

fight

MAGAZINE

IN MEMORIAM

REFLECTIONS ON OUR INSPIRATIONAL
FOUNDER, ANDREW WINTERBOTTOM

CONTACT CARDS

OUR NEW WAY TO SUPPORT
NURSES AND PATIENTS

PACK A PUNCH!

THE VALUE OF
SUPPORT GROUPS –
FIND YOUR CLOSEST
FIGHT CLUB

BACK IN
THE SADDLE
UPLIFTING STORIES
FROM BLADDER
CANCER SURVIVORS

TERMINAL
DIAGNOSIS?
WE TALK END OF LIFE
ISSUES WITH BLADDER
CANCER PATIENTS
& PALLIATIVE
SPECIALISTS

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It's time to really talk about some difficult things.

Welcome to the 8th edition of our *FIGHT* magazine.

This edition is dedicated to Andrew Winterbottom.

We are starting this edition of the *Fight* magazine on a very sad note. Our dear friend and founder, Andrew Winterbottom, died on 31 May 2019. This *Fight* magazine was one of his creations, and I bring some comfort in knowing that it continues after his death.

This edition celebrates a successful Bladder Cancer Awareness Month, explores bladder cancer support groups, and also focuses on Andrew's passions: talking about uncomfortable things and patient empowerment.

Before he died, Andrew asked us to ensure that this edition covers 'the difficult stuff' and asks the question, 'What happens when treatments don't work?'. It was quite tricky to pull all this information together while still ensuring that the magazine remains uplifting, encouraging and inspiring. Hence, we have placed this subject matter in a discrete section, so that you can decide to read these articles if and when you wish.

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

You can also read about the results from recent research studies, as well as a summary of all the major clinical trials that are currently recruiting bladder cancer patients in the United Kingdom.

Team FBC

As a charity, Fight Bladder Cancer's aims are simple. We have four key objectives:

SUPPORT

Supporting all those affected by bladder cancer

AWARENESS

Raising awareness of the disease so it can be caught early

RESEARCH

Campaigning for and supporting research into this much-ignored disease

CHANGE

Affecting policy at the highest levels to bring about change

At the time of going to press, discussions about the UK leaving the EU were still in process. Depending on the outcome of the Brexit negotiations, 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.

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.

fightbladdercancer.co.uk

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

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

 [FightBladderCancer](https://www.facebook.com/FightBladderCancer)  [BladderCancerUK](https://twitter.com/BladderCancerUK)

 **bladder
CANCER**

Registered charity 1157763

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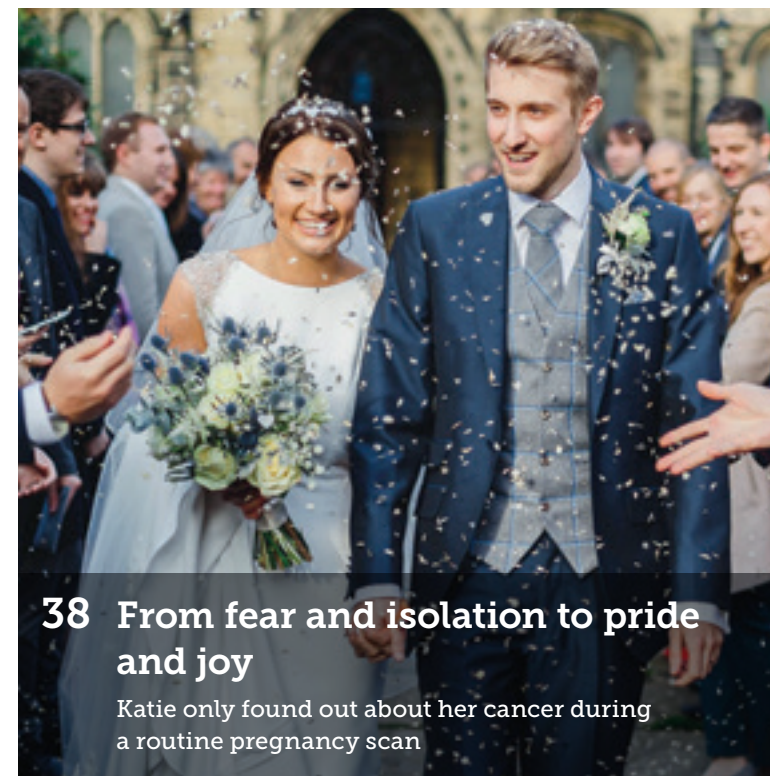
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SUPPORT

ONLINE FORUM

Our confidential forum now has 4,588 members. In the past month, we have had over 424 posts and almost 28,000 comments and reactions. Currently our most popular time for interaction is Monday evening. The forum is monitored by admin and moderators 24 hours a day, 7 days a week.

TELEPHONE AND EMAIL SUPPORT

Our telephone support line is available from 9.30am to 4.30pm Monday to Friday on **01844 351621**. There is a voicemail for messages outside these hours or when we are very busy. In the past month, we averaged 6 calls a day, with an average handling time of 5 minutes.

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



FIGHT CLUBS

We now have Fight Club support groups throughout the country, including **London, Glasgow, Glan Clwyd, Newcastle and Southampton**.

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

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

As well as attending our own Fight Clubs, we also get invited to other support groups around the country to talk about issues from a patient's angle. We recently visited the University College London Hospital and the Wolverhampton Bladder Cancer Support Group, where our talks included news about the charity and the ways it can provide support to patients and carers. If you are a member of a local support group that might want to join our network, please get in touch with us at sophie@fightbladdercancer.co.uk

AWARENESS

FIGHT MAGAZINE

Fight magazine is shipped to major urology centres around the UK. If you don't see a copy of Fight magazine in your waiting room, please contact us at info@fightbladdercancer.co.uk.

BLADDER CANCER AWARENESS MONTH

During the month of May, Fight Bladder Cancer led the British activities for Bladder Cancer Awareness Month. We also worked with the European Cancer Patient Coalition and the World Bladder Cancer Patient Coalition on the global activities. On Twitter, **#BladderCancerAware** reached 2.6 million people. Globally, Fight Bladder Cancer was the most active Twitter account related to **#BladderCancerAware**, and had the most mentions. Fight Bladder Cancer was featured in media articles published by *EurActiv*, *The Scotsman*, and *Health in Wales*. During the month, we held 8 corporate events, 14 healthcare professional events, 7 individual fundraising events, 6 Fight Club support group events, and 2 awareness walks in Chinnor and Bournemouth.



FIGHT BLADDER CANCER IN THE NEWS

Following the death of Fight Bladder Cancer's founder, Andrew Winterbottom, tributes were produced by the *Oxford Mail*, *Thame Gazette*, *Mix 96*, and BBC Radio Oxford. The *Oxford Mail* noted that Andrew 'will be remembered for his determined and courageous charity work and previously enjoyed a successful career as an architect'. Read more about Andrew on pages 8-10.

EUROPEAN ASSOCIATION OF UROLOGY

Fight Bladder Cancer gave a presentation on our work at the European Association of Urology Congress in Barcelona. We shared the latest edition of the *Fight* magazine and talked about how European urologists could get more involved in Bladder Cancer Awareness Month. We have also joined the European Association of Urology Patient Advocacy Group and participated in the inaugural meeting, to ensure patients have an active role in the association.



THE INSTITUTE FOR CANCER RESEARCH BIOMEDICAL RESEARCH CENTRE

We exhibited at the Royal Marsden and the ICR Biomedical Research Centre. The educational open evening held talks by world-leading clinicians and researchers within the urological cancer field. We spoke to visitors who wanted to be educated about bladder cancer, its signs, symptoms and how to get help.



BRITISH ASSOCIATION OF UROLOGICAL SURGEONS

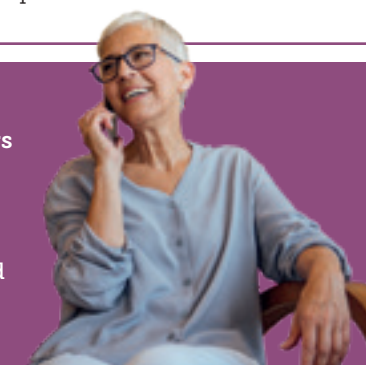
We were happy to return to Glasgow for the BAUS annual conference. We were delighted by the sight of many old friends who visited our stand along with new visitors who came to talk and gather information for their patients.

RESEARCH

EXEMPLAR RESEARCH PROJECT

Fight Bladder Cancer is now recruiting people with bladder cancer and their carers for research interviews to collect the views and experience of people affected by bladder cancer.

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



TRANSITIONAL ONCOLOGY AND UROLOGY RESEARCH

We visited Guy's and St Thomas' NHS Foundation Trust for a focus group with patients and TOUR (Transitional Oncology and Urology Research) team. During this meeting, we expressed the need for more research on interventions to improve mental health for people affected by bladder cancer.



We participated in Cancer Research UK's Early Diagnosis Research Charities Coalition meeting, to plan how to improve the early diagnosis of cancers. Workshops were held to boost key opportunities for British cancer charities to harness our collective energies, resources and funds, with an emphasis on cross-cancer ideas.

NATIONAL CANCER RESEARCH INSTITUTE

Fight Bladder Cancer is an active member of the National Cancer Research Institute's Bladder and Renal Cancer Clinical Studies Group. We recently launched a survey on patient priorities for bladder cancer, which will guide future research.



LIFE AND BLADDER CANCER STUDY

We contributed to the protocol for longitudinal and cross-sectional patient-reported outcomes study of Yorkshire (UK) patients, which was published in the *British Medical Journal*. This is a study collecting patient-reported outcomes to explore longer-term health-related quality of life in bladder cancer survivors.

INTERNATIONAL KIDNEY CANCER COALITION

We attended the International Kidney Cancer Coalition 2019 Summit in Lisbon to share the conclusions of the World Bladder Cancer Survey we organised in 2018. It was exciting to share our experiences in an international setting with many urological patient advocacy groups. Read more on page 16.

'Fight Bladder Cancer lifted that very dark cloud that was over my head when I was first diagnosed with bladder cancer and helped me to cope with the fear and anxiety of the unknown. I knew I had someone I could call on 24/7. Not only were they a great support to me, but also to my sister, who has been my main carer.'

Tracy

CHANGE

BLADDER CANCER EXPERT WORKING GROUP

For the past two years, Fight Bladder Cancer has been working with other bladder cancer charities, professional groups and clinicians to identify and propose solutions to the challenges faced by the bladder cancer community in identifying, treating and managing the disease. The Bladder Cancer Expert Working Group has convened each year since 2017. During that time, the group produced a report, 'Addressing Challenges in Bladder Cancer', which proposed a number of recommendations including reforming waiting time targets, increasing research investment, developing simplified diagnostics tests and improving patient access to quality sources of information and support.

