Fight Bladder Cancer

from the charity

#13

fight MAGAZINE

LOOKING AFTER YOURSELF

DIET, EXERCISE, SLEEP, LIFE-BALANCE

A HEALTHY MIND

COMMUNICATION, COMBATTING ANXIETY, MINDFULNESS

PRACTICALITIES

COPING WITH FATIGUE, BLADDER REPLACEMENTS, FINANCES

WE FOCUS ON LIVING WELL WITH CANCER:

HOW TO LIVE YOUR LIFE TO THE FULL

SEX

LEARNING TO DISCUSS AND FACE CHANGES WITH POSITIVITY

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

THIS MONTH'S CONTRIBUTORS

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LABC Research Team

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Head of Project Twenty21 – Drug Science

Carolyn Humphries
Food writer and author

Heather James
Uro-oncology CNS, Glan Clwyd

Young Lives vs Cancer

Macmillan Cancer Support

Maggie's Cancer Charity

Stewart O'Callaghan
Founder & Chief Executive Live Through This

Peter Biernis, Gareth Griffiths, Amanda Phipps, Gordon, Rosalind and Douglas Alexander
Bladder Cancer Patients & Carers

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

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

Please 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.

Fight Magazine

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If you are not already subscribed, visit **www.fightbladdercancer.co.uk/contact-preferences** to order a free print copy or digital download of this magazine

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.

Living well with Bladder Cancer

Welcome to the 13th edition of our *FIGHT* magazine.

This edition is dedicated to living well with bladder cancer. We have some fantastic articles on diet, exercise, sleep, life balance, communication, anxiety, mindfulness, fatigue, bladder replacements, finances and sex.

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

We also have plenty of ideas for Bladder Cancer Awareness Month, and how you can get involved.

Despite the challenges of the pandemic, we are delighted to be able to share with you some amazing fundraising and campaigning activity that continues throughout the year for Fight Bladder Cancer.

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

Cancer plus the threat of Covid-19 is a horrible combination, adding further stress to an already challenging time of our lives. Please remember that you are not alone on this journey. There is a whole Wee Family 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.

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

fight bladder CANCER

fightbladdercancer.co.uk

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If you find a word or abbreviation you don't understand use our FBC glossary on page 63

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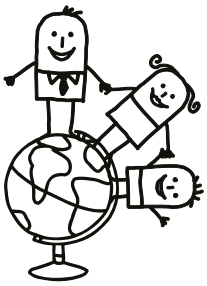
LIVING WELL WITH BLADDER CANCER

A guide to help you live life to the full.

FEATURES

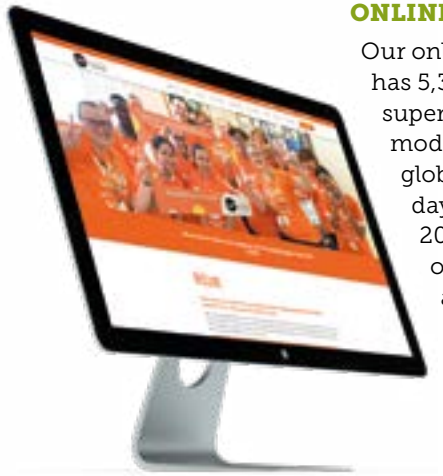
REGULARS

FBC round up



Find out what has been happening at Fight Bladder Cancer

SUPPORT



ONLINE FORUM

Our online private forum now has 5,351 members and is supervised by admin and 10 moderators from around the globe 24 hours a day, seven days a week. In November 2021 we had 381 posts and over 18,000 comments and reactions. Currently the most popular time for interaction on our forum is after dinner on Tuesdays.

'Everyone is so honest and supportive here, it has made us feel truly humbled and grateful. This group has shaped our whole outlook on his journey so far into a mostly positive one, and we thank everyone whoever takes time to post for that.' *Caroline*

TELEPHONE & EMAIL SUPPORT

Our telephone support line is available from 9.30am to 4.30pm Monday to Friday on **01844 351621**. As many of our staff are now working from home, this number is redirected to our mobiles if there is no one in the office. There is a voicemail for messages outside these hours or when we are very busy. We receive and make over 600 telephone calls a year, with the average duration of each call being 19 minutes.

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

'Thank you for your brave, ongoing hard work and efforts.' *Lina*

'Thanks for the Zoom this evening, I found the information very valuable. What a great session!' *Karen*

ZOOM SUPPORT

We now host monthly Zoom support groups. This has given us an opportunity to be in touch with people like never before. Our virtual meetings can be attended by people from places such as Portsmouth, Yorkshire, Scotland – all at the same time. We are therefore able to offer an enhanced sense of humanity and community. For information about future Zoom support groups see our website at **fightbladdercancer.co.uk** or contact us at **support@fightbladdercancer.co.uk**

WEBSITE

We are in the process of updating our website to ensure that we continue to give up-to-date information on treatment options, clinical trials and support. Over the past year we had 37,000 unique visitors and 34,000 downloads. The most popular time to visit is Sunday afternoons. Visit: **fightbladdercancer.co.uk**

COVID-19

Fight Bladder Cancer continued its support of patients and carers during the various lockdowns with its private online members' forum and online support groups. We continue to update our forum with COVID-19 news and keep our COVID-19 webpage up to date. The support team attend regular meetings held by NHS England and Cancer52 (a collective group of cancer charities) to stay on top of new developments.

Fight MAGAZINE

We are now offering a digital version of the *Fight* magazine, as well as free posting of this magazine directly to patients, carers and health professionals throughout the UK. Our office manager organised the posting of 1,574 copies of *Fight* magazine #12 to 630 addresses, and it was emailed to another 521 households. To sign up for your free digital or physical copy, please visit: **fightbladdercancer.co.uk/contact-preferences**

> 'I was so pleased when I found your magazine in the urology clinic.' *Trisha*

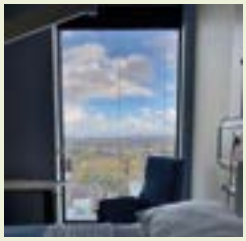
CONTACT CARDS

We supply high-quality, free, personalised contact cards for all medical professionals working with bladder cancer patients. Order yours at **fightbladdercancer.co.uk/contact**

PATIENT INFORMATION BOOKLETS

Our series of Patient Information Booklets has been sent out to hundreds of health professionals and patients around the UK. These booklets, produced by Fight Bladder Cancer, are unique because they are large-print, full colour, full of photos of real-life survivors, endorsed by medical professionals, and filled with handy tips from others who have gone through the same journey. So far, we have sent folders containing the complete set to 230 health professionals and individual booklets to 477 patients. Healthcare professionals can order their complimentary binder at **fightbladdercancer.co.uk/folder**. Patients can order their copies at **fightbladdercancer.co.uk/patientinfo**. They can also be downloaded from our website at **fightbladdercancer.co.uk/downloads**

SCOTLAND



Fight Bladder Cancer took a trip to visit our many supporters, friends, colleagues and partners in the central belt of Scotland from 25 to 27 October. Our aims for the trip were to:

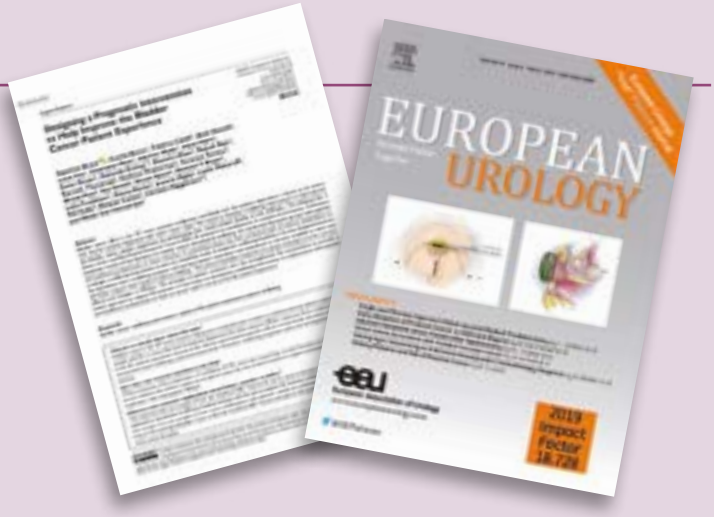
- **Improve awareness of Fight Bladder Cancer and the work we do in the realms of patient support, awareness, research, and policy advocacy in Scotland and across the UK.**
- **Listen and learn from patients, carers, health professional colleagues and friends about how we can be most effective in the region.**
- **Build and grow our relationships with patients, carers, health professionals, and supporters in Scotland**

We were thrilled with the success of our trip – we reached many new hospitals, clinicians and specialists who we were able to tell all about our Patient Information Booklets, support groups, fundraising opportunities and community champions and patient advocate programs.

Some of the FBC Team: Anne, Melanie and Amy

> 'Many thanks for your informative reply. I saw a consultant yesterday and thanks to the information contained in your booklets, I was able to ask the questions I needed answers to.' *Anita*

RESEARCH



Fight Bladder Cancer was a co-author on a paper published in Inquiry on Designing a Pragmatic Intervention to Help Improve the Bladder Cancer Patient Experience. This paper outlined a wellbeing intervention that was designed in collaboration with patients and healthcare professionals to meet an unmet need in terms of the bladder cancer patient experience, without overloading the healthcare system.

Fight Bladder Cancer Trustee Jim Catto was a co-author on a study on Quality of Life After Bladder Cancer which was recently published in European Urology. **You can read more about the findings on pages 37–39.**

HELP US WITH RESEARCH: If you have been affected by bladder cancer and would like to take part in research to improve services, please complete the sign up form on our website and we will be in touch with opportunities to take part in various studies: fightbladdercancer.co.uk/signup

POLICY

'Fight Bladder Cancer's campaign was life changing for patients ... The policy change was impressive ... it was superbly executed.'
Communiqué judges

WAITING TIMES

Fight Bladder Cancer won the Communiqué award for Excellence in Communications for our Cancer Waiting Times Guidance campaign, which means that bladder cancer patients will have faster access to treatment after an urgent referral from their GP.

ACCESS TO IMMUNOTHERAPY

When bladder cancer maintenance immunotherapy treatment was not recommended by NHS in England, we submitted an appeal against NICE's decision. The appeal was upheld, and a third Committee meeting will be scheduled.

INNOVATIVE LICENSING AND ACCESS PATHWAY PATIENT REFERENCE GROUP

We were selected to join the Innovative Licensing and Access Pathway Patient Reference Group. The Patient Reference Group will work with the Medicines and Healthcare Products Regulatory Agency, the Scottish Medicines Consortium and the National Institute for Health and Care Excellence to ensure that patient views are an integral part of delivering the Innovative Licensing and Access Pathway ambition.

EXEMPLAR

We held a symposium at the British Association of Urological Nurses Symposium to design a plan for how health professionals and patients can work together to improve the bladder cancer pathway, and spoke at the British Association of Urological Surgeons (BAUS) Section on Oncology meeting about the need for a national bladder cancer audit.

Lydia

EUROPEAN ASSOCIATION OF UROLOGY

We participated in a strategy meeting with the European Association of Urology patient advocacy group to improve the urology patient journey. We also spoke at the European Association of Urology and European Association of Urology Nurses congress about how they can better understand the patient experience and highlighted how to address needs of the patients before and during their treatment.

AWARENESS

ECONOMIST CANCER SERIES

We spoke at the Economist Cancer Series about the potential benefits and risks that machine learning and artificial intelligence can bring to cancer research and treatment.

WORLD BLADDER CANCER PATIENT FORUM

We were featured in the World Bladder Cancer Patient Forum and spoke about how our Patient Information Booklets can boost joint decision making between patients and healthcare professionals.

MAY IS BLADDER CANCER AWARENESS MONTH

During the month of May, Fight Bladder Cancer will lead the British activities for Bladder Cancer Awareness Month in collaboration with the World Bladder Cancer Patient Coalition. The theme is 'Don't go Red. Go to a Doctor'.

See page 9 for more details!

World Bladder Cancer Patient COALITION

WORLD BLADDER CANCER CONGRESS

A patient representative from Fight Bladder Cancer, Melanie Costin, was invited to speak at the World Bladder Cancer Congress about the experiences before and after bladder removal, and how healthcare professionals can improve their communications with patients.

IN THE NEWS

Fight Bladder Cancer was mentioned in the *Mail Online, The Courier Evening Telegraph, Lancashire Post*, and *Devon Live*.

From the Chair & CEO

OPINION
JOHN HESTER
FBC Chair of Trustees

OPINION
DR LYDIA MAKAROFF
FBC Chief Executive

In March of 2020 the mandate to keep going, as well as the adrenaline rush of our sudden new reality, kicked the Fight Bladder Cancer team into gear. We are proud of the work we've done since then, especially considering all the revenue and resource obstacles we've faced. At Fight Bladder Cancer, we rose to the challenge and doubled up on our mission to inform and connect the bladder cancer community.

For patients and carers alike, each season of the pandemic has been challenging in its own way, and this one has been no exception. Balancing the demands of treatments and check-ups, while cases rise and fall, has taken a toll on all of us. The joy of gathering is coupled with the lingering effects of a pandemic that is very much ongoing.

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

As spring arrives at last, new possibilities are on the horizon. Depending on where you are, the plants may be rising through the earth, the birds may be back, or the cherry trees may be in bloom. Let's jointly begin the journey from the devastation of the pandemic to new hopes.

We're here for you – to offer dedicated support to everyone affected by bladder cancer.

Our private Facebook forum is still available 24/7 for anyone affected by bladder cancer. Patients and carers, family and friends are all welcome to join at

facebook.com/groups/bladdercanceruk

Please do visit if you need somewhere to talk, let off steam, and find like-minded people for advice and a chat.

How to get involved this May, for ...
BLADDER CANCER AWARENESS MONTH

fight bladder CANCER

Wee Are Family!

May Is Awareness Month

Let's share stories of hope, optimism and love this May for Bladder Cancer Awareness Month!

May is the time for our global campaign to shine the spotlight on bladder cancer. Let's paint the town orange and inject some fun into proceedings as spring takes hold, whilst at the same time raising awareness of bladder cancer and encouraging early diagnosis. Look at our **31 Days of May Activity Calendar** on page 11 for inspiration on how you can spread the word.

Don't go red. Go to a doctor

World Bladder Cancer Patient COALITION

We are so excited to be working with other patient-led organisations around the world – in Canada, Australia, America, Europe and beyond – under the banner of the World Bladder Cancer Patient Coalition.

During Bladder Cancer Awareness Month, we want to spark conversations that drive awareness around the symptoms of disease. Most things we're embarrassed about are harmless. These symptoms, however, might not be.

We want you to talk and share your personal stories. The topic of embarrassment is something that just about everyone can get involved in. We all have stories to share. Share the moment you discovered a symptom, the embarrassment you overcame and your relief that you acted on it when you did. Invite others to share their embarrassing moments on social media and help raise awareness about bladder cancer.

If you see blood in your pee, need to pee more frequently or have what you think could be a UTI ... **Don't go red. Go to a doctor.**

This year we launch a new campaign for May **'Don't go red. Go to a doctor'** to get more people talking about bladder cancer and its most common symptom. The Fight Bladder Cancer community has always been one of the loudest voices in May. We invite you again to tell your bladder cancer story, share a moment or a guilty pleasure you might be embarrassed about and help someone overcome their own.

Activities for Bladder Cancer Awareness Month

Whether you're a patient, family member, carer, employer or part of a healthcare team, we hope you'll all get stuck in and join us to raise awareness this May!

Why not make something orange? Fill your front window with orange pictures? Or even dress up as a pumpkin (perhaps not for the whole month, though!).

31 Days of Bladder Cancer Awareness!
Let's share stories of hope, optimism and love this May for **Bladder Cancer Awareness Month!**

Rising to the occasion

Adapting their work arrangements in response to the needs of our membership in these unprecedented times, the Fight Bladder Cancer team has continued to:

- Provide the additional support patients and families need
- Keep our community informed of changes to the healthcare system
- Encourage people to join peer-support groups
- Keep in touch with fundraisers and donors
- Pursue our policy work to improve the treatment experience of cancer patients

Will you take a Wee Walk

to raise awareness & raise funds?
giving.fightbladdercancer.co.uk/cf/weewalk2022

We are encouraging friends and families to take up this annual activity for all people affected by bladder cancer. Many people are walking on Sunday 8th May, but you can organise a walk any day of the month. Taking a 'wee walk' for bladder cancer means that you are part of a global movement – happening in Canada, America, Australia and across Europe. We're joining together in solidarity to raise awareness and fundraise to fight this disease.

Visit our website **fightbladdercancer.co.uk** for more ideas and call us for advice or tips!

THANK YOU!

We appreciate every single person who has contributed to our Bladder Cancer Awareness Month in the past, and we really hope we can continue to work together this year.

Bubbles for bladder cancer

Initiated in memory of patients who have lost their fight (and in solidarity with those who are still fighting), blowing bubbles on 31 May each year has become even more poignant since we lost our inspirational founder, Andrew Winterbottom, in May 2019. Take a moment on 31st May to blow beautiful bubbles in memory of friends. Please remember to take pictures and shout about it on social media, with the tag **#BubblesForBladderCancer**

Don't forget to shout about your ideas and activities!

Use the social media tags **#DontGoRed** & **#BladderCancerMonth22**

Follow us on Twitter **@bladdercanceruk**

Follow us on Facebook at **facebook.com/BladderCancerUK**

Visit **fightbladdercancer.co.uk**

Email us at **info@fightbladdercancer.co.uk**

Call us on **+44 (0)1844 351621**

How can you donate?

It couldn't be easier.

