flooded in and over 330 people donated to her page, raising a huge £4,100. Wow!

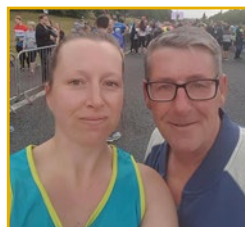


Massive thank you to **David Day** for asking his friends and family to sponsor him to give up alcohol for Dry November. He's raised over £180 for FBC – thank you so much!

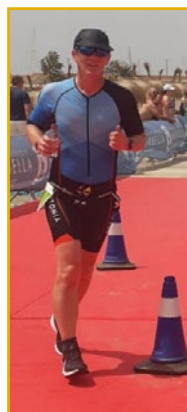
When **Paul Stewart** was recovering from his bladder removal surgery four years ago, he made a commitment to do the coast-to-coast walk from St Bees to Robin Hood's Bay to raise awareness for bladder cancer. Completing the first stretch of the huge 190 miles this year, Paul has already raised over £1,000! Thank you and best of luck for the rest of the journey!



Thank you so much to **Tracey Lake** for running the Great North Run for us and raising almost £300, after her father passed away last February. Tracey usually ran the GNR with her dad and decided to run this year in his memory. What a lovely way to carry on such a wonderful tradition.



Huge thank you to **Nick Edwards** for raising a massive £2,307 for Fight Bladder Cancer by completing the Marbella Ironman in memory of his dad. Nick swam 2km, cycled 90km in the mountains and ran 21km, all under the blistering heat of the Spanish sun!



Massive thank you to our mini-hero **Isaac Fretwell** for running the Muddy Race for Life for Fight Bladder Cancer after his dad was diagnosed. At only 11 years old, Isaac is a superstar fundraiser and has managed to raise a whopping £1,143! Congratulations and well done, Isaac!

The FBC Team get quizzing!

The **Dinton Hermit** pub ran a very successful fundraising pub quiz for Fight Bladder Cancer, raising a huge £201! It was a wonderful evening raising awareness of bladder cancer, with some of the FBC staff even coming to play along.



Huge shoutout to **The Southampton Urology Centre** for organising an awesome Ice Hockey fundraiser. They raised £700 for us and thank you to everyone who was involved in the game. Also, congrats to the Guildford Phoenix team for winning their league, and the cup final!



An unbe-leaf-able fundraiser!

Huge thank you to bladder cancer patient **Paul Davies** for holding a wonderful plant sale fundraiser at the Marldon Apple Pie Fair in Devon and raising £250 for the charity. What a lovely way to raise awareness for bladder cancer!

As Paul's own 'stress buster', gardening can be a really great way to relax and rewind. So if you've also got lots of baby plants, cuttings or flowers that that you could sell, why not see if there's anywhere

local to you where you could also set up a fundraising stall?

It's super-easy to turn a hobby or something you love doing into a fundraiser for Fight Bladder Cancer. Anything from baking, crafting, gaming or performing as part of a local group can be turned into a fundraising activity. Please just get in touch and we'll help you organise something creative that helps raise essential awareness for bladder cancer.



Thank you to **Lorraine Gaytten** for cycling over 100 miles from Wolverhampton to Aberdovey and raising a huge £585 for bladder cancer. What an amazing achievement!



Special thank you to **Hazel McGhie** and her friends and family for completing their annual walk of Cumbrae in memory of Hazel's dad, Clive. We're very grateful for your continued support and hope you enjoyed all the wonderful views along the walk.



After **Frankie Cooper's** dad was diagnosed with terminal bladder cancer last year, she and her boyfriend **Ben** decided to run the South Downs Marathon to help raise awareness of the importance of getting diagnosed early. Doing practice runs all around London (sporting the FBC orange shirts!) and then running the marathon itself, Frankie and Ben



have raised a massive £5,622 for the charity. Thank you both, so much!!

Thank you to **Liz and Neil Lewis** for completing the final part of their 500-mile Spanish Camino walk and raising a huge £1,568! The last stretch of 200 miles took them from Leon to Santiago Compostela, with such beautiful views and scenery – can we please come next time?



Big thank you to **The Curritas**, a team of four friends who decided to take part in Battle Cancer 2022 after the father of one of the teammates was diagnosed with bladder cancer. They smashed both the challenges on the day (and their £300 fundraising target), raising an incredible £1,221! You all definitely deserve to put your feet up after such an exciting day!



After two of **Diane McGhee's** family members were sadly diagnosed with bladder cancer, Diane decided to get her trainers back on after ten years without running and take on a half marathon. She absolutely smashed her fundraising target, raising an amazing £1,575 for the charity. Thank you, Diane!