WAITING TIMES



Fight Bladder Cancer joined representatives from the British Uro-oncology Group, The Urology Foundation, British Association of Urological Nurses, Action Bladder Cancer UK, and British Association of Urological Surgeons to meet with representatives from NHS England to discuss the Waiting Times Standards. At the moment, the TURBT (trans urethral resection of bladder tumour) can sometimes be classified as a definitive treatment rather than a diagnostic test. This misclassification can artificially stop the clock, and can result in a delay in treatment, because the hospitals are not pushed to reduce the gap between referral and treatment. NHS England has agreed to review these standards and take our recommendations into account.



NICE

In May we attended the annual NICE (National Institute for Health and Care Excellence) conference in Manchester where they were celebrating 20 years of NICE. NICE provides national guidance and advice to improve health and social care. It was wonderful to attend some interesting lectures, and to hear so many discussions about the importance of the patient voice in the NICE process. We also contributed to a recent NICE scoping consultation looking at examining the cost effectiveness of combining different treatments for advanced bladder cancer.

SCOTTISH MEDICINE CONSORTIUM

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

EUROPEAN CANCER PATIENT COALITION

Fight Bladder Cancer has been a board member of the European Cancer Patient Coalition for the past three years. In June, we sent a patient representative to speak at their Annual Congress to share their cancer story, as well as to outline the current challenges and opportunities in bladder cancer.



'Through my interactions with the members of the Fight Bladder Cancer forum, I found a warm place to share my fears and received honest and forthright answers to my questions. Fight Bladder Cancer is a vital community that many people around the world have come to rely on. This is because most treating clinicians are unable to provide first-person experience with their patients. Doctors are able to share clinical statistics, but they can't directly say 'this is what chemotherapy feels like' or 'here is what will happen to your dignity during bladder diagnostic or treatment procedures'.

Lynne

EUROPEAN FEDERATION OF PHARMACEUTICAL INDUSTRIES & ASSOCIATIONS

We recently travelled to Brussels to participate in the EFPIA (European Federation of Pharmaceutical Industries and Associations) Patient Think Tank and Steering committee. During this meeting, we contributed to the co-creation of guidelines on how patient organisations and the pharmaceutical industry should interact with each other.

ALL.CAN

Fight Bladder Cancer is an active member of All.Can UK, a multi-stakeholder platform dedicated to improving efficacy by focusing the healthcare system on what matters to patients. We discussed the recent patient survey results of almost 4,000 cancer patients and carers from more than 10 countries. Based on the responses to the survey, we identified four key opportunities for improvement: ensure swift, accurate and appropriately delivered diagnosis; improve information-sharing, support and shared decision-making; make integrated multi-disciplinary care a reality for all patients; and address the financial impact of cancer.

ADVANCED CANCERS COALITION

Fight Bladder Cancer joined forces with a number of UK charities to become part of the Advanced Cancers Coalition. In June we gave a presentation at the UK Imaging and Oncology Congress conference in Liverpool on how we can improve the quality of care for people with advanced cancer. The coalition is focused on addressing the unmet needs of those living with advanced cancers. Read more on page 16.



CANCER PREPAREDNESS AROUND THE WORLD

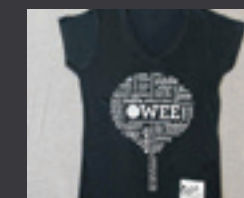
We contributed to a paper by The Economist Intelligence Unit on 'Cancer Preparedness Around the World'. We emphasised that cancer survivors are not well looked after or given a support structure after the acute phase of treatment. Cancer survivors often struggle with financial debt, problems returning to work, stigma, fatigue and mental health issues.



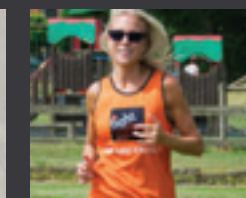
The FBC Shop

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

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



T-Shirts



Sportswear



Wristbands



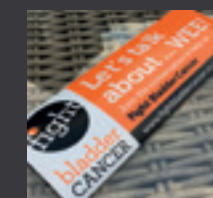
Pin Badges



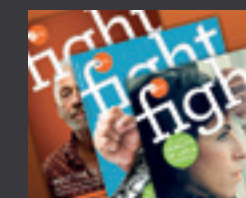
Tabards



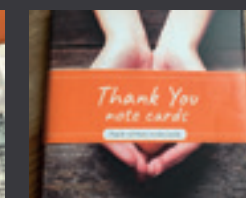
Fundraising Products



Window Stickers



Fight Magazine – Print & Digital



Thank You Notecards

Visit: fightbladdercancer.co.uk/our-shop

One battle is lost ... but the war goes on

It was with great sadness that we announced on 31 May the death of Andrew Winterbottom, our inspirational founder and indefatigable chairman.

In October 2018, Andrew revealed that he had a terminal diagnosis of bowel cancer and stepped down from his day-to-day management of the charity to concentrate on his own health. He had chemotherapy, which he undertook to prolong his quality of life, and continued to participate in planning the future of Fight Bladder Cancer when his health allowed.

Andrew chose Lydia Makaroff to be the new Chief Executive of Fight Bladder Cancer. On learning the news of Andrew's death, she said:

'Our deepest sympathy goes to his wife Tracy and all of Andrew's family. He will be profoundly missed by everyone who knew him. It is a huge achievement to have founded this charity for fellow patients. It has provided love, comfort, information and support to thousands of bladder cancer patients and their families. Our future work at Fight Bladder Cancer will be his legacy.'

Since he began the charity after his bladder cancer diagnosis in 2009, Andrew's determination and courage have been an inspiration to many. He launched Bubbles for Bladder Cancer, now an annual global event each May, and recently attended the inaugural meeting of the World Bladder Cancer Patient Coalition, which he was instrumental in creating.

It is poignant that he died on the last day of Bladder Cancer Awareness Month, which he saw develop into a global movement.

Today Fight Bladder Cancer supports thousands of patients and their families every year. There are currently over 4,000 people regularly using the support forum.

Andrew was a man full of creativity. Before his death, an Andrew Winterbottom Memorial Fund was founded to enable ideas benefitting bladder cancer patients to become a reality. Andrew was 65 years old, and is survived by his wife Tracy, his children and grandchildren.



Bringing bladder cancer into the spotlight

One of Andrew's great achievements was to make more people aware of bladder cancer.

He publicised, for example, that:

- bladder cancer is not a rare cancer, even though it is hardly ever talked about
- 18,000 people are diagnosed with invasive and non-invasive bladder cancer each year in England alone (Kockelbergh, et al. 2017. J Clin Urol, 10(1S) 3–8)
- of 200 cancers, bladder cancer is the fifth most common in Europe. For men, it is the fourth most common (Ferlay, et al. 2018. Eur J Cancer, 108: 356–387)
- the majority of people diagnosed with bladder cancer are over 60 years old, but increasingly people of all ages, from children and young adults to the middle aged, are being diagnosed
- despite this high occurrence, it receives less than 1% of the funding for cancer research
- it is the only cancer today where prognosis is actually getting worse; the five-year survival rate in Europe for men with bladder cancer is 69%, but only 62% for women

The symptoms

The main things to look for are:

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

About Fight Bladder Cancer

Today Fight Bladder Cancer is a national organisation operating from its headquarters in Chinnor, Oxfordshire. It is involved in support, awareness, advocacy and research.

Its forum has over 4,000 active members. The charity's work is patient-focused, but it is used by many leading urologists, oncologists, specialist nurses and researchers nationally and internationally. Its website currently receives well over 200,000 unique visitors a year.

For more about Fight Bladder Cancer visit www.fightbladdercancer.co.uk

Tracy Staskevich, co-founder of Fight Bladder Cancer, recalls her visionary, crazy, driven and wonderful husband.

My husband, Andrew was a truly extraordinary man. So what can I tell you about the co-founder of one of the most influential bladder cancer charities in the world, an architect, visionary, rebel, husband, father, grandfather and Blue Peter badge holder?

Andrew was super smart, and kind and funny too. He was passionate about things he believed in and lived life on the edge of crazy. As an architect he also had this immense talent for making things.

Just a few years after we met, and following a year of mixed symptoms, Andrew was given the worst kind of news – that he had Stage 4 bladder cancer. They told him his chances of survival of this rare form of the disease were less than 6%. Andrew being Andrew though, he decided he was going to be one of the small percentage who lived.

During his post-surgery recovery period, Andrew had one of his trademark ideas that would turn out to transform both our lives. Bladder cancer, we had quickly discovered, was ignored. There was no charity here in the UK to help those affected, no support and very little information. The idea started small: that we could start a local support group for those affected, where people could share their stories and learn from each other. With this in mind Andrew set up an online forum which we called Bladder Cancer Support. However, in the weeks and months that followed, and as the forum numbers grew from a handful to hundreds, it became apparent that the problem was much, much bigger and the need for real support and information for all those affected was overwhelming. We needed to, as Andrew put it at the time ... go large or go home ... so Fight Bladder Cancer was born.

Something I would like to share

with you all, is how hard it was to get anyone to listen in those early days. The wider medical community weren't listening and weren't interested – all channels, it seemed, were closed to us. We had virtually no money so we had to fund everything ourselves and beg and borrow other resources where we could. It is only because of Andrew's immense drive, vision and tenacity that Fight Bladder Cancer exists and that it has become the worldwide force it is today, lobbying for change, raising awareness, offering support and help to all those affected, wherever they are in the world.

For the last ten years it was his baby and gave him his own reason to fight. The premise was simple enough – create a community, build a Wee family and end up with something that changes lives. Not just now, but for every newly diagnosed bladder cancer patient to come.

In the midst of all this, what many people didn't realise was that Andrew was still combating his own medical problems. During the decade we built FBC into the game-changer charity that it is today, he was blue-lighted to hospital more times than I can count – he had other surgeries and almost didn't make it through resus a couple of times. He also suffered from ever-advancing kidney failure as a result of his initial bladder cancer.

Fight Bladder Cancer grew from strength to strength, and was joined just over three years ago by The Wee Bookshop and Café, a charity shop and community resource unlike any other.

Fast forward then to last year, when at the start of the year, ten years after his initial treatment, Andrew was discharged as a bladder cancer patient and given the final all clear. Unfortunately the radiographer's confidence was misplaced and by

summer Andrew was diagnosed with a Stage 4 bowel cancer and told it was terminal. He was more driven than ever – with an anticipated 6 to 9 months prognosis he was determined to achieve as much as he could in the time he had left. He concentrated on his biggest dream yet – a worldwide initiative, ensuring that patients in every corner of the globe wouldn't be alone. This was his primary focus through his gruelling chemo regime.

Andrew's dream came to fruition at the beginning of March when we flew to Barcelona, his favourite city, to launch the World Bladder Cancer Patient Coalition – the culmination of a decade's work. He was so happy and proud that he had such a large part in its creation. With over 27 countries already joining the coalition, he has ensured bladder cancer patients across the globe have a voice.

He was a man with a unique flair for fashion, as can be attested to by anyone who saw him in one of his crazy shirt and bright sneakers combinations. Let me tell you that is a look that not many men can carry off.