- visit **fightbladdercancer.co.uk/donate**
- send us a cheque payable to Fight Bladder Cancer to 51 High Street, Chinnor, Oxon, OX39 4DJ
- point your phone at this QR code
- text **BCAM2022** to **70085** to donate £5

SCAN ME

We will always spend your donations with care, and adjust our services and support to meet the most pressing needs of anyone affected by bladder cancer. (Reg. Charity 1157763).

31 DAYS of Bladder Cancer Awareness!

31 ideas for sharing, fundraising, creating and doing – throughout May.

More details at fightbladdercancer.co.uk/aware

Update your profile pic with our frame

1

Tweet about **##Bladder Cancer Month22** and tag us **@Bladder-CancerUK** 2

Sign up for a **Fundraising Challenge!**

3

Send us your **Bladder Cancer Story** 4

Request your free **Car Stickers**

5

Host a **Wee Dinner Party**

6

Take a photo of a beautiful orange sunrise or sunset

7

Take a **Wee Walk** for **Bladder Cancer**

8

Buy a **FBC wristband** from fight-**bladdercan-cer.co.uk/ shop**

9

Share your messages of hope with FBC on social media 10

Complete and colour our dot-to-dot butterfly **fightbladder-cancer.co.uk/ dot** 11

Shout out about **#In ternational NursesDay**

12

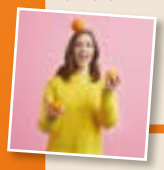
Have an **Orange Themed Picnic** 13

Buy through **smile. amazon. co.uk** to support FBC 14

Bake an orange drizzle cake – yum!

15

How many **oranges** can you juggle?



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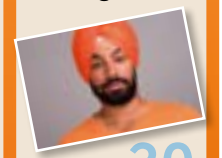
Make a donation Text **BCAM2022** to 70085 to give £5 17

Shout out to nurses using **#European Cancer NursesDay** 18

Share an embarrassing symptom and your relief that you took action **#Dont GoRed** 19

Wear **Some Orange**



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Plant some **Orange Flowers** or **Carrots**

21

Visit our online shop at **fight bladder-cancer. co.uk/shop** 22

Talk to **five** people about bladder cancer 23

Email **mela-nie@fight-bladdercan-cer.co.uk** to join our Zoom support group 24

Ask your GP to request an awareness kit at **fight bladder cancer.co. uk/gp** 25

Create a **Facebook Fundraiser** 26

Read our free **Fight magazine**

27

Send a thank you card from **fightbladder-cancer.co.uk/ cards** 28

Let people know we are there for them 29

Donate your fundraising to **Fight Bladder Cancer** 30

Blow bubbles for **#Bubbles-ForBlad-derCancer**

31

Set up a monthly gift at **fightbladder cancer.co.uk/ donate**

1st June

Cut out this calendar and put it on the fridge or the kitchen wall to share with the family. We look forward to seeing you take part in the coming weeks.

THANK YOU.

SPECIAL FEATURE

Living Well with Bladder Cancer

The special feature in this edition looks at some of the things that can help and support you through your cancer journey, and give you the strength and courage to live life to the full.

Here's 10 top things our patients have identified that encouraged them to see the glass as half full, not half empty. What would your top 10 be?

1. **Friends and family** – 'my wife was my rock, always there for me' .
2. **Fight Bladder Cancer private online forum** – 'I jump on the forum when I'm low so I never need to feel stupid or alone.'
3. **Your CNS** – 'it was great to see a reassuring face at worrying times'.
4. **Practical tips from other patients** – 'take snacks to your chemo sessions', 'avoid Dr Google', 'a lovely warm bath to relieve cramps'.
5. **Be patient** – 'I was told to be kind to myself, not to rush recovery and eat what I fancied'.
6. **Breathe** – 'I downloaded an app to my phone with breathing exercises that helped if I felt anxious'.
7. **Ask questions** – 'there are no silly questions; if you think of it, it needs an answer'.
8. **Seek professional support** – 'everyone needs help at times; I had talking therapy and now I'm going from strength to strength' .
9. **Laugh** – 'whatever you do, don't lose your sense of humour'.
10. **Live!** – 'don't just survive but live your life to the fullest; do whatever you want to, when you can', 'I got my energy back and just wanted to have new experiences, to celebrate being me'.

The *Fight* back catalogue

This is edition #13 of our *Fight* magazine, and we have amassed an extensive range of features by patients, carers and professionals across the bladder cancer spectrum. Each edition has a special feature focusing on one aspect of bladder cancer care.

Fight #1: *Our inaugural edition*
Fight #2: *Quality of life*
Fight #3: *Sex and relationships*
Fight #4: *Robotic surgery*
Fight #5: *FBC manifesto*
Fight #6: *Hopes and dreams*
Fight #7: *Nurses*
Fight #8: *In memoriam*
Fight #9: *Cancer and the workplace*
Fight #10: *Mental health*
Fight #11: *Carers*
Fight #12: *Multi-disciplinary teams*

To download a copy of any of the magazines, go to fightbladdercancer.co.uk/downloads

If you prefer a print edition, call (0)1844 351621 or email info@fightbladdercancer.co.uk

To sign up to receive *Fight* magazine on publication, go to fightbladdercancer.co.uk/contact-preferences

Share how you feel

ARTICLE
JANE BLOFIELD
Urology Oncology CNS, Kent


Jane Blofield

... it will help you and those who care for you.

To be given a bladder cancer diagnosis has a huge impact on life. Suddenly the control you have over your 'everyday' is impacted by this new, unwelcome intrusion, which no-one wants and no one invited to the party.

I am a Urology Oncology Clinical Nurse Specialist at Kent and Canterbury Hospital, with an oncology background of 15 years. I love my job and I find my patients and their families and friends a constant source of inspiration and admiration. And I want to share with you something that has been demonstrated to me over and over again.

Communication can really help you.

A problem shared is a problem halved, goes the old saying – and I agree. First of all, tell people you have cancer. Your family and friends are there to support you and they will want to help. Talking about your diagnosis and how you feel can help you and your family understand what you are going through and it makes them feel they can do something to lessen its impact.

> Cancer is not something to be ashamed of, it's something that happens to one in two of us.

Talking about and sharing your diagnosis with your loved ones and friends will not only give you emotional support, but studies[1] have shown that support can also help you to accept and adjust to your diagnosis.

Accept support from family, friends and neighbours. It is not a sign of weakness to ask for help or to feel unable to cope on your own. What's more, on the practical side of things, you are sure to welcome offers of lifts to appointments for treatment, trips to the supermarket to stock you up with basics and, if you're lucky, more home-cooked meals than your freezer can cope with!

Share how you feel

Having that support can make you feel less alone and more in control. Most of you are lucky to have people desperate to support, to listen and to help, so I say use them, talk to friends about how you feel, don't hold back – so many of you tell me about feeling afraid, angry, sad, positive, tired and sometimes alone. Share that with those closest to you.

Try your local support group

Before the Covid-19 pandemic, we ran a local Fight Bladder Cancer support group, and I'm desperate to get ours back up and running as soon as we safely can. If a support group is your thing, then ask your CNS where your local group meets up and when. A support group is a great place to talk to others going through the same thing, the same treatments, and to talk to other people fighting bladder cancer at different stages, from newly diagnosed to finished treatment stage. And if you are not a group type of person then that's totally okay too. You'll find what suits you.

But I do ask you to take just one thing away from my ramblings, please share how you feel with at least one other person who is close to you.

It will help you – I can promise you that.

[1] Costa-Requena G, Ballester Arnal R, Gil F. The influence of coping response and health-related quality of life on perceived social support during cancer treatment. Palliat Support Care. 2015 Jun;13(3):683-9. doi: 10.1017/S1478951514000418. Epub 2014 Apr 28. P

It's my life, I'm alive ...

and I don't take anything for granted!

ARTICLE
AMANDA PHIPPS,
FBC forum member

Out of the blue, Amanda was diagnosed with muscle-invasive bladder cancer in September 2020. She talks about how her cancer has been a life-changing experience.

When I got my diagnosis, I was devastated. My world fell apart. The following months were a whirlwind of tests, three courses of chemotherapy, a radical cystectomy and the formation of a neobladder.

Choosing the type of ileal diversion is a very personal choice and the options offered can vary depending on individual circumstances; not everyone is suitable for all. I was offered the chance to have a neobladder, which has been a journey on its own, but, despite the challenges, I am still glad I chose this option.

There are no silly questions – but watch out for the wrong answers!

While I was making my decisions and going through treatment, I was desperate for answers and consulted Dr Google – a big mistake but a common one, I'm told. But at least it meant that I found the Fight Bladder Cancer website and forum and they became my lifelines. The website provided simple, relevant, factual information and the FB group was full of people in a similar position to me, even if our treatment plans were different. Everyone was so supportive. They understood if I wanted a rant, had answers to my frequent questions and shared their honest experiences. I laughed at some of the posts and cried at some, but that's the nature of this beast! One thing I never felt was judged or silly for asking anything. And I've made some incredible friends.

How my diagnosis changed my life

I went through a cycle of emotions when I was diagnosed – disbelief, anger (why me?), sadness, fear – then all over again after my surgery. My operation took 10 hours. With every week post-surgery, I gradually started to feel better and felt able to do more, although it was nine months later that I commented to my husband that I felt more like me.

My experience has changed me emotionally, physically, mentally and sexually, but with help and support from FBC, people I met, support groups, professional help, family love, time and experience, I am living a full and active life. It hasn't been an easy journey, but I am so proud of where I am and proud to share my story. My life now involves catheters, diet restrictions, bladder washouts, and meticulous planning of trips – but it's my life and I'm alive.

My advice for other cancer patients would be to:

- **put yourself first** and make time for you
- **listen to your body** and allow yourself the time to heal – in my house we called it 'repair and recuperating'
- **ask for help** and never feel alone – find out who your CNS is, where your nearest Macmillan centre is, connect with people on FBC and attend their forums
- **try to find a way to learn to live with cancer, but not in fear of it** (I say that as if it's easy when it is anything but!). Some days this feels impossible but other days are easier – I'm still working on it. I have started writing a bucket list (not that I think I'm going to die but it has kicked my ass and made me think about things I'd like to do/see/have and be). I plan things each month to tick off as I've achieved them, which is very satisfying!

My experience has changed me emotionally, physically, mentally and sexually, but with help and support from FBC, people I met, support groups, professional help, family love, time and experience, I am living a full and active life.

Why I decided to fundraise

It took a while before I could focus on anything other than the cancer and its treatment but I decided to fundraise for FBC, as they had helped me so much. I organised a few events, which I absolutely loved planning, including a drop-in coffee morning and raffle and dipping in the sea in November – although I wasn't brave enough to take the plunge myself.

From these events, I'm proud to say I raised a total of £1,441.20! – every little bit really does help! I honestly can't describe the satisfaction I feel from fundraising and, more importantly, knowing that the money I've raised will help the charity continue the incredible work it currently undertakes.

Foods to **Fuel the Fight**

How to eat sensibly when nothing takes your fancy

CARER STORY
CAROLYN HUMPHRIES
Food writer and author

Some people get really hungry when on cancer treatment, others find it a struggle to eat. Either way, you need to aim for that healthy, balanced diet everyone talks about. Here are some great tips on how to go about it.

Eat some of these every day to build your strength

- **A rainbow of fruit and vegetables** – the more colours the better. These contain phytochemicals, which are thought to have a protective effect against cancer and its spread. Many are also antioxidants, which may help your fight too! Include some **cruciferous vegetables** – Brussels sprouts, leafy greens, watercress, swede, turnips, radish, kohlrabi, cauliflower and broccoli. These all contain a chemical called allyl isothiocyanate, which can help protect DNA against carcinogen damage. All fruits are excellent, but **pomegranates, blueberries and cranberries (juice or fruit)** are particularly powerful antioxidants and especially good at relieving any cystitis symptoms.
- **Other foods rich in antioxidants** are protein-rich **whole grains, pulses, nuts and seeds (and their oils), seafood, poultry and lean red meat (venison and goat are particularly good as they are lower in saturated fat).**
- **Omega 3 polyunsaturated fat** can reduce inflammation and act as a natural pain blocker. You'll find it in oily fish (like **anchovies, salmon, mackerel, sardines, herring), flaxseed oil (the seeds whole will only really give you fibre), rapeseed oil, and walnuts, soya beans, pumpkin seeds and their oils.**
- Eat more **naturally fermented foods.** This will not only help your body's immune system but can help with any upset tummy during treatment. Go for **live bio yogurt**, soft bloomed **cheeses** like Brie or Camembert, blue cheeses, brined cheeses, like Feta, and well-matured (over six months) hard cheeses, such as aged mature Cheddar or Parmesan, **sourdough bread, sprouted seeds and legumes** (like bean sprouts), **miso paste** (great mixed with boiling water for a soothing soup even when feeling poorly), and **fermented soya products**, such as tofu.

Tips to help you cope with eating

- Eat little and often.
- Drink plenty of water.
- Soups and smoothies go down easily.
- Go easy on the caffeine.
- Make your food look appetising. Have a small plate, arrange food attractively and add a garnish – even just a parsley sprig.

FASS foods

Cancer itself and chemo can alter how food tastes – it may taste metallic or just weird. Adding more flavour can help the palatability, so make good use of herbs and spices and remember the acronym FASS: Fats, Acid, Salt, Sugar.

Fats: Use good-quality oils such as olive, rapeseed, sunflower or nut (walnut, hazelnut and sesame taste great). Put some good butter or butter spread on your toast or high-energy scones (see recipe).

Acid: A squeeze of lemon or lime juice can be added to lots of dishes or use citrus fruits or pomegranate arils to add zip and verve.

Salt: Sea salt flakes can add texture, useful minerals and bursts of flavour.

Sugar: A little honey or maple syrup can work wonders in anything from a salad dressing to a slight lift in a tomato-based dish.

High-energy snacks

When you need something to give you an energy hit, try these ideas.

- Cereal or fruit and nut bars.
- Crackers with nut butter.
- Dried fruits like dates, figs, mango.
- Banana or malt bread.
- A handful of raw nuts (with raisins, if you like!).

Energy-boosting mini-meals

MINI QUICHES

Line sections of a tartlet tin with shortcrust pastry. Add sliced mushrooms, diced tomato, a few prawns, flaked tuna with some sweetcorn or diced cooked chicken. Top with grated Cheddar cheese. Beat egg and milk (1 egg to 150ml milk), season and pour in. Bake at 190°C until set and golden. Serve warm or cold.

MINI SANDWICHES

Make a wholegrain bread sandwich with some cheese, chicken, oily fish, nut butter or hummus and some salad leaves. Cut it into bite-sized squares or mini triangles.

BITE-SIZED ENERGY SCONES

Rub 30g butter into 85g spelt flour, 2 tsp baking powder, a pinch of salt and 1 tbsp sugar (optional). Stir in 1 heaped tbsp ground almonds, a handful each of dried blueberries, cranberries and raisins (or use mixed dried fruit) and a handful of sunflower seeds. Mix with plain yogurt to form a soft but not sticky dough. Pat out to about 2cm thick and cut into 2.5cm squares or rounds (a shot glass works!). Place on baking paper on a baking sheet. Brush the tops with yogurt. Bake at 190°C for 10 minutes until risen, golden and the bases sound hollow when tapped. Serve warm or cold, split and buttered.

TOASTED, BUTTERED SOURDOUGH SLICES

Top with hummus, avocado mashed with a little lime juice and a few chilli flakes, chopped hard-boiled egg and cress or tuna in mayonnaise, or olive tapenade (from a jar). Serve with a salad garnish.

BUTTERNUT SQUASH, CARROT AND RED LENTIL SOUP

Simmer peeled and diced squash with sliced carrots and onion and some red lentils in chicken or veg stock with a pinch of chilli powder and dried oregano. Blend until smooth and season to taste.

MIXED VEG SOUP

Dice a rainbow of veggies – potato, carrot, leek, cabbage, beans, swede – anything you have. Place in a saucepan and cover with chicken or vegetable stock, about 2cm above the veggies. Add a bay leaf and some black pepper. Bring to the boil, then part-cover and simmer until tender. Discard the bay leaf and blend until smooth, adding 2 heaped tbsp dried milk powder. Taste and re-season. Serve with grated cheese, if liked.

SUPER SMOOTHIE

Blend 150ml cold milk with 2 heaped tbsp porridge oats, 1 ripe banana, 1 heaped tbsp dried cranberries, 100g mixed frozen berries, ¼ teaspoon ground cinnamon, 2 tbsp live bio plain yogurt, 1 tsp honey. Blend until smooth.

EASY MAC CHEESE

For one small portion, cook a large handful of macaroni in boiling water until tender. Drain but keep about 4 tbsp of the cooking water with the pasta. Over a very low heat, stir in a spoonful of dried milk powder, some grated Cheddar and black pepper and stir until thick and creamy.

You may also be interested in Amanda Allen's article ***'Eating well can help your healing'*** in *Fight 12*. To download a copy, go to **fightbladdercancer.co.uk/downloads** or see page 12.

When Anxiety CREEPS IN ...

... here are some ways to kick it out!

There's a lot to cope with when you are dealing with bladder cancer diagnosis and treatment, and Melanie takes a look at how bladder patients (and carers) can find ways to deal with the anxiety this triggers.

ARTICLE
MELANIE COSTIN
FBC Support Services Manager

Stress is a part of life

Anxiety is a form of stress, often that part of stress that deals with the 'what ifs' – when we encounter an unfamiliar situation and our mind goes off at a tangent, floundering around for solutions.

Both stress and anxiety are part of normal, everyday life. They help to motivate us, to keep us on our toes and ready to do our best.

But if the worrying situation has gone and the feeling of fear is still there or gets worse, then it can affect your ability to get things done and can stop you enjoying your daily life.

