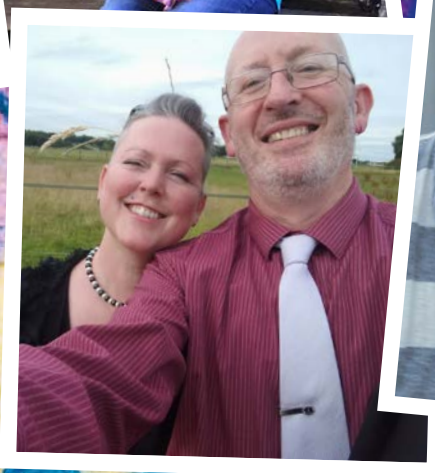
Fight Bladder Cancer
from the charity
11

fight MAGAZINE

FOCUS ON CARERS: THE PRESSURES & REWARDS OF CARING FOR SOMEONE WITH CANCER



YOUNG CARERS
HOW TO HELP LIGHTEN THEIR LOAD

CARING FROM A DISTANCE
HOW YOU CAN STILL CARE IF YOU DON'T LIVE NEARBY

SHE IS MY ROCK
REAL STORIES FROM BLADDER CANCER CARERS

THE CARERS' A TO Z
A UNIQUE AND PERSONAL SURVIVAL GUIDE TO GETTING THROUGH DIFFICULT TIMES

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

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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.**

Working to Fight Bladder Cancer

Welcome to the 11th edition of our *FIGHT* magazine.

This edition is dedicated to all our amazing carers, loved ones and family members who walk with us on our bladder cancer journey.

There are many different types of carer. Young carers, long-distance carers, spouses, siblings, neighbours and friends. This magazine includes personal stories from all types of carer from around the United Kingdom, as well as advice and information about helpful resources. 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 from home.

Cancer plus the threat of Covid-19 is a horrible combination, adding additional stress to an already challenging time of our lives. Please remember that you are not alone on this journey. There is a whole Wee Family with you. Fight Bladder Cancer is here to help you every step of the way.

We offer free 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.

Despite the challenges of the pandemic, we are delighted to be about 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.

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

Contents

If you find a word or abbreviation you don't understand use our FBC glossary on page 70

SPECIAL FEATURE
BLADDER CANCER CARERS

Underpinning the whole care system is the group selfless individuals who care for their family and loved ones though their cancer journey.

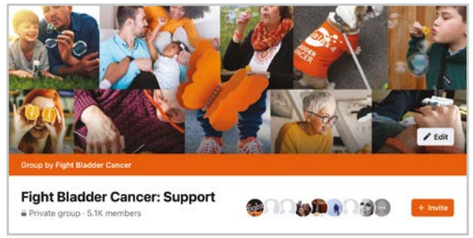
FEATURES

REGULARS

FBC round up

Find out what has been happening at Fight Bladder Cancer

SUPPORT



ONLINE FORUM

Our online private forum now has 5,063 members, and is supervised by admin and 10 moderators from around the globe 24 hours a day. In the past month we have had 450 posts and over 24,000 comments and reactions. Currently the most popular time for interaction on our forum is early afternoon on Fridays.

'The best thing about the forum is you can go on it day or night, and you know that someone is going to be there.' *Brent*

TELEPHONE & EMAIL SUPPORT

Sue Williams

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 1,000 telephone calls a year.

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

'Your Support Services Manager has been a star in every way – utterly approachable, consistent, caring and treats all with dignity. PLUS she delivers results in spades. Additionally, she is positive but realistic! She gets my vote as "simply the best".' *Colin*

'I would just like to say to all at Fight Bladder Cancer ... Just keep doing what you do ... I for one, feel blessed to be part of this amazing bunch of true warriors, but most of all, true people who show how negative vibes can be quickly turned to a wonderful display of human kindness and genuine heartfelt love.' *Steve*

ZOOM SUPPORT

Melanie Costin

We now host monthly Zoom support groups. This has given us an opportunity to be in touch with people like never before. Our new 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. Past topics have included a Virtual Christmas Get-Together, a Chat About Non-Muscle-Invasive Bladder Cancer with nurse Ann Moore, and Activities for Staying Cosy. For information about future Zoom support groups see our website at **fightbladdercancer.co.uk** or contact us at **support@fightbladdercancer.co.uk**

FIGHT MAGAZINE

As many urology centres have now removed reading materials from their waiting rooms due to the risk of COVID-19 transmission, we are now offering a digital version, as well as free posting of this magazine directly to patients, carers and health professionals. If you have not yet signed up for your free digital or physical copy, please visit: **fightbladdercancer.co.uk/contact-preferences**

Fight Bladder Cancer intern Kate Moore

Sign up for your free copy of *Fight*!

'Thank you to the team for producing this excellent magazine in these difficult times!' *Liz*

CONTACT CARDS

We supply high-quality, free personalised contact cards for all Medical Professionals working with bladder cancer patients. Order yours here: **https://tfaforms.com/4864593**

PATIENT INFORMATION BOOKLETS

We have proudly launched our Patient Information Booklets. The information 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. Healthcare professionals can order their complimentary binder at **tfaforms.com/4857974**

COVID-19

Fight Bladder Cancer continued its support of patients and carers during lockdown with its private online forum and online support groups. Understandably the amount of support and the kind of information we needed to provide gave us a considerably larger workload, particularly when reassuring patients and keeping abreast of news and developments.

We 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 to stay on top of new developments.

We also contributed to the Global Cancer Coalitions Network's survey and report on Covid-19's Impact on Cancer Patient Organisations Worldwide. The report found that 'the majority of organisations provide essential services – often adapted to the online environment – with reduced budgets, staff and volunteers, for a patient population whose needs in terms of support and information have increased significantly.'

By far the majority of respondents 80% said that technology had helped to redefine how they connected with their community of patients and supporters in a lasting way

GLOBAL CANCER COALITIONS NETWORK

COVID-19: Impact on Cancer Patient Organisations Worldwide in 2020

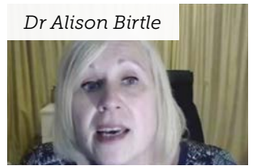
RESEARCH

EXEMPLAR PROJECT

Fight Bladder Cancer has completed interviewing people with bladder cancer and carers for research interviews to collect the views and experience of people affected by the disease. These interviews form part of Fight Bladder Cancer's Exemplar project, which will define what exceptional services for people affected by bladder cancer would look like. If you would like to know more about this project, please contact **research@fightbladdercancer.co.uk**

EUROPEAN SOCIETY FOR MEDICAL RESEARCH

Medical oncologist and Fight Bladder Cancer trustee Dr Alison Birtle spoke at the European Society for Medical Research, and emphasised that chemotherapy remains the backbone of advanced bladder cancer treatment, and after chemotherapy, maintenance immunotherapy is currently the optimal therapy.



Dr Alison Birtle

QUALITY OF LIFE AFTER BLADDER CANCER

Urologist and Fight Bladder Cancer trustee Jim Catto was a co-author on a paper about Quality of Life After Bladder Cancer that was published in the journal *European Urology*. The study was a cross-sectional survey of patient-reported outcomes that found that patients living with bladder cancer often have reduced quality of life, which may be worse than that for other common pelvic cancer patients. Age and other illnesses appear to be more important in determining the quality of life than treatments. Many patients have sexual problems, and many have financial worries.

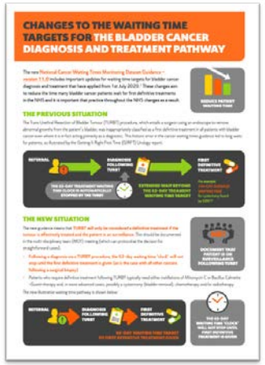
BLOOD IN PEE CAMPAIGN

The evaluation of the NHS's **#BloodInPee** campaigns from 2013 to 2016 found that 'the increase seen in bladder cancer incidence both overall and in those referred urgently with a suspicion of cancer is a major success of the campaigns.' Knowledge of blood in pee as a symptom of kidney or bladder cancer significantly increased from 27% to 44%, and advanced bladder cancers diagnosed resulting from an urgent GP referral increased by 8.2%. An additional 168 cases of advanced bladder cancer were diagnosed after the first campaign, 115 cases after the second campaign, and 277 cases after the third campaign.

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 this form and we will be in touch with opportunities to take part in various studies: **tfaforms.com/4875753**

POLICY

TURBT

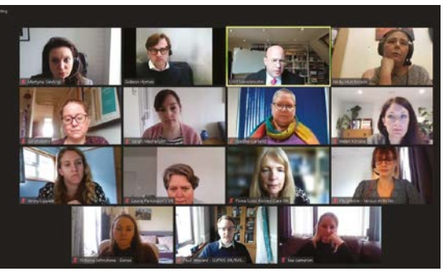


Fight Bladder Cancer has successfully campaigned for changes in the English National Cancer Waiting Times Monitoring Dataset Guidance to ensure that TURBT is no longer automatically classified as a definitive treatment. We worked with other charities to produce an infographic to be distributed to hospitals in England, and we are also campaigning for similar changes in Wales, Scotland and Northern Ireland.

MY DIAGNOSIS COUNTS

Lydia Makaroff

In previous reports, NICE (the National Institute for Health and Care Excellence) has said there were only 10,233 cases of bladder cancer diagnosed each year, because they only counted advanced bladder cancer, and not the other types of bladder cancer. Fight Bladder Cancer put together the true statistics and published the results in a previous edition of this *Fight* magazine (*Fight* #6). NICE held a public consultation, we sent them our data showing that there were 20,500 people diagnosed with bladder cancer each year, and now NICE have updated their statistics based on our research.



ALL-PARTY PARLIAMENTARY GROUP ON VULNERABLE GROUPS TO PANDEMICS

Fight Bladder Cancer joined the virtual meetings of the All-Party Parliamentary Group on Vulnerable Groups to Pandemics. All-Party Parliamentary Groups (APPGs) are informal cross-party groups. They are run by and for Members of the Commons and Lords, and also involve people and organisations from outside Parliament. We spoke about the need for improved communication about changes to treatment plans, prioritised care of cancer patients, and investment into videoconferencing for remote consultations.

NICE METHODS OF HEALTH TECHNOLOGY EVALUATION CONSULTATION

NICE recently asked all charities to review the way that it decides which medicines should be available on the NHS. We submitted our response, stating that we believe that NICE should state how it uses the views of patient organisations to make its decisions.

THE ECONOMIST'S WAR ON CANCER

We spoke at the *Economist's* virtual event to emphasise that we must focus our investments on what matters to patients, and involve patients from the start. To achieve better outcomes, we must listen to the patient experience when we conduct research and look to reduce inefficiencies in cancer care.

SCOTLAND

The Fight Bladder Cancer Scottish Steering Group is working on a Scottish Development Plan, which will enable the charity to register with the Office of the Scottish Charity Regulator and seek funding for a Scottish Development Officer.

AWARENESS

WORLD CANCER DAY

We supported World Cancer Day on 4 February and recognised that our commitment to act will lead to powerful progress in reducing the global impact of cancer. 2020 marked the midway point of the three-year 'I Am and I Will' campaign. 'I Am and I Will' is an empowering call-to-action promoting personal commitment and represents the power of individual action taken now to impact the future. We joined in a discussion about the psychosocial impact of isolation as part of the Global Cancer Coalitions Network webinar for World Cancer Day. We spoke about all the ways we support our patients and family members, in order to reduce isolation and increase a sense of community.

GP PACK

If you run a GP surgery or private practice, we have free posters about the signs and symptoms of bladder cancer and the support that's available. To receive your pack in the post, please complete this form: **bit.ly/3mHEqQf**

FREE CAR STICKERS

We have designed car stickers to raise awareness. To receive yours, complete the form at: **bit.ly/2FM8muc**

CLEAR ON CANCER

We worked with the NHS on their 'Clear on Cancer' campaign: ***Just a bit of blood? Just speak to your GP***. The campaign focuses on encouraging the public to contact their GP if they are worried about a symptom that could be cancer. The NHS has introduced a range of measures to ensure the safety of patients, including COVID-secure wards, and the 'Help Us, Help You' campaign will help to reassure patients that they can receive medical care safely.

NURSES OF THE YEAR

Hilary Baker, Lead Clinical Nurse Specialist for Uro-oncology and Fight Bladder Cancer Trustee, was one of the British Journal of Nursing's Nurses of the Year.


Hilary Baker

UROLOGIST TRAINING

Mr Param Mariappan, Consultant Urologist and member of our Scottish Steering Group, gave a UroToday presentation explaining the importance of quality indicators for the TURBT procedure for taking a bladder cancer biopsy. He emphasises the importance of having a comprehensive checklist of quality indicators, and the importance of experience, supervision and training.

BRITISH ASSOCIATION OF UROLOGICAL NURSES

We attended the virtual British Association of Urological Nurses congress. We hosted Zoom drop-in sessions to listen to nurses, and shared all the ways that we can help them support their patients. Their President Jane Brocksom stated, 'Courage is inner strength and the power to respond to challenging situations. It is doing what needs to be done when our resources are pushed to the very limit. The biggest reward is in the teamwork.'

BRITISH ASSOCIATION OF UROLOGICAL SURGEONS

Fight Bladder Cancer attended the virtual congress of the British Association of Urological Surgeons. We promoted our new Patient Information Booklets, and learned about the latest developments. James Catto, urologist and Fight Bladder Cancer Trustee gave an update on the imaging, surgery and trials of bladder cancer.

From the Chair

OPINION
JOHN HESTER
FBC Chair of Trustees

The past months have been very stressful for bladder cancer patients but possibly even more so for their carers. Many patients have had appointments for tests or treatments postponed or cancelled. This has resulted, in many cases, in mental anguish which has manifested itself in various ways. Some have become moody or snappy and said hurtful things, whilst others have withdrawn into themselves.

Carers, looking out for the primary needs of their charges, have now had to deal with these other additional concerns as they appeared – all the while thinking, ‘Please don’t contract the virus’.

Caring, by its very nature, so often means carers are focusing all their attention on their charges, whilst at the same time forgetting to take care of themselves.

Carers, please look after yourselves, and if you find you are becoming stressed or disillusioned, thinking ‘how do I deal with this?’, post to the Fight Bladder Cancer forum, have a good rant or even phone and ask to talk to someone – there are Bladder Buddies for carers too. **You are not alone.**

In closing, everyone, please stay positive and above all, stay safe.

Note from the CEO

OPINION
DR LYDIA MAKAROFF
FBC Chief Executive

I know I’m not alone in saying this has been an incredibly challenging year – ‘unprecedented’, to use a now over-familiar word. This pandemic has affected our lives in so many ways that it can be hard to look back on how things have changed.

We’ve been isolated from friends and family at a time when natural anxiety makes the support of those close to us all the more important. A year ago, it would have been unheard of not to bring someone to hospital visits – now so many people have faced these alone. Appointments have been delayed, bringing more worry. On top of this, the closure of retail and hospitality has had a far-reaching impact, and many people have faced financial insecurity.

Along with lots of charities, Fight Bladder Cancer has inevitably seen a drop in donations and fundraising, as events we used to hold throughout the year have been postponed. Whilst we held off for many months, sadly we have had to furlough some of our team on a part-time basis this Spring, and we look forward to a time when we can all be back in the office.

We can hope that brighter times are ahead, though. **We’re still 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

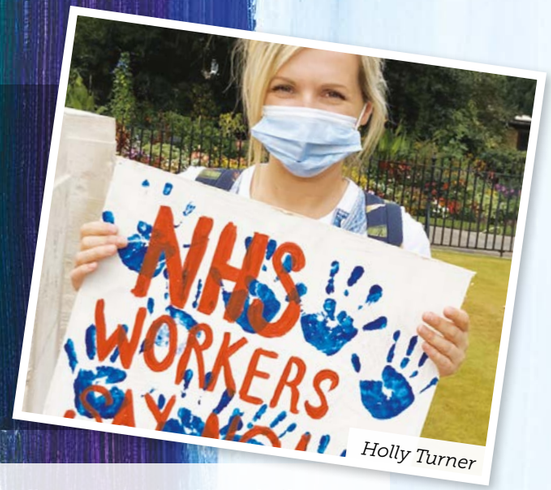
Please do visit if you need somewhere to talk, let off steam, and find like-minded people for advice and a chat.

GMB UNION

OPINION
HOLLY TURNER
NHS Nurse & GMB Rep

Give our NHS heroes a proper pay increase

Alongside other health unions, the GMB, the union for NHS staff, is calling on the government to reverse a decade of real-terms pay cuts for NHS staff, turning clapping for carers into cash recognition by awarding health keyworkers an early pay rise.



Holly Turner

My name is Holly, I am a GMB rep and an NHS nurse. Nurses, healthcare assistants, paramedics, porters, cleaners and all healthcare staff have stood firmly at the forefront of the fight against Coronavirus from the very start, even putting themselves in danger due to huge failures by the government to address PPE and testing issues.

These are workers who have had to be separated from their families, who in desperation have had to source their own PPE from eBay and who in July 2020 were excluded from the public sector pay rise.

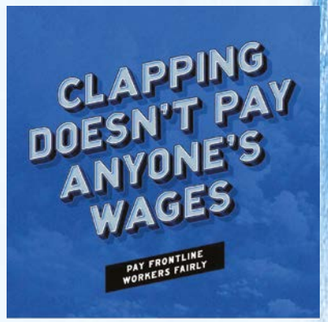
The public recognised the value of our keyworkers from the start, coming out to clap for our carers every Thursday during the first lockdown. Now it's time for the government to recognise our worth.

NHS staff are now in year three of a three-year pay deal, which GMB members voted against not just because of its complexity but because it represented a real-terms pay cut for many; negotiations will start in 2021 for the next agreement.

The GMB and other health unions now want the government to provide the funding needed to commit to an early pay rise for all those providing services to the NHS, whether employed directly by the NHS or by private contractors. The current crisis has accentuated the crucial role of all NHS staff in maintaining the health of the nation, and the least ministers can do is reverse the decade of real-term pay cuts which their government imposed.

I spoke to other NHS workers, and asked them collectively what our demands should be. With regards to pay, 15% was agreed to be the least we are owed, and #NHSPay15 was born.

Fighting for the rights of workers has NEVER been more important than right now, and my fellow NHS workers inspire me to believe that we can achieve this pay rise.



The stress on NHS staff has never been so high, as they continue to go to work, despite a decade of pay freezes and cuts and despite the NHS being at breaking point as a result of a decade of austerity.

Under pressure

Prior to the COVID-19 outbreak, the NHS was operating under huge pressures, with 100,000 staffing vacancies. Now, a year later, as lockdown continues to ease and tighten, nothing changes for our healthcare workers. Staff were left on the front line dealing with the pandemic with no PPE or regular access to testing.

A request for fair treatment

The GMB is calling on the government to seriously commit to all of the demands in their blueprint for negotiation. This includes:

- **workers being paid correctly for all the hours they work, as many NHS staff have been left to work additional hours unpaid or at lower rates of pay throughout the crisis**
- **involving the trade union reps in all discussions regarding redeployment and returning to work for the vulnerable.**

It's all very well to applaud the efforts of our keyworkers but nothing would raise their morale quite like a financial recognition that they are valued and a settlement that repairs the last ten years of cuts.