It is quite something to share life with a man who leaves such an extraordinary mark on the world – whether walking past one of his buildings on an iconic London street, riding one of his crazy rides at a theme park or listening to the heartfelt thanks of thousands of patients and families who feel they are not alone because of what he built. That's quite a legacy.

I miss Andrew so much, but I remind myself of what he repeated to me many times in the last few months of his life – that I had to get on out there and LIVE. That is what he would want for us all. That we should continue to believe that one person really can make a difference and that in the end, it is only kindness that matters.

Andrew's amazing legacy



Val and I had known Tracy for many years, but we first met Andrew when he was a practising architect. I knew vaguely that they had developed a website and were running an infant charity called Fight Bladder Cancer. But in January 2014, I got my own bladder cancer diagnosis and it all became very personal. I started to take more of an interest in the work and commitment that Andrew and Tracy were putting into the charity, funding it primarily from their own pockets, then nominating trustees and beginning local fundraising.

Knowledgeable and committed

When I was diagnosed, I had to choose between surgery and BCG treatment and who better to fire my questions at than Andrew and Tracy, who kindly agreed to a discussion over lunch. Val and I had been on the FBC website and compiled a list of questions; I don't think we asked a single one. Andrew started talking and, with Tracy offering her insight, covered everything that we were wanting by way of information. Four hours later, I had made my decision.

A master of the one-liner

Between then and my op, Val and I spoke fairly often with Andrew and Tracy, who were veritable mines of information and always kept things upbeat, like the time we were discussing post op recovery and Andrew – his face dead pan – came out with 'Beware – not all farts are dry!' – apparently a common occurrence.

Energetic and decisive

A few months after my RC, Val and I met up with Andrew and the late Sarah Peet in Liverpool, to look after the FBC stand at the BAUS conference. Typical Andrew, he left newbies Sarah and I to hold the fort and welcome visitors to the stand while he went

OPINION

JOHN HESTER, FBC Chair of Trustees

from meeting to meeting around the conference hall, seeing various trade bodies and pharmaceutical establishments. On one of his returns to the stand he turned to us and said, 'Now that you have experienced this aspect of what FBC is trying to do regarding awareness and fundraising, I am appointing you both regional co-ordinators so you can make a real difference in those areas'. Neither of us even thought of objecting.

Larger than life

In the early days of the charity, with a stand at the BAUS and BAUN conferences, we were often overshadowed by huge, expensive, corporate stands, while ours was a simple, eight-foot table covered with an orange cloth and dotted with two computers displaying the FBC website, and various posters, pamphlets, wrist bands and t-shirts. There was quite a lot of Sellotape, blue tac and sticky-back plastic holding it all together.

But we didn't need anything more swanky because we had Andrew – in great demand from all and sundry and totally in his element. Sometimes we had ten or more nurses at a time, giving contact details, picking up posters and brochures, asking questions, and commending him for setting up an organisation to which they could refer patients.

At one conference, at breakfast, Andrew met us all beaming from ear to ear. We had all gone to bed after dinner the night before, as we could not justify the cost of tickets to the BAUN ball. Andrew was surprised and delighted to be woken by a phone call from the president of BAUN, that the nurses had voted FBC the stand of the conference and wanted to make a presentation. Where was he? The presentation was made the following morning instead – a reward for Andrew's drive and vision.

Inclusive and indefatigable

Having gained official registered charity status, Andrew was always looking for the next challenge, which resulted in the Wee Bookshop & Café. He was never shy of asking people to help and would often just assume you'd be able to take on whatever he offered. I don't think the word 'no' meant a lot to him! That is the way I became involved, and later became the first of the Bladder Buddies.

It wasn't long afterwards that Val and I met with Andrew for a meal. As dessert arrived, Andrew said to me, 'I have something important to ask you but I need to ask Val something first.' He turned to Val and said, 'Will you please become a trustee of FBC?'. She considered for a moment, then agreed. 'In that case,' Andrew said to me, 'will you be chair of the trustees?' I had no option. How could you say no to this man and his incredible vision to Fight Bladder Cancer?

Andrew's terminal diagnosis was a severe blow to everyone close to him – to everyone associated with him in fact – but we have not lost his spirit because it underlies everything we do.

He has shown how drive, determination, energy and sometimes sheer bloody-mindedness are what is needed to make a difference, and FBC will forge ahead, buoyed by the momentum of its founder and original driving force, and those of us who are now trusted with Andrew's legacy will not let him down.

John Leslie Hester

From our CEO

In her first year as CEO, Lydia talks about her memories of Andrew and her visions for the future of Fight Bladder Cancer.

ARTICLE

LYDIA MAKAROFF,
FBC CEO



I first met Andrew Winterbottom, the founder of Fight Bladder Cancer, when I was the new director of the European Cancer Patient Coalition and he was the new treasurer. Over the years, we worked together to establish European Bladder Cancer Awareness Month and I learnt so much from him. He taught me the value of being authentic, different and compelling.

Last year, when he learned of his terminal bowel cancer diagnosis, he and the trustees asked me to apply for the job of CEO. I was delighted to learn that my application had been accepted, and I feel so fortunate to have been given the opportunity to manage the daily operations of such an impactful and inspiring charity.

One of my fondest memories of Andrew is blowing bubbles with him in Barcelona, at the launch of the World Bladder Cancer Patient Coalition. He was so proud to know that Fight Bladder Cancer had been a founding member of this new organisation that is now the global voice of people affected by bladder cancer.

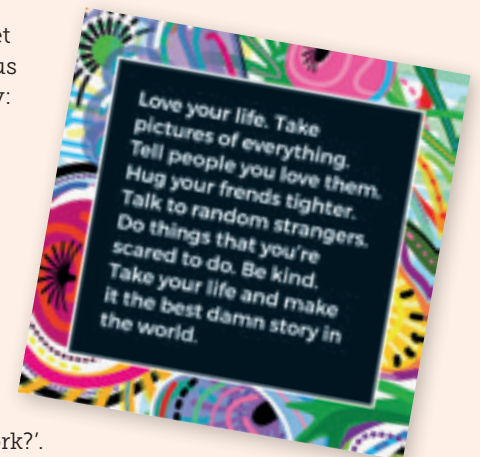


Since Andrew's death on 31 May 2019, I miss his daily support and advice. I miss his energy and his optimism, his insights and his warm hugs.

I am so thankful to him for establishing a strong foundation, and hand-picking a passionate and dedicated group of trustees, staff and volunteers. The advice and guidance of Andrew's wife and charity co-founder, Tracy, has also been invaluable.

When I am faced with a difficult decision, I often think to myself 'What would Andrew do?', and remember his advice not to be a 'busy fool' and always to ask myself 'so what?' when considering how a project will truly impact bladder cancer.

I will never forget the advice he gave us on his 65th birthday:



Before he died, Andrew asked me to ensure that this edition of the magazine covers 'the difficult stuff' and asks the question, 'What happens when treatments don't work?'

It was quite challenging to pull all this knowledge together while still ensuring that it remains the heart-warming, supportive and empowering magazine that we all love. Therefore, we have put this topic in a separate section, so that people can opt to read these articles if and when they choose.

Looking forward, it is my mission to grow the charity, continue his legacy, and ensure that everyone affected by bladder cancer knows that they are not alone. My goals for the organisation include stronger collaborations, louder patient advocates, greater transparency, and more diversity and inclusion.

I am well aware that most of the money that comes into the charity is from individual donations. To all our supporters: thank you so much for your trust and support. If it wasn't for all your amazing backing, we couldn't do all this work. Part of my role will be to ensure that we continue to be a transparent and frugal charity.

Thank you.

Lydia

UCL support group proves its benefits to patients

ARTICLE
HILARY BAKER
Lead CNS for
Uro-oncology,
FBC Trustee

Patients, carers and professionals all benefit from exchanging information, and were unanimous in wanting a bladder cancer support group for University College London patients to share their experiences and cancer journey. Set up in November 2016, the informal group is facilitated by the support and information staff and the bladder cancer CNSs.

Patients, partners and carers are all invited from within the network across north and north-east London, and all patients diagnosed with bladder cancer are encouraged by the CNS team to attend the group, by providing them with a printed flyer about the dates and venue.

Friendly and welcoming, there is a great sense of camaraderie and fun within the group, which numbers 15 to 20 people per session. All of them bring different cancer experiences and treatments and they have 'buddied' together and are very supportive, kind and attentive to one another – a group with common experiences and concerns and members who provide emotional and mutual moral support.

Confirming the evidence

There is much evidence in the literature to show the benefits for some patients of attending a support group, following a cancer diagnosis. Such groups:

- improve quality of life through meeting psychological needs
- provide information and oncology support, which can change throughout the patient's cancer experience
- empower the patient to take an active role in their cancer care
- help them take control back into their lives (Stang et al 2009).

Patients become advocates for their own life and health through support and encouragement from others, education, trying to maintain a 'normal' lifestyle, accepting help, developing coping strategies and joining the 'fight against cancer'. This enables them to gain a more holistic role in treatment decisions, reducing their levels of anxiety and depression.

Carers found groups to be educational, supportive and proactive in reducing stress of the disease among their family and friends.



Are they representative?

Research also indicates that groups with a joint leadership of healthcare professionals and patients have the best stability and tend to retain members (Pomery et al 2016). Healthcare Professionals (HCP) describe self-help groups as a positive for peer support, but many doctors are sceptical and concerned with the possible negative views and misinformation within them. Bell et al 2010 reports that groups do not always represent people of different ethnicity, men and those of lower social groups.

Seale et al (2006) described, for example, how women tend to view the groups as a nurturing place to exchange emotional support and gain new friendships. Men, on the other hand, saw them as a way of obtaining information, but were more reluctant to attend with a cancer identity. Although more women than men join support groups, the majority of both populations (67% for women, 87% for men) do not actually attend any support group meetings for a variety of different reasons (Krizek et al 1999).

It is therefore crucial that the HCP is creative and flexible in informing newly diagnosed patients about support groups to encourage diversity of access.

Online groups

The internet and social media offer a new way for people to join virtual communities, and patients find the experience encouraging and feel better informed (Ginossar 2008). Online options provide support for people who have little spare time, live long distances away from patient groups or find them uncomfortable; they also provide privacy and are often chosen by those who want to come to terms with their cancer in their own way. Patients can also write their own personal journal, feel less inhibited in sharing experiences via discussion and chat rooms.

Unfortunately, website information is not monitored and regulated by HCP, hence the information provided is not always accurate. People are encouraged to register and are advised to use a pseudonym for privacy.

'I find the support group extremely helpful. It's great to be among people who have been through or are going through all stages of treatment and major surgery, who are happy to share their knowledge and experience with others who may be anxious or uncertain. We have guest speakers who are experts in their field and the specialist nurses are always on hand for help and advice.'