Why we feel anxious

One in six of us will be affected by some kind of stress, anxiety or depression at some time in our lives. Anyone undergoing bladder cancer treatment has a lot to cope with, so it's hardly surprising that they are more likely to feel anxiety that can be difficult to control.

The good news is that most people find themselves in a better place when they get their full diagnosis and can start a treatment plan. Meanwhile, there are plenty of things you can do to help.

How to recognise anxiety

You may think this is obvious, but it is worth understanding the main symptoms and why they occur as that will help you take back control.

Anxiety happens because a part of your brain (the amygdala) thinks that there might be something it needs to protect you from so it goes into the instinctive fight-or-flight mode.

This floods your body with a mix of things like oxygen, hormones and adrenaline that make you stronger and faster, more alert and powerful, so that basically you can fight for your life or make a run for it.

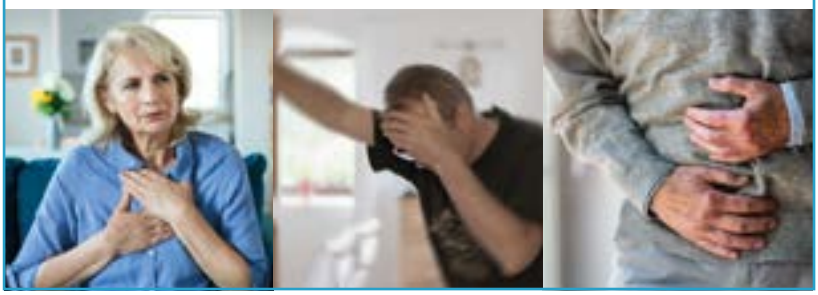
It's a normal and healthy response and we all have it.

The problem for people suffering from anxiety is that this response can activate more quickly and not always de-activate when it should. Instead of relaxing back to normal when the brain realises that there's nothing to flee or fight, the body is flooded with chemical fuel that has nowhere to go.

PHYSICAL RESPONSES

This chemical causes physical changes, all because the body is getting ready to fight or run.

- **Your breathing becomes shallow** to conserve oxygen and send as much as possible to your muscles. You might feel breathless or talk more quickly and your face may go red from the blood rushing to it.
- **You might feel a bit dizzy or confused** because oxygen builds up and carbon dioxide drops. Your heart races to get the oxygen around your body and can feel like it's literally beating out of your chest.
- **Your arms and legs might go tense or shaky** from the fuel rushing to them.
- **You might get a bit clammy or sweaty** or have cold hands when your body starts cooling itself down to stop it from overheating.
- **You may end up with butterflies** or feel queasy and with a dry mouth because any activity that is not essential to your immediate survival – and this includes your digestive system – begins to shut down to conserve energy.



THOUGHTS AND FEELINGS

- **You can feel upset or even angry** because this same part of your brain also controls emotions, so when it's in fight-or-flight mode it's switched right up to high volume. You may feel like bursting into tears.
- **You may have negative thoughts**, trying to make impossible predictions or worrying about what might never happen.
- **Over-worrying about physical symptoms** is common. While you should always mention symptoms to your urology team, thoughts are just thoughts and you need to let them go.
- **You may feel overwhelmed or out of control**, sometimes rising to a panic that seems to come from nowhere.
- **Feeling separate from your physical self** or your surroundings is also possible.

BEHAVIOURAL RESPONSES

- **You may avoid people or certain situations** that make you feel more anxious, such as a get-together or anything unfamiliar.
- **You may bite your nails** or fiddle with your hair.
- **You may feel compelled to perform certain habits** that don't seem to make any sense, such as having to touch the door handle a certain number of times before you leave the house.

Dealing with anxiety

There are lots of ways to manage anxiety by strengthening the brain so it can protect you.

Remember you need the zzzz

If you are anxious, you may have difficulty sleeping, either falling asleep, or waking up and not being able to get back to sleep. When you are still and quiet and trying to relax, negative thoughts or worries seem to see it as an open invitation to get the party started in your head!

Establish a relaxing bedtime routine and try mindfulness or breathing exercises.

The article on sleep on page 50 should give you more ideas.

Breathing and relaxation

It's hard to believe that something as simple as breathing can help control anxiety but strong, deep breathing – inhaling fully for a count of five, then exhaling completely – starts the relaxation response that calms down the surge of chemicals causing the horrible feelings of anxiety. There are several breathing exercises in 'Scanxiety' in *Fight* #10.

FIRST AID FOR A PANIC ATTACK

Help stop a panic attack by following this simple exercise to take back control. Try to name:

- **five things you can see**
- **four things you can hear**
- **three things you can feel**
- **two things you can smell**
- **one thing you can taste**

The brain has to focus on the activity and this allows it to calm down.

Talking

It's common to avoid talking about how you feel, especially as you may feel that others won't understand, or that you'll be judged or considered weak. But you are not alone. More people will have been where you are than you think! Pick up the phone and ring us at Fight Bladder Cancer – on 01844 351621.

We can just listen, or we can talk things through, point you in the right direction, or help you to join our private forum full of people who know how it feels.

Exercise

Any activity that gets your heart going is great for dispelling anxiety. Find something you enjoy and try to fit it into your schedule – ideally several times a week.

Mindfulness

While anxiety is fuelled by the what ifs, mindfulness keeps the brain in the present, focusing on and enjoying what is happening now. It can improve your concentration and ability to focus and help ease stress and depression. It can also stimulate the brain – and it's always good to have more brain cells at times like these!

You can achieve mindfulness through meditation and breathing exercises, but anything that totally focuses your attention on the now is good, even something as simple as a walk in the park really noticing the sensations of the air on your face, or the sound of the wind through the trees. (See also page 22).

Get professional help

If things seem to be getting out of hand, there's no shame in asking your GP for help. They will be able to discuss your options and may offer you medications that can help for a short while.

So if you find yourself feeling anxious, remember:

- Anxiety has nothing to do with courage or strength – people with anxiety can be some of the strongest and bravest people you know.
- Everyone needs help at some time in their lives – don't be afraid to reach out.
- There is plenty of help out there and you will beat it!

Scanxiety

This article is based on Melanie's full feature, 'Scanxiety', which appeared in our issue on mental health, *Fight* #10. Download it from **fightbladdercancer.co.uk/downloads** (or see page 12).

Mindfulness & cancer

What does it have to offer?

'Our sorrows and wounds are healed only when we touch them with compassion.'

Jack Kornfield

ARTICLE
TRISH BARTLEY
Mindfulness-based teacher and author

Mindfulness practice can help us rediscover a sense of balance at times – and this can help a lot.

Trish Bartley has been teaching mindfulness to people with cancer for over 20 years. She has written two books on the subject and has had cancer herself twice and is now well. She shares some ideas about mindfulness, and a simple exercise you can try.

Being told you have bladder cancer (or any cancer) is very tough. The words land in the ear but it is hard to make sense of them. For many people, at that moment, it is almost as if the thinking mind stops functioning and all that remains is the fear that grips the body – tightens around the chest or constricts the belly. Sometimes, there is no fear but instead a sense of numbness, almost as if nothing much is happening at all.

Perhaps it was different for you – but at some point in this cancer journey, anxiety, fear, loss or even anger may well be present – and all of them are normal. We are told over and over that the psychological impact of cancer diagnosis and treatment is often harder to bear than all the physical challenges of treatment and maybe even pain.

I remember reading about this impact in a research article many years ago, and it has been confirmed repeatedly both in my own experience and that of the many people with cancer who I have taught. Anxiety and uncertainty are so pervasive and hard to deal with. All the thoughts that start with words like 'what if ...' or 'if only ...' or 'why me?' take us down paths of dread and regret. I very much hope that this isn't the case for you! But I fear that it may be for many.

Mindfulness is not a magic cure for any of the above – unfortunately, life is not like that. However, mindfulness practice does offer us ways to learn how to step out of the thoughts that often make things worse – and come back to what is happening in the present moment, here and now. This takes practice and a certain sort of discipline or effort – for the worrying thoughts can be very 'sticky' and compelling in their own way.

Mindfulness practice invites us in the first place to find some place in the body to focus on – perhaps the feet on the floor or the hands in the lap.

That may sound strange – **but perhaps try it now.**

Feet on the Floor

As you sit here holding the magazine, experiment with moving your attention into the soles of your feet ... what can you find there?

Can you feel sensations of contact between your feet and what they are resting on? – maybe the texture of the carpet, the feel of your shoes, the solid of the floor beneath you.

See if you can just rest there for a few moments and if thoughts come in – which they probably will – just notice and come back to your feet again and the weight going down, pulled by gravity, holding you.

People talk about feeling more grounded and steady. By coming back to sensations in the body, we can find our 'anchor' again.

And when this is established, like a new habit, we then have more space to notice the things that we enjoy and that matter to us – like the smile of a child, or the smell of clean sheets, or clouds racing across the sky – or maybe snowdrops appearing in the garden.

How does mindfulness help?

We tend to live in our heads worrying about the future or dwelling in the past. We also have a tendency to be on autopilot a lot of the time – when the mind is not much aware at all, being pulled to this, or trying to avoid that. When the experience of cancer comes along on top of that, we may find that we lack the resources to manage things as we would like to.

Practice makes perfect

Mindfulness practice is easy to do – but a challenge to remember (because the mind is so busy, engaged elsewhere). The most effective way to learn is to go on an eight-week mindfulness-based programme – but if you are in the middle of treatment, that may not be possible. You might look for mindfulness resources online to listen and follow. I have written a book for people with cancer who want to learn mindfulness independently in the comfort of their own home. ***Mindfulness: A Kindly Approach to Being with Cancer*** has a website with plenty of practices that I have recorded, including some specially designed to support you during treatment.

However, you can also start very simply with practising Feet on the Floor a few times every day, for a few moments at a time and see how you get on. Perhaps you might decide to do it at specific times – such as when you stand waiting for the kettle to boil; when you pick up your phone; when you are sitting in a hospital clinic waiting room; when you get out of bed first thing; and last thing before getting into bed. Feet on the Floor is known as the First Aid Practice for people with cancer. By practising it every day, just for a few moments, and cultivating the habit, we then may find it is there when we need it – when life feels anxious and uncertain. We can find a way of coming back to feel more grounded and steady.

Feet on the Floor can also be practised standing and walking. If you are lying in bed at night unable to get to sleep, you might try practising 'Body on the Bed' (Feet on the Floor – lying down!).

Finally, coming back to the quotation at the beginning of this article, finding ways to take care of ourselves with kindness is the best medicine that there is. This is no different from mindfulness. The two go together.

Learning to bring awareness to how you are feeling right now is a really skilful way of bringing care and kindness to yourself, as best you can, and to all that is happening to you right now. Befriending.

Finding ways to take care of ourselves with kindness is the best medicine that there is.

If you would like to have a guided practice of Feet on the Floor, you can find one on the home page of Trish's website **trishbartley.co.uk** and also on **youtube.com/channel/UCOhFkdbme--S-OBmYZvlBjQ** where you will also find other practices

To find mindfulness teachers near you or who offer online courses, go to **bamba.org.uk/** and fill in your postcode

DRIVING FORWARD

How one man passed the test of cancer

PERSONAL STORY
GARETH GRIFFITHS
FBC forum member

Diagnosed with bladder cancer in 2015, Gareth had to give up his job as a driving instructor while he went through cancer treatment. FBC Support Services Manager, Melanie Costin, asked him about his experience of living well with bladder cancer.

What was your job before diagnosis?

I am an Approved Driving Instructor and I was working full-time, with some unusual hours, too, so work life was pretty busy.

When were you diagnosed?

I noticed symptoms in 2014, including blood in my urine, and went to the doctor several times. It wasn't until towards the end of 2015 that I was eventually diagnosed with highly aggressive muscle-invasive bladder cancer.

What were your first thoughts?

Much the same as most people, I expect! I retreated to the bathroom at the hospital, and I'm not ashamed to say, there were tears in my eyes. It really knocks you sideways to hear someone tell you that it's cancer. My first thought was 'why me?'!

What was the key thing on your cancer journey?

Determination. I really believed I would beat it and I told everyone that – even though there were some low moments.

Did you work during treatment?

Initially, yes. I managed to keep working for around four months but then I started chemotherapy. That's when the fatigue began to creep in – not just feeling tired but completely exhausted.

What were the biggest challenges?

Once I had my biopsy, I did suffer with blood clots in the bladder. That was while I was still working and it made a two-hour lesson a bit of a challenge!

When did you return to work?

I had my radical cystectomy in May 2015 and opted to have a neobladder, which I got used to quite quickly. I then returned to work around five months later.

How did your colleagues and clients react?

Well, being self-employed, I didn't have an employer to worry about; I believe many are very sympathetic. I just had my clients to think about and – fair play to them – they were all very sympathetic. Some needed to move ahead with their training, which is fair enough as I didn't know when I would be back at work, but about half waited until I was fit and well.

Do you have any ongoing problems?

Due to having a neobladder, I am prone to the odd UTI, but nothing I can't handle.

How are you now?

I am pleased to say I am now back to full health, I'm back at work and regularly attending the gym to keep myself fit. It's a shock to learn that you have cancer and can be a battle to get through it, but it is a timely reminder that you should live life to the full – and that's what I'm doing.

Do you have any messages for people who have recently been diagnosed?

Stay strong ... Keep positive ... Wee can beat this!

Fighting cancer-related FATIGUE

ARTICLE
HEATHER JAMES
Uro-oncology CNS,
Glan Clwyd

When your condition or your treatment leave you feeling exhausted, there are things you can do to relieve the problem.

Fatigue is persistent tiredness which is not relieved by sleep or rest and is out of proportion to your recent activity. Many people dealing with bladder cancer find themselves battling with this problem. Here, CNS Heather James, explains why it can happen and what you can do about it.

Why do people with cancer get fatigue?

There is a lot about fatigue that is not yet known, but our understanding is improving all the time. Fatigue can be caused by many things.

- Uncontrolled growth of abnormal cells requires energy, especially when cancer is advanced.
- Cancer forms toxic substances in the body and changes how cells work.
- Bone metastases, or secondary growths, can cause anaemia.
- Substances called cytokines are released by the body fighting the disease and these trigger the immune response.
- Metabolic changes caused by advanced cancer cause cachexia, a wasting syndrome, leading to reduced appetite, weight loss and muscle wasting.
- Treatments change protein levels in the blood which are linked to the inflammatory process.
- Effective treatment leads to a build up of cell waste. This takes energy to clean up and repair.
- Pain uses up energy and reduces rest and sleep.
- Frequent urination can also make rest and sleep difficult.
- Anxiety and stress add to fatigue.


Heather James

While many bladder cancer patients will not suffer fatigue, for those who do it can be overwhelming, unpredictable and frustrating.

Who gets fatigue?

It is thought that up to 80% of cancer patients will suffer from fatigue at some point during their treatment, although it is more associated with advanced disease or cancer treatments such as chemotherapy, radiotherapy and immunotherapy. While many bladder cancer patients will not suffer fatigue, for those who do it can be overwhelming, unpredictable and frustrating.

The effects of fatigue

Fatigue does not just affect the physical ability of a person but also cognition and emotions. Fatigue:

- Reduces energy, stamina, strength and productivity.
- Reduces concentration and memory and can cause word-finding difficulties.
- Causes anxiety, frustration, anger and low mood.
- Reduces motivation.
- Changes self-identity.
- Affects social life, relationships, family, wellbeing and employment.

What can I do if I have fatigue?

The first thing you should do is to recognise the symptoms. We all feel tired at times and having a bladder cancer diagnosis is stressful and will make you more tired as you try and come to terms with your diagnosis or possible diagnosis. You may need to undergo surgery and perhaps have further scans and tests before deciding on a treatment plan. The waiting between appointments is often the most tiring and stressful but this is not fatigue.

Normal tiredness improves after a good night's sleep or after a relaxing short break or time spent with friends and family. Fatigue is something quite different.

It is unpredictable and can happen at any moment; you cannot control it. It alters day-to-day functioning and has a negative effect on your quality of life. If you think you have fatigue you should talk to your healthcare team.

Assessing your experience

Some healthcare teams will help you to assess the degree of your fatigue using an Edmond Symptom Assessment System (ESAS) scoring tool which asks you to score your fatigue on a scale of 1–10:

1–3 = mild fatigue

4–6 = moderate fatigue

7–10 = severe fatigue.

They may ask you to complete a diary and to try to identify any contributory factors, the quality of the fatigue and how long it lasts in order to find better ways of managing your fatigue.

They should also do a physical assessment, checking for anaemia and nutritional defects, and reviewing medication, fluid electrolyte imbalance and mobility.

Treatment of physical causes

Some of the physical causes of fatigue can be treated, depending on the circumstances. Blood transfusions or iron supplements may be given, and nutritional supplements may be of benefit. For those with advanced disease and fatigue, the use of anti-inflammatory drugs or methylphenidate have been found to be helpful for some patients.

Coping with fatigue

For many, there is no obvious physical cause that can be treated and you will have to find ways to adapt to cope with your fatigue.

Physical activity is known to improve fatigue. Those with severe fatigue should be referred to an occupational therapist for an individual programme and a falls risk may need to be completed.

Other ways to manage fatigue

Those with mild or moderate levels can benefit from group exercise – yoga, swimming or any other moderate-intensity aerobic exercise – and functional resistance training. Many areas have exercise referral schemes to help those who are not already active to access local sports facilities with individualised support being offered – speak to your nurse or GP about what's available in your area.

The 5 P system to help you manage your fatigue

- **Plan:** Write lists of the things you need to do.
- **Prioritise:** Do the most important things first.
- **Pace:** Allow yourself longer for each activity than you did before and try and stop before you become too tired.
- **Permission:** Allow yourself to take things easy and be kind to yourself.
- **Position:** Make things easier; sit rather than stand when possible.