On the anniversary of his stepdad's death, **Jonny Greenwood** wanted to fundraise in his memory. He decided to turn his favourite hobby, race car gaming, into a fundraiser and hosted a two-hour tournament live on YouTube, collecting almost £175 in donations. Amazing!

Thank you so much to **Catherine**, her dad, **Anthony** and **David** from The Poole family for taking on the Yorkshire Three Peaks challenge in memory of Catherine's nan, Irene. Walking a huge 25 miles and ascending up to 5,200ft, what an inspirational achievement that you should all be so proud of.



Joanne Grinnell ran 60 miles in September after her mum was diagnosed with bladder cancer. Thank you, Joanne, for raising a huge £650 for Fight Bladder Cancer!

A family effort!

When **Sue** was diagnosed with bladder cancer last October, her family knew that they wanted to help raise awareness and funds for the disease that Sue was fighting so bravely. **Les, Sonya, Sarah and Rachel** from the **Partington family** decided to take on FBC's 21 fundraising challenge, by incorporating the number into their activities for the 21,181 people that are diagnosed in the UK each year. From walking 21km, doing 21 burpees each day, they stepped up and raised a £1,025 for the charity.

Thank you to you all, and for getting Eric Morecambe involved too!



Teamwork makes the dreamwork!

The team at **HSBC Belfast** got together to fundraise for FBC, in support of one of their colleagues whose father had just been diagnosed. They decided to collectively run, swim or cycle 1000 miles in a month and raised £200, wow!

BLADDER CANCER AWARENESS MONTH

Raising awareness & taking on challenges

The generosity and spirit of our supporters has always shone through during **Bladder Cancer Awareness Month**. For ideas on how you can fundraise in May see pages 45–47.

Facebook fundraisers

From birthdays to anniversaries or just to help raise funds, Facebook fundraisers are a great and easy way to raise money for Fight Bladder Cancer. They're super-quick and you can share the link to all of your contacts really easily. Facebook don't charge anything for processing donations, so 100% of the money raised comes directly to the charity.

Visit www.facebook.com/fund/BladderCancerUK/ to set up your fundraiser or get in touch with Amy if you need any help at amy@fightbladdercancer.co.uk



In memoriam

Giving to charity when someone dies can be a wonderful way to honour their memory. We are immensely grateful to those who choose to remember loved ones who have died by giving a gift to Fight Bladder Cancer. We work with our trusted partner MuchLoved to help create lasting and personalised tribute pages, where you can leave messages of remembrance, light candles that will burn on the page forever and share cherished photos.

If you would like to learn more about ways to fundraise or donate in memory of a loved one, please get in touch at amy@fightbladdercancer.co.uk. Or you can scan the QR code below to set up a page on MuchLoved.



much  **loved**

Raise some money & have some fun!

WE NEED YOUR SUPPORT

FBC is committed to:

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

Our services are in more demand than ever but we rely on voluntary donations so we can only achieve our goals with your support.

Whatever you choose to do – fundraising, donating, volunteering or raising awareness – thank you.

We can help you fundraise!

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

giftaid it



Registered with
**FUNDRAISING
REGULATOR**

Our biggest and best BLADDER CANCER AWARENESS MONTH

Wow, what a month!
We're hugely thankful
to everybody who
helped us to raise
awareness and funds
for #BladderCancer
Month22. It was
immense!

fight
bladder
CANCER

There were some truly epic fundraising efforts taking place across the UK from Scotland all the way down the country to the south coast in Bournemouth. Whether you were running, walking, swimming, crafting, baking or bubble-blowing – every single person who was involved during the month is a superstar in our eyes.

Thanks to all our Wee Walkers

The Fight Bladder Cancer Wee Walks are always a highlight of Bladder Cancer Awareness Month, as they bring the community together in an inclusive way to chat, make friends, share stories and raise awareness and funds. Our 2022 events were certainly no exception!

Wee Walks are a super-simple way to raise awareness for bladder cancer. All you have to do is grab your family (or a group of friends), let us at the office know you're planning on walking for bladder cancer and we'll help you with the rest by sending you our materials. It couldn't be easier!

Wee Walks took place near our HQ in Chinnor, in Bournemouth and Falkland, and they were all a lot of fun judging by these pictures!

Having a gggrrreat time!

Take one tiger costume, one sunny day, and a group of fabulous fundraisers, and what do you get? A fantastic Wee Walk on Bournemouth seafront! We love these pictures from the event which was organised by Fight Bladder Cancer supporters Paul and Deb Major.

Our Chinnor and Falkland events were equally fantastic, even if there were no tiger costumes in sight. The weather was beautiful, the scenery equally so, and a great day was had by everyone involved. Can you spot yourself in our photo highlights reel?



What went on in Scotland

We've always had incredible support from a small but mighty band of Scottish bladder cancer patients and their families, but this year they surpassed themselves. Here's just some of what they got up to during May.