The sites are often run by patient-led charities to gain support and offer advice, and they are popular with many families and carers. Members can share personal experiences, offer or ask for help in finding reliable information about treatments, and benefit from the experiences of other patients (Zhao & Zhang 2017). Patients report they can talk openly about feelings which they can't discuss with friends and family because they felt pressured to 'be brave' and not upset people.

Timing is important

When to take part in a support group is a complicated and personal choice for patients.

Many patients find that at diagnosis there are too many problematic emotions to cope with, and sharing and listening to other people who have had cancer is just too distressing. If a patient is feeling overwhelmed with their diagnosis, this is also not a good time as it will make it impossible to feel they belong to the group. Sometimes, it is simply a matter of chemistry, and patients can try another group where they feel they have a better fit.

Equally, some patients find a support group can help them through the loneliness they feel on diagnosis and find mutual support a source of comfort and encouragement.

Different groups for different folks

Support groups should help patients talk about their feelings and develop skills to cope with changes taking place in their life. Some studies have shown that people who visit self-help groups have an improved quality of life (Weis 2003) and survivorship (Thaxton et al 2005).

There are different models of patient groups; some offer individual or group counselling, others have a focus on education about cancer to help patients feel more in control through knowledge and personal discussion. (Boland et al 2018).

Groups are most often run by non-professionals, peers who have been through similar problems and crises to call on their own life experiences. They all offer people who have been through a cancer experience a way to bond quickly with others, provide comfort companionship and a safe place to go with their fears and guilt. Many people report groups can be fun, by laughing about their experiences as a cancer-survivor with those who have travelled the same cancer journey (Olliffe et al, 2009).

Some groups have an open membership, which means the members come and go freely within the group and the membership can change with each meeting. This may suit someone who cannot commit regularly, however they may lose out on stable friendships. Other groups have closed membership where the group achieves a certain number of members and then is restricted to new membership, and patients are expected to commit to a number of sessions of attendance. The advantage of this type is constancy of the group members, who can potentially develop long-standing, supportive friendships, although they can be difficult to maintain given the demands of the illness.



'When I was diagnosed I felt shocked, frightened, angry and so much more. I joined this group with its welcoming, happy staff who always make time for you. A chance to meet and talk with others "all on the same road". The group has become my extended family.'

The group meets at the Macmillan Cancer Centre in Huntley Street, WC1E 3AG every third Thursday of the month from 12.00-13.30, with refreshments. Sessions alternate between group discussion and educational sessions.

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Our Fight Clubs pack a punch

Patients and carers all need support to help cope with the effects of a bladder cancer diagnosis and treatment. The challenge for Fight Bladder Cancer is to meet their varied needs and our local support groups are part of the range of services we have put in place throughout the UK.

The National Institute for Clinical Excellence's 2003 guidelines on supportive and palliative care emphasise the role of self-help and support groups, and confirm that patients, their families and carers need access to supportive care, which should be provided throughout the patient's pathway.

Support groups provide a forum for patients to access help and overcome some of the psychological trauma that accompanies a cancer diagnosis.

Looking for your local support group or perhaps you'd like to set one up at your hospital? Contact us at info@fightbladdercancer.co.uk

We currently have FIGHT clubs in:

Cambridgeshire	Glan Clwyd, Wales	Southampton, Hants
Canterbury, Kent	Glasgow, Scotland	Stockport, Cheshire
Chinnor, Oxon (covering Oxon, Bucks, Herts)	Lancaster Newcastle	St Barts, London

We are also supporting other local groups across the country, by providing speakers as well as printed materials.

As well as talks and discussions on treatments, side-effects and quality-of-life issues, we have found that groups also like to have talks on:

- diet and nutritional advice
- awareness campaigns
- financial and benefits advice
- fundraising events
- bladder cancer research

At Fight Bladder Cancer we are always here to give advice and support to help your group find its feet and move it forward for you and your fellow patients and carers.

If you would like to help set up a local support group in your area, please get in touch at info@fightbladdercancer.co.uk. Join our online support group at www.facebook.com/groups/bladdercanceruk/

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Visit fightbladdercancer.co.uk/our-shop for more information.

World Bladder Cancer Patient Coalition

A new global voice for people affected by bladder cancer



For the first time ever, people affected by bladder cancer now have a global voice. The World Bladder Cancer Patient Coalition was officially launched on Monday 18 March 2019 at the European Association of Urology congress in Barcelona, Spain.

Approximately 430,000 people are newly diagnosed with invasive bladder cancer around the world each year.¹ Globally, there are 2.7 million people who are currently living with bladder cancer.² In the Western world, bladder cancer is the fourth most common malignancy in men and the eighth most common in women.³ About 1 in 25 Western men and 1 in 80 Western women will be diagnosed with bladder cancer sometime in their lives.² Women are 23% more likely to die from the disease compared to men with bladder cancer.⁴

The Bladder Cancer Advocacy Network (USA), Fight Bladder Cancer (UK) and Bladder Cancer Canada worked together to establish the World Bladder Cancer Patient Coalition. We invited Action Bladder Cancer UK, BladderCancer.org.au Australia, Blaerekreftforeningen Norway, Les Zuros France, and PaLiNUro Italy to join

the inaugural meeting and become full members. Other patient advocates, health professionals, academics, policy-makers, researchers, and representatives from the pharmaceutical and medical device industries also attended the launch event.

Piyush Agarwal, of the Center for Cancer Research (US) National Cancer Institute, spoke at the launch event. He said, 'The World Bladder Cancer Patient Coalition unites patients around the world, giving them a powerful voice in the fight against a lethal disease that significantly impacts not only their survival but also their quality of life. The World Bladder Cancer Patient Coalition aims to create a global voice that hopes to alleviate much of the pain and suffering associated with bladder cancer.'

'Treatment, research and support for bladder cancer patients varies widely across the globe and even within countries,' said Ken Bagshaw, bladder cancer patient and President of the World Bladder Cancer Patient Coalition. 'It's critical that we mobilise bladder cancer patient organisations across the world to help ensure the best possible outcomes for patients.'



ARTICLE LYDIA MAKAROFF
Vice President, World Bladder Cancer Patient Coalition, Belgium
CEO, Fight Bladder Cancer, UK

The World Bladder Cancer Patient Coalition is governed by a board of directors. This board is composed of people diagnosed with bladder cancer, carers of bladder cancer patients, and those engaged with bladder cancer organisations at the national level.⁵

The missions of the World Bladder Cancer Patient Coalition are to:

- foster an international community of people affected by bladder cancer
- advocate for access to the best possible bladder cancer information, support, and care
- build alliances with health professionals, policy makers, academics, researchers and industry

In its first year of operations, the organisation will focus on Bladder Cancer Awareness Month in May, producing a regular newsletter for stakeholders, and developing a toolkit to help establish and build national bladder cancer patient organisations.

The World Bladder Cancer Patient Coalition welcomes other bladder cancer patient organisations to apply for membership. To be eligible for full membership, organisations must:

- be supporting or rendering services exclusively to bladder cancer patients and their caregivers
- and/or be raising awareness, promoting research and empowering organisations that support or render services to bladder cancer patients and their caregivers
- a bladder cancer patient organisation.

The World Bladder Cancer Patient Coalition benefits from the support of AstraZeneca, Bayer, F. Hoffman-La Roche AG, IPSEN, Merck Sharp & Dohme, and Photocure. The work of the organisation is the sole responsibility of the World Bladder Cancer Patient Coalition.

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Spreading the word

How contact cards will make a difference

An £18,000 grant from NISA Retail Ltd's Charity – Making a Difference Locally – will help Fight Bladder Cancer launch contact cards for nurses.



ARTICLE
EMMA LOW,
FBC Head of
Fundraising and
Development

It's the simple ideas that are often the most effective. Newly diagnosed patients, especially, need the vital support service and authoritative information provided by Fight Bladder Cancer. Thanks to the backing of brand and grocery wholesaler NISA's Making a Difference Locally, thousands of people who have just been diagnosed with bladder cancer will be given contact cards by their urology teams – meaning they can always find support during times of need.

This new project will provide much-needed support for urology cancer nurse specialists who will distribute the cards to their patients. The cards will carry both the local clinic's contact information as well as the details of how to access dedicated support and information from Fight Bladder Cancer.



Lydia Makaroff, CEO of Fight Bladder Cancer said:

'As a patient-led charity for bladder cancer, we want to reach as many people as possible. This is an important initiative because it could reach over 23,000 patients and carers every year. By co-ordinating closely with nurses, who are the lynchpin for patient care in bladder cancer, Fight Bladder Cancer will enable patients to access the right information when they need it most.

We know that specialist urology nurses are often the first people to see a new patient and they play a part at every stage of diagnosis, treatment and care. But they are overstretched and under-resourced. As a consequence, it is often difficult for them to give the level of support they would like to offer their patients. This simple initiative will help to fill the gaps for patients at a very important time. By handing a new patient one small card, nurses will be signposting patients to charitable services which we, Fight Bladder Cancer, are providing 24 hours a day so they can access reliable information and have a place to share worries and concerns.'

Support when and where it is needed

The new cards will be issued to hundreds of specialist nurses across the UK.

Laura Noble, CNS from Newcastle Upon Tyne Hospitals NHS Foundation Trust helped to develop the cards. She says the initiative will improve the experience for patients and help clinical teams to provide access to other valuable dedicated services:

'Because there is so little in the way of support for bladder cancer patients, Fight Bladder Cancer makes a huge difference. They have helped many of our patients through difficult times. They also support us as nurses by enabling us to provide patients with a source of information and support that we know we can trust.

In future it would be great to see every bladder cancer patient being given a contact card for their CNS together with information about how to reach Fight Bladder Cancer when they are first diagnosed. This will really help nurses and give patients and their carers 24-hour access to support.'

Nurse Specialist Laura Noble, from Newcastle is championing this contact card support initiative.



What do the charity's users think?

Feedback from people using the FBC online social media forum describe the support they receive from other patients and carers as 'wonderful'. One user commented:

'I soon realised I was not on my own. I got most of my information from Fight Bladder Cancer, having learnt very quickly not to trust Dr Google! I don't know what I would have done without Fight Bladder Cancer. People I have never met have become my new family. I can laugh with them and cry with them.'

A look at the numbers

The need for the contact cards is clear.

- Bladder cancer is the fifth most common cancer in Europe.
- It is the most common cancer in Europe amongst men.
- Every year 18,000 new patients are diagnosed in England alone.
- It is estimated that over 100,000 people in Britain are living with bladder cancer.
- Over 4,500 people die of the disease in England every year.

Fight Bladder Cancer is working hard to make more people aware of this neglected disease.

We have now begun distributing the contact cards. If you're a patient or carer please do talk to your nurse about keeping a stock of the cards. If you're a healthcare professional, please contact Emma Low on **07787 518599** or getinvolved@fightbladdercancer.co.uk to find out more about placing an order.

SPECIAL FEATURE

END OF LIFE

Over the next few pages, we focus on an issue many cancer patients fear – what happens when treatment options run out and you are faced with a terminal diagnosis.