Our NHS heroes don't need a clap, a badge or even a snack box – they need a proper pay increase.

NHS workers have been heroes on the frontline during this pandemic. Yet despite all the warm words from the government, NHS workers have suffered a decade of real-terms pay cuts.

The public recognised our members' worth from the start of this crisis. Now it's time for the Government to do the same.

Please sign the GMB petition calling on Matt Hancock, Secretary of State for Health and Social Care, to give these heroes the pay increase they deserve.

- A 15% wage increase, or £2 p/hr, whichever is the greatest.
- Unsocial hours enhancements on sick leave for all staff.
- A commitment that NHS pay will never fall below a real living wage again.

Sign now:
gmb.org.uk/campaign/give-our-nhs-heroes-proper-pay-increase

Need help?
Members requiring help should contact their local GMB Region via **gmb.org.uk/gmb-regions** or email **info@gmb.org.uk**

ARTICLE
SOPHIE MAGGS
FBC Community
Engagement Manager

Thrilled with a **successful launch!**

In the last issue, we announced the launch of our series of **Patient Information Booklets** – now we are back to give you an update ... and we've made some great progress.

Our prime target has been to distribute reference folders containing the ten booklets to our medical professional colleagues across the UK. These reference copies allow medical teams to determine which of the booklets are appropriate for each patient, so they can be sent directly to them by the FBC team, by email or post.

Designed for patients at every stage of their bladder cancer pathway, the clear and straightforward booklets contain targeted guidance and advice that is fully endorsed by patients, medical professionals, and the teams at BAUN, BAUS and BUG.

As increasing numbers of both folders and patient booklets are sent out, we are thrilled to have received such great feedback already.

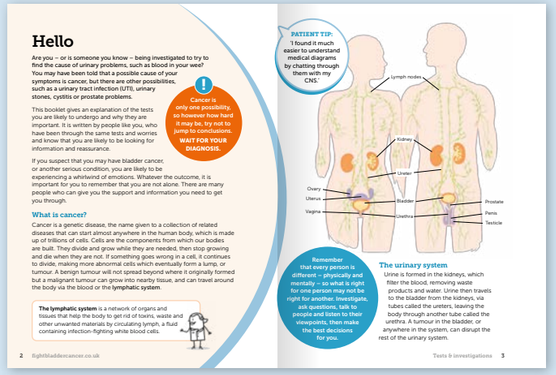
'A very high-quality, comprehensive resource by Fight Bladder Cancer. I would recommend clinicians managing Bladder Cancer to use these.'

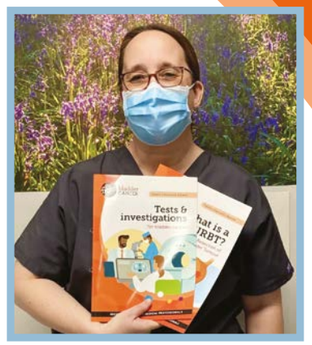
Param Mariappan,
Urological Surgeon, Edinburgh,
December 2020

See the details on the opposite page for how to order your folder.

Heather James,
Uro-Oncology CNS, Glan Clwyd, highlights the benefits she has already seen for her patients:

- **The booklets back up verbal communications with your patients**, which is helpful when there's a lot of information to take on board.
- **Patients gain confidence in their medical team** when what they read supports what they've been told.
- **Patients feel cared for**; they provide the opportunity for further discussions and the chance to ask questions.
- There is an understandable fear over what treatments are possible, because of Covid-19, so **discussion allows us to be honest about what's available now**.
- **Patients can read the booklets, put them down and then review the information with their team.**





Our series of 10 booklets comes in a handy binder for all medical professionals.

Available to order by Medical Professionals

Free Patient Information Booklets Folder

The booklets are a great support to patients to reinforce what we tell them in the clinic."

Rebecca Rushton
Specialist Urology Diagnostic Nurse
– East Sussex HealthCare NHS Trust

'Thank you for your help with our patients; ordering is easy to follow, booklet content is brilliant.'

Ansu Manoj
Urology CNS Lead, Northern Devon HCT

'Loving the new booklets, they are so user friendly.'

Anna Cornwall
Uro-Oncology Nurse Specialist, Southampton

'The books were very informative and in clear laymen's English so easy to understand. They broke things down nicely and had clear illustrations. I liked the bright colour scheme, and it makes it a nice 'go to' booklet. The information followed on nicely and it was very reassuring and took the fear out of the radiotherapy. It ticked all the boxes.'

Carer of bladder cancer patient

Patient copies come in a handy smaller size

Please contact Sophie for more information on the other materials available to help support you with your patients
sophie@fightbladdercancer.co.uk
07920 164706

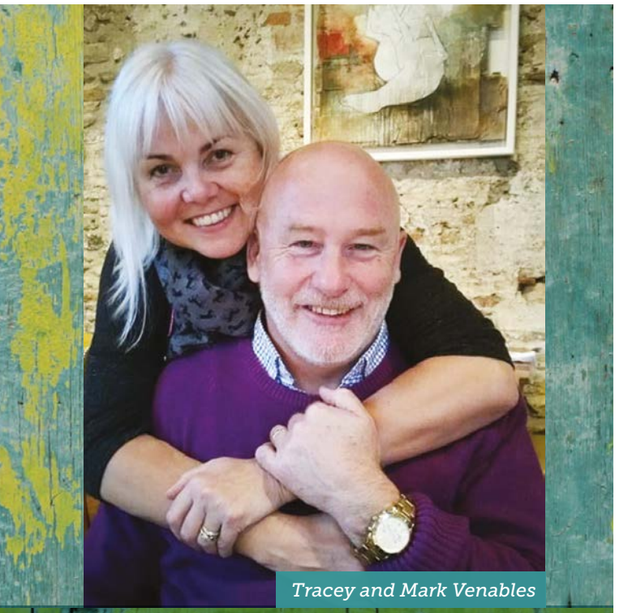
ENDORSED BY
The British Association of Urological Surgeons
British Association of Urological Nurses
British Uro-Oncology Group

SCAN ME

GET IN TOUCH TO RECEIVE YOUR MEDICAL PROFESSIONAL'S FOLDER
01844 351621

PATIENT STORY
MARK VENABLES
FBC Forum Member

Let's introduce you to the 'perfect patient'



Tracey and Mark Venables

Avoiding unhealthy vices could mean a better outcome to your treatment

At 63, Mark was doing some consultancy and working as a trustee for a social enterprise organisation while his wife, Tracey, helped at a charity supporting local vulnerable families. A keen golfer, members of a lively Anglican church and a ukulele band, Mark's retirement seemed to have got off to a great start.

My wife, Tracey, and I met when we both worked for John Lewis, and we've now been married for 15 years. We little thought our early retirement would take such a turn – but then no one imagines that this kind of thing is going to happen to them, do they?

The first ominous signs

Early in 2019, I had two episodes of blood in my pee and was treated for UTIs. My GP also organised blood tests and an ultrasound to check for any prostate issues.

But after six months with no answer to continuing discomfort, and after a third episode of blood in my pee, I referred myself to a urologist. A CT scan and cystoscopy confirmed a small (1cm) tumour in the dome of my bladder.

A nasty shock

Soon after that I had a TURBT operation to remove the tumour but the pathology results revealed that the tumour was muscle-invasive and aggressive. Having expected just monitoring and perhaps BCG treatment, we were now faced with chemotherapy and then either bladder removal or chemoradiotherapy.

Two days after getting this news we discussed the chemotherapy with the oncologist but I never made it home as heavy bleeding following the TURBT meant I was admitted to hospital to have my bladder irrigated. I went home after three days but was re-admitted the next day feeling really unwell and with a very high temperature – it was acute urinary sepsis and there were some very dodgy moments.

Although we were assured the chances of a cure were good, I was very aware that there was a significant possibility that I wouldn't make it.

From chemotherapy to surgery

The next week I started the first of three cycles of chemotherapy, lasting for nine weeks, during which time I had more appointments to discuss my treatment options and I decided to go for the radical cystectomy (RC).

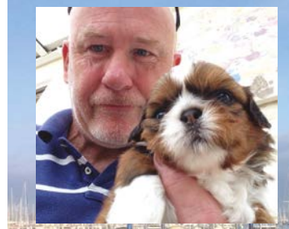
Four weeks after the chemo finished, I had the RC, which went well (apart from being sick after the op) and I was discharged after eight days.

And back to my new normal

Things are now going really well. I am 13 weeks on from the operation and life is close to 'normal' again. The best news was that the pathology results confirmed there was no cancer left in my bladder or outside it, indicating that bladder removal had been my best option. The consultant gave us the happy news that my chances of long-term cure were the 'best possible' following an RC.

Any cancer diagnosis which leads to chemotherapy and two operations is going to lead to profound life changes.

During the chemotherapy, life ranged from relatively normal to resting up and being tired and staying at home, although the fatigue only hit me for three or four days of each three-week cycle. Following the RC operation, the focus has been on a steady build up in exercise combined with a healthy lifestyle.



The mental challenge

A diagnosis of bladder cancer is a huge shock. Suddenly you have to face several months of treatment and the worry of all the tests and results. You come face to face with your own mortality.

Being part of the FBC support group has taught me that the impact of treatment and operations varies hugely – we are all different! My advice to anyone is to stay positive and don't base your expectations on the experience of others. I had a relatively easy time with chemotherapy and never lost my appetite. My bag has had only one leak in 13 weeks and that was minor and sorted out in five minutes. It's also important to have specific goals so you have something to look forward to. I booked a couple of short breaks during 'free' weeks of chemotherapy and I planned to build up to playing a full round of golf about four months after the RC operation. In the event, I played 18 holes after 12 weeks, which gave me a huge boost, especially as the following day we went into 'lockdown' to fight the Coronavirus – I had got there just in time!

Looking for the positives

The main positive for me has been the success of the treatment. My chances of a full recovery have improved significantly since the sobering prognosis after the tumour was removed and examined. At the time, the surgeon said I was the 'perfect patient' to come through it as I am fit and do not have too many unhealthy vices! I held onto this assessment and the three Fs (faith, family and friends) have helped me through. My wife would add food to the list and the fact that I never lost my appetite helped my recovery immensely.

Fight Bladder Cancer has been such a help

The FBC website was great in helping me understand bladder cancer and the treatment options, and the support group has also been brilliant. There was loads of good advice soon after my diagnosis and around the time of the RC. As time has gone on, most of my input has been supporting others, which is very satisfying!

My plans for Awareness Month

I had planned to do the walk and to help man a stand outside our local hospital. However, it is looking like we may not be able to do these due to the Coronavirus outbreak. But I am sure I will be able to find some useful ways of supporting BCAM virtually as it is so important to spread the word about Fight Bladder Cancer.

I'll fight even harder in extra time

Given three weeks to live after his cancer diagnosis, ex-professional cricket player and rugby enthusiast, Peter Luft, was determined that final whistle was not for him.

What first made you seek a doctor's advice, Peter?

I first realised something wasn't right at the beginning of 2018. I was an airport worker at the time and I realised I was going to the toilet much more than usual. I had a lot going on at the time as my mum was just going into residential care and I had other priorities so I put it off for a while.

The next time I realised something was wrong was in March 2018. I met up with friends to watch the Six Nations in the Isle of Man and when I went to the toilet I couldn't go, I had the feeling of needing to wee but couldn't, as if there was some kind of blockage. I had to ask my wife to pick me up and take me to A+E. They managed to put a catheter in to temporarily sort out the issue, which they thought was a pre-malignant penile problem.

They weren't thinking about bladder cancer at all, but they did refer me to the urologist at Arrowe Park Hospital in Liverpool for a cystoscopy. Afterwards, the urologist said: 'I wasn't expecting that.' Nor was I – it was stage 3 bladder cancer.

INTERVIEW
KATE MOORE
FBC Intern

Peter Luft

What happened after you were diagnosed?

Between November 2018 and January 2019 I was at the Noble's Hospital in the Isle of Man having chemo sessions in preparation for my RC and IC. In February I was at Arrowe Park again for a six-hour iron infusion in preparation for surgery, I felt like the bionic man!

I was back and forth from Isle of Man to Liverpool a great deal because there is no radiology department in the Isle of Man and only one oncologist. It could get very tiring but luckily there is a great relationship between the two hospitals.

In March 2019 at Arrowe Park, I had an RC which turned out to be a ten-and-a-half-hour surgery, ending up in the ICU. I had been fitted with a stoma bag and was getting used to that while I was there for a few weeks; the nurses were excellent. In June I had follow-up surgery to remove my waterpipe (urethrectomy) and by around August 2019 I was feeling much better and back to normal; in the September I had a scan and got the all clear which was just great!

So everything started to look up from there?

Unfortunately not. In January 2020 I was chairman at Finch Hill Cricket Club and was coaching the juniors for pre season when I started getting pain in my back, which worsened over the next couple of months..

After an appointment in early April, I ended up staying in the hospital for eight days. My oncologist told me the cancer had spread to my spine; their plan for me was to start on immunotherapy then radiotherapy, which happened from April to June.

I started a weekly course of chemo in August. The first three weeks were fine but after ending my fourth session with the usual 'see you next week', that all changed. With hindsight, I must have had some underlying infection as I suddenly became very ill and was violently sick. Back at home, I started getting terrible chest pain as well as pain in both my arms and neck. I had to lie down to try and control my breathing. We managed to get an ambulance to the house and I was taken straight to A&E.

I was told I had had a mild heart attack which had resulted in a little scarring but no stents were required. They said it was unlikely to happen again but I would need cardio physio. The pain eventually went away after four hours but I remained in hospital with a brilliant team for five days.

I was moved to an open ward but I went downhill again – my temperature shot up and my blood pressure was rapidly dropping; it turned out I had contracted sepsis. I was very ill and lost a lot of weight as I didn't eat properly for a month.

> It was as that point that I was given three weeks to live but my response was "I'm going to fight this."

The sympathy cards made me more determined. I just thought to myself, 'What are you on about? I'm still here!' Around the end of October, things started to turn around. My appetite returned and I started feeling much better.

What side-effects did you get from the radiotherapy and chemotherapy?

None with radiotherapy, but chemotherapy is different. I was very tired and my mouth was always dry; I felt dehydrated and my hair started falling out.

Did you have any problems during the pandemic?

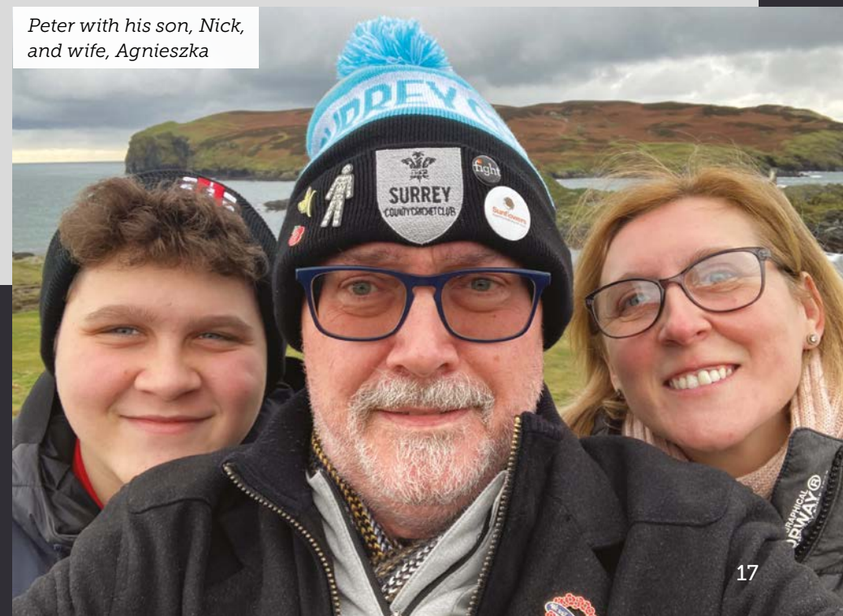
I have been really fortunate and haven't had any cancellations or missed appointments. You just have to go for it and try and put COVID to the back of your mind.

What would you say to patients going through the same thing as you?

> I would say the most important thing is your mental health, spreading awareness of bladder cancer and educating others about the disease so that more people know about it. Like many others, I had never heard of it when I was diagnosed.

> You just have to go for it and try and put COVID to the back of your mind.

Peter with his son, Nick, and wife, Agnieszka



Peter's Top Tips!

- Stay positive
- No negative thoughts
- Stay strong
- Believe in yourself and believe you can get through it because only you can fight it

Peter with some of his fundraising team

How are you feeling now?

I am feeling much better. I am putting weight on and making sure I get stronger for my next chemo sessions. I have managed to stay positive throughout my journey – I think that's because I learnt to maintain a strong and positive attitude as a professional sportsman. My network of support has also been brilliant and I am so grateful to my wife, family and friends. I had loads of visitors when I was in hospital and have had many people get in touch from school colleagues, friends and even the owner of my favourite rugby team!

How has FBC helped you?

The FBC team has been so kind and helped a huge amount, especially when I was doing my fundraiser last year. I really cannot wait to meet the team when the COVID restrictions are lifted.

I always try to help the charity on Twitter and the other social media platforms. **The awareness of bladder cancer is like preaching a gospel – it's so important to educate, share your story, and get knowledge of the disease out there. It's the 5th most common cancer in the UK, 7th in Europe, yet receives less than 1% of national funding from Cancer Research UK so we must talk about it; it cannot be a forgotten cancer.**

Have you heard of a Mitrofanoff?

Fortunately for Nicky, she took note of the posters in the pharmacy where she worked and went for a check-up when she found blood in her wee.

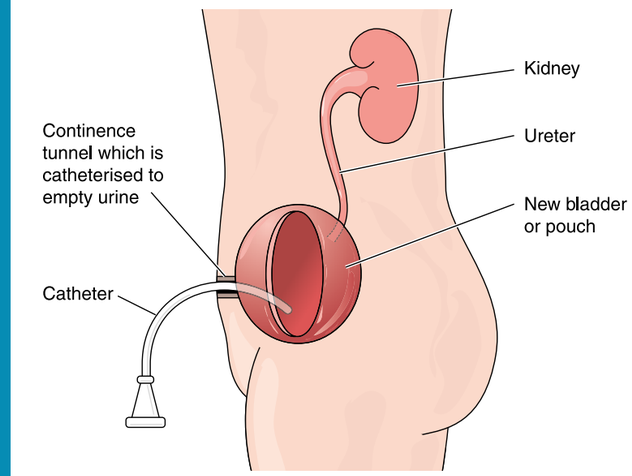
Me and my amazing husband Mick

PATIENT STORY
NICKY JOHNSON
FBC Forum Member

Me and my lovely chicken Tina

Hi. My name is Nicky and I'm 51 years old. In May 2018 I noticed a small smudge of blood when I went to the toilet. I had seen notices up in the pharmacy where I work about going to get it checked out if you notice blood. Thankfully, I did go to the doctor, and after tests and a procedure where they look into the bladder, it was found that I had multiple tumours in my bladder.