Ness Bridge, in the centre of Inverness, was lit up orange for Bladder Cancer Awareness Month. Kathleen MacKenzie, Clinical Nurse Specialist at Raigmore Hospital, organised for the bridge to be lit. What a show-stopping way to raise awareness for bladder cancer!

Other members of Team-Scotland spent a day raising awareness at the Gyle shopping centre in Edinburgh, and organised the annual Falkland Wee Walk, which was well attended and lots of fun.

Huge thanks to everyone who supported our events in Scotland for Bladder Cancer Awareness Month!



Orange is the colour of Porthcawl

We're extremely lucky to have support from nursing staff at hospitals across the UK who share information about our work, distribute our Patient Information Booklets – and get involved in fundraising too.

The team at the Porthcawl Medical Centre was busy fundraising and raising awareness of bladder cancer throughout Bladder Cancer Month. They decorated the surgery and their collection tins to encourage people to donate, staff paid to wear orange for the month of May, and they baked yummy cakes to sell. Thanks everyone!

Who fancies an orange picnic?

The team at Liverpool University Hospital have also been getting involved. Robyn Tennant and colleagues at Broadgreen Urology Department set themselves a steps challenge to raise funds for Fight Bladder Cancer, walking 21,000 steps a day between them every day in May. Great work Robyn and team! They also organised an orange-themed picnic with a donated food hamper raffled off to the nurses – what a great idea!



Lust for life!

The amazing David Ritchie (see page 40) ran the Blackpool Marathon to raise money to support our work. David was diagnosed with bladder cancer in 2019, and this was his first marathon since diagnosis and surgery to remove his bladder. David said, 'If you are going through the initial stages of diagnosis, be assured that you can get through this trauma and come out with a renewed lust for life, having been reminded of how precious it is.' A true inspiration!

Don't wait to take action

Shanina McLeod ran the Hackney half marathon to say thank you to Fight Bladder Cancer for supporting her Mum, Caron. Shanina says, 'Please keep going back to your doctor if something isn't right. Don't wait. If you feel like you are making a fuss over nothing, you could in actual fact be doing exactly what you need to do to save your life.' So far, Shanina has raised over £1,400, which is brilliant news!



Step lively!

Mr Param Mariappan, Urological Surgeon and Director of Edinburgh Bladder Cancer Surgery set himself an ambitious target of 300,000 steps to be walked during May – and ended the month having walked over 350,000! Param says, 'Fight Bladder Cancer is a great charity that supports patients and carers affected by Bladder Cancer, as well as clinicians and researchers – this work requires funding.'

If you'd like to reward his monumental efforts, you can donate on our website at giving.fightbladdercancer.co.uk/pf/param-mariappanbladdercanceraware22 We hope you have had a much more restful June, Mr M!

Braving the cold

Throughout May, Brenda Kelly swam over a mile every day in her local reservoir in memory of her dear husband, Turlough, who was a bladder cancer patient. She braved the chilly waters and raised an amazing £4,000 for Fight Bladder Cancer. Thank you so much, Brenda!

To every single person who raised funds for us during Bladder Cancer Awareness Month, thank you! With the funds raised, Fight Bladder Cancer will be able to continue supporting patients. We really want to carry on improving the lives of people affected by bladder cancer, and with your support we can.

WHAT ARE YOU DOING FOR BCAM 2023?

We want to hear all about what you're planning!

From taking on our **21** fundraiser or organising your own Wee Walk with your family, there's so much you can do during May to raise awareness.

Please email us at getinvolved@fightbladdercancer.co.uk to let us know what you're getting up to and how we can help you.



THANK YOU!

Meet the STIMPSONs!

PERSONAL STORY
ZOE STIMPSON
Patient and forum
member

When you are family, you all pull together

Sitting in the waiting room on 8 July 2021, my biggest fear was the cystoscopy. I knew about bladder cancer, as my younger sister had been diagnosed in September 2019. She had some risk factors; I had none. As far as I was concerned this was just a routine referral as traces of blood had been found in my wee.

It was likely to be a gynae issue as I had bled once a month for three months following my second Covid vaccine (a common occurrence in menopausal women, according to Google).

Then those words 'I have seen something of concern on your ultrasound scan'.

I was on my own; my husband was parking the car. My world fell apart as the consultant asked me if I had someone with me. Phil arrived to find me in pieces with the shocking news:

I had bladder cancer.

My consultant couldn't have been kinder. He understood that I was totally unprepared for this news. But at that appointment I was introduced to Sophie, my CNS, someone I was to get to know really well over the next year. I was also given leaflets about Macmillan, Maggie's, Fight Bladder Cancer and other cancer charities.

Shock and overwhelming fear mixed with disbelief that this could be happening to us. How would we tell our children?