As fatigue has many causes, some people benefit from Cognitive Behaviour Therapy (CBT) or Acceptance and Commitment Therapy (ACT), although availability of these varies across the UK.

The University of Southampton and Macmillan have an online tool called 'RESTORE' to support people living with cancer-related fatigue and this can be found at **Macmillanrestore.org.uk**

Untire

The free Untire app has NHS approval and 'aims to help users gain better control of their energy levels by getting and keeping them mentally and psychologically active.
The programme offers a combination of insightful themes, such as sleep, anxiety, setting limits and nutrition, guidelines for managing energy, exercises to build strength, activities to reduce stress, and tips to improve mood.
For questions about the app contact **support@untire.me**

And ... Sleep

It is also important that you have a good night's sleep. Try to avoid sleeping during the day but do rest if you need to. Stick to a routine, going to bed and getting up at the same time. Don't go to bed hungry but reduce fluid intake for a few hours before you go to sleep to reduce night-time trips to the toilet. Keep the room at a comfortable temperature, dark and quiet, and avoid TV, phone or computer screens for 30 minutes before you go to sleep.

For more help, speak with your health care team and talk to others with cancer. Try joining the Fight Bladder Cancer forum at **fightbladdercancer.co.uk/get-help/getting-support**

If you are suffering with cancer-related fatigue, remember, you are not alone. There is help available, so ask your CNS.

Let's talk about LGBTQ+ SEX, BABY

A frank look at how cancer can affect the sex lives of LGBTQ+ people with cancer

This article explores some of the common issues facing bladder cancer patients through an LGBTQ+ lens and its recommendations may be useful to many patients across the gender and sexual orientation spectrums.

We don't talk about sex enough. For LGBTQ+ patients, this barrier can feel even greater as society often feels less able to talk about the sex we have. However, this can (and must) change, one frank conversation at a time. As LGBTQ+ people affected by cancer we have a right to talk about our sex lives in the way that feels most genuine to us and to ask for help specific to our lives.

ARTICLE
STEWART O'CALLAGHAN
Founder & Chief Executive,
Live Through This

Talk about what you need

Coming to terms with potential changes in your sexual function is an important part of the healing process and may begin with conversations within ourselves, thinking about our sex life before treatment and what it might look like afterwards.

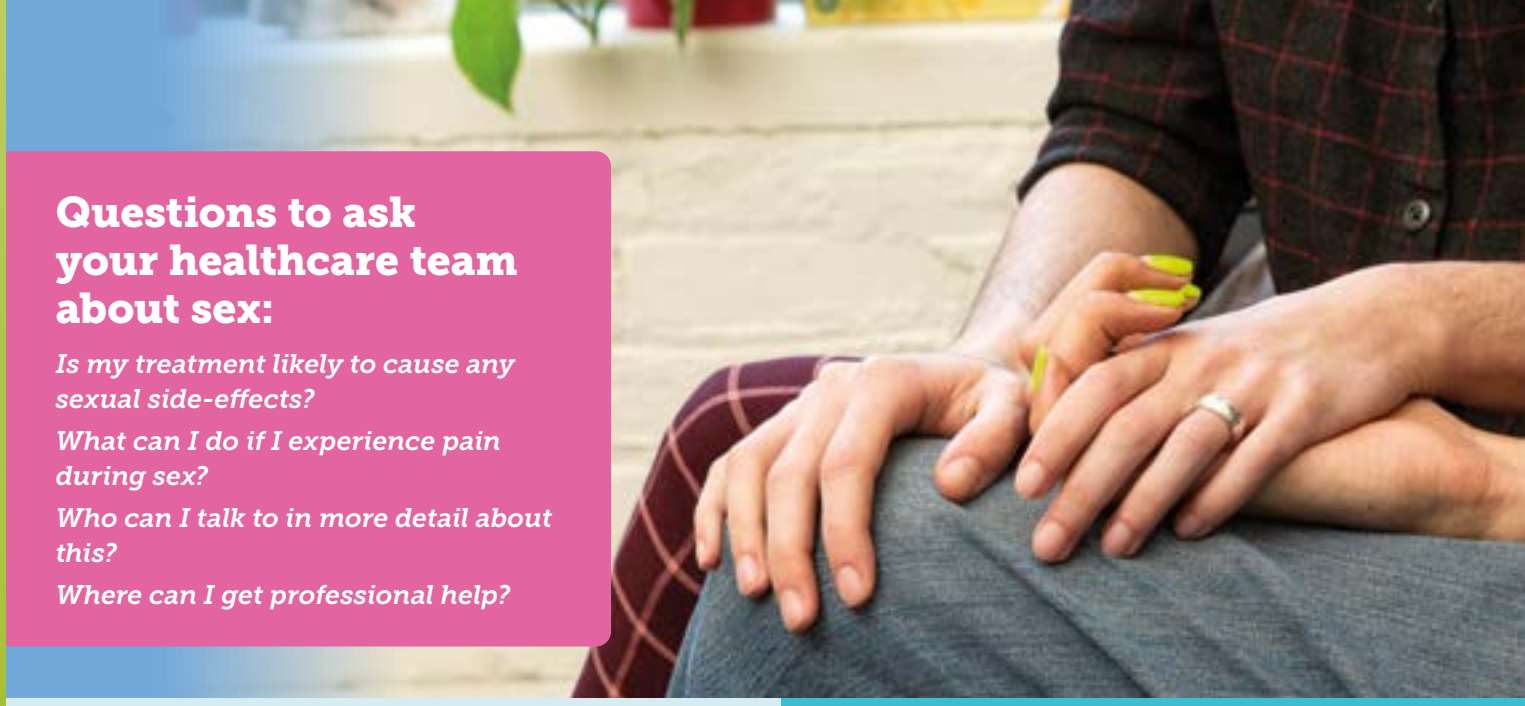
You may want to discuss these thoughts with your partner(s), particularly when describing any changes in comfort or pleasure. Open communication about consent and setting boundaries can help with this. It may feel unusual at first but doing so can help you relax into a moment, knowing that it won't stray into any area or activity you're not feeling ready for. This open communication also allows people to explore new activities or toys that might support your sex life after treatment.

Sex and intimacy are the key themes of Fight magazine #3, which includes articles on many aspects of sex after bladder cancer treatment.

Find a digital copy at **fightbladdercancer.co.uk/3** or email us at **info@fightbladdercancer.co.uk** to have a free print copy sent to you in the post.

"Your life really does a deviation from our lovely norm! My last scan was good though. Looking forward to my first Christmas as a married man!"

"Daniel", bladder cancer patient



Questions to ask your healthcare team about sex:

Is my treatment likely to cause any sexual side-effects?

What can I do if I experience pain during sex?

Who can I talk to in more detail about this?

Where can I get professional help?

Dealing with change

It can also help you to express your fatigue to your partner(s) and prioritise your intimacy needs. This might look like scheduling sex, or it might be engaging in intimate contact without the expectation of sex to follow. If you are unsure what these boundaries might look like or are not sure yourself of the changes that treatment has left you with, masturbation can be a useful way to re-establish a connection with your body and its sensations.

Finding out more

Information about sex is often split into 'men's issues' and 'women's issues', but when we think about our sexual anatomy and interest after treatment, the same concerns arise for most patients: how much sensitivity remains? how much blood flow can reach the genitals? and how does this affect our mood and our willingness to engage in sex?

Erectile dysfunction can be an unfortunate and common side effect for some. This may be related to the psychological impact of going through cancer or it may be a result of your treatments. If your bladder is removed, it is often done along with the prostate and seminal vesicles, which will stop you from ejaculating. If you are used to prostate stimulation as part of your sex life, this will no longer be possible if the prostate is completely removed. However, there has been recent progress in nerve-sparing surgeries where the bundle of nerves that drive this pleasure can be saved. This can also help with maintaining erections. These approaches are relatively new and Dr Hasan Qazi, Consultant Urologist and Surgeon, asserts that 'patients should absolutely be having a discussion about organ and nerve preservation.'

Talking about sex and preserving pleasure in your penis, prostate, clitoris or G-spot with your clinicians can help you to discuss your individual needs, treatment goals and help you to prepare for any changes.

'To be honest, not being able to have sex and more importantly an erection had been my biggest problem to try to come to terms with and cope mentally. I had anxiety and depression, and an overwhelming feeling of mourning ...

Thanks to the Fight Bladder Cancer forum, I now feel reassured and more positive for my future. Slow progress is better than no progress. Stay positive and don't give up.'

"George", bladder cancer patient

Solutions for erectile dysfunctions

There are a range of drug treatments available for people affected by erectile dysfunction and they can come as a pill, injection or urethral suppository. If these options do not work or are not your preference, you might consider a penis pump coupled with a cock-ring. Sex shops (both physical and online) sell a good variety of these and finding one that excites you can be a way to build erotic anticipation. These erectile aids may seem like they might 'kill the mood' by reducing the spontaneity of intercourse, but try bringing them into your foreplay and see their use as an initiation of sex to share with your partner(s), helping you to become accustomed to your new normal.

Image: Zackary Drucker: The Gender Spectrum Collection

Communicating before sex

Clear discussion of consent and pleasure is a great way to check in with your partner(s) when talking about or planning sex. Here are some potential questions you or your partner(s) may want to try:

- ***Think about all the times we've had sex. What made those times special?***
- ***What's your favourite way for me to let you know I want to have sex?***
- ***When is your favourite time to make love and why?***
- ***What is something you've always wanted to try?***
- ***How often would you like to have sex?***
- ***When do you feel closest to me?***
- ***Do you want to introduce a 'safe word'?***
- ***What do you need from me when we have sex?***
- ***How exactly do you want to experience pleasure?***

Isabel White, Psychosexual Therapist and Cancer Nurse, believes that, 'It is important to focus on re-writing or co-creating a new sexual script for you and any partner(s) for your current and future sexual wellbeing.'

If these methods don't address the issue – and with some pre-existing conditions they may not – there is still the option of a penile implant. White believes in a personalised approach to patients' needs and that for some people, the implant might be the best option – so there should be no shame felt in undergoing this procedure. Many men who have received an implant share their 'sexcapades' on active forums, describing in detail the sex that they're having, ranging from long-term partners to casual encounters with strangers.

These forums contain tips for successful sex, such as wearing a condom to support the head of the penis when penetrating, and how the implant fares during anal sex. One common theme shared by these posts is how proud they are of their implants and their ability to have sex with confidence.

To read an interview with a patient who received a penile implant, see **fightbladdercancer.co.uk/3**.

Adjusting to a stoma

Some people who acquire a stoma as part of their treatment feel that it affects their body image and becomes a barrier when engaging in sex, either with others or alone. If you do find that you want to cover a urostomy pouch, Etsy sellers have a range of high-waisted underwear specifically for pouches with a sewn-in pocket for comfort. These may also be useful for casual encounters if you don't want to explain your stoma. You might also want to explore other sex-based clothing, outfits or outerwear that covers your midsection. Many sex shops have a variety of options, and it can be great fun to explore what makes you feel comfortable and turned on. Choices range from cotton and lace to the more adventurous, flexible and form-fitting neoprene. It's all about what makes you feel good.

'On receiving my diagnosis, I was only given one option and that was to have a Radical Cystectomy. Without it, my life would be curtailed. My husband and I did have a discussion with my surgeon about having children. This was never an issue for us so was dropped.

Post op we found intimacy in the strangest places in that for the first time, my husband would help me shower daily. I think this in a strange way gave us both a chance to get accustomed with our new buddy ... the stoma!

For us sensuality is the bedrock of our life together. We both do a sort of mutual grooming on each other, hug whilst watching TV and have an appreciation of today. Obviously, life has changed for us, but sensuality has become the alternative to sex as we knew it pre Radical Cystectomy.

The thrust and lust of life takes a back seat, and sex in its more sensual form takes the driver's seat. It doesn't stop following a Radical Cystectomy ... it simply takes another avenue!'

"David", Bladder cancer patient

Dilation therapy

You may be recommended dilation therapy if your treatment has impacted the width or depth of your vagina. This can happen because of either surgery or radiotherapy. Menopause can also play a part in penetrative discomfort, whether it occurs before, alongside or is triggered by your treatments. If you find the dilators provided to you not very appealing, you can try using dildos or vibrators instead, which may be more comfortable or exciting.

It is important to follow the dilation schedule provided, so consider taking the dilators with you to a sex shop and compare them with the options available for both size and comfort. Don't worry about looking out of place, sex shop staff have seen it all and are happy to help! You might also want to try using a vibrator instead of the dilator or dildo. White suggests that '*Vibratory stimulation can encourage blood flow into clitoral, vulval and vaginal tissues and help our vaginal lubrication response, making penetrative or insertive sexual play more comfortable and pleasurable.*'

Lubrication

When shopping for any new insertable sex toy, lubrication is a must! Be sure to find one that is non-toxic, water-based and does not have any scents, flavours or excess sugar in its ingredients. Most sex shops will have testers or can guide you to the best lube for the kind of sex you want to have and/or toy you want to use.

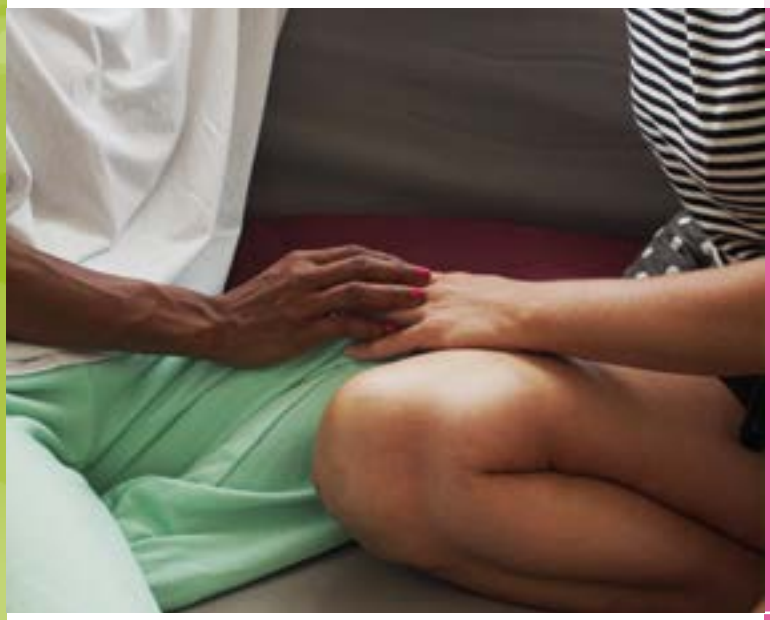
If you are experiencing menopause, you may also want to ask your doctor about oestrogen gels that can be applied directly to the vagina to help with dryness and discomfort. These gels are also safe to use if you are trans and/or non-binary, and won't affect any testosterone therapy if they are used as prescribed by your doctor.

Exploring penetration

A strap-on is a dildo that can be attached to the groin of the wearer by two main options: a harness which leaves access to the anus, or comfortable and tight boxer briefs that have a sewn-in holster. If you don't have a penis, they can be a great way to experience being the penetrative partner (the top). If you do have a penis, they can be a way to explore penetration for a range of people, including those with erectile dysfunction, phalloplasty, shorter penis length and metoidioplasty.

Many strap-ons on the market have hollow chambers and can function as sleeves or extenders. Some have textured insides and there is even an option that has a hole at the urethra of the dildo so that if it is sucked on, you can feel the suction inside the hollow chamber. Check out RodeoH.com for a large range of options, including both realistic and non-realistic dildos in various shapes and sizes that can be used with a strap-on.

If you are on the receiving end of the penetration but have experienced a change in the depth to your vagina, you may want to try a set of Ohnuts, which slip over the shaft of your partner or their toy to help control the penetration depth. They work as a soft buffer, helping you to relax into the moment. Some people also explore anal sex as an alternative to vaginal penetration. Again, remember your lube!



Communicating during sex

Good communication doesn't just happen before sex. Being able to communicate during intimate moments is a great way to check in on each other and be sure of shared pleasure and enthusiastic consent.

- *How does that feel?*
- *Are you comfortable?*
- *How do you feel about ...?*
- *I'd love to try ... How about you?*
- *How does it feel when I ...?*
- *What can I do to please you?*
- *Nod if you want more of it.*
- *Show me how you like it.*
- *Are you okay to keep going?*

Masturbation sleeves

Masturbation sleeves can also be a great tool for exploring new approaches to penetration. Open-ended options, like the Quickshot, can be used to support issues with depth. Closed-end masturbation sleeves have a range of textures that might be interesting to explore if you have a penis, but your sensitivity has been affected. Simple and soft options like the Tenga range offer a variety of suction strengths. These toys are great to use alone or with a partner and might be particularly useful for those struggling to engage in anal sex due to issues with erection firmness.

Non-penetrative sex

It's important to remember that not all sex is penetrative! There are many externally focused toys that we can engage with. These can range from small toys. like clitoral suction toys, up to larger devices like the Doxy Wand, which may be helpful for those with reduced sensitivity. The wand can also be paired with a Tenga egg, turned inside out and stretched over the wand's head for additional textural options. Oral sex can also be a great way to enjoy non-penetrative sex.

If you are worried about incontinence affecting your ability to enjoy receiving oral sex, Lizzy Scott, Senior Therapeutic Radiographer, recommends the NHS Squeezy phone app to strengthen your pelvic floor and dental dams for any additional concerns related to incontinence or chemotherapy. Dams now also come in underwear styles from Lorals Panties, which can make them easier to use and feel more erotic. These can be found via SpectrumBoutique.com, which is an online sex shop with information and trusted products. More information can also be found on the emerging platform **SexwithCancer.com**, a cancer-patient-led sex shop in the UK.