We look at what to expect at end of life, discuss palliative care and talk to a bladder cancer patient about their own experience of living life with a terminal diagnosis.

We start with an article by award-winning author Kathryn Mannix, written in response to this email from FBC Founder Andrew Winterbottom in March this year:

Hi Kathryn

My personal situation is that I am now terminal myself and came upon your fabulous book after my wife was recommended it. I have to say it has made a significant difference to my attitude to my forthcoming death. For that I want to send you a personal thank you for writing such a compassionate and insightful book that I recommend to all.

My ask is, would you be able to write a small piece for a future edition of our *Fight* magazine? This follows on from past editions that focused on sex and intimacy with a diagnosis, another area that is sadly not discussed enough.

Thanks again for your book, it has given me a significant amount of peace for my last months, however many they be.

Warmest wishes

Andrew

Andrew Winterbottom
Founder and Director, Fight Bladder Cancer

With the End in Mind

Knowing more about what to expect at the end of life can be a huge comfort both to the patient and their loved ones.

After a career in palliative care, working with more than ten thousand people as they approached the end of their life, I'm pretty familiar with the pattern of events as we die. I'd hoped throughout my career that better public information about normal dying would console people; that my patients would have fairly realistic expectations, and so feel some confidence that dying itself might not be so bad.

Sadly, this has not been the case. Not because the truth doesn't console people – it really does – but because the truth remains buried under newspaper scare stories, media publicity about unusual, horrible deaths, and death scenes on TV and film that are incredibly unlikely. Real dying won't make good drama, which is great news for all of us. But only if we can get good information.

Looking closely at what lies ahead is a consolation

Eventually, in an attempt to redress the balance of information, I used my experiences to write a book about dying. It simply tells real stories about how people who we might think of as 'dying' are mainly getting on with the business of living. It tells how different people managed real situations like pain or nausea, anxiety or panic, talking to their families or deciding when to change from pursuing more treatment to pursuing more pleasure in the life left to live. It describes the process of normal human dying, right to the last breath.

It tells readers exactly what to expect, by inviting them to 'visit' real people through their stories.

Normal dying is a gradual process of increasing tiredness, progressive onset of unconsciousness, and changes in the breathing cycle until breathing very gently stops.

The response has been phenomenal, and quite unexpected. It became a best seller, was short-listed for a prize, and I have been inundated with letters and messages to say how knowing more has helped people to be less afraid of what lies ahead, or has allowed bereaved people to make sense of what they saw as a loved one was dying.

It's made me even more certain that the best way to deal with our natural fears about death is not to push them aside, but to get more information, and to look at death closely. I'm delighted to have been invited to write about it for this magazine, and I hope you'll find it helpful.

A repeating pattern

Firstly, it's worth saying that any illness so severe that it kills people follows a very similar pattern towards the end of life. People feel tired. They do less before they run out of energy. You may already be finding that. In which case – that's normal. Whatever the illness, the pattern is the same in the end.



ARTICLE
DR KATHRYN MANNIX,
Author & Palliative Specialist

The illness we die of, of course, might cause some specific symptoms. That's something worth getting expert advice about as early as possible. For diseases that interrupt the flow of urine from the kidneys, this may cause the kidneys to perform less well, causing a set of symptoms familiar to kidney specialists and palliative care experts that may include tiredness, nausea, hiccups, twitchy muscles and drowsiness. It's possible to work around the symptoms to some extent so get advice, don't just put up with it.

Advance care planning or ACP is the process of developing a plan for your future care as your disease progresses. It should express your decisions and preferences, and be developed with your medical advisers.

If the illness puts pressure on abdomen and pelvis, the symptoms might include bloating, bowel irregularity, colic, nausea, vomiting – or no symptoms apart from tiredness.

Having a plan for your own set of symptoms, tailored to you, and with a backup plan for if you're too sleepy to take medications by mouth, is good planning. In future you will be glad of that plan, even if it never needs to be used. It's like an insurance policy: if you need it, you're covered.

The process of dying

Here's what we see when somebody is dying. Here's what you'll see if you're watching it happen to someone. Here's what the people around you will see when it's your turn. Because sooner or later, we all have a turn.

- Tiredness is the main symptom. Sleep is its treatment. Snoozes and naps restore our energy levels for a while, but as time goes by energy levels drop faster and further. We become sleepier: some people spend days being mainly asleep, but waking up for conversations, a favourite TV show, a few bites to eat. Then off to sleep again. So far, so not very Hollywood.
- Eventually dying people simply sleep all the time. In fact, it's not just sleep: for some time during the sleep-wake-sleep time, they have been slipping in and out of unconsciousness without noticing it. We don't notice when we become unconscious. It doesn't feel like falling asleep. So we become gradually more deeply unconscious, possibly still occasionally waking but eventually we are simply unconscious all the time.
- The unconscious brain only does one thing: it runs breathing on an automatic cycle. This cycle goes from fast to slow, and moves between deep and shallow. We don't control our voice box any more, so the breath might make sounds as we breathe. This isn't pain, or attempts to talk: it's unconsciousness.
- At some points the automatic breathing might be shallow and fast. This isn't breathlessness, it's just unconsciousness.
- Sometimes we ignore the tickle of saliva in the back of the throat – that's a sign of being very deeply unconscious, because otherwise we'd cough or swallow to clear it. If the breath is coming in and out through a small pool of liquid like that, it bubbles through, and the noise is sometimes called 'the death rattle' – it's a sign of deep, deep unconsciousness.
- And then, during a period of shallow breathing, sometimes now with pauses in breathing, there will be an out-breath that just isn't followed by an in-breath. As gentle as that. It won't frighten anyone. No drama. Just very quiet.

My experience is that family members find it deeply consoling to be present as someone they love is dying, and the better they understand the changes taking place, the more confident and prepared they feel. Just as a midwife describes what to expect during labour to a pregnant mum and her birth partner, then reminds them of it all again as it's happening for real to make them confident that the process of labour is happening as expected, so we benefit from understanding the process of dying well ahead of time. Then, when it's happening for real, we can remind each other that this is normal; this is what happens; we can do this.

And we can do this. Good preparation helps. I hope knowing what to expect will help us all to be less afraid, better able to insist on the best care to enable dying to be peaceful, and to get on with the pleasure of living until that time comes.

Kathryn Mannix's first book *With the End in Mind* was published in 2017 to critical acclaim. Shortlisted for the Wellcome Prize in 2018, it has become a widely recognised text for aiding our understanding of death. Further details can be found at www.amazon.co.uk/End-Mind-How-Live-Well/dp/0008210918/



'I have to say your fabulous book has made a significant difference to my attitude to my forthcoming death. For that I want to send you a personal thank you for writing such a compassionate and insightful book that I recommend to all.'

Andrew Winterbottom,
Co-founder of FBC &
former CEO



What is palliative care?

Dr Stephanie Chisolm puts the spotlight on palliative care.

Providing first-class palliative care is hugely important not only to patients but also to their families and loved ones. Here, Dr Stephanie Chisolm looks at the provision of the best palliative care.

Also called supportive care or symptom management, it is a common misconception that palliative care is the same as hospice care, but that's not the case. While all of hospice is palliative care, not all palliative care is hospice because palliative care is offered much earlier in the disease process. Patients can transition to hospice once cancer treatments are no longer controlling their disease. At that point they receive only palliative care. While patients are still receiving cancer treatment, they may receive palliative care in addition to their cancer treatments.

Holistic

The crucial thing about palliative care is that it is **holistic**, so puts not the illness but the patient at the centre and looks to **manage** the physical, psychological and spiritual problems faced by patients with serious or life-threatening illness and their families. The goals of palliative care include improving the quality of life by preventing or treating, as early as possible, the symptoms and side-effects of the disease and its treatment; to offer social support systems to patients and caregivers; and to integrate psychological and spiritual aspects of care.

Who gives palliative care?

Palliative care is not the preserve of one department but involves an inter-disciplinary team approach. Any healthcare provider can provide palliative care by addressing the side-effects and emotional aspects of cancer during the normal course of treatment. Some healthcare providers are specially trained in palliative care and work with, not in place of, the primary oncology team. A palliative care team may also include social workers, pharmacists, registered dietitians, nurses, physician assistants and therapists.

TERMS YOU SHOULD KNOW

You may well come across these terms when you are investigating palliative care.

- **Chemotherapy:** The treatment of disease by means of chemicals that selectively destroy cancerous tissue.
- **Hospice:** A healthcare facility or support for the terminally ill at home. Hospice focuses on pain control and emotional support for the patient and their family.
- **Palliative care:** Specialised medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.



ARTICLE

DR STEPHANIE CHISOLM
Director of Education and Research, Bladder Cancer Advocacy Network USA

Questions to ask your healthcare team

Find out about the services available to you and always consider a second opinion if you are not satisfied with the answers you receive.

- Does your hospital have a palliative care service?
- How can I be seen by a palliative care specialist?
- Will you and my palliative care team communicate about my problems?
- Who can I call if I have a question about palliative care treatment that I am receiving?

The elements of palliative care

All patients are unique and have specific needs but the following list provides examples of many current issues that palliative care will address.

Physical

- Pain or other complications from cancer itself, treatments or surgery.
- Nausea/vomiting during and after chemotherapy or other treatments.
- Fatigue during BCG treatments, radiation or during chemotherapy or immunotherapy.
- Sexual problems caused by surgery or other treatments.
- Nutritional status before, during and after cancer therapies or surgery.

Emotional

- Supportive care for feelings of depression, anxiety or fear, for patients and their families.
- Sadness about body changes with post-surgery urinary diversion management.
- Talking to children and other loved ones about cancer.

Spiritual

- Incorporate spiritual care according to patient/family needs, values, beliefs and culture background.

Other issues

- Questions about legal forms such as advanced directives and healthcare power of attorney.

Myths about palliative care

- **If I receive palliative care, that means I can't have any more cancer treatment:**
FALSE. Incorporating palliative care into cancer care has resulted in higher patient satisfaction. If your cancer doctor refers you to a palliative care specialist, they will work together to optimise your quality of life.
- **I don't have pain, so I can't get palliative care:**
FALSE. Palliative care addresses much more than just pain. Examples of issues that are addressed in palliative care include nausea, vomiting, fatigue, appetite loss, sleeping problems, depression, anxiety and much more.
- **I didn't get chemotherapy for my bladder cancer, so I can't get palliative care:**
FALSE. Some patients experience bad bladder symptoms after treatments like BCG or radiation, and pain or bowel problems after surgery. Palliative care can be used for these types of problems, too.

When is palliative care used in cancer care?

Palliative care is incorporated to promote the best quality of life (QoL) throughout a patient's cancer experience, beginning at the time of diagnosis, throughout treatment and the end of life.

Where is palliative care received?

Palliative care is offered at cancer centres, clinics, inpatient units at hospitals and at home.