They found it was an aggressive form of cancer and after biopsies and more investigation, they also found more cancer in my urethra. They had to remove my bladder and my urethra, and they explained that I could have an operation that meant the creation of a new bladder from a section of my bowel. They would attach my appendix to it and the inside of my belly button to create an internal reservoir, with a mitrofanoff – like an outlet valve – so that I could catheterise my urine through my belly button.



Important choices

I was told that if the operation did not go to plan I might wake up with a bag instead, but it still seemed to be the best option for me. Better alive with a bag than dead.

I am two years on from my operation now, and so far so good – no cancer. The experience inspired me to write a book – called *The parts of me I can live without* – which really helped me put things into perspective. I am back at work and doing the usual normal things, just going to the loo four times a day to catheterise, and I always carry the catheters with me.

I am so grateful to Addenbrooke's hospital, the skilled surgeons and the specialist nurses, plus everyone who looked after me.

Take a step at a time

If you have just been diagnosed, take things one step at a time, get all the information you can and speak to others. Usually there are choices to make, sometimes they are difficult to face, but you can do this, and believe me when I say, life goes on and you will get there.

Bladder Cancer **Carers**

On the following pages we are highlighting the role of the wonderful partners, children, family and friends who step up to the mark and care for their loved ones when those close to them are diagnosed with bladder cancer patients.

FBC Co-founder, Tracy Staskevich, looks back at the birth of FBC

In the middle of the night, while my husband, Andrew, was in hospital awaiting surgery, my desperate searches for information on bladder cancer drew a complete blank here in the UK – nothing! So at visiting time in hospital the following day, we decided that we must do something to address the shortfall – and Fight Bladder Cancer was born.

Tracy Staskevich

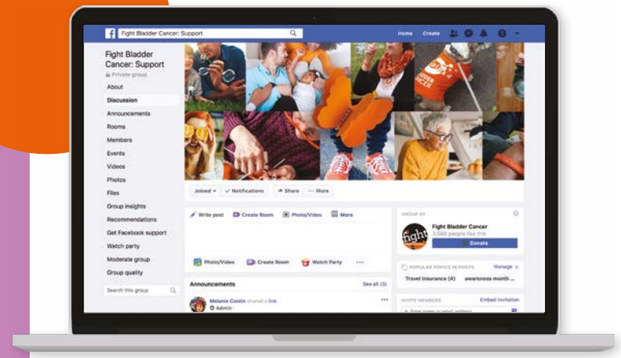
From the outset, it was clear that it was not just patients who needed good-quality information, support and resources, but also those who loved them, the carers who play such a huge role in any cancer diagnosis. It is these loved ones who are just as affected by a bladder cancer diagnosis – whether it's a partner, family member or dear friend. It is often the carers who are the ones on the internet in the middle of the night searching for information.

They are the ones trying to keep life together during hospital trips and treatments, and whose difficult role is to sit on the sidelines and endure the endless worry and uncertainty that loving someone with a bladder cancer diagnosis brings.

This is why Fight Bladder Cancer has ALWAYS had, and will ALWAYS have, carers at its heart alongside patients and why it will always offer support and information to ALL those affected by the disease.

10 Tips for Carers

1. **Help in any way you can** – sometimes the small gestures mean more than you think.
2. **Find something you love doing** and do it for yourself.
3. **Take some time out**. You need your own time and space to deal with what's happening.
4. **Find the right way to communicate** that suits both of you.
5. **Tackle any guilt you feel head on**. This is not your fault.
6. **Find someone to talk to about your feelings**. You don't have to be alone.
7. **Eat, rest and sleep** – you need all the energy you can muster.
8. **Be very wary of 'Dr Google'**; he can easily lead you to worst case scenarios which may not be relevant.
9. **Cultivate a good relationship with the CNS or medical team**; they are there to help you.
10. **Join the FBC forum** where you can feel supported and support others as you tackle these life-changing circumstances.



The Fight Bladder Cancer forum is for everyone!

The Fight Bladder Cancer private forum is available 24 hours a day, 7 days a week. **It is a safe space for everyone who is affected by bladder cancer – not just patients**. Anyone who has someone with bladder cancer in their life is welcome to join.

On the forum you will find over 5,000 other people who have been affected by bladder cancer. Here you can find people sharing their triumphs and challenges, their small joys and daily frustrations. It is a wonderful way to connect with other carers, and a wealth of knowledge for any questions you may have – large or small.

We have forum members of all ages and genders, and who live all around the world.

If someone you love has bladder cancer, then the Fight Bladder Cancer forum is for you.

Join us at:
facebook.com/groups/bladdercanceruk

CARER TIP:
'The great thing about the forum is being able to post questions, no matter how silly they may seem, and get answers from others in the same position.'

Don't put off today what you can do tomorrow

CARER STORY
VAL HESTER
FBC Trustee & Carer

FBC Trustee and retired nurse, Val Hester, shares her journey to acceptance when her husband John, was diagnosed with bladder cancer


Val with her husband, John

John and I are great procrastinators – not good when your lives are touched by bladder cancer. We grew up in the same village, attended the same secondary school and started dating the month before I began nurse training in London, so he has been testing my patience for over four decades now!

I worked in the NHS for 38 years and was due to retire in August and start working as John's PA. It was July when John said, 'I think I've got a problem: I have an odd sensation when I wee.' As a community midwife, my kit contained a set of urinalysis indicators so I tested a sample. When the strip showed the highest level of blood, even though none was visible, I told John to make an urgent appointment with our GP. But he was off long-term sick and John refused to see anybody else and was prepared to wait ... so we waited.

In September, with no appointment in sight, we flew off on a planned holiday to Albuquerque, drove through Colorado, were delayed through flooding with a three-state detour to avoid a collapsed interstate, then through Yellowstone to Montana. All that time, my concern level was high. We had to endure frequent bathroom stops and John began to have issues with his stream. Finally home, we made an appointment to see his GP in October. Four months delay! Procrastinating!

I was assuming it was a prostate issue, common among men of a certain age and fairly easily treated. I had scrubbed for the procedure in theatre many years ago and knew the outcome was usually good.

I have known Tracy, one of the co-founders of Fight Bladder Cancer all her life – we were next door neighbours and our fathers worked together.

In November we were talking with Tracy and Andrew about their newly established bladder cancer forum, little knowing how influential it would be in our future. They encouraged us to get moving urgently with John's appointments.

At John's request, I went with him for his appointment. The GP tested his sample and took a history and so it all began: a cystoscopy, multiple scans and two TURBTs.

Then there were long periods of the most horrendous waiting until finally, the day after his 67th birthday in January, the diagnosis was confirmed: he had bladder cancer. Trust John, healthy all his life – just the odd chest infection until I convinced him to give up the damned cigars – then he goes straight for the big C!

I was devastated. It is a traumatic time to live through and remain strong for your partner, to be the support they need during the process.

Eventually, for John, it was a choice of BCG or RC; he chose RC.

He explained his decision to me and I totally supported him but I was shocked and found it incredibly daunting – but it was his choice to make, not mine.

He had his RC in March, and was very demanding on the visiting front. My days were incredibly long – I was working full time plus two hours travelling to visit. John maintained a positive mental attitude and was determined to be home as soon as possible. Disturbed nights followed, and a long, slow recovery from a major op – with the inevitable wet beds to deal with. To say it was tiring ... Plus this stubborn man was still working full time, initially from home and soon back in the office. He was doing shorter days but was no less fixed in his work ethic. Eventually, I caught up with the lack of sleep.

Because they caught the cancer so early, John has had no other treatments than the TURBTs and the RC. But he has not been without other health problems: a large hernia around his stoma, and surgery that left


Val with FBC Founder, Andrew

him with a massive infection; and an aortic aneurysm needing two more surgeries. And still this wretched man was working!

The FBC forum was a great support for us individually both before and after surgery (aIthough I refuse to be friends with John on Facebook – if he has something to say he can tell me face to face).

Andrew invited me to be a Trustee of Fight Bladder Cancer, to which I agreed, then he asked John (so I was first, ha! ha!). We are very proud of our association and support the charity as best we can. Life goes on. We are now almost seven years since his RC, have both retired but continue in our roles as Trustees of the charity.

We were just coming to terms with retirement when COVID struck and, like everyone, it has changed a lot of our plans. As a carer you need to be brave and try not to show your concerns at times.

You have to remain calm when you want to just scream or cry; to remain patient when you are desperate for just the tiniest bit of time for your very own.

It is incredibly difficult when you depend on your partner to support you. I saved up my worries during the bad times and used a journal to express myself and later, when John had recovered from his operations, shared them with him.

Thankfully John understands. So do many of the members of our superb forum, and day or night they are there for every one of us in our times of need. I still need them.

The big C becomes the predominant thing in any relationship. But it should not stop you living your lives as individuals. We all have wants and needs. Life is short, LIVE IT.

John commented:

'If Val had included only part of her journal, this story would have been much longer. She scarcely touches on her feelings about my obstinate determination and I know that at times I was unreasonable, especially when, as a nurse, she knew the ramifications of treatment. Even so, she came through for me.

Although I was signed off three years ago, I am aware that Val still has a thought at the back of her mind that it might come back. Even now I don't really appreciate how much that concerns her.'

Val's Top Tip!

Try expressing your fears and thoughts in a journal.

SPECIAL FEATURE: CARERS

The Carers' A to Z **Survival Guide**

Tracy with her husband, Andrew Winterbottom

Tracy founded FBC with her husband, Andrew Winterbottom, and together they grew the charity from a midnight despairing response to finding no information on bladder cancer to the thriving and influential charity it is today. Sadly, Andrew lost his battle with cancer, but Tracy fights on.

Here is her moving and inspirational A to Z, which should be required reading for all carers.

The magic hour

First, let me tell you about the magic hour. In the many years of Andrew's appointments, mad dashes to A&E, operations, results clinics and the like, I realised the impact of those first sixty minutes of receiving news about your loved one – I called it the magic hour. Not that I would ever fall apart in front of my bloke, oh no. In front of him, I was a rock – steadfast and strong, constantly waving my virtual 'you can do it' pom poms in a frenzy. Cartwheeling hope and positive mental attitude in every direction like a Duracell-powered cancer-beating cheerleader.

The magic hour is what I never let him see ... the first hour I was alone with the news. I remember the very first magic hour, when the consultant told us it was a large tumour. So large they had been unable to remove it all with the TURBT and they were pretty sure it had grown out into the prostate and beyond the bladder wall. So large that on the chart on the wall it was the very last diagram in the set, ominously labelled 'Stage 4'. (There was no Stage 5.) We sat huddled together on his hospital bed as we discussed what we'd do between now and the six weeks we had until they'd remove his bladder in an eight-hour operation. We joked about the size of the parties we'd have, how much we'd drink and then we decided to get engaged. I left at the end of visiting time with a kiss and a smile, waving my way down the corridor.

Even now I'm not sure how I made it back to the car park from the urology ward. As I unlocked the car door, my legs crumpled beneath me and I wailed. Sobbing into the steering wheel, I pounded my fist on the dashboard and screamed at the sky at the utter unfairness of it all before disintegrating into a pile of salty tears and snotty gulps. It took me fifty-six minutes that day.

Three thousand, three hundred and thirty messy seconds to get a grip, get myself together and start formulating a coping plan. I left the magic hour behind and entered my other new default setting as a carer ... War mode.

ARTICLE
TRACY STASKEVICH
FBC Co-founder & Carer

When someone you love is diagnosed with cancer it is like being run over by a truck. You feel completely powerless. Make no mistake, being a carer and watching someone you love face cancer, from diagnosis through treatment and beyond, is going to be one of the hardest things you have to cope with in life. There is constant uncertainty, waiting, impossible decisions and many hours of worry ahead of you. It will change your life.

To be honest, being a carer was not something I was initially very good at. For a start, I'm a massive control freak and having to stand by and watch terrible things happen to the man I loved (that I could do absolutely nothing about) was horrifying. I also make an exceptionally poor nurse, running low on both sympathy and patience in equal measure, so as you can probably tell it was a role I found extremely challenging. Nothing in life can prepare you for it.

In front of him, I was a rock – steadfast and strong, constantly waving my virtual 'you can do it' pom poms in a frenzy.

Over a decade later and I understand just how important being armed for the battle ahead is in terms of keeping your sanity as a carer. I learnt the hard way the best route to staying sane in a situation over which you have absolutely no control. Andrew and I talked a lot over the years of his illness about the difficulties of loving someone with a cancer diagnosis and we agreed that emotionally it's as tough a journey as being the patient ... in fact, sometimes it's worse. **So here's my essential A to Z survival guide to help you navigate this rocky path in your role as carer.**

A is for anger

I have always been something of an angry young woman, so although it wasn't a surprise that I was angry at Andrew's diagnosis, the sheer extent of my rage was. I was outraged that this could happen to us and that cancer had stomped its way into our lovely life, broken everything and then walked away. When your partner is diagnosed, it's normal to feel as though you have been cheated of your future and to strike out at those you are closest to, often the person who has been given the cancer diagnosis themselves. Let yourself feel this way and acknowledge the change in your lives rather than trying to cover it up and hope it will go away. (It won't.) Talk openly about it. Then try and use the emotion to make positive differences in your life, focusing on the things you have both always wanted to do. Often cancer can be the impetus you need to make significant changes in life outlook ... for the better.

B is for build

Build a support network – as big as you can and as fast as you can. Remember, this network is for YOU, not the patient. When Andrew was in hospital initially, I tried to do everything myself. I thought I had to be some kind of caring superhero. I managed to keep it up for a month and then I was signed off by my doctor for six weeks with exhaustion. So, build that network and take every scrap of help offered to you. Let someone come and do your housework or take a few loads of washing from you.

Welcome friends who offer to cook you dinners or drop in something for the freezer.

It's good for you and it actually also helps them, as they feel they are actively doing something useful.

So, next time someone utters that immortal line, 'Well, if there's anything I can do ...' make sure you take them up on it.

C is for cry

You cannot keep this emotion locked inside of you. It's much too big. Wail, shout, curse the gods and let it out. Scientists still don't know why crying makes us feel better; there are all kinds of theories about tears containing excess stress hormones which are washed away when we cry. Whatever the science behind them, tears do help, so grab a box of tissues, wrap yourself in a duvet and as Elsa in *Frozen* so wisely advises, 'Let it go.'

D is for depression

There is a vast difference between having a bad day and slipping into a constant state of darkness through which there seems no escape. When you are a carer it's easy to ignore the warning signs that accompany depression until you are sucked beneath its suffocating hold. You are busy concentrating on existing, surviving one day at a time.

If you feel constantly overwhelmed, are unable to cope, aren't sleeping, or feel you cannot carry on, then please go to see your GP straight away. There is so much they can do to help and often talking about these feelings is enough to start loosening their grip.

E if for educate

What did you know about bladder cancer before it came into your life? For most people it's nothing, and one of the key problems with the disease is that no one really talks about it. If we are ever to improve outcomes and treatments, we must make a significant change – that means talking about it as much as possible. So tell people. Talk about your loved one's diagnosis and treatment. Yes, you might feel weird at first but you'd be surprised by the number of people who have also had the disease affect someone in their life. Remember, bladder cancer is the fifth most common cancer here in the UK.

If we all started talking more about bladder cancer, it would raise awareness, not only with individuals but also GPs, which in turn could make a big difference to early diagnosis. By educating yourself about bladder cancer, you will also feel better prepared for what the disease may throw at you both in the future. Knowledge is power.

F is for friends

A cancer diagnosis can really clarify relationships with friends and family. Friends you have been close to for years can suddenly disappear from your lives with the appearance of the C word. Many people are unable to cope with the reality of a friend's mortality and refuse to accept any change to the status quo. On the upside, we found many friends stepped up in a way we couldn't have imagined, becoming stalwarts in our battle ... they laughed with us, they cried with us and celebrated all the little steps to recovery along the way.

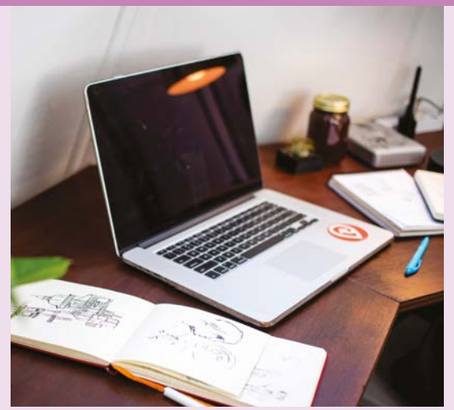
When Andrew was finally diagnosed with terminal cancer it was this mini band of brothers who would show up in the hospice, to trim his hair, rub his back or just hold his hand. You will need these people to be your rock. Be prepared for this kind of substantial friendship shake-up and be honest with your family and friends. It can be incredibly upsetting to lose people over something you cannot control, but you may find by talking to them about what's happening you can get things back on track. FBC has a great downloadable booklet that tells you more about talking to family and friends about bladder cancer.

G is for Google

Do not sit alone at your iPad or laptop of an evening searching for everything you can about bladder cancer on Google, especially not if you've had a glass or two of wine. If you rely on Dr Google for advice, not only will you scare yourself half to death on what's going to happen to your loved one, but you will probably end up thinking you're also developing a brain tumour. (Ask me how I know!) Do use only reputable sites like fightbladdercancer.co.uk to get good information on every aspect of bladder cancer and don't forget to talk to your medical team. They are there to help you both.

Many friends stepped up in a way we couldn't have imagined, becoming stalwarts in our battle ... they laughed with us, cried with us and celebrated all the steps along the way.

Tracy and some of her support team



H is for hospitals

When Andrew was first diagnosed, my worst phobia was hospitals. Just the smell as I walked in was enough to make my stomach clench with fear and send me scurrying to the nearest loo where I would try hard not to be sick. You can imagine, then, that his cancer diagnosis and subsequent surgeries was one of the most effective forms of aversion therapy ever!

Within a few months, the hospital was like my second home, I knew all the staff and would happily while away the hours at my bloke's side with nary a care. An important thing to remember about hospitals is that they are generally full of people who care. Your medical teams and support staff are the front line in any cancer battle and they will have your back. Remember, too, that you are all on the same side, so if things aren't going to plan or you feel concerned in any way about treatments or medical care, talk to them at once. If you don't get the right feedback, then go higher up the management team.

Being a carer will test your relationships in ways you haven't imagined, and with it your own resilience.

You should feel confident and happy with the treatment your loved one is receiving, and if you are in any doubt at all, you can always ask for a second opinion.

I is for inner strength

Personally I am not religious, but I do have an inner resilience that sees me through (it comes to the fore when I enter war mode). For others, this is their belief in a god or other faith. Whatever it is that gets you through a tough patch, you need to rely on it now. Remember to focus on other times in your life when you have overcome difficulties and faced problems. Remind yourself that you are bigger than what is happening to you and that you will get back to your real self soon. Be mindful and trust that you can and will move forward.

Whatever it is that gets you through a tough patch, you need to rely on it now.