Although they were adults, they were still our children.

Many tears

Of course, we did tell them. They coped, as did we. Many tears were shed over the next few days but before the end of July I was in for my first TURBT, an op that became all too familiar. In the following six months I had CT scans, two TURBTs, six sessions of BCG and suffered a fractured ankle and crushed foot after my horse tripped and landed on my leg. It was time to get fit!

If you fall down, you get up again

Six months later, sitting around the dinner table enjoying a post-Christmas meal, we got thinking about New Year Resolutions, and what we could all do. I had no doubts. I wanted to take control of my life again after the shocking diagnosis of bladder cancer just after my 57th birthday.

Getting outdoors and challenging ourselves was something we all had in common, and we liked the idea of bringing everyone together to do something as a family. The idea was raised that each of us could push ourselves to cover the furthest distance possible during January.

We aimed to – quite literally – move ourselves on as far as possible from my cancer diagnosis!





Riding my horse, Monty, was still pretty uncomfortable so I swapped one saddle for another and took up cycling. The rest of family took up the challenge to support me and raise money for FBC, three running the other two cycling. We all signed up to our challenge on Strava and made sure to celebrate each activity as the month progressed.

Quite a task

And it was a challenge! My son and his wife, Olly and Mish, moved to Australia on 7 January, so they completed their challenge in the hot summer – and with jet lag and new jobs too. Poor Ellie, my daughter, got Covid and had to delay until February when the weather wasn't so kind and a shorter month meant less time! My husband, Phil, did an epic cycle of 119 miles in one day, coping with hills, wind and rain as he cycled from our home in Gloucestershire to friends living close to Exmouth. He managed a fantastic 500 miles that month!

All together now!

Working as a team allowed us to reach so many friends and family, and the response we got was amazing. Increasing awareness, raising money and getting fit. I still can't quite believe how generous everyone was. My sister would have been so proud of us all.

I miss sharing my news and talking through the journey that I am going through. She was not so lucky, diagnosed with MIBC with metastases at the age of 48. She was so strong and positive but sadly only lived for 11 months after diagnosis. I am so proud of what I have done, although I only cycled 100 miles during the month, I was still working as a paediatric physio three days a week as well as teaching a few hours of Pilates.



I have never been good at sitting still and I have had issues with sleep for many years, but fatigue after BCG was huge – as well as dealing with frequent trips to the loo.

My family are so supportive, firmly believing that we can beat this.

I remember when Sarah used to call after appointments or treatments, I was gobsmacked by how she dealt with it. She always said I would do the same. It's true, you have to get on with it. Some of it isn't pleasant but it's all so much better than the alternative. Phil has found it hard; it took him a while to take it all in and read about my treatment, but I am so lucky, I was diagnosed early with NMIBC Ta grade 3.

My family are with me every step of the way. We can beat this.



Download *Fight* #13 for some advice on dealing with cancer-related fatigue from fightbladdercancer.co.uk/downloads

FBC patient

'I consider her words less a last testament and more a manifesto for life.'



Life Is Beautiful

Thoughts on my life

I don't know whether it's because I have reached this point in my life, or whether people just think I must know the answer to these things (I don't), but lately I have been asked more and more about the meaning of life. And, well, what do I know?! I haven't travelled nearly far enough or read anywhere near as much to be qualified to answer that question.

Life has thrown an awful lot at me these past few months, but I have tried to keep a skip in my step and a smile on my face. It's not always been easy, especially with everything I've had to endure along the way, but I've always found it's better to be happy with a smile on my face than to be a moody old cow. Besides, who wants to walk around with a face like a slapped arse?

For me, life was never about what knowledge I acquired, or how far I travelled, or who I knew, or what I achieved.

Of course, I loved to learn about the people I met and the places I travelled to. And my achievements may seem small, but they meant something to me.

I learnt to street dance ON THE TELLY. I also learnt there is a time and a place for Lycra and it's not on my thighs.

I also wrote a cook book! It did not sell thousands of copies, or even hundreds, but I am really proud of it. Writing those recipes with Pan's mum and sister were some of the most joyous days of my life.

I started a business. It was only small and meant I was elbow-deep in chickpeas every Wednesday morning – and I still swear I'll never make my own houmous again – but working

on those farmers' market stalls was absolutely hilarious – even though we ended up spending way more than we ever earned. Damn that lovely, fresh organic produce.

Maybe that is why I was always happy with my lot in life.

I never felt the need to strive for more ... I've always found my happiness in other things, like a proper cup of tea, Sainsbury's cheese balls and family-sized crisp packets, an Aperol spritz on a sunny afternoon, a glass of Whispering Angel on Pan's pay day and a good Italian red with a huge bowl of pasta, Adèle's latest album (I love you, Adèle), shackets, pizza, salted caramel ice-cream.