Asexuality

There are many people – who may or may not be having sex – who do not experience sexual attraction. You might suddenly wake up and find you have no sexual attraction to others, or you might have always felt like this. A lack of interest in sex can also be caused by some anti-anxiety and anti-depression medications. Asexual people have the same emotional needs as everybody else and are just as capable of forming intimate relationships. You can learn more about asexuality at **asexuality.org**

"I only found out about Fight Bladder Cancer in June. Up until then I felt I had an invisible cancer and that I was invisible too. It's nice to know I'm not alone and I'm very glad to be 'found'."

Malcolm

Relationships and pleasure

Ultimately, sex is about connection and pleasure – whether it's with ourselves or those around us. Cancer can undoubtedly shake up our lives and affect our feelings of vulnerability and sexual interest. However, the importance of sexual wellness should not be overlooked by ourselves nor our clinicians. Rebecca Martin, Advanced Nurse Practitioner and Lead Nurse, affirms that it is *'important to empower patients to open the dialogue' and for clinicians to 'allow the space in our clinical practice to do that'.*

Fight magazine

Sex and intimacy are the themes of **Fight magazine #3**, and it includes articles on many aspects of sex after bladder cancer treatment. To download a free copy, visit **fightbladdercancer.co.uk/3**

To request a hard copy call **+44 (0)1844 351621** or email **info@fightbladdercancer.co.uk**

To sign up for your free copy of future editions, go to **fightbladdercancer.co.uk/contact-preferences**

With thanks to

Isabel White (she/her), Psychosexual Therapist and Cancer Nurse, Perci Health Ltd and The Edinburgh Practice | **Lizzy Scott** (she/her), Senior Therapeutic Radiographer, Leeds Cancer Centre | **Hasan Qazi** (he/him), Consultant Urological Surgeon, St George's Trust | **Rebecca Martin** (she/her), Advanced Nurse Practitioner/Lead Nurse, The Royal Marsden Hospital

Live Through This: The UK's only LGBTQ+ cancer charity, led by and for the community. **www.livethroughthis.co.uk**

PERSONAL STORY
PETER BIERNIS
FBC forum member

TAKE CONTROL of your own healing

Diet, exercise, communication and laughter all helped Peter get through bladder cancer and beyond

I was diagnosed in 2016 when I was 56. I went to the doctor because I had quite a lot of blood in my pee. It only happened once, although with hindsight, I had a routine check-up with my GP a year earlier when they spotted some blood in two pee tests so the cancer could have been there then.

I was sent to hospital where the doctor examined my bladder and told me that I had a tumour about the size of a one pence piece. He said he couldn't be sure but it looked like bladder cancer. To be honest, I think he was sure even then. I had a CT scan and a TURBT, which confirmed that it was BC and it was TA G3, which is on the surface of the bladder but quite aggressive.

I used to smoke – which could have been a possible link – but I gave up about 10 years ago. I also worked with oils and fuels so there is another possible link. I could have just been unlucky.

Treatment wasn't fun but I got through it

They recommended 12 courses of BCG, holding the solution in your bladder for about two hours each time. It was horrible. I felt as though I had flu for about 24 hours and was in quite a bit of pain – but I stuck with it.

Then I had some follow-up TURBTs, as the doctor wanted to take biopsies. I had quite a few red patches which he thought was down to the BCG but needed to keep an eye on it. This went on for around 12 months and fortunately the cancer stayed away. We did discuss an RC (bladder removal) but that was not needed.

I have to say my consultant, Mr Sharma, was very good. He talked to me about keeping fit and healthy after treatment, including alternative therapies. I have been having a check-up every six months, although I have just gone onto 12-monthly check-ups.

If you want to find out more about TURBTs, ask your CNS for the FBC Patient Information Booklet or visit fightbladdercancer.co.uk/downloads to request a digital or hard copy.

I do consider myself lucky. I went through loads of emotions during the early stages and I still worry when check-up time comes around. There have been tears and I often felt sick to my stomach. However, it became quite apparent that this was a stress reaction – it's amazing how the brain can play tricks on you. I really felt physically sick when there was nothing physically wrong. I got a bit depressed at times and felt very down.

TAKING CONTROL

The only thing to do was to take back the control I felt I had lost. I am a former rugby player and supposed to be a big tough lad. I wasn't going to let this beat me.

I watched and read a lot about ways to improve my health. I started taking turmeric and still do. I eat lots of fruit and veg and drink plenty of water. Every day I make my own healthy smoothies with lots of greens and I quite enjoy homemade lemon water. I still enjoy a drink but only in moderation.

I learnt to meditate, which helped me no end and, in fact, was the start of a more relaxed lifestyle. I tried to get out and walk pretty much a couple of days after having BCG sessions. At first I felt rubbish and could not go very far but I was in the countryside and felt nature was starting to heal me. I have always enjoyed walking and cycling and have now taken up cold water swimming.

TAKING ON THE BIG ONE

I have never been a runner but I did want to tackle a marathon, so some friends and I decided to do the Night Walk in London, which was a full-length marathon for Cancer Research. This was during my treatment phase and, while I was in some discomfort, I did feel doing something positive helped me.

We decided to downsize and as I was able to take early retirement from my job, we moved to a small cottage in Cornwall. This has allowed me to slow down and really enjoy life – with plenty of fresh air and exercise.

I was determined to get on with doing things I wanted to do.

POSITIVITY CAN HELP YOU HEAL

I think having a positive mental attitude helps you overcome problems. It doesn't always work but I honestly believe we can improve our own health by having the right attitude and that, in some ways, is just as important as mainstream medications and treatments. There have been fabulous advances in medicine but many doctors just want you to take the pills and that's the end of it. I think that's the beginning and we should all make sure our lifestyle contributes everything we can to preventing illness and improving our own health.

There have been fabulous advances in medicine but many doctors just want you to take the pills and that's the end of it. I think that's the beginning ...

TALK ABOUT IT

Another important factor is talking to other people. As well as my family and close friends, for me, two people really stand out: Melanie from FBC and one of my nurses, who I got to know quite well. I also always tried to have a chat with my consultant in the early stages to understand what was going on. Talking about their problems is an area men struggle with at times. We think we are supposed to be tough and grit our teeth and get on with it. That's not good for you.

THE HEALING PROPERTIES OF NATURE

I have never been someone to sit at home and I enjoy the outdoors and nature. It's a great healer for me and I would often go for a walk and find somewhere quiet where I could relax in nature. This really helped to heal my soul.

I am now just over five years down the road. Of course, everyone is different but things have gone well. In my humble opinion, trying to get on with life as much as possible is vital. I am not talking about becoming an athlete, just moving, doing something you enjoy. Eating a healthy diet, avoiding the processed stuff as much as possible, will make a real difference. As a bonus, I also lost quite a bit of excess weight, reduced my cholesterol and came off blood pressure medication. Also do have a laugh whenever you can, and do something silly from time to time.

That's how I found my path.

Understanding The Impact Of Bladder Cancer

ARTICLE
KATE ABSOLOM
on behalf of the
LABC research team

An update on the Life and Bladder Cancer (LABC) project

Life and Bladder Cancer (LABC) is a study collecting Patient Reported Outcome Measures (PROMs) from those affected by bladder cancer. These outcomes can be used to answer questions important to patients, families and medical teams (see box). Quality of life and the long-term implications of bladder cancer are poorly understood as information is not gathered as part of healthcare. To help address this problem, LABC was established to obtain in-depth information about living with and beyond a bladder cancer diagnosis. Funded by Yorkshire Cancer Research since 2015, the work is led by Professor Jim Catto (University of Sheffield) and Professor Adam Glaser (University of Leeds) with input from a wider research team from the two universities.

The Life and Bladder Cancer (LABC) project

- What will life be like after you are diagnosed with bladder cancer?
- What health problems might you have in the short or longer term?
- How could the cancer or treatment impact on everyday activities like work, sex life, and general wellbeing?

LABC collected PROMs via questionnaires designed to capture the impact of cancer and its treatment on general health, quality of life and social lives. Obtaining this information directly from patients is vital to get a person-centred perspective on the consequences of bladder cancer.

Also, by linking the patient reports with individual treatment details we can try to understand what may lead some people to experience more problems than others.

What did LABC involve?

We set out to deliver two separate studies to explore the quality of life of patients during treatment and years later. Eligible patients were from Yorkshire, Humber, North Derbyshire or South Tees with experience of any type of bladder cancer (muscle invasive and non-muscle-invasive). In summary:

STUDY 1

In study 1, treatment centres across the regions recruited patients recently diagnosed with bladder cancer and we followed participants up over their first 12 months of treatment. Patients were asked to complete PROMs at the start of the study and then every three months for a year.

STUDY 2

Study 2 involved the completion of a one-off snapshot PROMs survey by people between 1–10 years beyond a bladder cancer diagnosis. Eligible people were identified through a national cancer register and questionnaires were sent out in the post with a freepost envelope.

The choice of PROMs used was guided by feedback from the LABC clinical and patient advisory group and other research conducted in this area. The final questionnaire packs included a range of measures and questions that covered general assessments of physical and mental health and more specific symptoms and side effects, such as problems with bladder or stoma function and sexual activity. The PROMs also asked about social life, lifestyle behaviours and employment/work status.

STUDY 2

For study 2, the questionnaire responses were linked with clinical data from the national cancer registry. This gave us more information about the types of treatment patients had received and allowed us to explore how treatment impacts on longer-term outcomes.

A patient advisory group has been involved in the project throughout: attending meetings, helping to interpret findings and contributing to papers.

What progress has been made so far?

Information collection for both studies is now complete. Across both studies we were able to collect data from over 2,000 patients, making it the largest bladder PROMs study in the world. For study 1, a total of 351 newly diagnosed patients were recruited and over 230 returned questionnaires for all the time points. For study 2, the one-off PROM survey was completed by 1,796 participants.

In the last year, the project team has been exploring the data participants provided, analysing the results, and preparing reports for publication. Our initial focus has been to analyse and write up the findings from study 2, the one-off PROMs survivorship survey. The first paper was published in May 2021 in the journal *European Urology* and describes the main quality-of-life outcomes.

We are currently finalising a paper describing sexual functioning and our next priority will be to look at patients' experiences of social and emotional distress and the factors associated with problems in these areas.

What have we found?

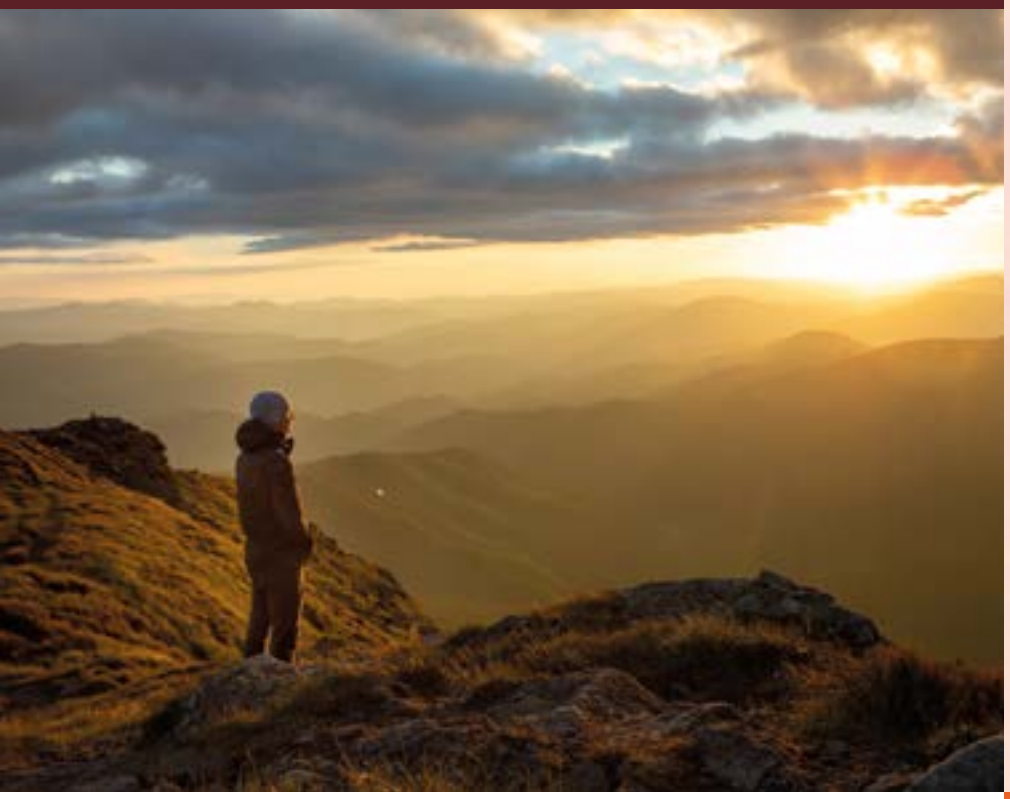
So far, the results suggest that for people living 1–10 years beyond a bladder cancer diagnosis:

- **Overall quality of life is similar** regardless of treatments received or type of bladder cancer.
- **Worse quality of life is seen in those who are older and in those with other long-term health conditions.**
- **Around 30% of the group said they are sexually active.** However, more sexual problems were reported by men, those who are younger or had received more extensive cancer treatment.
- **Younger people reported more financial problems.**

We compared the bladder cancer group with health PROMs data available from previous UK cancer studies involving people living beyond a bowel or prostate cancer diagnosis. We found that the bladder patients reported significantly more problems than the other groups.

The findings are important as they may help support treatment decision-making for patients and clinical teams in the future. We identified a need to explore sexual functioning in more depth in future studies.

It is important to acknowledge the study limitations. First our study samples are not representative of the wider ethnic groups across our region or the UK. Also, participants were more likely to be younger and from more affluent postcode areas than those who declined to take part. Therefore, we should be cautious in assuming the findings fully reflect the views and experiences of the wider bladder cancer population.



What's next for LABC?

LABC is funded up until the end of April 2022. Over the coming months we will be working hard to complete the analysis and study reports. We are looking forward to understanding what can be learnt from the results of following up patients during the first year of bladder cancer (study 1) and seeing if we can identify patients with different quality-of-life profiles. We hope the results will help future patients and clinical teams make treatment choices, improve knowledge of the impact of bladder cancer and help direct supportive care.

Useful links and references

The Life and Bladder Cancer website: **lifeandbladdercancer.org**

Recent LABC paper published in *European Urology*: **sciencedirect.com/science/article/pii/S0302283821000737**

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Will cancer treatment affect my fertility?

Having children might be the last thing on your mind – or the thought of losing the option might be devastating. This article talks about how cancer treatment can affect your fertility and how fertility preservation treatment could help.

ARTICLE
Young Lives vs Cancer

Whether your fertility will be affected will depend on your individual situation, the treatment you have, and which parts of your body are involved. With bladder cancer, the reproductive organs are often affected.

Your ovaries can be affected by some types of chemotherapy, radiotherapy, surgery or hormone treatment, damaging your eggs. This can lead to early menopause. If your womb (uterus) or vagina is being treated, this can also cause fertility problems.

Sperm production can reduced or stopped by some kinds of chemotherapy and radiotherapy.

Your sex drive, or ability to have an erection or vaginal dryness can also be affected by chemotherapy, radiotherapy, hormone treatment or surgery. If it hurts or your bits are dry and sore, make sure your partner is aware and get some advice. There are plenty of gels and lubricants available over the counter, online or via your medical team.

It's very normal to feel less confident and have less interest in sex while you're having treatment or are dealing with the after-effects. There are some great organisations that can help you to feel better about your body and regain some confidence so if you feel this way, make sure you check them out (see box). Join the Fight Bladder Cancer forum, ask your CNS or explore **youngminds.org.uk/young-person/coping-with-life/body-image/**

Look Good Feel Better: lgfb.ca/en/

Trekstock's RENEW programme: trekstock.com/finished-treatment-were-here-to-help-you-get-active

Teenage Cancer Trust's Find Your Sense of Tumour Conferences: teenagecancertrust.org/get-help/how-we-can-help/support-programmes

Changing Faces: changingfaces.org.uk/advice-guidance/

Young Minds: youngmind

What can I do about my fertility?

Fertility preservation treatment might allow you to have children in the future and it is something you should be offered if your treatment is likely to affect you.

If you have testicles, you might be able to freeze some of your sperm before your cancer treatment starts, in case you want to have biological children in the future.

If you have ovaries, you might be able to save some of your eggs before your treatment starts so they can be used to try for a child in the future. Freezing an embryo (an egg that is fertilised with sperm) may be another option. In this case, permission is needed from both partners at every stage, including if you want to you use it in the future.

Sometimes it is possible to freeze tissue from an ovary that contains immature eggs. This tissue can then be placed back in your body after cancer treatment to try and get your ovaries working again. This is a developing technology and only available in a few centres in the UK. Ask your cancer team whether this option is available.

A tough decision

Being confronted with this dilemma after your cancer diagnosis, and at this stage of your life, must feel wrong and unfair. Being asked to decide about having children in the future and whether you want to preserve your fertility, especially if you haven't really thought about it, could feel overwhelming and you may not feel ready to make this decision. Also, it sometimes needs to happen quite quickly before your cancer treatment starts, so you might have to decide within a limited time.

Communication is key

Try to talk it out with people you love and trust, including your nurse or doctor, as they can help you understand more about the options. An open and frank discussion to help you access appropriate fertility preservation treatment is an important part of good cancer care.

If you're in a committed relationship, it's your choice whether you talk to your partner about this or not but do make sure you are doing what feels right for you.

What if I've already had my cancer treatment or am in the middle of it?

Each individual case is different, but you can ask your GP or cancer team to arrange fertility tests after your treatment is finished.