J is for journey

I'm not going to lie ... this is going to be tough. Being a carer will test your relationships in ways you haven't imagined, and with it your own resilience. But it is a journey. At the start of it, things may feel insurmountable and you might not be able to imagine ever reaching the end. But you can ... and you will. Day by day you will learn more, grow more, gather more support and be a little further ahead. Slow and steady in this instance definitely wins the race. Just take one step at a time.

K is for kindness

Be kind to yourself. You do not have to be the living reincarnation of Florence Nightingale to be a good carer (so step away from the lantern, okay?). Set yourself realistic goals and do what you can. Luckily there are no carer police so you will not be arrested on the days you cannot bring yourself to be nice or look after anyone (not even the cat). Some days are just like that. Tomorrow is another day and it will be better, I promise.

continued on page 34

SPECIAL FEATURE: CARERS

CARER STORY
ROBIN FEAST
FBC Forum Member

She is still my rock

According to his wife, Robin usually has to ask what to write in Christmas cards, which makes us even more grateful that he sat and thoughtfully wrote about his experience as a carer for this feature in *Fight* magazine.

Robin and Corrina

Corrina had been 'lucky' enough to have her initial tests by the NHS at a private hospital in Worthing and that's where we were sitting, opposite the kindly consultant, when he said, 'I really am so sorry to say this but it is cancer'.

I remember I was holding Corrina's hand, but a lump had blocked my throat and a pounding, throbbing heartbeat had filled my head and I didn't know what to say. 'I promise we will look after her for life,' he continued. What the hell does that mean? I thought. Does that mean a short life? a long life?

Making our own decisions

Corrina had been unwell for ages and it was only as a result of our suggestion to her GP that she saw a urologist and finally got her diagnosis. We had become quite good at 'asking' for tests, and even deciding treatment protocols, whilst our middle son was having treatment for a rare paramalignancy called Langerhan's Cell Histiocytosis when he was a baby. He had four years of chemo on and off but nobody knew what to do so **we** researched and decided, together, what treatment schedule to follow. Our son – although on medication for Diabetes Insipidus – is now, thankfully, a healthy, active 25-year-old young man.

But that was different – we did that together, or maybe it shouldn't have been different but it seemed it was now.

Not a promising track record

I am an optimist, glass-half-full person, but also a run-and-hide, head-in-the-sand person too – not a brilliant combination.

My Dad was ill for a long time with dementia and epilepsy when I was a teenager and my default setting was to run. I'd be out most of the time, smoke loads of dope and hide in the haze, leaving my amazing Mum and older brother to do all the caring.

I didn't really talk

It was Corrina who taught me strength during those initial years with our sons but now this was different and I felt as though I was sinking.

I played football with a group of friends and we had planned to cycle round the Isle of Wight the weekend after the consultation. 'I can't go now,' I said. 'Yes you should,' Corrina said. 'You need your friends.' I ashamedly jumped at the chance to run and went.

I did manage to cycle round the Isle of Wight but I didn't really manage to talk to any of my friends. I told a couple, got some 'So sorry to hear that,' but we didn't really talk. We're men after all, we don't do that!

It's very difficult to care for the most precious person in your life.

Caring for the one you love most

The next few years went on with Corrina suffering the pain and indignities of treatment and the debilitating side-effects. I tried to support her through treatment but I did let her get on with dealing with everyday life, such as cooking, cleaning, looking after the boys and pets when, with hindsight, I should have helped more.

Part of me wanted to start distancing myself as self-protection should the worst happen and yet part of me wanted to be there all the time so as not to waste precious moments.

Treatment went on, different hospitals, London and Worthing, different consultants, different tests, different advice.

'You should have your bladder removed' was a big one from a top consultant but Corrina stuck to her guns – even when she was having a really rough time with the BCG treatments – and here she is ten years later, currently cancer-free, with her bladder, still living, still MY rock, MY support. She's the strength I draw from, so I thank my lucky stars every day that things have gone the way they have so far.

As a postscript I'd say we found FBC very late in our journey and I wonder if I would have been more supportive if I'd got advice from all the other wonderful FBC members during our journey. Friends, and family sometimes just seem to drift away, cross the street, not know what to say, so say nothing. But here on the FBC forum there is always someone to talk to, get advice from or just listen.

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 forum there is always someone there for you.

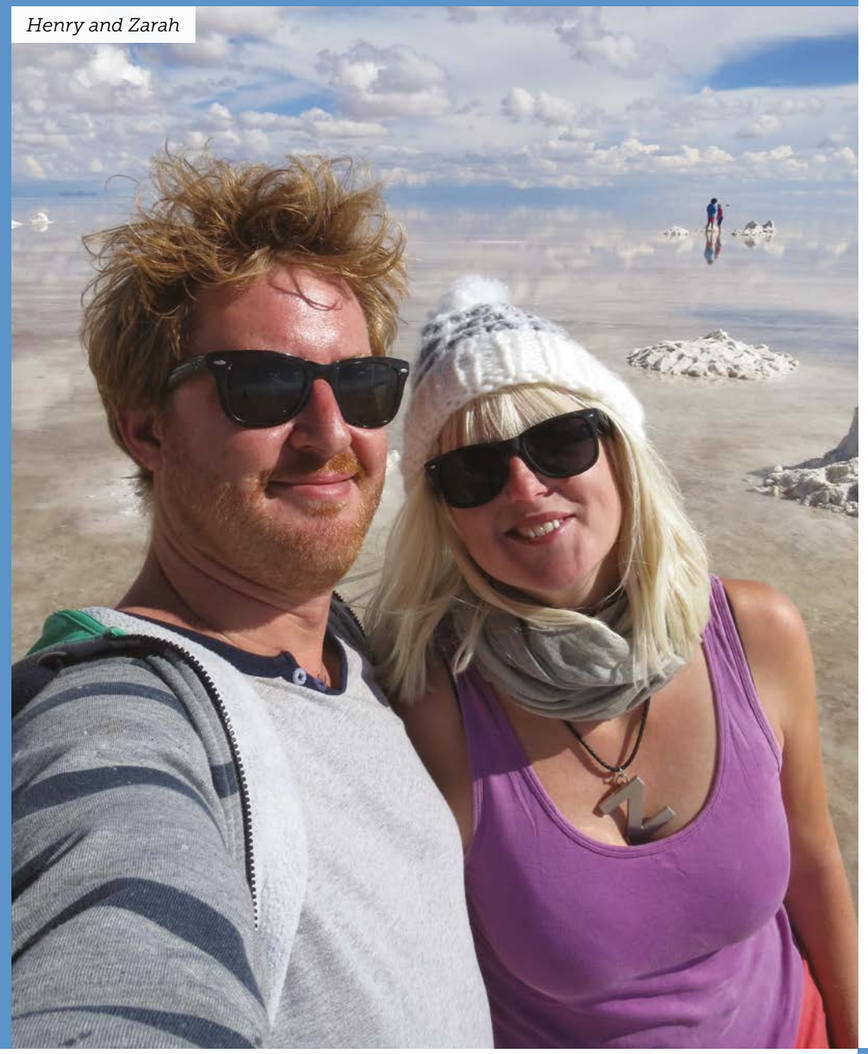
Robin and his family

SPECIAL FEATURE: CARERS

We do the best we can – we can do no more than that

When his partner Zarah first showed signs of bladder cancer, Henry took the advice of a friend to immerse himself in something he loved to help get him through.

As a science writer for Cancer Research UK, that led him to begin researching into the unknown that was bladder cancer in an effort to make sense of, and give them strength for, the difficult times to come.



Henry and Zarah

ARTICLE

HENRY SCOWCROFT
Cancer Research UK
Science Writer and
FBC Forum Member

'They think there's something in my bladder.' And so it began.

In early 2016, my partner Zarah started having sharp kidney pains and noticed blood in her urine. It wasn't the first time it had happened – far from it. She'd had recurrent urinary tract infections since she'd been a teenager, and this was the latest in a regular series. They usually cleared up after some antibiotics, and we weren't overly worried. But this time, the pain had got so bad it had prompted a precautionary trip to the GP, who'd thought it might need an ultrasound scan. She was 37.

The scan had revealed a mass, prompting a cystoscopy. And that was when they used the word 'cancer' for the first time.

But it wasn't the first time Zarah had heard it, and that was very much my fault. Talking about it was (and still is) literally my job. For the previous 14 years, I'd been a science writer for Cancer Research UK, covering the latest research for the charity's website and newsletters ('If you mention cancer one more time I'll only go and get it,' she'd say). Over the years, there was almost no aspect or type of the disease that I hadn't covered in some form.

Except, it seemed, bladder cancer.

It was odd. I'd become pretty familiar with the lie of the land, so to speak, for almost all the different types of cancer – so much so that I carried in my head a sort of dark version of the game 'Top Trumps' – a top-line summary of the unique features of different forms of the disease. Prostate, bowel, lung, ovarian, various leukaemias and brain tumours, melanoma – I could list stats, symptoms, genes, drugs. But when Zarah was diagnosed with bladder cancer, I drew a blank. I knew next to nothing. Cinderella cancer indeed.

How that changed over the next nine months. Zarah's diagnosis was confirmed after a rigid cystoscopy (TURBT) as being stage 4. There was no point in removing her bladder – the disease had already spread. 'Our aim will be to contain things as best we can,' her oncologist told us, with gentle yet devastating understatement.

And so began a whirlwind, manic, exhausting experience of being the primary carer of someone with advanced, life-limiting cancer.

And so began a whirlwind, manic, exhausting experience of being the primary carer of someone with advanced, life-limiting cancer. Diary management. A second pair of ears in appointments. Helping check if her nephrostomy bag was showing below the hem of her dress. Being a shoulder to cry on. Helping keep friends and family informed. Pain management. Shuttling clean pants and freshly made smoothies to the ward. Trying to be, and remain, a rock, not a burden. Looking for options. Helping get the catheter in. Holding her hand.

'If you mention cancer one more time I'll only go and get it,' she'd say.

SPECIAL FEATURE: CARERS

I learnt many things over the following months. Patience, for one thing. How to distract and calm an acute needle-phobe, before injecting her with anticoagulant, another.

A key lesson, imparted by a friend early on – herself a cancer survivor: 'Find something you love doing, and carve out time to do it'. It was sound advice. As a writer with a science background, I make sense of the world through understanding how it works, then writing about it. So it was with Zarah's ordeal. The emails I sent to friends and family to keep them up to date with our travails became a sort of therapy for me – I would stay up late, polishing their content, explaining terms like 'nephrostomy' and 'checkpoint inhibitors'.

But the most important advice of all was to try and focus on the positives – on the hope, on the next milestone, on the next day, to keep on moving forward, one step after another, because to look ahead too far, at what might be on the horizon, was to look into a place I did not want to see.

Yet alongside this relatively conventional support, I was also able to offer Zarah help in a radically different, and unusual, way. Thanks to my job, I had become good friends with a number of eminent cancer researchers, and when Zarah was diagnosed I instinctively, desperately, turned to them for help. What had caused her tumour? Could they 'read' its DNA? And would they look for any clues as to how best to hold it at bay?

They could. They did. But, alas, their analysis revealed little of help. Zarah's tumour had no Achilles' Heel. My best, most unusual efforts to save her were fruitless. She died in October 2016, full of the finest immunotherapy drugs available to humanity, delivered thanks to a trial at Barts Hospital, but too late to have an effect against the accelerating advance of her cancer.

To lose a partner in one's thirties is a cruel and devastating plot twist to one's life. To lose them after a decade writing about the disease that killed them is an even crueller irony. After Zarah's death, my efforts to find closure, to derive meaning from the experience, led me back to the researchers who tried to help her, to the DNA from her tumour, and to a series of blood samples she'd donated to research.

We've looked deep into those samples, to try and learn more about the cancer that took her life, and about what makes bladder cancer tick. I've learned so much. That cancer is a complex, Darwinian disease, that adapts and responds to treatment. That the traces of DNA in a patient's bloodstream can – and will – one day be used to track their disease more accurately, less arduously than can regular CT scans or cystoscopies.

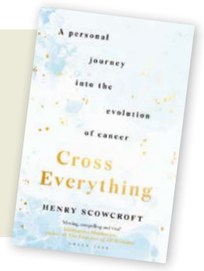
Learning this has helped me make sense of Zarah's death, and given me a renewed confidence that medical research will improve things for us all – including those of us with bladder cancer – in the future.

As well as collating these data, I also metaphorically dusted off the emails I'd sent, expanded upon them, and combined this with

To lose a partner in one's thirties is a cruel and devastating plot twist to one's life. To lose them after a decade writing about the disease that killed them is an even crueller irony.

what we'd learnt from Zarah's tumour. It led to a book – *Cross Everything* – a hybrid mish-mash of which I'm incredibly proud: a memoir, a popular science book, a meditation on grief, and a call-to-arms for more research on bladder cancer. It is also a testament to a remarkable woman, whose spirit I hope lives on in everyone who reads it.

Bloomsbury and Henry Scowcroft are kindly offering Fight magazine readers a 30% discount on Henry's book *Cross Everything*. Simply go to bloomsbury.com/crosseverything and enter the code CROSS30



My story is perhaps unique – a science writer who wrote about the science of his loved one's cancer. But perhaps not so unusual, underneath it all. We who care for our loved ones all tread a similar path – the search for answers to questions, the desire to support and assist, the need for a bit of space to allow us to be the best carer we can be. We carry out our task with whatever skills we have, through the prisms our lives have given us. We do the best we can – even though, sometimes, that isn't quite enough. But that's OK. We can do no more than that.

SPECIAL FEATURE: CARERS

The Carers' A to Z Survival Guide continued from page 27

L is for laughter and living

Just because cancer has come into your life doesn't mean you can't have fun any more. And what did your nan say? Laughter is the best medicine. It is okay to still live life, go out with friends, get a little tipsy and laugh. In fact it's probably more important now than ever. In the midst of treatments, medication and surgeries, it's easy to forget that there is life outside of the cancer bubble you are living in. Try and schedule some time for activities and things you both like that are fun. Even staying in and watching a good comedy DVD can be therapeutic.

Have you jumped in a puddle lately? Kicked leaves around? Gone outside after dark and gazed at the stars? If you don't keep an eye on it, cancer can consume your life and you become just a carer, forgetting who you really are in the process. Even through treatment and recovery, it's important that both you and your loved one do things that are 'normal', as it's these moments and memories that give your life balance. Give yourself a break from worrying, take time off thinking about the future and just live for the day.

M is for money

Depending on your job situations, cancer can put a huge strain on the household finances. The best advice here is to act sooner rather than later. Don't bury your head in the sand and hope for the best. Taking an active role in planning your finances through test, treatment and beyond will put you both back in the driving seat and eliminate an area of stress for both of you. Both Macmillan and the Citizens Advice Bureau have dedicated financial helplines with advice for carers and cancer patients.

If you don't keep an eye on it, cancer can consume your life and you become just a carer, forgetting who you really are in the process. Try and do things that are 'normal'.

It is okay to still live life, go out with friends, get a little tipsy and laugh.

N is for news

One of the most exhausting roles for a carer is that of news. It seems there are so many people you need to keep updated with what's happening that it can be completely exhausting. Then there is the emotional drain of repeating the same information over and over on the phone while listening to people repeat how sorry they are. Take control of this and make it easier for you to keep everyone up to date. A closed Facebook group can be a brilliant way of getting the current status out there with minimal effort – you post once and then everyone can see the information and comment on it. Or task others with calling and feeding the news through to other family and friends.

O is for operations

If anything is likely to derail you, it will be the sight of your beloved fresh out of theatre hooked up to a gargantuan pile of cables, machines, drains and devices, all the while emitting a cacophony of beeps. Utterly terrifying. So be prepared when it comes to operations. There is no law that requires you to sit at the hospital waiting for news while the patient is in surgery.

In fact, I recommend you don't. Instead gather someone from your support network and be busy. Go shopping, go to the movies, try a new dance class. Do anything you can to take your mind off what's happening. Otherwise the time will drag in a way you didn't think was possible.

Oh, and don't freak out if it takes longer than you think. This is why I recommend you keep busy. It's highly likely there's been a delay in getting the patient to theatre or the op start time, which knocks on to recovery. Maybe there just isn't a porter free to take them back to the ward. Try and relax if you are several hours past time and you haven't heard. This is generally an instance of no news is good news.

Lastly, when you do go and visit, remember that the patient is not going to be looking their best. They are probably awake at this point but may well be giving you the run down on past girlfriends or asking for a chicken curry. Take it easy on them, they've just had some class A drug equivalents so are riding 'high'.

P is for planning

Like all good battles, you are going to need a plan. You need to know who is on your side (see B is for build) and you need to know exactly what you are fighting against. First of all, speak honestly and openly with your medical team about what to expect both for your loved one and for you as a carer.

They'll be able to give you a good idea about the road ahead and the tests and procedures that come with it. Then do your research. Go back to the reputable websites and read as much as you can about what's going to happen. Ask your CNS about Fight Bladder Cancer's series of Patient Information Booklets so she can order the most appropriate titles for you. Talk again to the medical team if you have questions. If there are any questions you don't want to ask, you can always head to the FBC private forum where you can ask anything. Then plan in where you will need support and start asking for help: someone to do an extra visit to hospital when you need a night off, or to drive you to a results appointment. These little things can really make a difference when you are in the thick of it. Getting a plan puts you back in control.

Q is for Quack

Sure, I'd love to be able to tell you that there's a magic pill you can give to your loved one that'll make cancer disappear. I'd also like to believe there's another type that'll get rid of fat the way that sun melts butter, but we both know that that's about as real as the tooth fairy. When you are reeling from an initial diagnosis, it's natural to search around for anything that could make a difference. You are desperate for a cure and consider them all – cannabis oil, broccoli juice, turmeric tablets – once you start Googling, the list seems endless and there are hundreds of unscrupulous companies and individuals out there who will take advantage.

I can tell you what is true ... there is no conspiracy over this ... Cancer is not caused by sugar and the pharmaceutical companies are not in a grand plot to deny us cures. The truth is while some research is being undertaken to see if certain diets, lifestyles or substances mean you have a reduced risk of developing cancer, there is currently no scientific evidence to support any of these other claims. The only evidentiary data in bladder cancer supports quitting smoking and eating a healthy, balanced diet, low in processed meats with fruit, vegetables and wholegrains at its heart. Being blunt, I have seen a handful of people over the years turn their back on traditional medicine and treatments to pursue regimes sold to them by quacks and charlatans. Everything from clean water to cannabis oil. Want to ask them how that worked out for them? Well, unfortunately we can't because they are all dead. Evidence enough?

R is for results

I remember on one check-up on a six-monthly scan, we went in to see the consultant and he was fiddling with his pen a lot and seemed unable to look at us. He proceeded to tell us that they'd found something in Andrew's liver but it was too small to say what at this point, and we'd have to wait another three months for an additional scan to see how much it had grown and whether they needed to biopsy it.

If there is anything guaranteed to make your mind turn immediately to mush it is results day. Bad enough for us carers but worse still for the patient.