'Teardrops on the Dance Floor', *Love Actually* on Christmas Eve (Alan Rickman, I will NEVER forgive you). Sunday roasts, soggy dogs and crafty cats. Not forgetting trash TV – as low as you can go.

People. There is nothing better than connecting two people with something in common and seeing them hit it off. I love introducing friends to each other and watching new friendships blossom.

I am actually an incurable romantic at heart. The story of how I met my husband is still my favourite; my parents' love story is another one I love to tell, and I still get goosebumps when Vasso talks about the time she kissed Lefteris in the rain.

I can also spot a bad pairing a mile away. It makes me sad to see two people trapped in a bad relationship. Not enough to get involved though – leave that to the professionals! Shower your friends with love; this is when they need it the most. Also try not to marry a dickhead.

Family. My goodness, what I would do without mine? My family is large and loud and ridiculous on both sides. I love them and am infuriated by them in equal measure.

What they all have in common is they love to eat! So, that's what we do. Barbecues come rain or shine; roasts after the football every Sunday lunchtime; big glasses of wine and giant mugs of tea! There is never an occasion a cup of tea hasn't helped.

I was lucky enough to find my soul mate. Someone who loved me with every ounce of his being.

If you meet someone who offers his heart up to you so unconditionally, make sure you treasure it for LIFE.

And my baby. He is 12 now and my everything. My crowning achievement in life is my son. He is the meaning of MY life.

Life is made up of lots of wonderful moments, just like the one you are in right now.

**Life is beautiful ...
and so are you.**

Research & trials

Fight Bladder Cancer supports evidence-based medicine for all those affected by bladder cancer

To access our online glossary, go to fightbladdercancer.co.uk/get-help/glossary or scan the QR code.



A clinical trial is something that can be offered at any part of the bladder cancer journey, from suspected diagnosis, through investigations and different treatments, and in later follow-ups, or at the end of life.

There are many clinical trials in bladder cancer. These usually compare a new treatment which has the potential of working better or with fewer side-effects, with what is used as the 'gold standard'.

Different trials are available in different hospitals. This is because of either the complexity of the trial or because of the type of treatment or test involved. For example, studies of surgery or radiotherapy may only be open at the particular hospital or cancer centres where the operation or the radiotherapy takes place. All studies have particular tick boxes to confirm whether this study is the correct one for you and your cancer.



Ask your doctor ...

if you are suitable for **ANY** clinical trial. It is always helpful to take information with you for any trials that your doctor may not be familiar with. If the study is open elsewhere in the UK and it looks as though you may be eligible for this (and are prepared to travel), you could ask your doctor to refer you.

Current open bladder cancer trials

For more information about all current bladder cancer trials head to Cancer Research UK's dedicated portal at 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

PREVAILCTDNA

This study investigates the feasibility of using ctDNA to support cancer diagnosis and risk stratification where tissue biopsy is challenging.

Location: Royal Marsden Hospital Sutton, Surrey
ClinicalTrials.gov ID: **NCT04566614**

UROX BIOMARKER

This trial will need a urine sample from participants who are under investigation for possible bladder cancer and are due to undergo a standard-of-care investigative cystoscopy and biopsy. This study tests whether the UroX biomarker

can be detected in urine samples and therefore be a way of diagnosing patients. Both healthy volunteers and bladder cancer participants are needed.

Location: East and North Hertfordshire NHS Trust
ClinicalTrials.gov ID: **NCT03973307**

Non-muscle-invasive bladder cancer

CR108699

This study aims to evaluate recurrence-free survival in people treated with erdafitinib compared to their doctor's choice for people with high-risk non-muscle-invasive bladder cancer who harbour FGFR mutations or fusions and who

recurred after BCG therapy.

Locations: Christie Hospital Manchester, University of Sheffield Teaching Hospitals, Lister Hospital Stevenage
ClinicalTrials.gov ID: **NCT04172675**

KEYNOTE-676

This study is for people with 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 study looks at how well pembrolizumab works with BCG in people with bladder cancer.

Locations: Raigmore Hospital, St Bartholomew's Hospital, St Georges University Hospitals NHS Foundation Trust
ClinicalTrials.gov ID: **NCT03711032**

RESECT

RESECT is an observational study that evaluates the first step in managing non-muscle-invasive bladder cancer – the TURBT.

Location: London

ClinicalTrials.gov ID: **NCT05154084**

SUNRISE-1

This study is for people with high-risk Non-Muscle Invasive Bladder Cancer. TAR-200 is inserted into the bladder – it is an investigational product that is comprised of a drug (Cetrelimab) and a medical device. This study consists of 3 periods: screening phase (up to 42 days); treatment phase (up to 2 years); follow-up phase (up to 5 years). The total duration of study is up to 6 years and 7 months.