Based on material produced by the Bladder Cancer Advocacy Network (BCAN) USA. www.bcan.org

The Bladder Cancer Advocacy Network (BCAN) BCAN's mission is to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

www.bcan.org info@bcan.org

Watch BCAN's webinar on palliative care and bladder cancer www.bcan.org/palliative-care-bladder-cancer-webinar

My experience of death & dying

Anita Brown takes a sensitive look at how to navigate uncharted waters of both the practical and emotional aspects of facing your own death.

From the moment those words 'You have Bladder cancer' are spoken, you venture into unknown territory. You are thrown into a whole different world with a different language – full of scans, blood tests and appointments – and who would blame you if one of your first thoughts may have been, 'Oh god, am I going to die?'

Death comes to us all at some point, and no one knows how lucky they will be or how long they will live. But being diagnosed with bladder cancer means that this life journey has a much greater chance of being shorter than we might have hoped; we do not know what the future holds for us.

When I was diagnosed with small cell bladder cancer in 2016, it had already metastasised to my lymph nodes, liver and bones. The future looked pretty bleak. But I was lucky enough to have the right kind of support and help. I was encouraged to come to terms with the fact that I was dying and sooner or later this disgusting disease would take my life.

So, we set about making memories. True, they were often tinged with sadness – would this be my last birthday or Christmas? My last holiday or weekend with friends? But as we focused on making each event as good as we could make it, we began to learn very quickly that we should take the highs with the lows and make the most of being alive, right here and right now.

The last taboo

Death is a subject we try to avoid talking about but, in fact, we need to be more open and honest about death and dying. We need to speak about it more with our families and friends, to prepare both ourselves, and others, for our death. Because the one thing in life that will happen to us all is that we will die. So what do we need to know?

There are two aspects to consider: the practical and the emotional. Firstly, we need to organise ourselves, to take charge of what we can and be in control of the practical aspects of dying. The other side is the emotional side of death, which everyone will go through.

When you are told that you are going to die, so many things go through your head. Will it be quick? Will it be painful? How will it happen? Our minds go into overdrive and that's only natural in this situation. But, again, there are things you can do to come to terms with it.

This is a basic outline of both aspects of dying, designed for anyone, at any age. However, if you have a bladder cancer diagnosis, it is especially vital that you talk to your loved ones and make sure you have completed the relevant forms so that your loved ones know what you want to happen to you in the event of you being unable to speak for yourself.



ARTICLE
ANITA BROWN,
FBC forum member

THE PRACTICAL SIDE

Taking control of the practical side of death can feel overwhelming at first, when you don't know where to start or what you need to know or do. What's more if you have been diagnosed with something that could potentially take your life away, it puts everything into sharp focus. But having practical steps to take, and knowing that what you are doing will help your loved ones when you are gone, can actually help you deal with the situation.

MAKE A WILL

If you have not done so already, one of the first things you will need to do is to create a Last Will and Testament.

A Will is a legal document that will help to ensure that your money, property, investments and possessions – known as your Estate – will go to those who you want it to go to. You can have a solicitor or will writer draw up your Will, or you can buy a sample Will from a stationer's, or you can simply write down your wishes. Whatever you do, your Will must be signed and dated by you in the presence of two independent witnesses, who will not benefit from your Will, who also sign and date the Will and include their addresses and occupations.

A Will also requires an Executor, who will be in control of your Will and putting your wishes into practice after you have gone.

Go to www.gov.uk/death for more information on all these documents.

They will sort out any outstanding debts and taxes and will then inform anyone you have bequeathed money or personal items to. The Executor must therefore be someone you trust completely; they can be a member of your family or a close friend, or a solicitor.

One point to be aware of is that if you die 'intestate' – without a Will – everything will automatically go to your next of kin, although it may take longer to sort out your Estate. If you are living with someone but not married, your partner is not your next of kin and will therefore have no rights over your Estate.

A Will does not have to be held at a solicitor's office nor does it have to be registered until after your death. Whilst you are alive, your Will can be kept in a safe place, but do make sure your Executor knows where it is.

LETTER OF WISHES

In addition to your Will, or instead of a Will if you do not have anything of value, you can write a Letter of Wishes containing details about personal possessions. It is exactly what it says: details of what you would like to happen on your death. It can include who you want informed of your death, your funeral wishes and a list of specific items that you would like to go to family members or friends. It is not a legally binding document but will be a helpful guide for your Executor to ensure that your personal wishes are met.

LASTING POWER OF ATTORNEY

The Lasting Power of Attorney (LPA) is a legal document which allows you to appoint a person to act on your behalf, creating a legal relationship between yourself and a person of trust. Once signed and witnessed by two people, it comes into effect, so I cannot stress enough that you should choose people you trust absolutely.

There are two separate LPAs: one for your Health and Welfare and the other for Property and Financial Affairs and you need to complete both.

Giving someone a POA does not take away your right to manage your own property and money, although it is important to know that they will have the ability to access your money.

You can be as specific as you want in your POA documents and you may want to consider giving instructions for the POA not to use it until/unless you are unable to speak, or act, for yourself. This is known as 'springing'; for example, the POA does not come into action until a certain event takes place. Your POA will require an affidavit – a written statement confirmed by oath or affirmation, for use as evidence in court – showing that this event has taken place.

You can revoke a POA at any time. You will need to complete and sign a statement, signed and witnessed by two people.

DO NOT RESCUSITATE (DNR)

A DNR is a legal order, written or communicated orally, indicating that a person does not wish to receive cardiopulmonary resuscitation in the event that their heart stops beating. You can also add this to your advanced care plan. This does need to be signed by your doctor and will be added to all your medical notes.

AN ADVANCED CARE PLAN

An ACP is a document that will communicate your wishes in the event that you are unable to do so. I really cannot stress enough the importance of doing this. It is not a legally binding document but it is YOUR voice to express how you want to be cared for in a life-changing situation.

This can contain your wishes about organ donation, DNR (Do Not Resuscitate) refusing CPR, refusing treatments, home care or hospice care as well as any specifics about how you want to be cared for. This can be completed working alongside your healthcare team; they will know the limitations of any requests and will help and support you.

This can also be completed via a Lasting Power of Attorney Health and Care form (see left).

AN ADVANCED DECISION

An advanced decision (AD) is basically your living will. It is a written statement of instructions about your medical care in the event that you cannot express them. You can include your wishes about healthcare, and what you do or don't want to happen. It can also be called an advanced statement/directive, in which case it only covers the refusals of medical treatments. In it, you can record your wishes, feelings, beliefs and values, and anything that you feel is important to your healthcare.

You must be 18 years old and have full capacity to make this decision.

An AD is a legally binding document, allowing your healthcare provider (HCP) to see your wishes and act upon them, so you need to be exceptionally clear what you want or do not want to happen to you, and include a statement if you are refusing any specific or life-saving treatments. This needs to be signed in front of a witness, who should also sign and date it.

PREFERRED PRIORITIES FOR CARE (PPCS)

A PPC enables you to let other people know your general preferences and priorities for your care at the end of your life. This isn't a legal document and therefore can be changed and adapted at any point.

This document will allow those who you love, as well as healthcare professionals, to see what is important to you in respect of your medical and social care: your beliefs and values, and where and how you want to be cared for in the final stage of your life. It will also include information and contact details of other people such as your next of kin, LPA, doctors and consultants. I feel that this is a must!

All these documents require you to have the mental capacity to make the statements or choices you are making.

THE EMOTIONAL SIDE

When you are told that you are going to die, so many emotions run through your mind: disbelief, denial, fear, anger. You will be in shock, wondering if you misheard, or haven't heard everything that was said. You will desperately play that conversation over and over again in your head.

The first moments when you wake up in the morning will be bliss, because for those few moments you won't remember. Then it will come rushing back into your mind. Your heart will ache. You may find it difficult to catch your breath. The realisation hits you like waves crashing on a beach.

SCREAM, SHOUT, LET IT ALL OUT!

Most people feel totally overwhelmed – that is a completely natural reaction. You are likely to feel a confusion of every emotion all at once – and who would blame you? You must let that emotion out. Cry, shout, scream, clench your fists, do whatever feel like doing but let it all out or it can become suffocating. Now is not the time to be thinking about the practicalities.

THE STAGES OF GRIEF

We are used to thinking about grieving for someone else but when we know we have only a short time left to live, we need to grieve for ourselves. There are five stages of grief that we have to work through as we come to terms with a terminal illness. You may find that other sources say there are more or fewer stages but they do not vary much in essence and this is what you might expect. You may experience them one after the other, or, more likely, a mixture of them at any moment.

1 Denial – It can't be true!

At this stage, you are going to overplay everything you are told. You are going to wonder if you misheard the consultant, got the facts wrong. Everything will be such a jumble in your brain, you may wonder why your head hasn't exploded.

Denial is the brain's way of filtering bits of information to your brain, almost trying to soften the blow of the devastating news you have had. This is a huge and natural part of facing up to what is happening to you.

Denial only becomes dangerous if you can't move on from here. We all have to face things that we dread in life and none is as frightening as facing your own death.

2 Anger – why me?

Anger is the second phase: anger about what is happening to you or how unfair it is to you and your family. Allow yourself to express your anger: scream, shout, cry, sob your heart out.

You may even start being angry at yourself for the lifestyle choices you have made but it is not helpful to blame yourself. Who cares about that cigarette you smoked behind the bike sheds – it doesn't change the situation in any way. All you are doing, by blaming yourself, is making it harder. It is the here and now that counts and what is going to happen to you.

We all make good and bad choices in our lives and that's how we learn and grow as human beings. We have to live with those choices so please don't beat yourself up. Remember, too, that anger is a natural human emotion and you can harness the power of anger to give you strength to carry on.

I went and stood at my favourite place, Petersfield Pond, and screamed as loudly as I could. I screamed more, and cried and cried. I cried for all the things I wouldn't be able to do or see: my son getting married, my yet-to-come grandchildren, growing old disgracefully with my husband. I grieved for the life I hadn't yet lived, as well as for the loved ones I would leave behind.

By the time I had finished, I was exhausted and emotionally drained. But, do you know what?, it felt good to acknowledge those feelings that I had buried deep down inside and had not dared mention to anyone else – even to myself.

3 Bargaining – for our lives!

Having worked through your anger, you may start bargaining for your life with your god, or any other higher power you believe in. You may ask god to spare your life if you do something good, or to give you more time if you swear that you will change your unhealthy lifestyle.

Bargaining is just a waste of time. The harsh truth is that you have to remind yourself that what will happen, will happen and there is nothing you can do to change it. The sooner you can get past this stage, the more time you will have for enjoying the rest of your life.

4 Depression – energy at zero

No one is bright and breezy all the time – whether they are living with a terminal diagnosis or not – and you are certainly more likely to feel flat and low at times. You have to be able to see both sides of the coin. To appreciate happiness, you must first experience sadness.