When we came out, Andrew turned to me and asked me where the thing was in his body. His brain had gone

into shut down at 'we've found something'.

This kind of results amnesia is very common and the best way round it is a two-pronged approach.

Firstly, make a list of all the questions you want to ask before you go in and take the paper and pen in with you.

Ask your questions and write in the consultant's response on each point. Ask again if you need further explanation. Secondly, many urologists and oncologists also have no objection if you record the meeting on your phone, although you should always ask their permission first. This means that you can go back over what they've said in the comfort of your own home. If there are any outstanding issues or questions you have, you can then pop your medical team an email for clarification. Remember, there are no silly questions. If you need an answer to something in the wee small hours don't forget you can always head to the Fight Bladder Cancer private forum where someone is bound to come back with help and support.

S is for sex

If it's your partner who has cancer, it is going to affect your relationship, and intimacy. Realistically, you will have to work hard to make sure that cancer doesn't come between you in that way. Operations and treatments can have a very real physical impact on the patient. They may be tired, suffering from side-effects or feel weak. It's important during these times not to become isolated from each other.

You may also have concerns about what you can and can't do sexually during treatments. Your

clinical nurse specialist (CNS) is the best person to ask about this. You have no need to feel embarrassed as they'll be able to provide you with the information you need to make sure you and your partner are safe when you are intimate. Perhaps treatments have led to difficulties with the physicality of having sex? Don't let this become a barrier in your relationship. Urology teams always have a sexual health expert who can help with specific problems such as erectile dysfunction and other issues. Again, they see these problems every day and have a variety of treatments designed to get you up and running again! Try to continue to be tactile, hold hands, give a gentle massage, a tender hug, or lean in for a soft kiss.

T is for terminal

As a carer you can veer between bouts of extreme optimism and pessimism, depending on where you are in your loved one's cancer journey. That is entirely normal. Although the vast majority of bladder cancers are treatable and often lead to full remission, there are some patients who are told that they are facing an end-of-life outcome – as a carer this is about as tough as it gets. You will need extra support during this time. Ask your CNS for Fight Bladder Cancer's *Advanced Bladder Cancer* Patient Information Booklet, which has plenty of advice on coping at this difficult stage.

U is for uncertainty

You may be wondering how you can continue everyday life, with no idea about what the future holds. But actually, if you think about it, that's true for every single one of us. No one has any guarantees about what's going to happen tomorrow, next week or next year with or without a cancer diagnosis. Don't worry about your mortality. Get busy living and try and enjoy every day.

V is for virtual friends

The FBC private forum is full of patients and carers living and dealing with bladder cancer. I am proud to say it is one of the very best charity forums in the world and the advice and support offered on a daily basis is astounding and inspiring. When you are wondering how to get through the next day, or waiting for results or any other problem you can think of, there is a virtual member of the wee family on hand to pick you up, dust you down and put you back on your feet. Often the best answers come from someone who has trodden the same path, and with every type of age range and diagnosis represented, the shared wisdom is awe-inspiring.

Just go to fightbladdercancer.co.uk/getsupport and join up.

W is for waiting

I hope you are patient as you are going to get really good at waiting. For every test you must wait for results, then wait for letters to arrive detailing appointments and then the wait for possible operations. After all this, there is still the longest kind of waiting, the surreal time between check-ups when you can almost convince yourself that things are back to normal (until the pre-check-up nerves kick in). Added to this for the carer is the waiting to visit in hospital, waiting to find out how your loved one is, waiting for the doctors to tell you how it went ... I've tried every way of dealing with the waiting over the years ... to be honest, there's no quick fix. It just comes with the territory. Try being patient. If all else fails learn to crochet ...

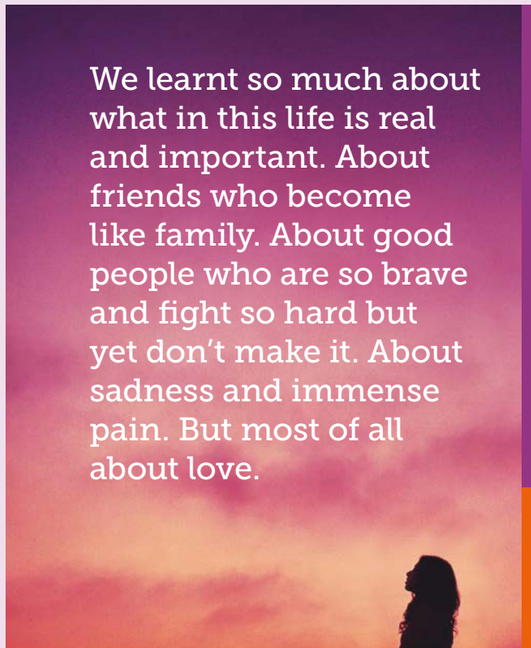
X is for X-rays, tests and treatments

Remember the feeling of hopelessness as you watch the person you love so dearly struggle with their diagnosis? Well, when you enter the tests and treatments phase of operations, it's going to get worse. Again, knowledge is your friend. By finding out any potential pitfalls up front, you can be well prepared for every eventuality. It's the little tips that help immensely, for instance knowing what kind of food is appetising to someone going through chemo, or the right kind of bed sheets to protect against night-time leaks for someone with a radical cystectomy. If you don't know where to begin, you can be partnered with a Bladder Buddy, a carer whose partner has had the same diagnosis and treatment as your loved one.

Y is for YOU

Being a carer is a demanding job. While everyone else is focused on the patient, you must make sure that someone is also looking out for you. And don't forget that you need to take care of yourself, too! Make sure you eat a balanced diet and take regular meals. This can be particularly challenging when you are managing hospital visits but this is where that wonderful network of supporters comes in. I remember returning home after a very challenging day and collapsing in the chair, then hearing the doorbell ring only to be presented with a plate of delicious Sunday roast from a stalwart friend. Wonderful! Take time out for yourself in the day even if it's just for a short walk and some fresh air to gather your thoughts. Me time is as important as ever. And sleep ...

To be on tip-top form as a carer you need to get good-quality and substantive sleep. Don't put your own needs last.



Z is for zen

Having been through over a decade of being a carer and seeing my late husband, Andrew, finally signed off as a bladder cancer patient (only to be diagnosed months later with a terminal bowel cancer) I can say without any doubts that these experiences have changed me and changed how I live and experience life. There were some immeasurably hard times. On the blue-light dashes to A&E in the middle of the night and arriving at the hospital to find my Andrew in resus as they fought to save him, I thought we would never survive it. But we did. And in between those times, over the ten years of his cancer battles, treatments and highs and lows, we learnt so much about what in this life is real and important. About friends who become like family. About good people who are so brave and fight so hard but yet don't make it. About sadness and immense pain. But most of all about love. It transformed my life, and led me to a new career as a Humanist Funeral Celebrant – bringing comfort to others who are going through some of their darkest moments.

Remember that life is a thing of beauty and something to treasure. And the very best we can do, for ourselves, for our loved ones and for those we have lost, is to go on out there and LIVE.

Caring for the carers

Without the selfless support of carers across the UK, the health system would surely collapse. Carers UK exists to help and support them – not least those children between 5 and 17 who take on such a heavy responsibility.

Carers UK is a supportive network for all carers and a movement for change – recognising both the value and the difficulties of the carer's role. The charity offers valuable support and information, is active online and on social media and has a forum at carersuk.org/forum where carers can let off steam, share a problem, and talk to other people who understand what they are going through. They have just produced a new guide on all aspects of caring, from practical tips to financial support.

carersUK

ARTICLE
EMMA WILKINSON
FBC Volunteer

Looking After Someone looks at the problems and decisions that carers may face on a daily basis, covering the challenges of the role in a friendly and accessible way. Crucially, it recognises that caring is difficult, and helps to reassure people who are finding it hard that they shouldn't feel guilty. It brings in points of view from other people in the same situation, with the key aim of reminding carers that they are not alone.

Dealing with professionals & friends

There are useful tips on dealing with a range of professionals, one of the many roles of the carer which some find difficult at first. This helps the carer to recognise the value of their own point of view, while retaining their main role of speaking up on behalf of the person they care for when there is a problem or lack of clarity.

Handling difficult conversations with family and friends is also covered, situations that takes courage, patience and bags of tact.

Looking after the carer

If they are not looking after their own mental and physical health and wellbeing, carers will soon find the pressure is too much.

> They need to eat, rest and sleep, take time out for themselves and not be totally absorbed in the caring role.

It is also important to have coping strategies to deal with stress, and learn to notice when the stress is getting too much. Support for people who feel isolated and under extreme pressure is available, giving reassurance that other people are in the same situation and there are people who can help.

The guide gives sound advice on the importance of taking a break – caring can be a full-time job, so it is vital for health and well-being that you have time to relax and recharge.

Changing relationships

Relationship dynamics can take a subtle or a drastic shift when one partner is ill and this should not be ignored. In the middle of the practical details involved in care, the guide gives advice on how to maintain what you can of the original relationship, while moving forwards in a practical and well-informed way.

Support

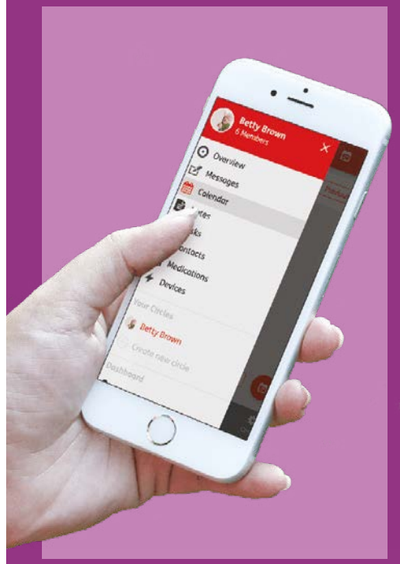
A carer's assessment is available to any adult caring for another adult who appears to have a need for support. It is carried out by the local authority of the patient, and carers can request an assessment if one hasn't been offered to them. An assessment should take a wide-ranging review of the situation, covering the carer's role and how it affects their life and wellbeing; how you feel about it; health, work, study and leisure; other relationships and social activities, and any impact the caring role is having on the carer's own life goals. It also covers more practical issues such as housing and what to do in an emergency.

Following the assessment, a range of support services may be available, including driving lessons, IT equipment or help with housework. Support is dependent on the financial situation of both carer and patient, but everyone is entitled to be given information and advice on local services to prevent needs from developing further.

The person being cared for should also be offered a needs assessment by their local authority, no matter what their level of need or financial means. This will look at their physical, mental and emotional needs, and the carer is entitled to be involved in this assessment. This could lead to home adaptations, allocation of a care worker or respite care.

Legal advice

There is legal advice on how to help manage someone's affairs, should that be necessary, with a view of the different types of power of attorney. Carers UK have a new contingency planning tool to help you prepare for the unexpected, at **carersdigital.org/mybackup**.



Jointlyapp.com

Carers UK have a new app, **jointlyapp.com**, which brings joined-up thinking to the area of care provision. For example, if a number of siblings are caring for a parent, this app can store and share information, medication records, calendars and contact details within a group – invaluable as a tool for keeping in touch with each other at the same time as juggling the demands of daily life.

Everyone is entitled to be given information and advice on local services to prevent needs from developing further.

Financial support

There is a range of financial support available to carers, in terms of benefits, help with Council Tax, fuel costs and NHS costs. There is advice at **carersuk.org** as well as a benefits calculator, guidance on who is eligible for Carer's Allowance, and how Carer's Credit works – a way of protecting State Pension rights if someone is unable to work due to caring responsibilities.

Lightening the load on young carers

The current estimate of the number of young carers in the UK is 800,000 – that's children aged 5–17 who care for an adult or family member who is recovering from treatment or suffering chronic illness. This is a huge challenge for these young people, changing the dynamic of the family, resulting in about a quarter of them missing schooling, and generally changing their childhood irrevocably.

Young carers are assessed by the local council 'on the appearance of need' so it is not necessary for anyone to make a request; the assessment is done using the whole family approach, which is explained in the Carers UK leaflet.

The assessment must involve the young carer themselves and the person they care for, but also take into account support offered by anyone else, the impact of the caring responsibilities on the young carer, and how their needs impact on other family members and those in the wider support network.

There are three crucial elements to the decision-making process.

Does the young person wish to continue caring? While the answer is usually that they want to continue, their own needs must be considered and not be allowed to be forgotten while they are caring for the adult.

Is it appropriate for them to do so? The adult should ensure that they have made a sufficient level of care available, so that the young carer is not required to provide inappropriate care.

What opportunities for education, training and work are available to them? The aim is that the young person should not miss out on education and social opportunities to an unacceptable degree.

Local councils then have a duty to provide support directly to the carer and demonstrate that the assessment has taken everyone's needs into account.

There are not many hard and fast rules, but the underlying aim is that local councils should give close consideration to the needs of all children or adults who are involved in the caring role.

The full copy of *Looking After Someone* is available in different versions for England, Northern Ireland, Scotland and Wales (in both Welsh and English). Visit **carersuk.org** to download the guide or investigate their range of information and resources for carers of all ages, including up-to-date information on the COVID-19 situation, which has temporarily halted distribution of printed copies.

Tips & tricks for family members

ARTICLE
LYDIA MAKAROFF
FBC CEO

We knew the members of our private support forum would be full of great advice, but even we were delighted with the response to our request for some tips and tricks for family members for this Carers' edition of *Fight* magazine.

MEDICATION

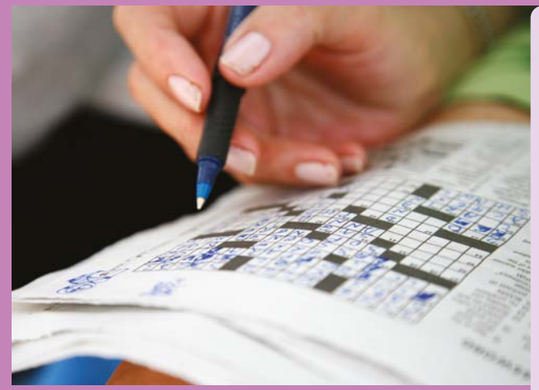
- If you're having chemo, maybe ask a family member to help with your medication. Chemo side-effects can make taking the right pills at the right time quite confusing – you'll feel much better if you get it right!

PAPERWORK

- Get printed copies of everything: lab results, pathology tests, scans, ultrasounds, x-rays. If you need a second opinion, these will be necessary. Having copies means that you know exactly what is found. Knowledge is power.
- I recommend keeping everything medical in a file, marked out with different dividers for different consultants.
- Have a list of medications with you at all times!
- My husband's medical file is now in two volumes and very thick. Having watched doctors trying to find info, we now have a summary of key treatments, and the dates, that always gets taken to any medical appointments. After a year or two, it's easy to forget some of the detail (or perhaps we want to?).
- Family members can sort out paperwork and bills, contact Macmillan for budget advice, apply for benefits, blue badges, etc.
- Keep a list of contact numbers for medical teams and also family and friends so you can ring or text with updates.
- I keep ALL the letters from the hospital and have a file with them in date order – it's really useful.
- Start a book, write down every appointment, result, phone call – you will surprised how thick and fast they come in the early days and if you are referred to different hospitals you will have all the information to hand

PROCEDURES

- Try to be at the hospital when the stoma nurse is present so you can learn the procedure.
- Never assume anything, always ask, however trivial the matter in question.
- Be supportive and understanding; also ask about night bags and stands for catheters, again something I wasn't told about.
- Take a note book – my sister-in-law came to all appointments and brought the said notebook – it proved very useful.
- Listen, take notes, remain calm and focused on what is being said.



APPOINTMENTS

- It was very strange dropping off my partner and picking them up afterwards. Make sure the patient has a phone and charger to keep in touch.
- Insist on coming along to all doctors appointments, whenever possible. This is scary stuff, and my partner was nervous every time she went to the doc, and she didn't always hear everything that was said or remember it.
- If you have to drop off and pick up, do something relaxing like taking a walk or distracting, like a crossword or sudoku, instead of sitting in the car worrying. For us, since I could not go in during Amie's chemo treatments, that became a good time for me to get some walking exercise, even get a take-out or drive-through lunch for myself, or go home and nap, if it was one of the long days. I was given this advice about what to do during the chemo treatments because after I dropped her off for the first one, I had a panic attack in the car and couldn't settle down, and the hospice house is right next door, so I went in and spoke with one of their staff. (I never told my partner about that.)
- You may have to advocate for them, ask questions at appointments and demand attention from professionals when you know something is wrong.
- I repeat back to the consultant what he has said, to make sure I understand! (Sometimes we tape it.)

AFTER TREATMENT

- The patient will be worried, tired, uncomfortable. After an RC they are in a bad way for the first few days and look dreadful.
- As a visiting family member, remember that you need to eat and sleep too. Make time for yourself. Casseroles and easy meals are essential. Following my partner's RC I was at the hospital from 9am to 1pm, home to walk the dog, have some tea and then back from 6pm to 9pm. Take snacks and drinks with you and a book to read – they like you to be there but sleep a lot.
- Buy extra bedding and pyjamas so they can always have one on, one in the wash and a spare.
- Don't hog the bathroom; they often need the loo at short notice.
- Don't allow them to be 'the patient' for too long or you will have no time to yourself! Clearly each person is different (underlying health etc.) but we are not disabled and activity is vital. Clearly it's more difficult if it is not part of one's normal lifestyle. This is an opportunity to make changes: life is a verb!
- Post RC, try to get them moved to a regular hospital room as soon as possible if they are experiencing confusion or delirium. It seems to help orient them.
- If someone is in pain, never accept an X-ray when a CT scan is available. When the cancer had spread to my partner's bones and she was in so much pain, an X-ray did not show the fracture in her humerus.
- As a family, we try not to dwell on the medical stuff.

SPECIAL FEATURE: CARERS

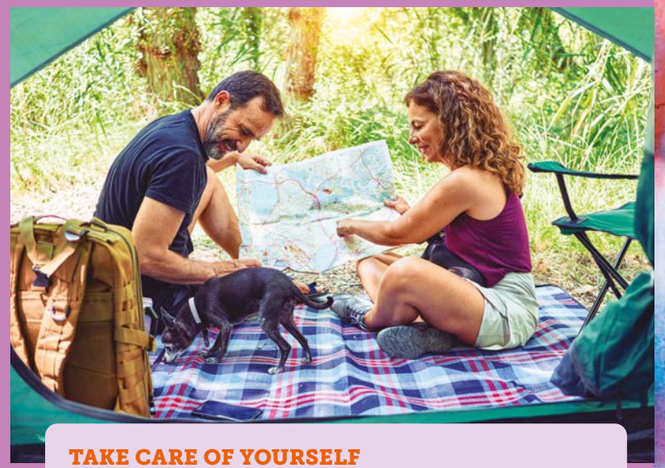
JOIN THE FIGHT BLADDER CANCER FORUM & GET SUPPORT

- The forum has been a revelation. Fight Bladder Cancer is a highly proactive charity: they do what they say they will do. They are highly approachable and incredibly supportive.
- Join the Fight Bladder Cancer support groups.
- Sign up for the Fight Bladder Cancer Fight magazine.