If you feel your fertility was never discussed with you properly and you are mid-treatment, go back to your consultant or someone on your team that you trust. It's important that any questions or concerns you have are addressed.

There are lots of organisations that help people with fertility problems, so don't feel like you must go it alone.

(See box page 40)

At Young Lives vs Cancer, we strive to make our information inclusive and accessible. We understand that people identify differently, and, for some, fertility could be a triggering subject.

We have tried to move away from talking about treatment for men and women and have also tried to degender reproductive organs – not referring to them as male or female.

If you have any thoughts about what we're doing well or how we can do better, please get in touch at getsupport@younglivesvscancer.org.uk

ARTICLE
MACMILLAN CANCER SUPPORT

Macmillan Financial Help & Guidance

Everyone can access financial help and guidance at Macmillan Cancer Support.

It may not be the first of your worries following a cancer diagnosis, but cancer can be tough on your finances. This is because you may find yourself earning less if you need to stop working or reduce your hours and may spend more on everyday costs such as your heating bill or travelling to hospital appointments. Macmillan Cancer Support's advice and guidance is available for everyone with cancer, so that no one has to face the financial impact of their diagnosis alone.

The following financial support is available at Macmillan, and the charity is urging anyone in need of help to get in touch to discuss financial concerns and explore what help may be available so you can get back to the things that matter most in your life.

MACMILLAN GRANTS

If you have a low level income and savings and you need help with the extra costs that living with cancer can bring, you may be able to apply for a **Macmillan Grant.**

Macmillan Grants are small, one-off payments of £350, which can be used towards things like extra clothing, home adaptations, help paying energy bills, the cost of travel to and from hospital, or any extra costs that may occur because of a cancer diagnosis.

They are created to provide extra help during challenging times, rather than to act as a replacement for other support, such as benefits.

A grant from Macmillan would not normally affect the benefits individuals are entitled to.

At **macmillan.org.uk** you can also find out more about additional **grants and loans** from local and national organisations that are available for people living with cancer.

MACMILLAN FINANCIAL PUBLICATIONS

You can also find out more about the support available through Macmillan with the following range of financial booklets available to order for free at **be.macmillan.org.uk**, or by calling the Macmillan Support Line, including:

- Help with the cost of cancer
- Financial guidance series
- Managing your debt
- Keep warm without the worry

The Macmillan website also has many handy tools to help you understand your options for financial support. These include:

- A budget planner
- Benefits checker
- Benefit calculator
- Information on how to get help with **transport**

You can find out more at **finance.macmillan.org.uk**

MACMILLAN BENEFITS ADVISERS

If you're ever unsure about how to access benefit support, Macmillan's benefits advisers are available seven days a week to discuss your concerns and options. They have specialist knowledge of benefits, tax credits and grants, and can offer you up-to-date advice.

Working in partnership with organisations such as local Citizens Advice and local authorities, Macmillan also provides free face-to-face benefits advice via over 100 services across the UK. To speak to someone in person, find your nearest Macmillan benefits adviser.

To speak to a Macmillan benefits adviser over the phone, call the **Macmillan Support Line (Mon–Fri, 8am–8pm and Sat–Sun 9am–5pm).**

MACMILLAN BENEFITS CALCULATOR

Macmillan Benefits Calculator helps to determine which benefits and financial support people may be entitled to, and can be used if you have cancer or if you are caring for someone with cancer.

The calculator uses information about your income, savings, pension and existing benefits. If you have a partner, you will need their financial information too. Once you provide the information, the calculator will review and advise on what you can claim.

MACMILLAN ENERGY ADVICE TEAM

People living with cancer often find they are spending more money to keep warm. If you are struggling with your utility costs – whether that's for gas, electricity, solid fuels or water – Macmillan's Energy Advice Team is available for guidance and support and can:

- Offer tailored or bespoke support for all utility providers, including assessing vulnerability needs
- Work with patients to identify grant and trust-fund eligibility to help with ongoing fuel costs
- Advise on boiler or energy efficiency schemes to help with energy-saving improvements or to replace an old boiler with a new energy efficient model

Find out more at **macmillan.org.uk/energycosts** or by calling the **Macmillan Support Line on 0808 808 00 00 (Mon–Fri, 8am–6pm).**

MACMILLAN FINANCIAL GUIDANCE TEAM

Whatever your needs, Macmillan's Financial Guidance team can support you to make financial decisions that are right for you and those close to you, including:

- Help you think through practical options such as taking early retirement to look after a loved one
- Talk through the pros and cons of accessing a pension on the grounds of ill health
- Discuss your mortgage and help you work out your options if you're struggling with repayments
- Guide you through an insurance claims process and explain the options
- Chat through your options if you would like someone to take control of your finances for you, such as Power of Attorney
- Help you to navigate the Estate Administration process if you were to lose a loved one to cancer, including Probate and Confirmation applications
- Provide you with information on writing a Will
- Give you a better understanding of financial products and how they work and make financial jargon easier to understand

Speak to the team by calling the **Macmillan Support Line (Mon–Fri, 8am–6pm).**

IF YOU LOOK AFTER SOMEONE WITH CANCER

If you look after someone with a lot of care needs you could be entitled to **Carer's Allowance**, and if you are receiving **Universal Credit** you might also be able to access the carer element, even if you do not qualify for Carer's Allowance.

If you get Carer's Allowance, or the carer element of Universal Credit, you are not affected by the **benefit cap.**

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else, which is important as you need to pay National Insurance to qualify for a **State Pension.**

FURTHER SUPPORT

Macmillan Cancer Support is doing whatever it takes to support everyone with cancer live life as fully as they can, providing physical, financial and emotional support. For information, support or just someone to talk to, call 0808 808 00 00 (7 days a week, 8am–8pm, times may vary depending on the service) or visit **macmillan.org.uk**

About Macmillan Cancer Support

At Macmillan, we give people with cancer everything we've got. If you're diagnosed, your worries are our worries. We will move mountains to help you live life as fully as you can. And we don't stop there. We're going all out to find ever better ways to help people with cancer, helping to bring forward the day when everyone gets life-transforming support from day one.

A NEW WAY TO WEE

Living with a stoma or neobladder

Anyone who has had or is anticipating bladder removal, will need to get used to a new way to wee that will be part of the rest of their life. That can feel quite overwhelming, so it is particularly important that you discuss your options in detail with your medical team to enable you to decide what is best for you, what will happen and how you will manage with your new way to wee.

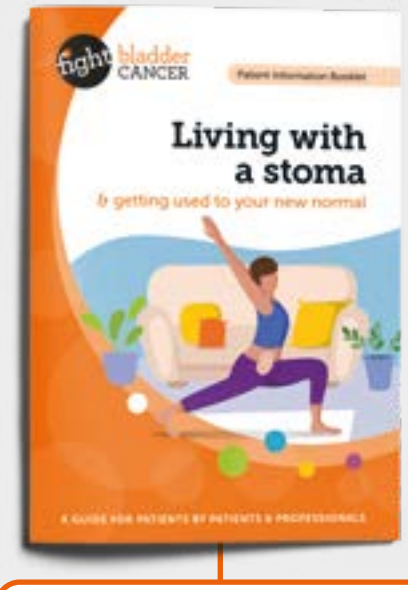
There are two main choices:

A **stoma** is a hole in the body made by the surgeon and using a small piece of bowel to link to your ureter, allowing the wee to drain out into a bag attached to your abdomen.

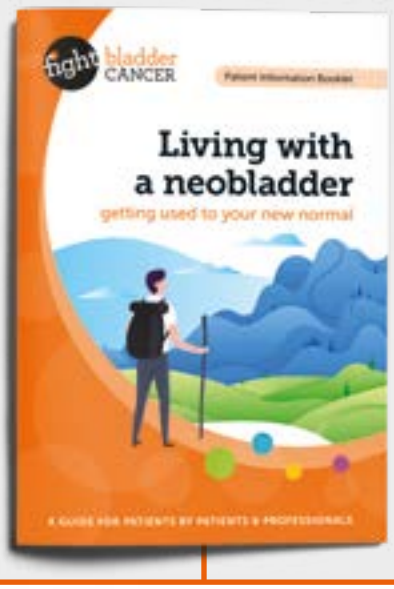
A **neobladder** is a replacement bladder made from a section of your abdomen.

Like anything new, it a will take a bit of getting used to, but most patients find that they can still do pretty much anything they could do before surgery.

Fight Bladder Cancer has produced two Patient Information Booklets giving full information on living well with a stoma or a neobladder, including:



Full advice from patients themselves from night-time tips to choosing supplies.



- **Making your choice**
- **Before & After the Op**
- **Getting used to your new way to wee**

- Emptying and changing the stoma bag
- Night routines
- Potential concerns
- Taking care of your skin
- Comfortable clothes
- Supplies
- Travelling

- Learning to use your neobladder
- How to empty your Neobladder

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

But I'm not a GYM BUNNY!

Exercise is important for all of us, and that means people undergoing cancer treatment, too. But what if the thought of a treadmill or a yoga class sends you scurrying for the sofa?

It's all very well to say find something you enjoy so you do it regularly and it helps both your health and wellbeing – it's quite another thing to achieve it!

I HATE EXERCISE!

The experts are right – exercise is good for you.

Here are a few ways to help you overcome your exercise aversion.

Is that a sport?

Who cares? Gardening, litter-picking, grocery shopping, housework – go for it with gusto and it'll be a workout.

Phone a friend

Find a like-minded friend and do it together.

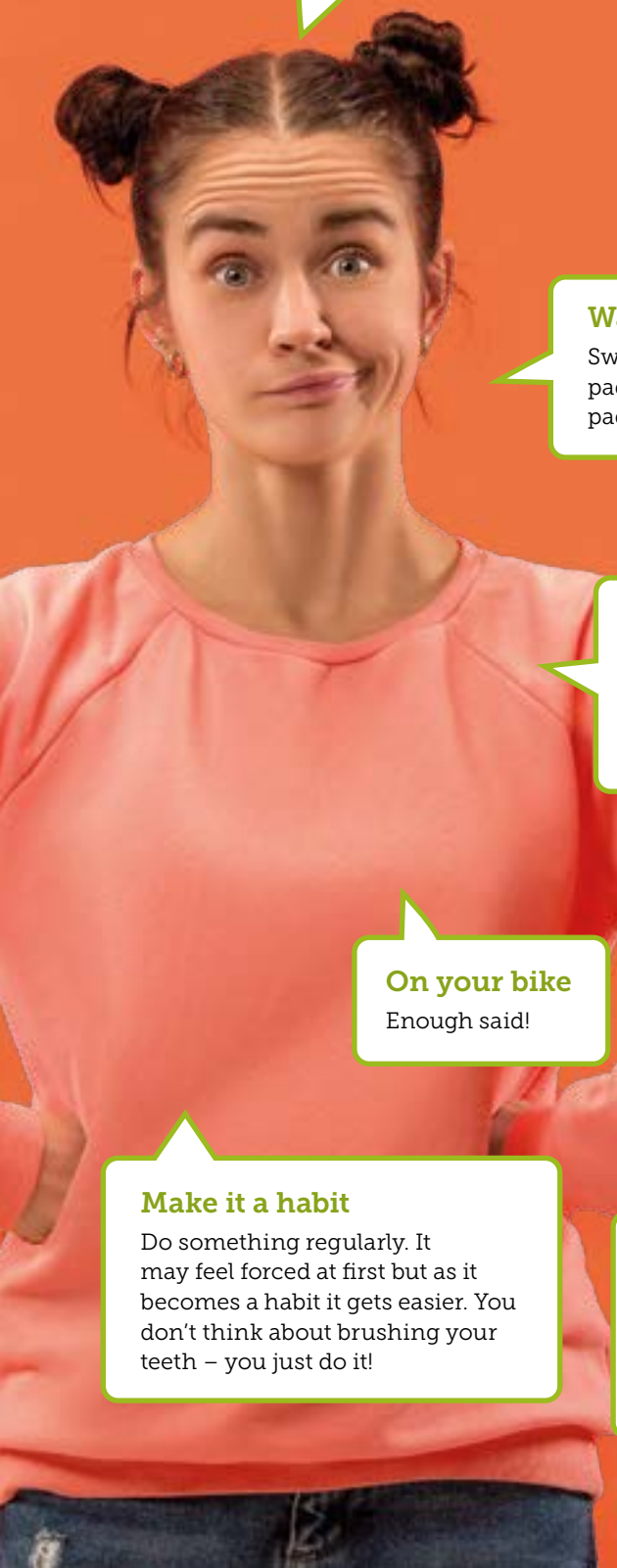
It's all in the mind

Try word association to get over your instinctive reaction to wince whenever exercise is mentioned! Every time you think 'exercise', repeat a positive word ten times, such as stronger, healthier, better, fitter, faster, higher. Choose a different word every day.

I need a zzzzz

A catnap after exercise is no bad thing as it allows your muscles to rest and repair.

ARTICLE
WENDY HOBSON
Fight Editor



It wears me out

You need to maintain a balance. Don't take on too much, rest after exercise and acknowledge that there are times when an old film and a snuggle on the sofa are what you need. That's okay.

Inside or out?

Choose exercise options suited to whether you are an indoor or outdoor person.

I feel such a fool

We all think it matters to other members of a class if we aren't that good, but they really don't care! But if COVID has taught us anything, it's that there is a wealth of free exercise videos online. Try some classes when you are home alone.

Water babies

Swim, sail, jump the waves, paddleboard, dive, doggy paddle, splash in puddles!

I can never achieve the objectives

Change the objectives! Overnight results are a fantasy. Choose one achievable target a week, pin notes anywhere to remind you. It could be just: I'll power-walk to the bus stop every day; I'll take the stairs up one floor, or I'll do one half-hour class on Zoom.

Music, music, music

Get the radio on and have your own kitchen disco. Try Zumba, Ceroc, line or ballroom dancing.

Leave the car on the drive

Leave yourself a bit of extra time and walk or bus instead of using the car for short journeys.

On your bike

Enough said!

Work with animals

Don't have a dog? Volunteer as a dog walker or go with a friend who has. Try horse riding or walk an alpaca!

Make it a habit

Do something regularly. It may feel forced at first but as it becomes a habit it gets easier. You don't think about brushing your teeth – you just do it!

Look to the East

Try tai chi, yoga, or even martial arts, such as karate or judo.

Lagging way behind the science

ARTICLE
MAGS HOUSTON
Head of Project Twenty21 – Drug Science

Fighting for better access to medical cannabis

Project Twenty21 was setup in November 2019 in response to the dire state of medical cannabis prescribing in the UK. Decades of stigma, stemming from racist propaganda and government policy based on lies, has led us to a point in time where 'cannabis' remains a challenging area in the UK.

Despite being legalised over three years ago for medical use, many of the population remain unaware that it is available now because so few prescriptions have been granted through the NHS. In August 2021, Drug Science made its festival debut at Product Earth – an expo celebrating the cannabis and hemp industries – and we were shocked to learn how few people there – already medicating with cannabis for conditions such as pain and anxiety – remained unaware they could apply for a legal prescription and obtain cannabis at a similar, if not cheaper, price than they were paying through the illicit market.

Breaking down barriers

A year on from legalisation, and only three NHS scripts written for whole plant cannabis, Project Twenty21 was launched in a bid to open up access through the private system. The key objectives were then – and remain now – improving access for patients and influencing NICE guidelines to support NHS prescribing. The latter is largely to blame for the lack of awareness around medical cannabis that we see in the UK today, together with a lack of quality education for potential prescribers and the fact that medical cannabis prescribing must be initiated by a specialist consultant, not a GP. There are still far too many barriers to access for patients.

What is Project Twenty21?

- The UK's biggest national medical cannabis real-world registry
- Multi-stakeholder partnership with academia, industry, clinicians and patients
- Gathering the largest body of evidence for the effectiveness and tolerability of medical cannabis
- Publishing data regardless of whether favourable or not
- Improving access to treatment for thousands of patients nationwide.

Why access medical cannabis through Project Twenty21?

- **Wider societal impact:** The data collected through the study provides us with evidence about the effectiveness of cannabis-based medicines, so moving us closer to the ultimate goal of better access to medical cannabis through the NHS.
- **Price:** Prescription costs are set at an affordable price, comparable with the illicit market.
- **Quality products:** The products available to patients are of the highest quality, all EU GMP compliant and manufactured by selected licensed producers. Product information leaflets, detailing cannabinoid content and terpene profiles, are available to patients for their prescribed medicine.
- **Trusted clinics:** All clinics on the study's **Clinic Directory** are CQC-registered and carefully monitored by the Drug Science team.

Student education

Over the last year or so, the Project Twenty21 team has helped provide better medical cannabis education for both patients and doctors. Through September, Project Twenty21 saw its first student campaign, enlisting the help of students up and down the country from numerous societies representing different UK universities. Key objectives were to raise awareness around the legal status of medical cannabis, as well as combat cannabis stigma amongst the youngest cohort of potential patients. 18-25 year olds only make up 10% of patients registered with Project Twenty21, with a disproportionate number of those being male (71%). Throughout Freshers week, students tagged and shared their posts on social media showing Drug Science posters, leaflets, flyers, stickers and badges being handed out during Freshers Fairs.

Drug Science

Spreading the influence

Now at over 2,000 patients with the project, the Twenty21 team is looking at ways in which it can influence medical professionals and the general public through conferences, events and webinars, such as Drug Science's virtual conference for GPs on 13 January. The event featured a series of bespoke talks and a panel discussing GP prescribing, how GPs can get involved and learn more about medical cannabis. Our hope is that we can change the legislation to allow GPs to prescribe freely in the UK in the future, as they already can in Jersey.

Every month, Drug Science releases updates on patient numbers and demographic splits as well as deeper dives into the data – these are called 'data nuggets' and can be found via the newsletter (sign up here: **drugscience.org.uk/project-twenty-21**.