Location: NHS Greater Glasgow and Clyde

ClinicalTrials.gov Identifier:

NCT04640623

Muscle-invasive, advanced or metastatic bladder cancer

BL13

This study is for people with muscle-invasive bladder cancer. This study examines whether a type of immunotherapy drug called durvalumab can be safely administered after initial treatment. This study will determine whether durvalumab after TURBT, chemotherapy and radiation improves disease-free survival compared to surveillance alone.

Locations: Royal Cornwall Hospitals NHS Trust, The Christie NHS Foundation Trust, The Royal Marsden NHS Foundation Trust – Sutton, University Hospital Southampton NHS Foundation Trust, Imperial College Healthcare NHS Trust – Charing Cross, Royal Devon University Healthcare NHS Foundation Trust, Nottingham University Hospital NHS Trust

ClinicalTrials.gov ID: **NCT03768570**

DISCUS

This study is for people with locally advanced or metastatic urothelial cancer. It is a randomised phase II study comparing 3 vs 6 cycles of platinum-based chemotherapy before maintenance avelumab immunotherapy.

Locations: Queen Mary University of London

Clinicaltrialsregister.eu:

2021-001975-17

EPRIMM

The investigators would like to test stool samples of patients with womb, cervix or bladder cancer having pelvic radiotherapy to see if there are differences in the type of gut bacteria between those who get severe bowel symptoms compared to those with mild bowel symptoms. They also want to see whether these differences in gut bacteria can tell who will develop severe bowel symptoms during or after radiotherapy and determine the effect of diet.

Location: Wythenshawe Hospital Manchester

ClinicalTrials.gov ID: **NCT04995809**

IGNYTE

This study looks at the drug RP1 alone and then RP1 in combination with nivolumab. This trial needs participants with advanced and/or refractory solid tumours. This trial will determine the drug's maximum tolerated and recommended dose. It is for a range of cancers and includes bladder cancer.

Locations: University of Leeds Teaching Hospital, Oxford University Hospitals NHS Trust, Beatson West of Scotland Cancer Center Glasgow, The Clatterbridge Cancer Centre NHS Foundation Trust Bebington, Royal Marsden Hospital London, Southampton General Hospital

ClinicalTrials.gov ID: **NCT03767348**

IMVIGOR011

This study is for people with high-risk muscle-invasive bladder cancer who have had a cystectomy. Patients will be followed up closely after their cystectomy and may receive the immunotherapy atezolizumab. This study is looking to see if atezolizumab can improve disease-free survival.

Locations: Belfast City Hospital, Addenbrookes Hospital, Western General Hospital, St James Hospital, Barts Hospital, University College London NHS Foundation Trust, Derriford Hospital, Royal Preston Hospital, Weston Park Hospital, Southampton University Hospitals NHS Trust, Royal Marsden Hospital (Sutton).

ClinicalTrials.gov ID: **NCT04660344**

JAVELIN BLADDER MEDLEY

This study is for people who have locally advanced or metastatic bladder cancer and have responded to chemotherapy. This study aims to assess the safety and efficacy of avelumab in combination with other anti-tumour agents as a maintenance treatment in participants with bladder cancer.

Locations: They are recruiting soon.

ClinicalTrials.gov ID: **NCT05327530**

KEYNOTE-866

This study is for people who have muscle-invasive bladder cancer. Patients will receive a drug called pembrolizumab along with chemotherapy and bladder removal or chemotherapy and bladder removal without pembrolizumab. This study looks at how well pembrolizumab works with chemotherapy and surgery in people with bladder cancer.

Locations: Aberdeen Royal Infirmary, Torbay Hospital, Kent and Canterbury Hospital, Lister Hospital, The Royal Marsden Foundation Trust, Imperial College Healthcare NHS Trust, Norfolk & Norwich University Hospital NHS Foundation Trust, Royal Cornwall Hospital.

ClinicalTrials.gov ID: **NCT03924856**

KEYNOTE-905/EV-303

This study is for people with muscle-invasive bladder cancer who are not eligible for cisplatin-based chemotherapy. Patients will receive either surgery alone, pembrolizumab plus surgery, or enfortumab vedotin plus pembrolizumab plus surgery. This study looks at how well pembrolizumab and enfortumab vedotin work together with surgery in people with bladder cancer.

Locations: Kent and Canterbury Hospital, Lister Hospital, Barts Health NHS Trust, The Royal Marsden Foundation Trust, Imperial College Healthcare NHS Trust, Western General Hospital, Royal Cornwall Hospital
ClinicalTrials.gov ID: **NCT03924895**

KEYNOTE-992

This study is for people who have muscle-invasive bladder cancer. Patients will receive chemoradiotherapy and might also receive a drug called pembrolizumab. This study looks at how well pembrolizumab works with chemoradiotherapy in people with bladder cancer.