Melanie Costin, Sue Williams, Danielle Marr, Lydia Makaroff

JOIN A SUPPORT GROUP

- To other partners I would recommend they find their own support. It affects you both and actually, in our situation, it affected our 14-year-old too. My hubby is not good even now talking about things but my daughter and I really needed to. I had brilliant counselling and honestly don't think I would have got through the first few months without that. It's hard supporting the person going through this and you need to look after yourself, too.
- Use the Fight Bladder Cancer Facebook support group. Everyone is so supportive. There's always someone to answer even the most silly question even at 2am!



TAKE CARE OF YOURSELF

- As the patient, we understand that you, our significant other, support partner, want to be there for us every minute of the day but we know to be strong takes a lot of inner strength. We also know you are hurting too. You are worried too. We know you need some time out and we want you to have that time for you away from the eye of the storm.
- THE best thing a family member can do is ... do not go on like it's a big deal, like it's 'the end'. A diagnosis of bladder cancer IS NOT a death sentence. You are not to worry. Worrying is the doctor's job. They will tell you what's happening. They will tell you what needs to be done and when it needs to be done. Do what the doctor says and do not worry. That's how I am a 29-year bladder cancer survivor.
- Please try to maintain some normalcy. Go out to dinner, have friends over, go on a hike and talk about something other than cancer.
- Breathe ... when things start to overwhelm you, just breathe! Stand up with your arms raised, and do three big, slow breaths in and then out.
- Try and have something to look forward to during and after treatment ... we would go to Wagamama's ... or take a picnic and go for a walk.
- Don't try to be brave. Cry your eyes out as much as you want and do not feel guilty!
- Try to laugh every day.
- Have patience but also remember it's ok to be frustrated or angry. We are human and it is unreasonable for us to be positive all the time when in these situations; there's nothing wrong with allowing ourselves to be real about our feelings. It helps that my husband and I are very open and talk honestly about how we feel.

Are we missing **half the story?**

ARTICLE
CHLOE THOMSON
PhD Student,
Edge Hill University

An investigation into how men view their role as carers

Hi, my name's Chloe. I'm 25, from Lancashire and am exploring the experiences of informal male carers for my PhD in Health.

Chloe Thomson

I studied for a degree in Health and Social Wellbeing (Edge Hill University), before completing an MSc in Dementia Care and the Enabling Environment (University of Salford). During this time, I worked as a dementia healthcare assistant within care homes and became interested in the stories of those I was caring for, specifically the care they had been given at home prior to entering 'formal' care. The opportunity to study a PhD and teach arose at Edge Hill University in 2018, which brings us to the present – the final stretch of my doctoral journey!

What is my research about?

My research is exploring the male experience of providing general or specific care to significant others, and the impact on mental wellbeing. I realise that the term 'informal care' is in itself an oxymoron – but this is the term most commonly used for those caring for family and friends. By using a combination of photography and interview, I have been uncovering the stories from men caring for their partners, children and parents.

Why is this research needed?

There is an overwhelming amount of academic literature focusing on the care experience, from a largely female perspective. This often reports on the pressures that women face alongside or from their care responsibilities, or highlights the support networks that women have access to. However, the male perspective is commonly neglected from this narrative. This made me wonder how men experience their care role, because 42% of UK carers are men – are we missing nearly half of the story?

What inspired me to conduct research in this field?

My inspiration for this area of research was two-fold; firstly, the need for learning more about the male experience of caring and how this might impact on future support, and secondly my personal experience. Working as a dementia healthcare assistant taught me about the caring dynamic, and highlighted that there is often a carer – or partner, family member or friend – at the centre of a patient's story as well. This made me wonder, where was the narrative from the individual providing that care?

Alongside this, I have known informal male carers personally, whose experiences have quite noticeably differed from women. Whether they have had less access to or knowledge about support, felt unable to reach out for support, been subject to expectations that they would remain working full time alongside their care role, or simply did not even identify as a carer. On the contrary, they experienced a greater bond with the individual they were caring for, found pride in their ability to take on this new role and 'perform' well, or felt empowered to prioritise their own time, hobbies or forms of escapism as a way of managing the stress that came with caring.

> I merely highlight the importance of listening to male carers, and discovering where change can be made to improve their experience, and where this differs from the female carer needs.

It is not to say that these are the shared experiences of every male carer, nor that female carers do not share these experiences at all.

The future

This research is still ongoing. Preliminary findings are being drawn but there are still more stories to be heard. If you or someone you know is interested in taking part and sharing your experiences as a male carer, you can contact me at **thomsonc@edgehill.ac.uk**

Some tough lessons to learn

CARER STORY
DEBBIE
FBC Forum Member

Debbie

'We have found a tumour' – the words you don't want to hear. When my husband was operated on for a long-standing kidney cyst and stone, the Grade 3 bladder tumour was the unexpected finding that came into our lives at the same time. With hindsight, maybe it wasn't unexpected by the medics, but it was by us. But we instantly knew it was a game changer.

Having received an all-clear on her husband's last flexi, Debbie looks back on her experience of caring for a loved one through cancer. It's been hard, but there is hope for the future.

He felt so unwell during the next week he spent in hospital that – apart from admitting our shock to each other – the diagnosis wasn't really discussed. At the time I didn't realise that was his way of dealing with things: to listen to the absolute minimum amount of information, tell no one except our grown-up children, and only mention it when an appointment was looming.

The patient is in charge

I found that really hard. Having worked in histology for over 40 years and then spent some time in Cancer Services, I knew much more about cancer, biopsies, scans, MDTs and so on than I was comfortable with now it was personal. This was my husband, not one of our patients. I wanted to talk but he didn't, so I just had to go with that and worry silently. So I guess that was the first lesson; let the patient set the agenda.

Talking really helps

It wasn't until several months later that I persuaded him to tell his friends, and once that hurdle was crossed it was big step forward. I have a good friend who I confided in who was a great support, so lesson two seems to be even if you can't talk to your partner, find someone to talk to about how you feel.

Guilt

Then there's the big G to deal with – and you can't escape it: guilt. Should I have suspected this? Should I have pushed for more frequent scans when he was under surveillance for the cyst? Would this have made a difference to the grading and the treatment plan? Then there's guilt feelings to get over when I take time out and go walking, leaving my husband at home. I feel bad leaving him home alone even though he is quite happy to have some quiet time. I don't go out much anyway – as I write we are still under strict COVID-19 restrictions – and it has become easier with time, but that little voice in the back of my head won't quite go away and niggles at me every time I 'desert my post' – or that's what it feels like.

Care for yourself

The realisation that our lives had changed forever was the next hurdle to cross. What about our children – how are they going to deal with this? What about me – what's going to happen to me? Then that initiated the guilt for thinking about myself, when I should be focusing on my husband. Lesson three, as a partner you have to look after yourself or you won't be fit to look after anyone.

That's easier said than done when there are days when it all seems too much to deal with. And when those days arrive, don't be shy to ask for help: talk to your friend, tell your partner how you feel, ring Macmillan or, even better, ask someone from FBC.

Staying positive is hard work

Anxiety: a feeling of worry, nervousness or unease about something with an uncertain outcome. That's the official definition but it doesn't convey that sick feeling about what the future holds, the hours lying awake in the dark when you can't sleep, the fear of the next phone call or the nervousness of opening the hospital letter that drops on your mat. And all the time, you are trying to keep up the positivity.

All of these will be very familiar to anyone with a cancer diagnosis and it's something that I have struggled to deal with, while trying to be upbeat and positive for my husband and family. It's mentally as much as physically exhausting. I try to keep life at home as normal as possible. I see my role as taking the day-to-day problems on my shoulders so my husband can concentrate on getting better. I'm the one who used to lean on him; he was happy-go-lucky and a definite que sera sera sort of person but the roles are now reversed and that is still a work in progress.

However, it's just over a year since he was diagnosed, with 12 BCGs completed and the last flexi clear, so progress being made. I'm less tearful and exhausted as time goes on and we have coped together, but each in our own way, and we are very thankful that none of the treatments has been cancelled or delayed during the ongoing Covid crisis.

It's mentally as much as physically exhausting. I try to keep life at home as normal as possible. I see my role as taking the day-to-day problems on my shoulders so my husband can concentrate on getting better.

I am immensely glad that I found Fight Bladder Cancer – interestingly through an internet search and not from the treating hospital. It definitely helps to know you are not alone and that there is always someone to talk to in the forum. I have not posted much but have learnt a lot by reading and it's always a cheery moment when I read of good news, and this gives us hope for the future.

SPECIAL FEATURE: CARERS

Being a long-distance carer

ARTICLE
SUE LONG
Maggie's Cancer Caring Centres

The fact that so many of us move away from our parents to develop our lives, university, careers or be with a partner, is a sign of modern times.

For most of us this works well. People cross counties and countries – never feeling completely cut off, as technology allows us to keep in touch as often as we need or wish.

However, the news that a parent or other family member has a cancer diagnosis can create a maelstrom of emotions and make the distance feel like an additional burden. It can feel even worse if they are becoming frailer and less well. Your daily life at home will pull you in one direction; the urge to be with the person who is unwell will be just as strong a pull in the other.

What is it like to be a long distance carer?

It's not easy, that's for sure, as there are plenty of emotions to grapple with in addition to the practicalities.

- guilt can creep into our hearts and minds for all kinds of reasons: you worry that other family members are carrying the caring load
- you may have to put work, your own family and partner first, making you feel guilty for not being there
- or, paradoxically, feel bad about being with the person with cancer, whilst other responsibilities feel neglected.

Juggling responsibilities and feeling stretched in many directions can take its toll – causing stress, lack of concentration, sleeplessness and anxiety.

You may also find you feel out of the 'information loop'. Parents often feel they need to protect their adult children from the emotional and physical challenges they're facing and, when living away, this can be frustrating. You won't be able to attend hospital appointments or be there to make decisions and you may feel left out. This can sometimes create situations where communication goes awry.

If you are only able to visit occasionally, physical changes, or perhaps deterioration, can seem more obvious and be a huge shock.

There can be a temptation to want to 'fix' things, and this can cause misunderstandings and resentment in those who live closer.

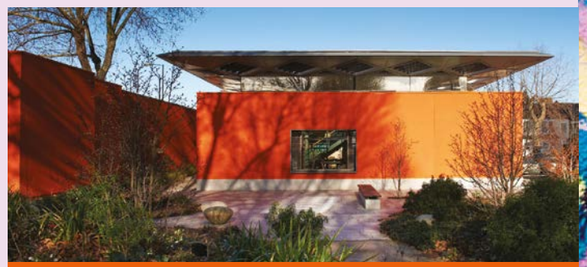
If you're the only relative, or friend, who has ultimate caring responsibility – then the worry about ensuring they're OK when you're not there – but also keeping your own life intact – can cause pressure. There's also the emotional component of not being able to be part of the 'big stuff' – discussions about the uncertain future, the possibility, for some, that recovery may not be possible, and all the heartache that brings.

Long-distance caring can work

Is it possible to care from a distance? Yes! – don't think you are in a hopeless situation. It can take some negotiating, and you may feel out of your control at times but you can do it. And I've put together some ideas which may help.

- **Technology can be a lifeline:** There are various apps available, which can help keep everyone in the caring 'loop' in touch with each other. Carer's UK's Jointly App (see page 40), for example, is designed to 'make caring easier, less stressful and more organised'. It means task delegations, information updates and reminders can be shared so that, near or far, you can all stay in touch and support the person with cancer.
- **Keep in regular contact:** Texting, Skype, Facebook, Zoom, WhatsApp or a simple phone call can all help you feel less distant, allow you to monitor when you might be needed and make sure that the person knows you're thinking of them. You can support siblings, carers or other family members, help them with any long-term planning and see where you can help – perhaps some online shopping, information gathering, or just that short text that lets them know you appreciate what they are doing.
- **Make a rota for key appointments:** Negotiate times with local carers so you can attend key appointments. It is a worth making sure your work knows the situation so you can ask for some flexibility in taking time off.
- **Join a meeting by video/phone:** It's not ideal but it can be done if everyone attending is happy with the idea.
- **Get to know the support network:** This can be professional, medical contacts as well as the informal network of friends and family. Asking them to let you know any problems that need addressing can be invaluable, whether your role is the primary carer or part of the team.
- **Have an emergency plan in place:** Organise a plan in advance for if you're needed in a hurry, co-ordinating work, school, partners, etc. so you can just swing into action. Have key emergency numbers available, plan travel arrangements, and ensure everyone knows what to do and who to call. Liaise with the carers, the GP and the person who is ill so that they do call you if needed. With the person's permission, check that your contact details are recorded as one of the next of kin.
- **Visit when you can:** Try to arrange physical visits, if possible and if safe – there is nothing like seeing someone face to face. It gives you all a focal point, and something to look forward to – and a chance for you to see how everything is being managed. Give yourself time to relax and enjoy their company – keeping the old familiar bonds open and being able to feel part of the situation. If it's not safe to meet indoors, consider a walk together outside.
- **Look after yourself:** This will all take emotional and physical energy, and you'll need time to absorb the situation, and maybe talk with others about how to manage the daily stressors. Find your nearest Maggie's Centre for support, practical advice and information for you as a long-distance carer, and join in the online conversations.
- **Don't let guilt get you down:** Accept that there are things you can do and things you can't and ignore the internal and external factors that press your 'guilt' buttons. The reality is that many people live a long way from those they love but the bonds of loyalty are stronger than geographical distance. Family members can implicitly or explicitly hint that they would like you home, but good will and good communication should ensure that everyone works together to make you still feel part of what is going on.

People don't always understand the anguish we go through when someone close to us emotionally, but many miles away in distance, is facing a life challenge. It's hard, and something that doesn't always get talked about. **You're not alone ...**



You'll find Maggie's centres alongside NHS hospitals and they can also support you online. They are a breathing space away from the hospital. They help people take back control when cancer turns life upside down, with professional support for anything from treatment side effects to money worries. All their support is free and you don't need an appointment or referral – just come in.

Find a list of Maggie's centres at:
www.maggies.org/our-centres/

This is based on an article originally published at blog.maggies.org

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

fight bladder CANCER

Wee Are Family!

May is Awareness Month

Time for our global campaign shining the spotlight on bladder cancer.

Once again we look forward to working with all of you – our friends, supporters and partners – during Bladder Cancer Awareness Month. After a long year of Covid-19 lockdowns, fear and sadness, we are hoping that this year's Awareness Month will see multiple stories shared about bladder cancer survival that will help to bring hope and optimism to patients and family-members affected by this disease.

Take a look at the enclosed leaflet with our 31 Days of May Activity Calendar for more ideas on spreading the word.

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

What orange idea will you choose this year?

Whether you choose to bake orange cakes, arrange a cheerful vase of orange flowers or simply dress up in as many orange clothes as you can find – we look forward to seeing your photos – don't forget to share them with us or post on social media with #bladdercanceraware2021. At the time of publication, lockdown restrictions appear to be on-plan for being eased, which means you can hopefully inspire your friends and family to join with you too.

Orange Goes Global

This year we are excited to be working more closely than ever with other patient-led organisations around the world – in Africa, Canada, Australia, America, and Europe – under the banner of the World Bladder Cancer Patient Coalition.

Bladder Cancer Awareness Month Digital World Tour

"Our international connection allows patient-led bladder cancer organisations to exchange visions, experiences and goals. Awareness month is an opportunity to bring bladder cancer to the forefront of the world's attention. We are thrilled to have FBC on board. Explore our digital world tour at **worldbladdercancer.org***"*

Alex Filicevas, Executive Director, World Bladder Cancer Patient Coalition

"I'm a bladder cancer patient and a Community Champion volunteer for Fight Bladder Cancer. This means I help the charity out by spreading the word about bladder cancer in my local company and in my community. This May, for Awareness Month, I will be taking Wee Walks in my Fight Bladder Cancer T-shirt and doing my best to spread hope and optimism to as many people as I can."

If you want to order a Fight Bladder Cancer T-Shirt, visit the shop on **fightbladdercancer.co.uk**. To sign up to be a Fight Bladder Cancer Community Champion – email **fundraising@fightbladdercancer.co.uk**

Will you take a Wee Walk
to raise awareness & raise funds?
giving.fightbladdercancer.co.uk/cf/wee-walks

We are optimistic that many of our friends and supporters will be allowed to take a Wee Walk by May and we have developed a special event fundraising page where you can sign up – and create either a family Wee Walk, a team Wee Walk with colleagues or a group of friends. Just scan this QR code. We do urge you to follow the rules and stay safe. Be inventive! Walk round your garden, like the admirable Captain Tom, set yourself a target and don't forget to share your plans with us at fundraising@fightbladdercancer.co.uk – especially if you want some tips or materials. .

Visit our website 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 became particularly poignant since we lost our inspirational founder, Andrew Winterbottom, on this day in May 2019. Take a moment on Monday 31st May to blow beautiful bubbles in memory of so many brave friends, 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 tag **#Bladdercanceraware2021**

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**
(if we are mega-busy, you can leave us a message)

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 BCAM2021 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.

How you can help people affected by bladder cancer – raise money & spread awareness this May

Get your friends and family on board; get involved with one of our ideas and take on a challenge with us!

Scan our handy QR codes to find all the info you need!

Family Fun!

Do your children or grandchildren need you to nag them to clean their bedrooms, load the dishwasher? Are they house-trained yet or would they benefit from some guidance! If this is the case, then get your family involved with Bladder Cancer Awareness Month by signing up to our **Mini Hero 12-Chore Challenge**, where – in honour of the charity's 12th birthday – children are being encouraged to take on 12 specific chores at home, in their garden or in their community during May – in return for sponsorship or donations. Families can sign up here at **giving.fightbladdercancer.co.uk/cf/mini-hero**

Calling all energetic folks!

Have you got what it takes to sign up to Fight Bladder Cancer's virtual fitness challenge? This 'sporting' **12K Step Challenge** gives you the option to either run or walk 12,000 steps for (any) 12 days during May to coincide with the charity's 12th anniversary. Ask friends, family and colleagues to join you (within government guidance), get fit and help raise awareness of the disease. Log onto the special page **fightbladdercancer.co.uk/run** and take up the challenge during Awareness Month.

Take a 'Wee Walk'

As ever, we are encouraging friends and families to take up this annual activity for all people affected by bladder cancer. Taking a 'wee walk' means that you are part of a global movement – happening in Canada, the USA, Australia and across Europe – joining together in solidarity, to raise awareness and fundraise to fight bladder cancer. Look at our Wee Walk Challenge webpage for more details. You can sign-up on this platform: **giving.fightbladdercancer.co.uk/cf/wee-walks** and press click to donate and leave your message. Or you can click the fundraise button to create your own family or staff team donation platform where people can share messages and you can update your friends and family.

You can get some more ideas from the enclosed Bladder Cancer Awareness Month leaflet!

Whatever you choose to do to participate in Bladder Cancer Awareness Month this May, please share with us on social media, via email or via our private Facebook Forum – in the ways highlighted on page 51.

If you have any questions or want to discuss your plans, then please give us a call on 01844 351621, we'd love to hear from you!