Whilst the first two years have provided a steep learning curve in many ways as the project found its feet within a new, emerging market, the stories of transformation from patients keep us going. Hearing a patient describe how they went from being unable to walk to being about to live a relatively normal life, walking and riding a bike only a year or so later, is truly remarkable – and that makes it all worthwhile. Twenty21 aims to keep going whilst funding is available, until 20,000 patients are registered and until the aim of NHS access is achieved. We look forward to releasing more data and findings throughout 2022 from the study.

If you wish to find out if you or someone you know is eligible to be prescribed medical cannabis through Project Twenty21, simply visit our website here and follow the steps to register: **drugscience.org.uk/project-twenty21-medical-cannabis-patients**

The NHS allows the use of medicinal cannabis products for nausea and vomiting due to chemotherapy.
IT CAN ONLY BE PRESCRIBED BY PRIVATE DOCTORS ON THE GENERAL MEDICAL COUNCIL SPECIALIST REGISTER. CANNABIS DOES NOT CURE CANCER.

You need a GOOD NIGHT'S SLEEP

ARTICLE
MAGGIE'S
Cancer Charity

...and there are better ways to get that than counting sheep

Sleep provides both rest and recovery, which is important for everyone's physical and emotional wellbeing. For those with bladder cancer, or other types of cancer, both the condition itself and the treatment can cause problems with your normal sleeping patterns. Here is some practical advice from Maggie's, the cancer charity, on how to make sure you are getting enough.

How can sleep be affected by cancer?

Sleeplessness – or insomnia – affects people in different ways. It can be when you:

- Find it difficult to fall asleep
- Wake up several times during the night
- Wake up very early and can't get back to sleep

Whilst the occasional lost night's sleep can feel manageable, ongoing sleeplessness can affect quality of life, and can lead to fatigue, anxiety, poor concentration and even depression.

You may feel that it's normal to not be sleeping well and be trying to put up with it, but there are ways to manage it so you should let your doctor know.

WHY DOES IT HAPPEN?

Sleep disturbances when you have cancer are very common. Unfortunately, they can also be complicated, and it may be a combination of issues that is causing your difficulty sleeping. These can include:

- The cancer itself
- Side-effects of treatments
- Pain
- Anxiety
- The effect of drugs
- Changes in hormones
- Other medical conditions
- Your sleeping environment

You may also have a history of sleep problems that have got worse since you were diagnosed with cancer.

What can you do about it?

It may feel like making sleep better is impossible, out of your control and an additional burden on top of everything else but there are ways to make things easier.

Create the best environment for sleep

It is relatively easy to make changes to your sleeping environment, which can help to create the right setting for sleep and re-establish natural rhythms.

- **A warm bath before bed can help you to relax.** You may like to add some fragrant oil to the bath, such as lavender or ylang ylang
- **Avoid caffeine and alcohol** too close to bedtime
- **Go to bed when you're sleepy.** If after 20 minutes you're still not asleep, you could get up again, and try again later
- **Make sure the room is dark**, so have thick curtains with blackout linings, or try a soft eye mask
- **Sprinkle a few drops of relaxing lavender oil** on your pillow
- **Avoid looking at screens at bedtime.** If possible, remove devices like phones, tablets and computers from the bedroom altogether

- **Keep a notepad by the bed** so if you wake up you can write down troublesome thoughts to free your mind so you can get back to sleep
- **It is best if the room is quiet.** If noise from outside – partners, children, neighbours, pets – is an issue, consider whether you could temporarily sleep in another room, or even try earplugs
- **Eating a snack before bed** that contains some protein and a complex carbohydrate can help: something like oatcakes with nut butter or a slice of toast with hummus
- **Getting outside in the fresh air** during the daytime can help re-establish natural body rhythms and encourage sleep, as can gentle exercise

Talk to your healthcare team

Problems with sleep often have physical causes: certain drugs, like steroids, being in pain, feeling sick or needing to use the toilet are common issues that can affect sleep. It's important to let your healthcare team know what is troubling you as they may be able to review your medication and how your symptoms are managed to make sleep easier.

Your doctor may prescribe a short course of sleeping tablets to re-establish a normal sleeping pattern. You can also buy over-the-counter remedies to help with sleep but do check with your GP or pharmacist if you're on any other medications which they might interfere with.

There is a close relationship between sleep and how you are feeling and one can often affect the other. Learning different ways to manage your emotions and reduce your stress can help to improve your sleep pattern.

Reducing stress and anxiety

- **Breathing exercises** can help to ease the body into sleep. Just try breathing in deeply to a slow count of five, then breathing out fully to a count of five. You can find more breathing exercises at **maggies.org**
- **Relaxation techniques** can also be helpful. Taking each muscle group in turn, tense the muscles for five seconds, then release, starting with your feet and working up through your body. You can also ask your CNS or search reliable sources on the internet for more options.
- **Fresh air and exercise** can be helpful in dispelling stress.

WHERE TO FIND MORE HELP

Join the private Fight Bladder Cancer forum at **www.facebook.com/groups/bladdercanceruk** and talk to other people experiencing problems.

Look on Maggie's website at **maggies.org** or get in touch with your nearest Maggie's and arrange to talk things over with a cancer support specialist or find out about relaxation sessions and sleep workshops.

PERSONAL STORY

GORDON, ROSALIND & DOUGLAS ALEXANDER
FBC forum members

It's a family affair

Proof that our advice 'don't go red – go to the doctor' is invaluable.

Douglas was diagnosed with bladder cancer, it had a major effect on his wife and son too.

Listen to Douglas's wife, Rosalind ...

We were getting ready to go on holiday. The cases were mostly packed and we were going down to Ayr for a presentation for a cruise that we had booked and were looking forward to immensely. Douglas went to the toilet before we left and came out and told me there was blood in his urine. I wanted him to go to the doctor then and there but he was having none of it and we went to the presentation. So, as soon as we got home, I made him go

Thankfully, our doctor forced the issue and said he would not cover his insurance for cancelling the holiday if he did not go for tests – this said with my approval!

In the time we should have been away on our cruise, Douglas had three consultations, two examinations and an operation in a matter of a month.

Douglas tends to think that if you avoid talking about a problem, it ceases to exist, so getting him to talk about his diagnosis was a big step forward for him. We were extremely lucky to have a very supportive family and friends and we got lots of phone calls inquiring about his progress – and we still do.

When we go out anywhere, he is very conscious of comfort stops but that's partly psychological as he manages very well. Cathy, the nurse he met when he had his first cystoscopy, was excellent at explaining what was happening and could happen and told him to phone anytime if he was worried. Knowing there was always someone to talk to was a real help.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about a problem it isn't there. So getting him
to be able to talk about was a BIG step forward
for him.
We were extremely lucky to have a very
supportive family & got lots of phone calls

Listen to Douglas's son, Gordon

When I first heard my dad had bladder cancer I wanted to help in any way possible. As well as being there for him (and my mum) and helping with hospital visits, I felt I needed to do more and I decided that I would do some fundraising.

I was already entered for the Glasgow Half Marathon on 29 March 2019 but given that I had previously run a marathon, I thought I needed to do something more challenging so that's when I signed up to run the Loch Rannoch Marathon two weeks later. After completing them both, I had helped raise £2,165.54 for Fight Bladder Cancer. Then a few months later the world changed when Covid-19 and lockdown hit.

Lockdown

One of the few good things that came of lockdown was that it really brought into focus how much your family means to you and how much you want to do to help them. Although many running events were cancelled or rescheduled, I hadn't put much thought into fundraising in 2020. I was only too aware that some friends and family were not as lucky as I was with a steady income during that period. However, when I saw that the charity had a London Marathon place for 2021 I thought this would be ideal for me for a few reasons: firstly to support my dad; secondly to raise the profile of the charity in the public eye at a time when supporting contributions had been hit all over the fundraising sector; thirdly to help me set a target to achieve as lockdown did have an effect on my fitness; and finally to bring the charity to the notice of people who weren't aware of it through its extensive television coverage and a huge kerbside presence.

The London Marathon had moved from its traditional slot of April to October 2020 due to Covid-19, and was scheduled for October 2021 so this gave me time to prepare and, more importantly, time to raise funds. Training would be fine as I already had the 16-week training plan I had used before. Thankfully, training this time would be over the summer months.

Thinking outside the box

However, my main worry was how to raise funds given that restrictions in Scotland were tighter than in other parts of the UK. Traditional coffee mornings, office fundraising events and just meeting people in the streets with a bucket asking for change seemed to be restricted options –

> **I had to think outside the usual collecting box!**

I decided to organise a Euro 2020 sweepstake. I contacted everyone I knew and asked them to spread the word. I emailed a few businesses asking for support. I contacted two Glasgow community magazines and they published my story in their monthly magazines; Mum did this in her local town too. Alongside all that, I set up a Virgin Money fundraising site and also, at work, set up an electronic noticeboard advising what I was up to and my progress – this in lieu of our usual water-cooler moments while we were all working from home.

By the time the event came around it had been two years since I had asked my friends and family to sponsor me so they were very generous. My employer also gifted £1,000 to my fundraising target, as they had done back in 2019, so this helped a great deal towards the total amount I raised which was £3,764.13, including gift aid.

I was so pleased with the amount raised and wanted to demonstrate to those who sponsored me how much it meant. I think I did that when I crossed the finish line, taking 8 minutes off my previous best. I think I can safely say I was ecstatic!

Rosalind's advice

My advice would be if you need to go to a doctor or hospital, take someone with you to help you to hear what is being said to you. Ask questions; if something is worrying you, it is not a silly question – there's no such thing. ***Talk about the diagnosis to friends and family or even the nurses, rather than bottle it all up, and don't panic. You are not alone.***

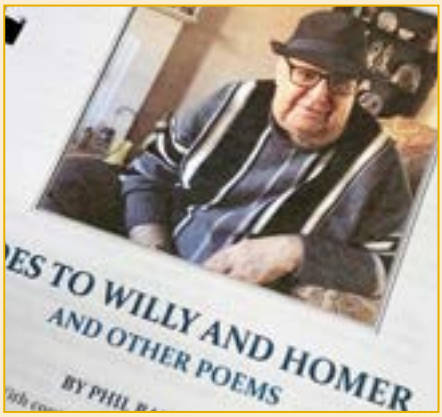
Fundraising round up

Autumn 2020 – Spring 2021

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.

Letting Creativity Flow

Thank you to **Philip** for writing and publishing a book of poems about his experience of living with bladder cancer. What a creative way to raise awareness! If you would like to order a copy, email **amy@fightbladdercancer.co.uk** for more details. All proceeds are being generously donated to Fight Bladder Cancer.



If you or someone you know has an upcoming birthday, wedding or event and might be interested in supporting FBC or setting up a fundraiser, please get in touch with Amy for details. It is through all your support that we are able to run our various services and advocate on behalf of bladder cancer patients in the UK.

FBC Fundraiser goes above and beyond ... literally!

On 18 September, FBC supporter **Jenna Allcock** organised a skydive with Delta colleagues in memory of a friend.

'We jumped out of the plane at 7000ft in memory of John Warburton who sadly passed away due to bladder cancer. We wanted to spread the awareness and raise as much money as possible for Fight Bladder Cancer. We are all very proud of the final total £1,320 and our achievement!' Jenna

Team FBC got their running shoes on for the London Marathon!

Massive congratulations to all our marathon runners (in London and virtually) for going out and raising awareness for Fight Bladder Cancer! We're so proud to announce that collectively they raised over £16,000 for us and we couldn't be more grateful! Pictured here are some of our #TeamFBC runners: **Murray Rogers, Gordon Alexander, Greg Weaver** and **Nicola Kelly**.

FBC Fundraising Superstars!

Massive thank you to **Adam Wilkinson** for raising a huge £2,000 for Fight Bladder Cancer after putting himself through a series of tough challenges, like the Chester Marathon and the Bolton Ironman, in memory of his father John. Thank you so much, Adam, you certainly deserve to put your feet up for a while!

Karen Akers raised £100 after her sister was diagnosed with bladder cancer, by taking afternoon runs along the River Great Ouse – thank you!

A family effort

After Zoe Stimpson was diagnosed in 2020, her family all came together and decided to do some fundraising for Fight Bladder Cancer. **Zoe, Phil, Ellie, Olly** and **Mich** took on the challenge of running/cycling a challenging 700 miles in just one month, with Olly and Mich even completing the challenge down under in Australia! We're so glad to have FBC supporters worldwide and thank you for raising a huge £2,252 for us!

In lieu of wedding favours, **Jess Stone** made a donation to FBC on behalf of her wedding guests after her mum was diagnosed with bladder cancer. Thank you so much Jess and congratulations to the new Mr and Mrs Comer.

Winter waves!

Mel and Jo from Gone for a Swim decided to organise a 'Chilly Dip' in the sea in support of their dear friend Amanda, who has been recently undergoing treatment. A group of brave swimmers endured the cold, wintery waters of Southend-on-Sea and together they've raised an amazing £265 for Fight Bladder Cancer. Thank you all!

Read more about Amanda's fundraising for us on page 14.

Mary's fundraising story

Thank you so much to **Mary Lovett** and her lovely Zumba instructor Lisa for organising numerous classes and bake sales in aid of Fight Bladder Cancer. The Zumba sessions sounded like they were a lot of fun and we're so grateful for the amazing amount of money you've raised for us!

'So much fundraising is done for other cancers – everyone knows about breast, bowel, prostate, etc., but you never hear about bladder cancer; it's as if we don't exist. We hardly get any media coverage and, when we do, it's mostly reported wrong.

When I did the first fundraiser, I asked the group what ribbon colours are associated with breast, bowel and prostate cancer and they all answered correctly. Then I asked what colours are associated with bladder cancer, and they didn't have a clue. I rest my case! So, my aim is awareness and to make sure no one is fobbed off by their GPs like I was!'

Mary Lovett

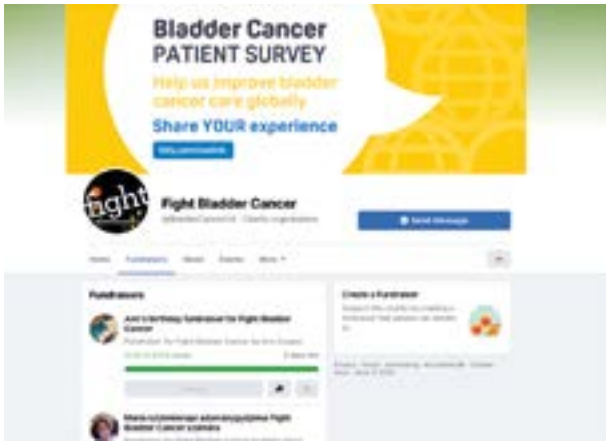
Phil Ladbrook's wife was diagnosed with Bladder Cancer last year and after several operations and chemotherapy, she is gradually on the road to recovery. He decided to fundraise for Fight Bladder Cancer to raise awareness and to show love and support to fellow patients as well as a massive thank you to the wonderful medical teams, support teams, carers and volunteers who looked after his wife. He completed the Royal Parks Half Marathon in 1.43.27 and raised an amazing £1,100.

Victoria Burton's sister was diagnosed at the start of 2017 and sadly lost her fight in the October of that same year; she was 37. Victoria wanted to do something in her sister's memory and the Plymouth Half Marathon seemed like a great idea. The pandemic gave Vicky more time to get ready to run and she helped raise £1,400 for us!

When **Yvonne's** husband Alan was diagnosed towards the end of 2020, she decided to take on the challenge of running 500 miles throughout 2021. She finished the last few miles just after Christmas and has raised an amazing £943 for us. Thank you, Yvonne!

Thank you to **Susan Storey and the Masonic Ladies** for organising a wonderful fundraising event for us, it looks like it was a lovely night and we're so grateful to you all for raising both awareness and an amazing £500 for us!

Huge thanks to **Charley Forde** for taking on the amazing feat of climbing the Three Peaks, in honour of her dear grandad, Roger, who passed away in 2016. Charley absolutely smashed the challenge and raised a huge £1,325 for FBC, thank you!



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 to set up 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 **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 is a touching 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.

'Michael spent his life teaching. He was highly respected and when he passed away from bladder cancer I received 140 cards, each and every one saying how wonderful he was, how respected and well thought of.

He was always so proud to hear how well his pupils did. Many of his pupils kept in touch over the years, keeping Michael updated with their marriages, births of children, and always thanking him for all the support he gave them when at school. He never once complained, and I am totally lost without him. In his memory people were very generous and donated £1,362.50 to Fight Bladder Cancer.'

Elaine Gibson

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 9–11.

Raise some money & have some fun! *giftaid it*

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**.

Registered with FUNDRAISING REGULATOR

What exactly are clinical trials?

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

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

Why trials are essential for patients

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

A clinical trial is not something to look at when all else fails. Many treatments we use today were developed as part of a clinical trial. For example, the use of chemotherapy at the same time as radiotherapy treatment was developed in the UK as part of a large study (called BC2001) and has changed practice around the world.

There are a number of clinical trials in bladder cancer. These usually compare a new treatment that has the potential to work better, or with fewer side-effects, than what is used as the 'gold standard'. Different trials are available in different hospitals. All studies have particular tick boxes to confirm whether this study is the correct one for you and your cancer. It may be that you and your type of bladder cancer do not match what we call the eligibility criteria for the study.