Location: South Devon Healthcare Foundation Trust
ClinicalTrials.gov ID: **NCT04241185**

MOMENTUM

This registry facilitates the implementation of the MRI-guided Linear Accelerator radiation therapy system to improve patients' survival, local and regional tumour control and quality of life.

Locations: London, Manchester
ClinicalTrials.gov ID: **NCT04075305**

**MORPHEUS MUC**

This study is for advanced or metastatic bladder cancer patients 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.

Locations: Barts and The London, The Christie NHS Foundation Trust Manchester, Churchill Hospital Oxford, Royal Marsden NHS Foundation Trust Sutton
ClinicalTrials.gov ID: **NCT03869190**

NCT03096054

This study is for people who have advanced or metastatic bladder cancer. Patients will receive a drug called LY3143921. This early study looks at the safety and ideal doses of the drug.

Locations: Belfast City Hospital, Western General Hospital Edinburgh, Beatson West of Scotland Cancer Centre Glasgow, Northern Centre for Cancer Care Newcastle Upon Tyne
ClinicalTrials.gov ID: **NCT03096054**

NCT03473743

This study is for people with metastatic or inoperable bladder cancer who test positive for the FGFR biomarker. This study will test the ideal dose of two drugs, erdafitinib and cetrelimab, and their safety and how well they work.

Locations: Addenbrooke's Hospital Cambridge, Colchester Hospital University, Royal Lancaster Infirmary, St Bartholomew's Hospital
ClinicalTrials.gov ID: **NCT03473743**

NCT03661320

This study is for people with muscle-invasive bladder cancer. This study looks at the use of the drug nivolumab with chemotherapy.
Locations: Chelmsford, York, Glasgow, Lancaster, London, Oxford
ClinicalTrials.gov ID: **NCT03661320**

NCT03782207

This study is for people with advanced or metastatic bladder cancer previously treated with chemotherapy. Patients will receive a drug called atezolizumab. This study looks at how well this drug works in people with bladder cancer.

Locations: Barnet Hospital, Royal United Hospital Bath, Clatterbridge Cancer Centre Bebington, Heartlands Hospital Birmingham, East Lancashire Hospitals NHS Trust Burnley, Addenbrookes Hospital Cambridge, Velindre Cancer Centre Cardiff, Diana Princess of Wales Hospital Grimsby, Royal Surrey County Hospital Guildford, Northwick Park Hospital Harrow, Huddersfield Royal Infirmary, Hull Royal Infirmary, Airedale General Hospital Keighley, Royal Marsden Hospital Kingston upon Thames, St Bartholomew's Hospital London, Royal Free Hospital London, Guys and St Thomas Hospital London, Queen Elizabeth Hospital London, St George's Hospital London, Royal Marsden Hospital, Fulham London, Hammersmith Hospital London, Charing Cross Hospital London, Maidstone Hospital, The Christie Manchester, James Cook Hospital Middlesbrough, Freeman Hospital Newcastle upon Tyne, Nottingham City Hospital, Churchill Hospital Oxford, Royal Preston Hospital, Weston Park Hospital Sheffield, Royal Stoke University Hospital, Royal Marsden Hospital Sutton, Torbay Hospital, Royal Cornwall Hospital, Pinderfields General Hospital Wakefield, Great Western Hospitals Wiltshire, New Cross Hospital Wolverhampton, York Hospital

ClinicalTrials.gov ID: **NCT03782207**

NCT03934827

This study looks at the safety and tolerability of the drug MRx0518 in people with solid tumours at 30 days post-surgery. It is a phase 1 clinical trial and will examine the drug's anti-cancer and immune system properties. Patients will need to be open to surgical removal of their cancer.

Location: Imperial College Healthcare NHS Trust
ClinicalTrials.gov ID: **NCT03934827**

NCT03955913

This observational study aims to identify participants with bladder cancer and selected FGFR aberrations through molecular testing of their archival tumour tissue.

Locations: Colchester Hospital University NHS, Royal Devon & Exeter Hospital, Queen Alexandra Hospital Portsmouth, Royal Preston Hospital, The Clatterbridge Cancer Centre Wirral
ClinicalTrials.gov ID: **NCT03955913**

NCT04069026

In this study, researchers want to gather relevant information regarding the safety of BAY2416964 and how well the drug works in participants with a type of solid tumour that currently available drugs cannot cure. Researchers want to find the highest dose of BAY2416964 that participants could take without having too many side-effects, how the drug is tolerated, and how the body absorbs, distributes and gets rid of the study drug.