Dealing with depression is tough. You will give yourself a hard time over everything, even expressing the wish that you don't want to be part of this life, by which I don't mean suicidal, although it can get that severe. I mean, not having the energy or the inclination to do anything, seeing life revolve around you and being glad you aren't partaking in it. I call it the 'why bother, I am going to die anyway' attitude.

If you are experiencing any of the above, please go and seek help. There are people out there who can make you feel much better. Your first port of call would be your doctor, go and talk to them about how you are feeling. You do not have to go through this process alone.

I cried for all the things I wouldn't be able to do or see: my son getting married, my yet-to-come grandchildren, growing old disgracefully with my husband. I grieved for the life I hadn't yet lived, as well as for the loved ones I would leave behind.

Your doctor can arrange counselling or perhaps prescribe you an antidepressant in the short term.

There are also many organisations out there with people just waiting to help you, for example, the Samaritans and Macmillan. Fight Bladder Cancer has trained staff who will answer any worries or fears that you may have.

Hopefully once you have admitted to yourself that you aren't yourself right now, you can start to feel a little better.

5 Acceptance – I feel at peace

This final stage of grief is when you slowly reach the point at which you can come to terms with what's going to happen to you.

We are all very different and reach this point in our own way. Some people will gather all the information they think they will need to fully understand their situation, and others will be mindfully and blissfully unaware. (I think I am a bit of both really.)

When we think of the word 'acceptance', it implies that we happily accept our situation. In this case, I doubt if I know of anyone who has happily accepted that they are going to die. I do, however, think that there must come a time when we know what is going to happen and we are ok with that because we don't have any other choices. I also wonder if we accept our fate because it is so much easier than trying to fight it.

Living with dying

These five stages of grieving enable us to come to terms with a life-limiting illness. Just like our emotions, they won't all come neatly in order, one after another, or last a set length of time, or each be experienced just once. Every experience is unique.

I wouldn't wish living with dying upon anyone. It is immensely hard. But the one thing that I have taken out of this diagnosis is that being in control, as much as I can, helps to alleviate my fears; speaking about it ensures my wishes are known; and writing it all down helps to comfort me.

I am making memory boxes for the ones I love and writing letters to them; I have found this very emotional but very therapeutic. I never want them to forget just how much I love them and cherish them. The boxes are filled with my perfume, a jar filled with personal notes, things that will make them laugh and things that may make their heart ache. We have also glued all our photos from our days out 'making memories' into a scrap book (even though these days out are so hard). I try to live in moment as much as possible and try not to worry about the future. My life is simple.



Life is precious and we have so little time here, we really need to try to enjoy the moments we have. Value the small moments, the moments that we might easily dismiss as unimportant: your husband leaving a drink on your bedside table with paracetamol, in case you wake in the night; laughing so much with your best friend that your sides ache and you forget about the cancer. Don't waste a single one of those precious times.



BLADDER CANCER awareness month



Report Back and THANK YOU!

This year, the UK's **Bladder Cancer Awareness Month** in May was bigger and better than ever. Once again, you all did us proud and, here at Fight Bladder Cancer, we were just thrilled to work with all of you. We had great fun responding to your fabulous ideas for splashing orange all over the place! Your enthusiasm and dedication is so encouraging and we can't wait to work with you all again in May 2020. **THANK YOU** for collaborating with us and helping us to raise awareness. Together Wee are Stronger and we firmly believe that **WEE ARE FAMILY**.

Here is just a short summary of activities that took place in 2019. We are so sorry that we can't include everyone – but your messages, photos and social media likes, shares and retweets really do make a **MASSIVE** difference.

More materials than ever before!

This year we created special Bladder Cancer Awareness Month guides for both health professionals and individuals. We also designed and sold car stickers and pens and created special silk wrist bands – remember to keep your 2019 band as the first in a multi-coloured collection.

Making a global splash on social media!

Social media platforms continue to be a vital communication platform for charities to spread their messages and build relationships. During May 2019 Fight Bladder Cancer worked with the European Cancer Patient Coalition and the World Bladder Cancer Patient Coalition to combine our voices and get attention for bladder cancer. The UK was the top location and Fight Bladder Cancer had the most mentions (42% of all #BladderCancerAware mentions globally).

On Twitter, the hashtag **#BladderCancerAware** reached 2.6 million people.

Fabulous partnerships with hospitals!

We were thrilled to work with hospitals across the country and had 19 urology, oncology or research healthcare teams taking part in events and activities to mark the month, including

Addenbrooke's; Southampton General Hospital; Darent Valley Hospital; Portsmouth QA Hospital; Guy's Hospital; Farnham Hospital & Centre for Health; Eastbourne District General Hospital; Glan Cwyd Hospital; Stepping Hill; New Cross Hospital, Wolverhampton; Freeman Hospital Newcastle; Northwick Park Hospital; Hinchingsbrooke Hospital; Basingstoke Hospital; Brighton Hospital; University College London Hospital; Glasgow Beatson; Stoke Mandeville Hospital; Canterbury; Sheffield University Hospital; Chelmsford Broomfield Hospital; Lancashire Teaching Hospital, Preston; Corbett Hospital, Stourbridge; Broadgreen Hospital Liverpool.

Don't forget to get in touch with the Fight Bladder Cancer team if you have ideas for ways to raise awareness and raise urgently needed funds in May 2020.

We are pleased to announce that Eastbourne District General Hospital won our inaugural Urology Fundraisers of the Year award. Kelly Smith and Nicky Milton – in the picture here – were the outstanding ringleaders for their department. The team raised a stunning £1,822 from their orange antics during May! **THANK YOU** so much to everyone who contributed and also to those who worked so hard to support us by organising activities and events!



Eager involvement from Fight Club support groups!

Fight Club facilitators in eight of our support groups ensured that meetings took place during May, which meant that patients and carers could come together during our special awareness month.

Brilliant support from corporate partners!

We had eight corporate events taking place during May. These included pharmaceuticals who held awareness stands and a staff lunch-time learning about Bladder Cancer; healthcare device companies who held staff fundraising activities; and local companies in Oxfordshire, near our headquarters – who held an awareness Walk for Bladder Cancer. **THANKS** to you all for your time and dedication.



To date the combination of these fundraising and awareness events have raised over **£20,000** for the charity and we assure you that every penny helps us to grow and develop our work – in particular providing much-needed phone and email support to newly diagnosed patients every day. We really want to **THANK YOU!**



'As a recent member of the UK Fight Bladder Cancer team I was delighted and truly impressed to see such a groundswell of commitment to Bladder Cancer Awareness Month from our friends and supporters nationally. We really do look forward to building on this year on year – so that bladder cancer stops being a Cinderella cancer and becomes far better understood and supported in the UK! Thank you for working with us.'

Please call Emma and Sophie on **01844 351621** to share your ideas. Or email us at emma@fightbladdercancer.co.uk/sophie@fightbladdercancer.co.uk. We love to chat to our friends and supporters and are keen to hear your stories and help you develop ideas for Bladder Cancer Awareness Month in 2020.

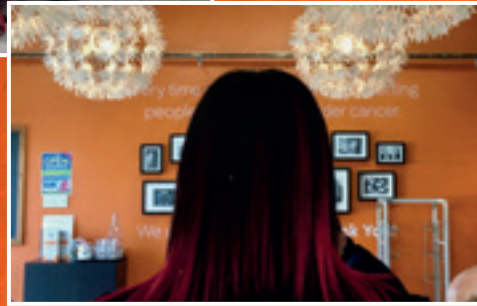


Multiple acts of generosity and fun orange events from patients, carers, friends and family!

We were excited to receive your news, stories and photos from multiple individual fundraising and awareness events organised across the UK. These ranged from 'wee walks' in Gibraltar to marathons in Edinburgh; barn dances in Yorkshire to football matches in Surrey. Too numerous to detail – we hope that a few of these photos capture your experiences and perhaps inspire you join us next year in 2020.

Events hosted by Fight Bladder Cancer.

As you know, we are just a small team but we worked hard in May 2019 to host our annual awareness walk in Chinnor, Oxfordshire, where our headquarters are to be found nestled into the Chiltern Hills. Well over 100 people arrived on Sunday 19 May to take part in blowing bubbles and our one-minute silence in solidarity for our absent friends and those experiencing bladder cancer around the world. The weather was good to us again and we stretched ourselves a little further this year with a four-mile walk, in addition to some shorter options. Kindly, our trustees Deb and Paul Major also hosted a walk along the promenade in Bournemouth and loads of fun was had there in the sunshine!



The Wee Bookshop & Café

If you haven't visited The Wee Bookshop and Café and you are within striking distance, you are missing a real treat – their Victoria Sponge is not the only delight on the menu! Go along to try out the great-value, home-produced food served by friendly staff in a unique environment.

Breakfast, brunch, lunch or tea are all available, surrounded by shelves of books to browse through. Plus there are special events held regularly, including singing, pottery and story-time sessions. And, of course, the knowledge that you are supporting such a worthwhile charity.

Having been open for four years now, they are number one locally on TripAdvisor.

Of course, there will be plenty of you who can't get along to the café itself, but there's no need to miss out now that you have our recipe for a perfect Victoria sponge. Why not invite your friends round to enjoy a slice with a cup of tea, or run a cake sale or even a Victoria sponge competition?

'Great coffee, food and second-hand bookshop, and all for a great cause'

Joe

'This little bookshop and cafe is a must visit. The service is excellent and speedy, with the friendly staff welcoming you with a smile. There is a great variety on offer from the menu, and the cakes are all homemade. I recommend this place for anyone wanting lunch or just a quick fuel stop! All profits go to patients fighting Bladder Cancer so it's all for a good cause too.'

Polly

'We stopped for lunch when travelling on M40. What a great find! Delicious food, fantastic coffee selection and top-notch homemade cakes. There's also a great display of second-hand books and we couldn't resist buying some. All profits go to a local cancer charity - a great reason to shop local!'

Kate

VICKY'S VICTORIA SPONGE

from the Wee Bookshop & Café



A staple of The Wee Bookshop & Café since day one, our classic Victoria Sponge is one of our best-selling cakes. It goes really well with tea and coffee – in fact, any drink!

Ingredients: (For 10 good slices)

200g caster sugar
200g butter, softened
4 eggs, beaten
200g self-raising flour
1 tsp baking powder
2 tbsp milk

For the filling

half a 340g jar good-quality strawberry or raspberry jam (we use MacKay's raspberry jam)
100g butter, softened
140g icing sugar, sifted
icing sugar, sifted, to decorate

- 1 Heat the oven to 190°C/fan 170°C/gas 5. Butter two 20cm sandwich tins and line with non-stick baking paper.
- 2 In a large bowl, beat together the caster sugar, softened butter, eggs, self-raising flour, baking powder and milk until you have a smooth, soft batter.
- 3 Divide the mixture between the prepared tins and smooth the surface with a spatula or the back of a spoon.
- 4 Bake for about 20 minutes until golden and the cake springs back when lightly pressed.
- 5 Turn onto a cooling rack and leave to cool completely.
- 6 To make the filling, beat the softened butter until smooth and creamy, then gradually beat in the sifted icing sugar.
- 7 Top one sponge with the jam. Spread the buttercream over the bottom of the second sponge, then sit it on top.
- 8 Dust with a little sifted icing sugar before serving. Keep in an airtight container and eat within 2 days.