Registered with FUNDRAISING REGULATOR

SHARING a common goal

ARTICLE
LINDSEY MORHAM
Great Bear Healthcare Content & Brand Manager

Great Bear Healthcare Nightingale Putting Patients First

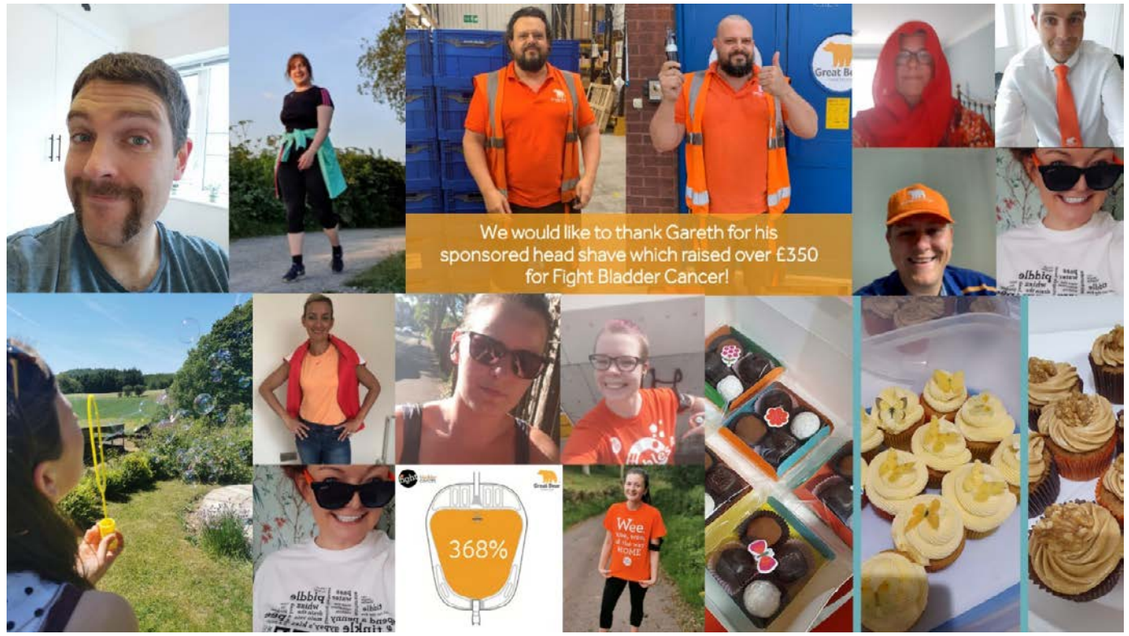
I felt that the charity's values clearly resonated with Great Bear's and was inspired by their passion for the cause.

In the midst of a pandemic, the team at Great Bear focused on what they could do, not what they couldn't

Great Bear Healthcare chose Fight Bladder Cancer to be their Charity of the Year in 2020. Lindsey talked to FBC Head of Fundraising, Emma Low, about the collaboration.

What made Great Bear Healthcare choose Fight Bladder Cancer as charity of the year?

In the summer of 2019, I read about the Wee Bookshop and Café in a copy of Fight magazine. It struck me as such a unique initiative that I was curious to find out more, so I arranged a meeting with the CEO of Fight Bladder Cancer, Dr Lydia Makaroff, who explained the story of the charity, how it came to be and the work that they do. I came away thinking that there was an opportunity to support them.



After further conversations, we made the decision to align with them. Our goals were to help them reach new audiences and help tackle the ongoing stigma with a cancer that, despite its prevalence, remains largely overlooked in terms of research and funding.

What activities have been particularly enjoyable?

Bladder Cancer Awareness month in May was a big highlight for us – we achieved our highest engagement across the organisation with some of our activities. From blowing bubbles to getting the younger cohort of our community to colour in some butterfly templates, it was great to see so many people getting involved.

The Fight Bladder Cancer '31 Days of May' Calendar was also great fun.

How did you overcome the fundraising challenge presented by Covid-19?

At the beginning of 2020 we were optimistic about hitting our fundraising target. One of our teams had entered a Tough Runner event, there were sweepstakes organised for the Euros and the Olympics, sponsored walks up Pen y Fan and a family fun day planned for the summer. Then, in March, Covid-19 struck. Sporting events were cancelled so we could no longer do a sweepstake; half marathons and mass participation events were cancelled so we could no longer use these to raise money. It was so overwhelming to try and think how we could still raise the £3,000 we set out to achieve, with many of our fundraising options curtailed.

However, the Great Bear team is never one to be defeated and, after a slow start, we turned our efforts to what we could do, rather than focusing on what we couldn't. In June, one of our warehouse team undertook a brave the shave and shaved his head, raising £215. From there, other teams got involved with step challenges, quiz nights, bake sales and 'Movember' efforts helping the donations to climb slowly but steadily towards our target. An end-of-year raffle gave us a final push and we ended up raising a total of £2,455 – a fantastic effort given the constraints that Covid-19 had put in our way!

How did the team at Fight Bladder Cancer support you?

The team at Fight Bladder Cancer were always on hand to help us come up with fun fundraising ideas and provide us with handy resources and toolkits. They helped us to set up a personalised online fundraising page that proved to be a real asset as we made the move to work remotely, as it acted as a centralised point for all donations so we could easily keep track on how we were progressing to our target.

Despite the challenges, the team at Fight Bladder Cancer remained enthusiastic and positive throughout and that really helped keep us motivated to achieving what we did.

What have been the benefits of collaborating with FBC for Great Bear Healthcare?

For us, the biggest benefit of collaborating with Fight Bladder Cancer was that, at a time when we all had to work remotely, fundraising for the charity united us in a common goal. It motivated us to think of initiatives that would allow us to raise money whilst also having lots of fun. The marketing team, for example, set the challenge to collectively walk the distance from our head office in Cardiff to Chinnor, Oxfordshire (where the charity is based) and back again over the course of the month. Not only was this a great way to collectively do a sponsored walk and raise money, it also incentivised the team to get out walking, and keep active during lockdown.

Collaborating also gave us access to some inspiring patient case studies. We interviewed Dorothy Markham, a bladder cancer survivor. It was a true pleasure to meet such a wonderful character and share her story amongst those who may be going through a similar experience – an opportunity that we wouldn't have had without Fight Bladder Cancer.

We ended up raising a total of £2,455 – a fantastic effort given the constraints that Covid-19 had put in our way!

Registered with FUNDRAISING REGULATOR

Fundraising round up

Autumn 2020 – Spring 2021

Here are just a few of the exploits of some of our wonderful supporters – we'd be nowhere without you, so a huge THANK YOU goes out to you all.

A regular supporter of FBC, **Helen Tabor** took on the Virtual London Marathon for FBC and raised a fab £435 for the charity, in memory of her dear Dad.

Piers Govier, with partner **Becci** alongside, raised more than £750 for the charity by completing the Virtual London Marathon. We're so grateful to you both for choosing to support FBC – thank you!

Karen Lillystone, and her dog **Scamp**, challenged themselves to complete the distance of the River Thames 'from Sea to Source' – which was an eye-watering 375km! Massive thanks to them both for raising more than £300 for the charity.

Dear friends **Lizzy** and **Emma**, accompanied by their dogs, **Stevie** and **Honey**, took on the challenge to walk 15km for Fight Bladder Cancer. With both friends and the dogs wearing FBC t-shirts, they raised a fantastic £1,300 – thank you so much!

When great friends **Paula Ryan** and **Naomh Gallagher** read about the FBC Virtual Halloween 5km event, they decided to sign up for the challenge. Raising more than £2,000 between them, we are so pleased that they did! Thank you both for battling the wind and rain to finish the distance.

When long-time supporters of the charity, **Sue** and **Sean Denny**, heard that Covid-19 had cancelled the Great South Run, they decided to create their own virtual event.

Massive thanks to them both for creating and completing the 'Not the Great South Run' and raising more than £1,250 for Fight Bladder Cancer.

We are so grateful to **Wayne Birch** who created his own virtual event in October. He walked more than 15k steps a day and went totally alcohol-free for the month to raise money for the charity and raise awareness of the disease. Taking on this challenge in support of his Dad, Wayne raised more than £2,300, which included support from his employers, Barclaycard, through their matched funding programme.

When **Nicola Kelly** lost dear friend, colleague and mentor, **Tony**, to bladder cancer, she decided to channel her energies into raising money for FBC and raising awareness of the disease at the same time. Having already completed a number of challenges, including the 2020 Virtual London marathon, she has her sights set firmly on the 2021 event in London. Her fundraising total has currently exceeded £2,000 and we look forward to supporting her future endeavours – thank you so much, Nicola!

Friends of FBC, **Sharon** and **Jenny Guy,** have created a range of FBC products as part of their Wensleydale Wicks collection. Each month they donate a percentage of the proceeds from the sale of these products to the charity. Thank you to them both for helping to raise awareness of the charity and the help it offers.

Why not take a look at the Wensleydale Wicks Facebook page too: **facebook.com/wensleydalewicks/**

Facebook fundraisers

Why not join in the fundraising fun?

Everyone who raises money for our work is a hero to us, and many are choosing to be FBC Facebook Fundraiser heroes! It's easy, it's successful – and you can do it for a special occasion – or no reason at all!

Online fundraising continues to grow as a way of supporting causes that are close to our hearts. It's fast and easy to set up and we are incredibly grateful to those who choose to create Facebook fundraisers in aid of FBC. They can be set up for any reason – birthdays, anniversaries or just to help raise funds. It takes less than two minutes to set up a Facebook fundraiser via this link: **facebook.com/fund/BladderCancerUK/**

SCAN ME

Facebook do not charge to provide this platform, so 100% of the money donated comes straight to the charity. We receive a payment twice a month of all donations that have been made across all pages, so we can access the money quickly and use it to fund the valuable support we can offer to patients and carers.

If you'd like to know more about fundraising in this way, then please do give Sophie a call, or drop her an email, **sophie@fightbladdercancer.co.uk** and she'll be happy to help.

Focus on Facebook fundraisers

Huge thanks to **Keith**, a bladder cancer patient from Northumberland, who decided to create a Facebook fundraiser for FBC in December. Keith wanted to raise money for the charity as he feels that it is a crucial information medium for all sufferers. Within four weeks, supportive friends and family had donated a fantastic £1,200 to the charity!

Massive thanks to **Brenda** and **Paul Clarke**, who, along with their children and grandchildren, walked, ran and cycled the distance of Cardiff to Benidorm (1,377 miles) in aid of the charity. They have collectively raised more than £1,430 for FBC and we think they're all fantastic!

Following her daughter **Rebecca's** cancer diagnosis, **Clare Graham**, supported by friends **Rhys**, **John**, **Jacqui**, **Molly**, **Lyndsey**, **Angie** and **Emma** all took part in the Virtual New Year marathon during January and have raised more than £760 for the charity.

We are so grateful to each of them for putting on their trainers and going out in all weathers to complete their challenge!

In Memoriam

We are incredibly grateful to the family and friends of the late **Paul McKenna**, whose wonderful gifts to the charity totalled more than £600. Paul passed away from bladder cancer in November and he asked for donations to Fight Bladder Cancer instead of flowers. Paul's son, **Graham**, is continuing to support the charity through several running events and we appreciate everything he is doing to continue to raise awareness of the disease.

You can get loads of practical help and support from our fundraising team. Call **01844 351621** or email **fundraising@fightbladdercancer.co.uk**

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 **sophie@fightbladdercancer.co.uk**.

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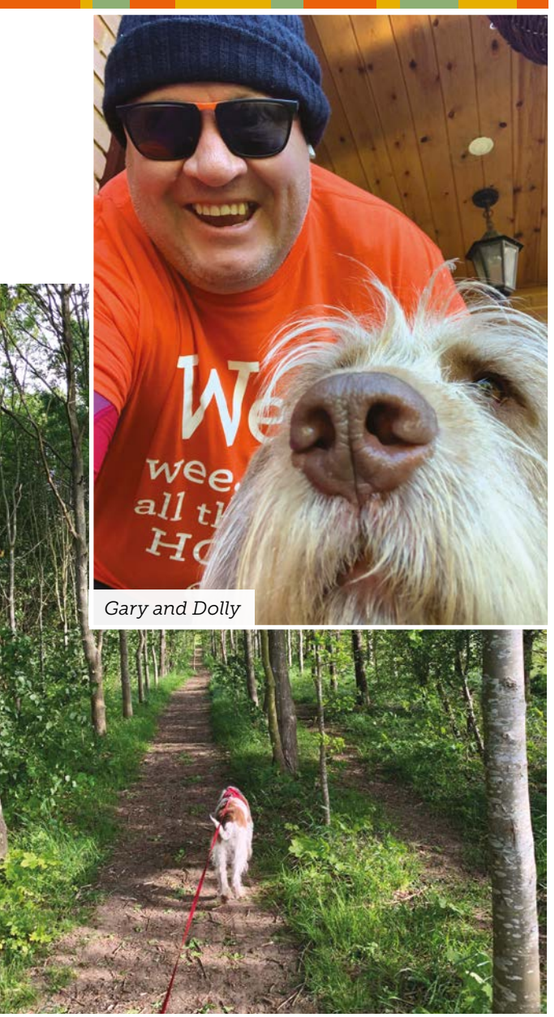
When you feel everything has come crashing down – there is still hope

PATIENT Q&A
KATE MOORE
FBC Intern &
GARY SALES
FBC Forum Member



Gary and Dolly

Gary Sales' diagnosis and treatment led him to suffering a depressive episode but he explains how taking on a challenge helped him turn feeling negative to positive.

How did you find out you had bladder cancer?

It was March 2017 when I first passed blood in my urine, and when it happened a second time, and more severely, I went to the doctor, even though the blood in my urine had stopped again. However, it turned out that I had an '11/10' reading and – although the doctor said it could be anything – I needed further tests.

I knew something wasn't right and headed for Google to do some research. Google is good for many things but not when you have to wait for your results for six days! I hadn't even heard of bladder cancer but that's where most things online pointed.

I had multiple tests but when I had my cystoscopy I could see on the screen that there was a mass and they told me that I had an aggressive 6cm tumour. A few weeks later I went for an operation and it was confirmed as grade 3 bladder cancer, although fortunately the cancer was non-invasive. Luckily since then I haven't had a tumour return.

What happened after your diagnosis?

Everything came crashing down. I went from travelling 80,000 business miles that year to not being able to work. I was stuck at home and starting a fight that was completely unexpected.

I soon began BCG treatment, which has been challenging. The first six treatments were fine and I thought it was going to be easy; I even went on holiday to Mexico half way through. However, after each of the next set of three, I had a few days feeling flu-like and feverish, followed by a lot of pain around my midriff, then a more flu-like state and every time I went to the toilet I would have to pass lumps.

This fight really has taken its toll on me. Emotionally I cannot wait to finish the BCG treatment. I suffered from depression in the second year of treatment and have not felt completely myself again.

Over the last six months I was going to the toilet six to eight times a night, which meant I was tired all the time and I couldn't focus enough to work. Now it's only twice, which makes such a difference. A lot of people refer to cancer as a battle but it seems as bit one-sided to me. I didn't choose this disease but I am not the kind of person who will let anything beat me easily. I am 48 with teenage kids and I have no choice but to keep on top of it and keep going.

How did you feel when the pandemic hit?

COVID has really worried me. Everything stopped overnight: my treatments were cancelled and there could be a possibility of relapse; my wife and kids were stressed; football – my passion and joy – ground to a halt. I decided I had to get it out of my head and I keep busy.

> So I decided on fundraising for the fabulous work at FBC. I'm a very competitive person, so when the team told me that the average fundraising goal was under £2,000 I decided I was going to smash that!

I decided on a walking challenge with my dog and called it the 13 days of May – to coincide with my birthday and Bladder Cancer Awareness Month. The plan was to walk 48 miles for my 48 years. I set up various fundraising pages, quietly thinking I'd be lucky to hit £1000. The response was incredible. We got so much media coverage locally it was unreal. I was asked onto BBC 3 Counties Radio twice! Not just my friends at work and my football club, people in my village who I had never met were giving me money and cheering me on. I ended up walking more than 70 miles and raised £2,750 for FBC – an amazing total that just shows the support around you!

Is there any advice you would give to patients coping with a similar situation during the pandemic?

KEEP BUSY: I have been a hard-working man all my life. Not being able to travel with business has been hard, so I have had to find other things to occupy myself – such as starting my own local football team – Real Haynes Football Club – and organising matches and coaching the lads.

BE ORGANISED ABOUT YOUR TREATMENT: Keep on top of your treatment schedule. Being organised with your administration, medicines and recommendations is vital.

BE YOUR OWN ADVOCATE. Be ready to ask questions and answer questions at the end of the phone. It's important to have a level of accountability for yourself and your treatment and don't blame others if things don't happen. As soon as I knew my hospital was back open, I was on the phone every day to book my operation.

GET IN TOUCH WITH FIGHT BLADDER CANCER: It was a lucky day for me when I found FBC. The charity has been great for me as I found that there can be so much bad knowledge out there. The knowledge and information I received from them was very helpful and informative, especially on the website. Simple and formal knowledge is so important for patients when you're first going through the tests and treatments. If I didn't know an answer to something, I have always been able to ask someone at the charity and get the help I needed.

Surround yourself with love. Have people around who love you and understand what you're going through. My wife looked after me, my mum helped out and my brother took me to the Isle of Wight to have a few days' break away from everything.

Friendship in adversity

Back in October, FBC spoke to bladder cancer patient and Children's Nurse, Naomh and Clinical Nurse Specialist Paula from Northern Ireland about the challenges they faced through the COVID pandemic and how they came together to raise money.

Naomh, tell us a bit about your diagnosis?

I was diagnosed back in June 2019 after feeling very ill around around Easter time. I had horrible abdominal pains and was constantly going to the toilet. I thought it was a 'gynae' problem as I had run out of my pill prescription.

With some persuasion from my work colleagues after I was very unwell on night duty, I took myself to A&E. The doctor instantly told me it wasn't a gynae problem as the blood was in my urine. She referred me as a red flag to urology for an appointment and I was sent home. About 10 days later, I went back to A&E and, when I explained my recent history, the doctor did an ultrasound there and then. He must have seen the tumour, which was extensive, and wasted no time in speaking to a urology consultant and sending me straight to urology, where a cystoscopy confirmed the tumours. I was admitted that evening and had the TURBT the next day.

I was told it was cancer after the histology from the TURBT. In July I had a CT scan which showed that it was likely the cancer hadn't spread outside my bladder. My consultant spoke to me about a cystectomy, which I then had in Belfast in Autumn 2019.

How did your friendship form?

Naomh: I met Paula in the December that year, when she came to my post op review for the cystectomy with my consultant. We met again in January 2020 when I went in for a second surgery and Paula came to see me every day, then when I went for a scan in February. Another surgery in March was cancelled but Paula kept in touch and also managed to get me the second to last appointment at the breast clinic before everything was shut down for the COVID pandemic (all was well fortunately).