Locations: Royal Marsden NHS Trust Surrey, Beatson West of Scotland Cancer Centre Glasgow, Christie Hospital Manchester
ClinicalTrials.gov ID: **NCT04069026**

NCT04254107

This trial will look at a drug called SEA-TGT to determine whether it is safe for patients with solid tumours and lymphomas. It will study SEA-TGT to find out what its side-effects are. It will also study whether SEA-TGT works to treat solid tumours and lymphomas.

Locations: The Royal Marsden Hospital Surrey
ClinicalTrials.gov ID: **NCT04254107**

NCT04389632

This trial will look at a drug called SGN-B6A to determine whether it is safe for people with solid tumours. It will study SGN-B6A to find out what its side-effects are. It will also study whether SGN-B6A works to treat solid tumours.

Location: The Royal Marsden Hospital Surrey
ClinicalTrials.gov ID: **NCT04389632**

NCT05057013

This study evaluates HMBD-001 for treating people with bladder cancer who test positive for the HER3 biomarker. The main aims are to find out the maximum dose of HMBD-001 that can be given safely to patients alone and in combination with other anti-cancer agents, more about the potential side-effects of HMBD-001 and how these can be treated.

Locations: London, Oxford
ClinicalTrials.gov Identifier: **NCT05057013**

PLUMMB

This study is for people with muscle-invasive or advanced bladder cancer. It aims to determine the safety and effectiveness of immunotherapy with radiotherapy. It is a phase 1 clinical trial and will start with pembrolizumab before beginning a radiotherapy course.

Location: Royal Marsden NHS Foundation Trust
ClinicalTrials.gov ID: **NCT02560636**

RE-ARM

This study is for people with cancer of the urinary system that has spread to other places in the body (advanced urothelial cancer). Patients will be receiving a drug called atezolizumab. Upon entering the study, patients will continue to receive atezolizumab and may also receive five doses of radiotherapy. This study investigates whether radiotherapy can improve response to atezolizumab for people treated for advanced urothelial cancer.

Locations: London, Manchester, Sutton, Truro
International Trial Number: **ISRCTN12606219**

REFOCUS

This study is for people with metastatic cancer or cancer that cannot be removed with surgery. People also need to test positive for the FGFR biomarker. Patients will receive a drug called RLY-4008. This very early study looks at the safety and ideal dose of RLY-4008.

Locations: Sarah Cannon Research

Institute London, The Christie NHS Foundation Trust Manchester
ClinicalTrials.gov ID: **NCT04526106**

RIO 018-17

Radical cystectomy (bladder removal) necessitates surgical reconstruction to allow urine drainage after bladder cancer. The current project will explore patient concerns and the aspects of their lifestyles and values that influence their choice of bladder reconstruction. It will also examine which of these concerns and values best predict satisfaction.

Location: Swansea University
ClinicalTrials.gov ID: **NCT03325231**

THOR

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

Locations: University Hospitals Bristol, St Bartholomew's Hospital London, Charing Cross Hospital London, The Christie NHS Foundation Trust Manchester, Derriford Hospital Plymouth, University of Sheffield, Southampton General Hospital, Royal Marsden Hospital Sutton
ClinicalTrials.gov ID: **NCT03390504**

VOLGA

A study to determine the efficacy and safety of durvalumab in combination with tremelimumab and enfortumab vedotin or durvalumab in combination with enfortumab vedotin in people ineligible for chemotherapy undergoing radical cystectomy for muscle-invasive bladder cancer

Locations: University College London Hospital, London Barts Cancer Institute
Soon recruiting: Sheffield Beech Hill Road Blackburn, Glasgow Beatson West of Scotland Cancer Centre, Gillingham Medway Maritime Hospital
ClinicalTrials.gov ID: **NCT04960709**
For our comprehensive glossary, go to **fightbladdercancer/glossary**

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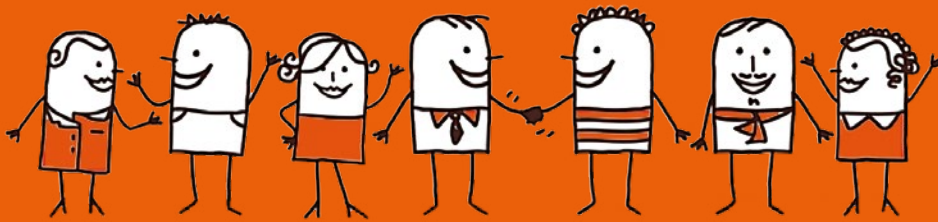
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Every time you work with us, from giving a donation to helping distribute our posters and patient information booklets, you're helping make a big difference to everyone affected by bladder cancer.

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**

'Especially during this time of isolation, I would say: if you are struggling, if you are in despair, or you need a kind ear, reach out on the FBC forum. There is always someone there for you.'

Robin Feast

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.

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we're here to help!



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