Knowing about what is on offer is very useful. You can find out information in the UK by going onto the website for the National Cancer Research Institute and clicking on the portfolio map for bladder cancer for an overview of current studies. **https://csg.ncri.org.uk/portfolio/portfolio-maps/**

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

How clinical trials work

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

Phase 1

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

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

Phase 2

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

Phase 3

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

Current open bladder cancer trials

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

The purpose of this study is to investigate the feasibility of using ctDNA to support cancer diagnosis and risk stratification where tissue biopsy is challenging due to infection risk, technical impracticalities and resource limitations.
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 is testing to see 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

CA045-009

The purpose of the study is to see if treatment with nivolumab plus bempeg or nivolumab alone, before and after surgery to remove the bladder, is more effective than surgery alone in participants with muscle-invasive bladder cancer who are not able to receive cisplatin chemotherapy.
Locations: Stevenage Hertfordshire, Leicester, London
ClinicalTrials.gov ID: NCT04209114

CHECKMATE 7G8

This study is for people with non-muscle-invasive bladder cancer. Patients will receive BCG, with the possible addition of the immunotherapy nivolumab. This is a study looking at how well these treatments work in people with non-muscle-invasive bladder cancer.
Locations: Glasgow, Bebington, Bournemouth, Coventry, Manchester, Sheffield, Stoke-on-Trent.
ClinicalTrials.gov ID: NCT04149574

CR108699

The purpose of this study is 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 harbor 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

CREST

This study is for people who have high-risk non-muscle-invasive bladder. Patients will receive BCG, with the possible addition of the immunotherapy sasanlimab. This is a study looking at how well sasanlimab works together with BCG in people with bladder cancer.
Locations: Barts Health NHS Trust, Charing Cross Hospital
ClinicalTrials.gov ID: NCT04165317

KEYNOTE-676

This study is for people who have high-risk non-muscle-invasive bladder cancer that is persistent or recurrent following BCG induction. Patients will receive a drug called pembrolizumab along with BCG, or BCG without pembrolizumab. This is a study looking at how well pembrolizumab works together with BCG in people with bladder cancer.
Locations: Raigmore Hospital, St Bartholomew's Hospital, St Georges University Hospitals NHS Foundation Trust
ClinicalTrials.gov ID: NCT03711032

RESECT

RESECT aims to be the largest multicentre international observational study evaluating the first and most important step in the management of non muscle-invasive bladder cancer (NMIBC), the transurethral resection of bladder tumour (TURBT).
Location: London
ClinicalTrials.gov ID: NCT05154084

SUNRISE-1

The purpose of this study is to evaluate the overall complete response rate in participants treated with TAR-200 in combination with cetrelimab or TAR-200 alone, or cetrelimab alone with Carcinoma in Situ (CIS).
Locations: Glasgow, Leeds, Manchester, Sheffield
ClinicalTrials.gov Identifier: NCT04640623

Muscle-invasive, advanced or metastatic bladder cancer

BL13

This study is for people with muscle-invasive bladder cancer. This study is looking at whether a type of immunotherapy drug called durvalumab can be safely administered after initial treatment. This study is to determine whether durvalumab given after standard trimodality therapy (maximal transurethral resection of the bladder tumour (TURBT) followed by concurrent chemotherapy and radiation) improves disease-free-survival when compare 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.
ClinicalTrials.gov ID: NCT03768570

BLADDERPATH

This study is to redesign the management pathway for patients with muscle-invasive bladder cancer by using an MRI scan rather than doing a transurethral resection of a bladder tumour (TURBT) to diagnose and more accurately and rapidly stage their cancer.
Locations: University Hospitals Birmingham NHS Foundation Trust, University Hospitals Coventry & Warwickshire NHS Trust, Sheffield Teaching Hospitals NHS Foundation Trust, Glan Clwyd Hospital, Derriford Hospital, Arrowe Park Hospital Birkenhead, Morriston Hospital Swansea, Manchester Royal Infirmary, Northwick Park Hospital Harrow, Royal Oldham Hospital, Nottingham City Hospital, St James's University Hospital Leeds, Norfolk & Norwich University Hospital, Royal Stoke University Hospital, New Cross Hospital Wolverhampton.
ISRCT Number: ISRCTN35296862

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

DPT02

This is a study to evaluate trastuzumab deruxtecan (T-DXd) for the treatment of people with bladder cancer who test positive for the HER2 biomarker.
Locations: Glasgow, London, Manchester, Northwood Middlesex, Sutton
ClinicalTrials.gov Identifier: NCT04482309

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 number/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 Identifier: NCT04995809

FIDES-02

This is a study for people with advanced bladder cancer who test positive for the FGFR biomarker. Patients will receive either a drug called derazantinib, or both derazantinib and another drug called atezolizumab. This is a very early study looking at the safety and ideal dose of derazantinib.
Locations: Barts and The London, The Sarah Cannon Research Institute London, University College London Hospitals, The Royal Marsden NHS Foundation Trust, Sutton
ClinicalTrials.gov ID: NCT04045613

IGNYTE

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

IMVIGOR011

This is a study for people with high-risk muscle-invasive bladder cancer and who have had a cystectomy. Patients will be followed up closely after their cystectomy and may receive the immunotherapy atezolizumab. This is a phase 3 study 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

KEYNOTE-866

This study is for people who have muscle-invasive bladder cancer. Patients will receive a drug called pembrolizumab along with chemotherapy and bladder removal, or chemotherapy and bladder removal without pembrolizumab.

This is a study looking at how well pembrolizumab works together with chemotherapy and surgery in people with bladder cancer.
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 who have muscle-invasive bladder cancer, and who are not eligible for cisplatin-based chemotherapy. Patients will receive either surgery alone, pembrolizumab plus surgery, or enfortumab vedotin plus pembrolizumab plus surgery.
Locations: Clatterbridge Oncology Centre Wirral, James Cook University Hospital Middlesbrough, Kent and Canterbury Hospital, Lister Hospital Stevenage, Barts London, Royal Marsden London, Imperial College Hospital London, Western General Hospital Edinburgh, Royal Cornwall Hospital Truro, Walsall Manor 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 is a study looking at how well pembrolizumab works together with chemoradiotherapy in people with bladder cancer.
Location: South Devon Healthcare Foundation Trust
ClinicalTrials.gov ID: NCT04241185

MOMENTUM

A registry facilitating implementation of the MRI guided Linear Accelerator radiation therapy system with the ultimate purpose to improve patients' survival, local, and regional tumor control and quality of life.
Locations: London, Manchester
ClinicalTrials.gov ID: NCT04075305

MORPHEUS MUC

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

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

NCT03170960

This study is for people who have locally advanced or metastatic bladder cancer. Patients will receive a drug called atezolizumab in combination with a new drug called cabozantinib. This is a very early study looking at the safety and ideal dose of cabozantinib.
Locations: Middlesex, Preston, Cardiff, London
ClinicalTrials.gov ID: NCT03170960

NCT03289962

This study is for people who have locally advanced or metastatic bladder cancer. Patients will receive a personalised cancer vaccine called RO7198457, with the possible addition of a drug called atezolizumab. This is an early study looking at the safety and ideal doses of the drugs.
Locations: Barts & London School of Medicine, Southampton General Hospital, The Royal Marsden Hospital Sutton
ClinicalTrials.gov ID: NCT03289962

NCT03473743

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

NCT03661320

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

NCT03782207

This study is for people who have advanced or metastatic bladder cancer, who have been previously treated with chemotherapy. Patients will receive a drug called atezolizumab. This is a study looking at how well this drug works in people with bladder cancer.
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 is looking at the safety and tolerability of the drug MRx0518 in people with solid tumours at 30 days post-surgery. It is a phase 1 clinical trial and will look at the drug's anti-cancer and immune system modulating properties. Patients will need to be amenable to surgical resection.
Location: Imperial College Healthcare NHS Trust
ClinicalTrials.gov ID: NCT03934827

NCT03955913

The purpose of this observational study is 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 tumours that cannot be cured by currently available drugs. 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 the way the body absorbs, distributes and gets rid of the study dug.
Locations: Royal Marsden NHS Trust Surrey, Beatson West of Scotland Cancer Centre Glasgow, Christie Hospital Manchester
ClinicalTrials.gov ID: NCT04069026

NCT04197986

This is a study to evaluate the efficacy of giving infigratinib, as additional treatment following surgery in people with muscle-invasive bladder carcinoma and the FGFR3 biomarker. The study enrols subjects with either bladder cancer post radical cystectomy or upper tract urothelial cancer post distal ureterectomy and/or nephrectomy.
Location: Sarah Cannon Research Institute London
ClinicalTrials.gov ID: NCT04197986

NCT04254107

This trial will look at a drug called SEA-TGT to find out 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

NCT04316689

This study will look at the safety and tolerability of the drug S-588210 in people with recurrent and/or metastatic solid tumours that cannot be removed by surgery. This phase 1 trial is for multiple different cancers and includes bladder cancer.
Location: University College London Clinical Research Facility
ClinicalTrials.gov ID: NCT04316689

NCT04349280

The purpose of this study is to evaluate bintrafusp alfa in people with metastatic or locally advanced bladder cancer. This phase 1 trial provides the first study of bintrafusp alfa in participants with metastatic or locally advanced bladder cancer that has progressed following platinum chemotherapy.
Location: London
ClinicalTrials.gov ID: NCT04349280

NCT04389632

This trial will look at a drug called SGN-B6A to find out whether it is safe for people who have 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 is a study to evaluate HMBD-001 for the treatment of 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. Its aim is to determine the safety, tolerability and effectiveness of an immunotherapy drug used in combination with radiotherapy. It is a phase 1 clinical trial, and will start with pembrolizumab prior to starting a course of radiotherapy.
Location: Royal Marsden NHS Foundation Trust
ClinicalTrials.gov ID: NCT02560636

RIO 018-17

Radical cystectomy (bladder removal) after bladder cancer necessitates surgical reconstruction to allow urine

STOP SMOKING

THE HELP IS OUT THERE!

Smoking is linked to all kinds of cancers, not to mention heart and lung disease. Cancer patient or not, it is best to stop. Here are a few ideas to help you kick the habit.

Think positive: Don't say you are 'giving up'; you are 'getting back' a healthier lifestyle.

List the benefits: With health at the top.

Don't keep it to yourself: Get everyone on your side.

Avoid your triggers: Identify what makes you light up and find strategies to avoid or endure them.

Check out the NHS advice: Explore the website. Call the free helplines to talk to a trained adviser (9am–8pm):

- **England:** nhs.uk/live-well/quit-smoking/ or 0300 123 1044
- **Scotland:** nhsinform.scot/healthy-living/stopping-smoking or 0800 848484
- **Wales:** helpmequit.wales or 0800 0852 219
- **Northern Ireland:** stopsmokingni.info

Exercise: Walk the dog, kitchen disco, swim, ride.

Relax: Try meditation, soothing music, yoga.

Join the FBC forum: Find support and friends at **facebook.com/groups/BladderCancerUK/**

Search 'stop smoking': For advice from reputable sources.

Chat to your pharmacist: Try over-the-counter gums or lozenges.

Ask your GP: They may offer nicotine replacement therapy in patches, inhalers, nasal sprays or medication.

Ecigarettes: More research is needed on effectiveness and safety. Talk to your GP.

Good luck – you can do it!

drainage. 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 is a study for people with advanced bladder cancer who test positive for the FGFR biomarker. Patients will receive either chemotherapy, a drug called erdafitinib, or a drug called pembrolizumab. This study will test how well these drugs work in people with bladder cancer. Locations: University Hospitals Bristol, St Bartholomew's Hospital London, Sarah Cannon Research Institute 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: Blackburn, Bristol, Gillingham, Glasgow, London. ClinicalTrials.gov ID: NCT04960709

FBC glossary

ACC Advanced Cancer Coalition

adjuvant after initial treatment to prevent secondary tumours

angiogenesis the development of a blood supply to a tumour

anterior exenteration surgical removal of a woman's bladder and reproductive organs

antiemetic a drug to counteract nausea and vomiting

B-cell response a natural immune response

basal relating to the base

baseline starting point for comparison

BAUN British Association of Urological Nurses

BAUS British Association of Urological Surgeons

BC bladder cancer

BCG Bacillus Calmette-Guerin, a treatment for early bladder cancer

BCQS Bladder Cancer Quality Standards

biomarker something by which the disease can be identified

biopsy a sample of tissue taken for examination

BLC blue light cystoscopy

BPH benign prostate hyperplasia

cannula a thin tube inserted into a vein in the arm or hand

carcinogenic cancer-causing

carcinoma malignant growth or tumour

catheter a thin tube

CCG clinical commissioning groups

checkpoint inhibitors drugs that prevent cancer cells from disabling protective T-cells

chemoradiation combination treatment of drugs and x-rays

chemotherapy treatment with chemicals toxic to the body's cells

CIS carcinoma in situ or flat tumour

CNS clinical nurse specialist

confocal laser endomicroscopy an advanced imaging technique for diagnosis

CT computerised axial tomography, a scan that uses a series of x-ray images to create cross-sectional views of the body

cystectomy removal of the bladder

cystoprostatectomy surgical removal of the bladder and prostate

cystoscopy a procedure to examine the inside of the bladder

cytokines cells that communicate an immune response

DAT device assisted therapy

DNA deoxyribonucleic acid

durable response rate the length of time a response is observed

DVT deep-vein thrombosis, a blood clot in a deep vein in the body

dysplasia abnormal development

dysuria painful or frequent urination

EAU European Association of Urologists

EBRT external beam radiotherapy

EBUS endobronchial ultrasound test for lung cancer

ECPC European Cancer Patients Coalition

ED erectile dysfunction

EMA European Medicines Agency, responsible for ensuring that all medicines within the EU are high quality, safe and effective

endoscope a medical instrument that is made to see inside parts of a person's body

enhanced recovery pathways methods of improving recovery times and experience

eosinophils white blood cells that fight off certain parasites and infections

ER enhanced recovery

expressed active

FDA Food and Drugs Administration (US)

FGFR fibroblast growth factor receptor

FGFR test laboratory test to see if a cancer has a mutation in a gene that could potentially be treated with erdafitinib

fMRI functional magnetic resonance imaging

gene forms of DNA, a collection of chemical information that carries the instructions for making the proteins a cell will need; each gene contains a single set of instructions

GI gastrointestinal

haematuria blood in the urine

HCP healthcare professional

Hickman line is a hollow tube inserted into a vein in the chest to deliver medication

histology the microscopic examination of cells

histopathological microscopic examination of tissue to identify disease

HNA Holistic Needs Assessment

HrQoL health-related quality of life

HSE Health and Safety Executive

ICER incremental cost effectiveness ratio

ileal conduit *see* urostomy

immune component part of the immune system

immunotherapy also called immune oncology therapy, treatment that stimulates the body's white blood cells to fight cancer; these drugs can help keep cancer cells from hiding from the body's white blood cells

inhibitory pathway a situation in which defensive cells are prevented from attacking foreign cells

intolerable toxicity the point at which the treatment becomes more harmful than the disease

intra-vesicle installations treatments administered directly into the bladder via a catheter

ITU intensive therapy unit

KW key worker

lines [of treatment] treatment regimens

luminal relating to the hollow inside an organ such as a blood vessel or an intestine

lymph nodes contain white blood cells, and are found all through the body

lymphangiogenic originating in the lymphatic system

macrophages white blood cells found within tissues

MDT multi-disciplinary team

metaplasia transformation of a tissue from one type of tissue to another type of tissue

metastatic cancer that has spread from its original place to another part of the body

MIBC muscle-invasive bladder cancer

MRI magnetic resonance imaging, a method of scanning using a magnet and radio waves

muscle-invasive bladder cancer cancer that has spread to the muscles of the bladder

mutagenic an agent that changes genetic material

neoantigens newly formed proteins that have not been previously recognised by the immune system, often as a result of tumours.

NMIBC non-muscle-invasive bladder cancer

OCT optical coherence tomography, a medical imaging technique

oncolytic cancer-killing

PALS Patient Advice and Liaison Service

PCT primary care trust

PDD photodynamic diagnosis – a technique where a special liquid is placed in the bladder before operating, so the surgeon is able to distinguish tumour cells from normal cells

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

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

PD-L1 test laboratory test to see if the drugs atezolizumab or pembrolizumab are likely to work in people who are not able to have chemotherapy

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

PET positron emission tomography

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

PFS progression-free survival

photodynamic diagnosis BLC or blue light cystoscopy

PHR patient-held record

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

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

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

priapism a persistent penile erection not necessarily associated with sexual arousal

primary endpoint answers to the primary questions posed by a trial

PROMs patient-reported outcome measures

proteases enzymes that break down protein

pyrexial having a body temperature above the normal range

QoL quality of life

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

radiotherapy treatment with radiation

randomised trial a controlled trial in which people are randomly assigned to different groups to test a specific drug, treatment or intervention; neither the participants nor the healthcare professionals know to which group each patient belongs

RCTs randomised control trials

refractory resistant

resection surgical removal

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

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

squamous scaly

stoma an artificial opening on the abdomen that can be connected to either your digestive or urinary system to allow wee or poo to be diverted out of your body

surrogate markers a reliable substitute for the disease

T-cell a cell that can attack a cancer cell

tachycardia abnormally fast heart rate

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

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

transitional cell cancer (TCC) most common urinary cancer

tumour abnormal masses of tissue that result when cells divide more than they should or do not die when they should; tumours can be benign (not cancer) or malignant (cancer)

tumour microenvironment the cellular environment in which the tumour exists

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

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

uropathy a disease of the urinary tract

urostomy a surgical procedure to create a stoma

urothelial of the urinary tract

UTI urinary tract infection

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

WBCPC World Bladder Cancer Patient Coalition

You can help us fight bladder cancer!

Call us on
01844 351621
or email
getinvolved@fightbladder.co.uk

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.

Don't forget, we're here to help!

fight bladder CANCER

Our range of materials is designed to help you and your patients

- Nurse contact cards
- *Fight* magazines (print & digital editions)
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Cited by the NHS as best practice in patient communication. Order your booklets now!

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