Paula gave her number to keep in touch as everything was up in the air, she always advised me who to get in touch with and who to speak to. If Paula hadnt managed to arrange that breast scan for me I would have been worrying the whole of lockdown if I had breast cancer on top of worrying about bladder cancer.

Paula Ryan

I would say to other patients that it is important to think of yourself and put your health first.

PATIENT Q&A
PAULA RYAN, NAOMH GALLAGHER & KATE MOORE
FBC Fundraisers & FBC Intern

The way everyone was cared for on the urology ward was amazing; the kindness of the staff was just incredible.

What was it like going into lockdown for both of you?

Paula: It was really scary because I had only recently started my new post and by March we were told everything was being cancelled, wards were being emptied and our hospital turned into an ICU facility. I was able to work in ICU for three weeks, but then had to shield as my father, who lives with us, was classed as vulnerable.

Naomh: I know exactly what patients are going through as I went through it last year. I have personally had a pre op and surgery cancelled due to the pandemic and I was so gutted. You don't know what's happening and you wonder how long it will go on for. I would say to other patients that it is important to think of yourself and put your health first. So despite the situation we are in, it is important to regularly phone up about appointments and surgery and try and get it if you can. Now I've had my surgery I haven't looked back and feel so much better. My friends thought I was still on medication after my cystectomy because I was so happy but it was because I was so relieved it was over, so I find it really upsetting to look at all these cancellations thinking 'that could have been me'.

I felt guilty that I had to stay at home, while my colleagues in the children's ward were facing the COVID-19 challenges each day. I was able to receive my surgery via a private hospital, but until that point you just don't know what's going to happen.

How did you hear about Fight Bladder Cancer?

Paula: I started learning more about Fight Bladder Cancer when I started at my new post as we had to refer our patients to websites to look at for information and support and FBC was the charity we recommended for bladder cancer patients.

Naomh: I had never heard of bladder cancer until my own diagnosis and then joined the Fight Bladder Cancer forum.

Where did you find out about the Halloween 5K run?

Naomh: I first saw the advert on Facebook and asked my husband if he'd join me in the challenge.

Paula: And then I came up with a bright idea and said 'come on, we will do it together'.

Naomh: I then realised there was no way I could get out of it! But I'm so pleased that I am well enough to do this challenge and have had some incredible support from my family, friends and work colleagues.
I have been so overwhelmed with the support and kindness I've received from everyone.

Thanks to Paula and Naomh for sharing their story and fundraising for FBC! They raised over £2,000 for the charity and we couldn't be more grateful.

Little TED Talks and people listen!

I started posting about Ted and our adventures on the forum, not knowing whether we would get many comments from it. We couldn't believe the response we got!

When Tony Skerratt started posting about TED's adventures on Facebook, he little imagined the response he'd get.

Tony, tell us a bit about your diagnosis

I was on a cruise in 2016 when I started getting awful back pain. I was told it was gallstones and was given tablets to break them down.

I then had a scan in which they saw 'something there we don't like'. and sent me for a TURBT and a biopsy. I asked the surgeon straight out if it was cancer – I wanted him to be honest – and told me truthfully that it was. I remember coming home from the hospital and bursting into tears. You hear the word 'cancer' and automatically think the worst and that your life is going to end, but it's not the case.

After my diagnosis I then had nine sessions of BCG treatment where I had no side-effects but unfortunately the treatment didn't work for me.

My bladder was then removed in July 2017. I had several complications with the operation from my bowel being twisted, resulting in additional surgeries, which unfortunately left me with a lot of scar tissue. I also contracted sepsis while in hospital. Long-term this means that I now have to be on a very strict diet of soft food. When my bladder was removed I was fitted with a stoma bag; this has changed my lifestyle slightly, but not dramatically.

Following my bladder removal, I had check-ups every six months, which then changed to every 12 months. I had a scan back in September 2020 and I was thrilled when the doctor gave me the all clear!

What gave you the idea about Ted?

My friend Ros on the forum put Ted on Facebook for sale and I bought him for a donation to the charity. We travel around the UK and Europe in our motorhome and Ted came with us and, just for fun really, I started posting about Ted and our adventures on the forum, not knowing whether we would get many comments from it. We couldn't believe the response we got!

What has Ted's story done for people?

I think he has helped to lift people's spirits during the pandemic. If I haven't posted about him in a while, people say 'lovely seeing you again, Ted, I wondered where you had gone.' It's as if he is a real person! Even people from the USA commented on the posts.

How has Fight Bladder Cancer's private forum helped you?

I think the forum is very good as you can ask questions knowing you'll get helpful answers, there are no sarcastic remarks and everyone is there to support each other. I have made friends on the forum and have messaged people outside of the group, too.

It's nice because I received help when I needed it and now I can give advice to others from my own experiences.

PATIENT Q&A
KATE MOORE
FBC Intern & TONY SKERRATT
FBC Forum Member

Even if posting about Ted and his adventures can cheer up just one person, then I am happy.

Looking back, what you would say to patients?

Just get checked as soon as you possibly can and don't hesitate to go to your GP if you have any symptoms. It could save your life.

Investigating the HYBRID trial

ARTICLE
HANNAH GRIBBLE
Trial Manager

PROF ROBERT HUDDART
Chief Investigator

ICR The Institute of Cancer Research

The HYBRID trial has been investigating whether weekly rather than daily radiotherapy is a suitable treatment option for bladder cancer patients and whether there are additional benefits of using advanced radiotherapy techniques

Bladder cancer is the fifth most common cancer in the UK, with over 10,000 people diagnosed each year with muscle invasive bladder cancer.[1]. Bladder cancer can be divided into two types: non-muscle-invasive bladder cancer, where the cancer is confined to the lining of the bladder, and muscle-invasive bladder cancer, where the cancer has spread into the muscle wall of the bladder and beyond. The latter is a life-threatening condition for which radical treatment is required. However, half of people with bladder cancer are aged over 75 years, many of whom are unable to have standard radiotherapy, being too unwell or unable to attend hospital each weekday for four to seven weeks.[1-4]

A recent audit by the UK's Royal College of Radiologists found that just under half of people with potentially curable muscle-invasive bladder cancer in the UK either receive no treatment or palliative radiation therapy only.[5] Although these people may be too unwell to receive standard treatment, many have a life expectancy of several years and, if left untreated, may experience significant cancer-related symptoms, such as pelvic pain, needing to urinate more frequently, and incontinence.[6] One way to potentially treat these people is to deliver a higher dose of radiation but less frequently than standard, for example weekly, with fewer doses delivered overall. This is known as ultra-hypofractionated radiotherapy.

In standard bladder radiotherapy, a CT scan is taken of the person's bladder and this is used to plan their radiotherapy, using the same plan for each treatment day. Because the bladder can change in shape, size and position from day to day, normally the radiotherapy plan incorporates large margins around the bladder to allow for these variations. The use of these large margins is likely to increase radiation to parts of the body near the bladder, such as the bowels. Because radiotherapy works by breaking DNA, it can also damage non-cancer cells, potentially causing more side-effects, which presents a concern for people who are already unwell.

A new technique called adaptive plan-of-the-day radiotherapy, uses either a small, medium or large plan which is selected on the day of treatment to more tightly fit the size and shape of the bladder than the one-size plan. This could be particularly important in weekly radiotherapy as fewer larger radiation doses are delivered making weekly radiotherapy an excellent context in which to investigate adaptive radiotherapy.

The HYBRID trial

The HYBRID trial was developed by UK researchers in collaboration with patient representatives. The trial aimed to find out whether adaptive plan-of-the-day radiotherapy would reduce non-bladder side-effects and see if weekly radiotherapy was an effective treatment option for people unable to have standard radical radiotherapy.

People with muscle-invasive bladder cancer were invited to take part if they were unable to receive surgery to remove the bladder or conventional daily radiotherapy for any reason. Those on the trial were put into two treatment groups: weekly standard radiotherapy using the same treatment plan each time; or weekly adaptive radiotherapy where one of three different-sized plans was chosen that best fit the bladder on each day of treatment. Six gray doses were delivered to participants in both groups six times over six weeks (total dose 36Gy).

The check-up schedule was designed to match the schedule that people would have followed if they did not join the trial. Three months after treatment, participants had a cystoscopy to check for any cancer remaining in their bladder. Both groups of participants attended regular clinic visits for 24 months after treatment and, if their cancer did return, they received further treatment as agreed by them and their doctors.

HYBRID results were published in a peer reviewed medical journal in 2020.[7] Between April 2014 and August 2016, 65 people joined HYBRID from 14 NHS hospitals; 32 people were put in the standard radiotherapy group and 33 people were in the adaptive radiotherapy group. Participants were aged between 61 and 94 years (average 85), 68% were male and 32% were female

Prof Robert Huddart

The HYBRID findings

HYBRID found that for a substantial portion of radiotherapy doses, a plan larger or smaller than the standard plan fit the participant's bladder better. Twenty-eight of 33 patients (85%) in the adaptive radiotherapy group received at least one dose of radiotherapy using the small or large plan. Overall, 76 of 193 radiotherapy doses (39%) were delivered using a plan other than the medium plan.

Three months after completing treatment, less than 30% of people in each group had experienced moderate to severe side-effects.

- **five out of 33 people who received adaptive radiotherapy reported moderate to severe side-effects related to radiotherapy; two of these were non-bladder side-effects**
- **seven out of 30 people who received standard radiotherapy and survived at least three months post treatment reported moderate to severe side-effects related to radiotherapy; four of these were non-bladder side-effects**
- **Forty-eight of 65 people were assessed at three months for signs of bladder cancer.**
- **22 out of 25 people who received adaptive radiotherapy were free of cancer, 17 out of 23 people who received standard radiotherapy were free of cancer**

Participants in the adaptive radiotherapy group appeared to have fewer non-bladder side-effects and were less likely to stop treatment early due to side-effects than those in the standard radiotherapy group. Additionally, people in the adaptive radiotherapy group were more likely to be cancer free three months after treatment. However, these differences were not statistically significant and larger trials are needed to confirm if the effect was due to treatment rather than chance.

Two years on

Two years after radiotherapy, nearly half of HYBRID participants were still alive. With high levels of cancer control in the bladder and a higher than expected number of people alive two years after treatment, HYBRID has shown that this weekly ultra-hypofractionated radiotherapy can be effective at controlling disease for people who are unable to attend hospital for daily radiotherapy, however further research is warranted.

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

Learn more at fightbladdercancer.co.uk/newdevelopments

Acknowledgements:
This report presents independent research funded by Cancer Research UK (grant reference number C8262/A14744) with program grants to support the work of the Clinical Trials and Statistics Unit and the Institute of Cancer Research (C1491/A15955; C1491/A25351). National Health Service (NHS) funding was provided to the National Institute for Health Research Biomedical Research Centre at The Royal Marsden and the ICR. HYBRID is led by Prof Robert Huddart at The Institute of Cancer Research and Royal Marsden Hospital, London, and Professor Emma Hall at the Clinical Trials and Statistics Unit at the Institute of Cancer Research, London (ICR-CTSU). HYBRID is coordinated by ICR-CTSU (Twitter: @ICR_CTSU), supported by the NIHR Clinical Research Network and registered with clinicaltrials.gov: NCT01810757.

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BLADDER CANCER CLINICAL TRIALS

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

UROX BIOMARKER

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

Newly detected or recurrent bladder cancer

ANTICIPATE X

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

Non-invasive bladder cancer

CHECKMATE 9UT

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

IROC

This study is for people with non-muscle-invasive bladder cancer or muscle-invasive bladder cancer who are going to have their bladders removed. Patients will have either robotically assisted bladder removal surgery, or open bladder removal surgery. The study will look at which type of surgery has a better number of days out of hospital, recovery and return to normal activities.
ClinicalTrials.gov ID: NCT03049410

KEYNOTE-676

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

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.
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.
International Standard Randomised Controlled Trial Number: ISRCTN35296862

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.
ClinicalTrials.gov ID: NCT04045613

JAVELIN MEDLEY

This is a study for people with locally advanced or metastatic bladder cancer. Patients receive a drug called avelumab, with the possible addition of the drugs utomilumab, PF-04518600, PD 0360324 and/or CMP-001. This is a study looking at how well these drugs work to treat people with bladder cancer.
ClinicalTrials.gov ID: NCT02554812

KEYNOTE-866

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

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. This is a study looking at how well pembrolizumab and enfortumab vedotin work together with surgery in people with bladder cancer.
ClinicalTrials.gov ID: NCT03924895

LEAP-011
This study is for people who have advanced or metastatic bladder cancer, and who either test positive for the PD-L1 biomarker or who are not eligible for chemotherapy. Patients will receive a drug called pembrolizumab, and perhaps another drug called lenvatinib. This is a study looking at how well these drugs work together in people with bladder cancer.
ClinicalTrials.gov ID: NCT03898180

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

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

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

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

NCT03289962
This study is for people who have locally advanced or metastatic bladder cancer. Patients will receive a personalised cancer vaccine called RO7198457, with the possible addition of a drug called atezolizumab. This is an early study looking at the safety and ideal doses of the drugs.
ClinicalTrials.gov ID: NCT03289962

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

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

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

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

NCT03934827
This study is looking at the safety and tolerability of the drug MRx0518 in people with solid tumours at 30 days post-surgery. It is a phase 1 clinical trial and the trial will look at the drug's anti-cancer and immune system modulating properties. Patients will need to be amenable to surgical resection.
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.
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 drug.
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.
ClinicalTrials.gov ID: NCT04197986

NCT04316689
This study will look at the safety and tolerability of the drug S-588210 in people with unresectable recurrent and/or metastatic solid tumours. This trial is for multiple different cancers, but includes bladder cancer. Participants will receive injections once a week for four weeks and then bi-weekly for eight weeks of the new drug.
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 trial provides the first study of bintrafusp alfa in participants with bladder cancer that has progressed following platinum chemotherapy.
ClinicalTrials.gov ID: NCT04349280

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

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.
ClinicalTrials.gov ID: NCT03390504

WAVE
This is a study for people with advanced bladder cancer. The aims of the study are to monitor the long-term safety of durvalumab, to provide continued treatment or retreatment with durvalumab to eligible patients, and to collect overall survival information.
ClinicalTrials.gov ID: NCT04078152

Institute of Cancer Research

ICR

Can you help our research?

We are looking for people from all backgrounds to answer our survey investigating people's attitudes to electronic questionnaires.

In many of our clinical trials, participants are given paper questionnaires to complete to tell us how they are feeling after their treatment

Handed out in clinic

Posted to participants' home addresses

We are looking to offer participants the option of completing these questionnaires online and would like to hear your views

You can answer the survey online at: bit.ly/3b5kXnH

You can answer the survey by phone or request a paper copy by ringing: 0208 722 4615

For more information, please contact the SPRUCE Study at SPRUCE-icrctsu@icr.ac.uk, phone 0208 722 4615 or visit our website: bit.ly/3bdBPIX

Many thanks!

This research has been approved by the Committee for Clinical Research at The Institute of Cancer Research. Data collected will be handled in accordance with The Institute of Cancer Research's policy on research data: **icr.ac.uk/legal/privacy/research-privacy-notice.**

FBC glossary

ACC Advanced Cancer Coalition

adjuvant after initial treatment to prevent secondary tumours

angiogenesis the development of a blood supply to a tumour

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

antiemetic a drug to counteract nausea and vomiting

B-cell response a natural immune response

basal relating to the base

baseline starting point for comparison

BAUN British Association of Urological Nurses

BAUS British Association of Urological Surgeons

BC bladder cancer

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

BCQS Bladder Cancer Quality Standards

biomarker something by which the disease can be identified

biopsy a sample of tissue taken for examination

BLC blue light cystoscopy

BPH benign prostate hyperplasia

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

carcinogenic cancer-causing

carcinoma malignant growth or tumour

catheter a thin tube

CCG clinical commissioning groups

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

chemoradiation combination treatment of drugs and x-rays

chemotherapy treatment with chemicals toxic to the body's cells

CIS carcinoma in situ or flat tumour

CNS clinical nurse specialist

confocal laser endomicroscopy an advanced imaging technique for diagnosis

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

cystectomy removal of the bladder

cystoprostatectomy surgical removal of the bladder and prostate

cystoscopy a procedure to examine the inside of the bladder

cytokines cells that communicate an immune response

DAT device assisted therapy

DNA deoxyribonucleic acid

durable response rate the length of time a response is observed

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

dysplasia abnormal development

dysuria painful or frequent urination

EAU European Association of Urologists

EBRT external beam radiotherapy

EBUS endobronchial ultrasound test for lung cancer

ECPC European Cancer Patients Coalition

ED erectile dysfunction

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

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

enhanced recovery pathways methods of improving recovery times and experience

eosinophils white blood cells that fight off certain parasites and infections

ER enhanced recovery

expressed active

FDA Food and Drugs Administration (US)

FGFR fibroblast growth factor receptor

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

fMRI functional magnetic resonance imaging

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

GI gastrointestinal

haematuria blood in the urine

HCP healthcare professional

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

histology the microscopic examination of cells

histopathological microscopic examination of tissue to identify disease

HNA Holistic Needs Assessment

HrQoL health-related quality of life

HSE Health and Safety Executive

ICER incremental cost effectiveness ratio

ileal conduit *see* urostomy

immune component part of the immune system

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

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

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

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

ITU intensive therapy unit

KW key worker

lines [of treatment] treatment regimens

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

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

lymphangiogenic originating in the lymphatic system

macrophages white blood cells found within tissues

MDT multi-disciplinary team

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

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

MIBC muscle-invasive bladder cancer

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

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

mutagenic an agent that changes genetic material

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

NMIBC non-muscle-invasive bladder cancer

OCT optical coherence tomography, a medical imaging technique

oncolytic cancer-killing

PALS Patient Advice and Liaison Service

PCT primary care trust

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

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

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

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

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

PET positron emission tomography

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

PFS progression-free survival

photodynamic diagnosis BLC or blue light cytoscopy

PHR patient-held record

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

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

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

priapism a persistent penile erection not necessarily associated with sexual arousal

primary endpoint answers to the primary questions posed by a trial

PROMs patient-reported outcome measures

proteases enzymes that break down protein

pyrexial having a body temperature above the normal range

QoL quality of life

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

radiotherapy treatment with radiation

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

RCTs randomised control trials

refractory resistant

resection surgical removal

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

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

squamous scaly

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

surrogate markers a reliable substitute for the disease

T-cell a cell that can attack a cancer cell

tachycardia abnormally fast heart rate

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

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

transitional cell cancer (TCC) most common urinary cancer

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

tumour microenvironment the cellular environment in which the tumour exists

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

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

uropathy a disease of the urinary tract

urostomy a surgical procedure to create a stoma

urothelial of the urinary tract

UTI urinary tract infection

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

WBCPC World Bladder Cancer Patient Coalition

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

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

- **Make a donation**
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- **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
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- Awareness posters & leaflets
- Monthly e-newsletter
- Patient information booklets

DISCOVER our new patient information booklets for the bladder cancer pathway!

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Fight Bladder Cancer is a registered charity in England and Wales (1157763)

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