The Wee Bookshop and Café is open 9am–5pm Monday to Saturday, 10am–4pm Sunday, serving breakfast, brunch, lunch (11.30am–2pm) and afternoon tea.

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For firefighter, Karla: 'My urostomy is my lifesaver.'



A former smoker and child of smokers, a firefighter with bladder issues from childhood, the chance of Karla contracting bladder cancer was higher than average

ARTICLE
KARLA STEVENSON,
FBC forum member

Hi, I'm Karla and I've been a firefighter for 19 years. I live with my wife Michelle, and my two-year-old child.

My bladder and I have always had a strained relationship. As a child, I suffered from frequent urinary tract infections (UTIs) and was even bullied by other children as a result of my bladder problems.

I spent a large part of my childhood living in a caravan with two smoking parents, so it was no surprise that, as a teen, I also took up smoking and smoked for about ten years.

I joined my local fire station as an on-call firefighter in the Scottish Highlands and, back then, it was almost seen as a badge of honour to be filthy after any incidents! I subsequently joined the full-time fire service and have now served in stations in Edinburgh, Glasgow and even Oban.

With hindsight, I had the right combination of markers to be diagnosed with bladder cancer, but I didn't know that at the time, and it didn't make it any easier to get diagnosed.

Early signs

I first went to my GP last September after I noticed blood in my urine.

I thought it was possibly another UTI and was told to go to the chemist where I had to complete a form to get antibiotics. The chemist then refused to give me antibiotics as I had blood in my urine and said I needed to go back to my GP. I went back to my GPs, filled out another form and left a urine sample and was told to expect a phone call. Later that day I was told a prescription had been left for me to pick up. I didn't even get to see a GP.

The antibiotics did not help, and I was still passing blood and blood



clots, although not constantly; it seemed to happen after I'd been active. My lower back started to hurt and eventually after two weeks and two more courses of antibiotics, I managed to get a GP appointment, when I was referred to urology.

Later that week, I passed a large amount of blood and was in a lot of pain, so I went to the out-of-hours GP, who phoned the on-call urologist. He told me not to worry as it was unlikely to be cancer due to my age, but to make sure my GP had done an urgent referral as nothing could be done without a scan and cystoscopy. This seemed more pressing, so I checked in with my GP the following day only to discover that she had made a general referral. In view of what the urologist had said, the GP surgery agreed to change the referral to urgent.

Two more weeks passed without news of an appointment, so I contacted my GP surgery to find out what was happening, only to discover that it had never been changed to urgent.

Finally I get some answers

I finally got a scan and cystoscopy two months after I originally went to my GP with blood in my urine.

They discovered a large tumour; it was cancer. By this point I was relieved to just get an answer!

My GP was shocked and apologetic. But I don't blame them for anything as on the balance of probabilities and the NICE guidelines, it was unlikely – although not unheard of – for women of my age to be diagnosed with bladder cancer. Awareness is key for patients and GPs – we all know early diagnosis saves lives!



Making choices

I had my trans urethral resection of bladder tumour (TURBT) in December, then three days before Christmas, my consultant called me in. It was T1G3 Transitional Cell Carcinoma (TCC). I had two choices – chemotherapy, radiotherapy and Bacillus Calmette-Guerin (BCG) treatment with a 60% chance of no recurrence over five years, or a radical cystectomy with an 85–90% chance of no recurrence over five years.

Without hesitation, I chose the cystectomy with the option of having an ileal conduit (urostomy).

As mentioned earlier, I didn't have the best relationship with my bladder and now it was trying to kill me! My pulse is way more important than my bladder. I'd done my homework and due to the high grade, the fact the tumour was only 1mm from my muscle layer and being mum to a two-year-old, I didn't feel like I had time to see if the chemo route worked. I didn't want to be ill with the side-effects for a long time, make my daughter worry, only for it to possibly fail and I would need the cystectomy anyway with the risk that the cancer had spread by then.

I chose to have a urostomy as I felt that it was the best fit for my lifestyle and that it was a less complicated operation, which would hopefully mean a quicker recovery.

Hospital risks

I had the cystectomy in February of this year. The operation was 10½ hours long and my bladder, uterus, cervix and all my pelvic lymph nodes were removed. But it all went well, and I was sitting up in bed in the High Dependency Unit (HDU) the next day eating sweet and sour pork!

Unfortunately, six days after my operation I contracted an infection in hospital which made me very ill. I lost two stone in weight and my spell in hospital was extended another two weeks. I was so weak, and my recovery was initially slow, but I set small goals, such as walking to the end of my street, to help things along.

I re-join the fight

During my recovery, with the invaluable help of Maggie's, the Beatson Charity, Fight Bladder Cancer and the Firefighters Charity, I returned to work in June on light duties and was given the all clear to return to full operational duties in August.

My urostomy has not stopped me living my life in any way but it does

take a bit of getting used to. In June I was key speaker at a Police and Fire Intersectionality conference where I also spoke about bladder cancer and life with a urostomy to 190 people – the first time I had ever spoken at a conference before. I am also hoping to visit the children's ward at my local hospital to meet children who have had or will be having stoma surgery.

The urostomy is an unfortunate reminder of the cancer and I'll always be looking over my shoulder, but I know that I have given myself the best chance and, if anything, the urostomy is a life saver.

I'd never heard of bladder cancer before my diagnosis but now I try to raise awareness and let people know that having a stoma is not the end of the world. There is hope and life after a bladder cancer diagnosis but catching it early is key. I'm so glad I persevered and listened to my body.



'Is it bad news?' ... 'No, it's good news!'

Richard discovers that the emotion of getting the all-clear can have more impact than the diagnosis!



You don't expect a digital prostate examination on what I thought was a normal Monday morning – but then that wasn't a normal Monday morning. At 63, generally fit and healthy, I hadn't been to my GP for years, but here I was in the waiting room, driven by a severe burning sensation when peeing.

I was fortunate enough to see a very proactive doctor who gave me a thorough examination – very thorough! A simple urine test showed microscopic traces of blood, invisible to the naked eye (haematuria). As a precaution I was given antibiotics in case it was just a urine infection, with an appointment to come back a few days later. But my symptoms had not changed by then so my doctor made an urgent referral to urology and I was seen within two weeks. Without the prompt action of my GP, this may have been a different story.

Over to the specialists

My first visit to urology was for an ultrasound scan, and afterwards I was given my folder of notes while I waited to see the doctor. I couldn't resist taking a look and reading the ultrasound report. One sentence stood out, 'Large hard mass on bladder wall'. Very scary, but even at that point, the thought of cancer did not enter my head.

The doctor confirmed that there was something so obvious on the ultrasound that there was no point in putting me through a cystoscopy but booked me in for an operation.

I waited several weeks for an appointment and carried on working, travelling around the country visiting clients. I was on one such visit when I went to the toilet for a pee and was horrified to see I was peeing pure blood. I phoned my boss and went home. I never went back to work

again as I later took the opportunity of early retirement.

My symptoms became worse and I began to suffer severe back pain, so I called the hospital again and they organised an urgent appointment.

Four days in hospital following a procedure under general anaesthetic called a TURBT (trans urethral resection of bladder tumour). The surgeon told me he had got it all. I naively thought that would be the end of it. I was allowed home when my pee stopped showing signs of blood, but I felt very fragile for a few days.

The 'c' word

A few weeks later, the bombshell dropped. At the follow-up appointment with my urologist, he sat me down and said the magic word: 'cancer'. This was the first time the word had been mentioned and it came as a complete shock. I was told my bladder needed to be removed, and then 'blah, blah, blah'. I didn't hear another word he said.

I received a summary letter a week later, and when you see things in black and white, that's when it really hits you. Muscle invasive and aggressive bladder cancer, T3pG3. Like many others, I consulted 'Dr' Google and things didn't look promising.

Testing, testing

A few more appointments followed by various CT and MRI scans, and then weeks later a further TURBT to tidy up

ARTICLE

RICHARD LYNCH,
FBC forum member

after the first. This time it took only several hours in day surgery.

More weeks of waiting and then an appointment with my consultant oncologist (who, it turned out, is regarded as one of the best in the field of bladder cancer). Following a multi-disciplinary team (MDT) meeting, I was given the option of bladder removal, or chemo-radiation and bladder preservation.

A tough choice

I did a lot of reading around the different options, joined several online communities and got first-hand reports from people who had similar decisions to make. Most of those given a choice – in some cases, it seemed people were not given an option – had gone for a radical cystectomy. I decided to try the other route and go for bladder preservation. I knew there would be risks whichever avenue I went down.

First chemo ...

My oncologist put me forward for a regimen of chemotherapy. Six weeks of gemcitabine and cisplatin. On a few occasions my bloods had not recovered enough, and so delays stretched my six weeks to eight. Fortunately, besides the odd queasy day, I didn't really suffer any ill effects. Even on the weeks when my blood counts were low, I still managed a few games of golf.

After a few weeks' rest, I had a PICC line fitted. No problems with this at all. More waiting and then back to hospital to have a chemo pump fitted to my line. Because the drug (5FU/MMC) was administered very slowly over a long period of time, side effects were minimal.

Then radio ...

Now on to radiotherapy – every weekday for six weeks. I had to travel to a different hospital for this, which was a 60-mile round trip daily. Many

thanks to the volunteer ambulance car drivers who transported me there and back each day. The treatment itself was painless and easy and I got into the daily routine. Again, no real noticeable side-effects from treatment besides some tiredness.

But it was after the treatment finished when the real fatigue set in. Although 'fatigue' is not quite the right word for it. Most people think of fatigue as having a long, hard day at work and coming home exhausted. Chemo-radio fatigue is on another level altogether. It feels like someone has stuck a pin in you and let all the air out. You feel yourself deflating, and have to curl up on the couch for several hours until it passes. Fortunately, this feeling gradually subsided as the weeks passed.

One thing about pelvic radiotherapy is the effect it can have on your bowels. Let's say, things happen suddenly. You get a two-minute warning and then you really have to go. This continued for a few months after treatment finished and I could not go anywhere without planning where the nearest toilets would be. Thankfully, things gradually got better.

Moving on, I had more tests and scans. A further rigid cystoscopy under general anaesthetic – just several hours in day surgery with few after-effects.

But things did get better

In March 2014, one year since my first GP visit, I had a follow-up appointment with my urologist for the latest test results. He sat me down and explained that the test results could not find any evidence of cancer. A word of warning here: being told you are clear of cancer can be more emotional than being told you have it in the first place.

Throughout my diagnosis and treatment, I had been very stoic and had taken everything on the chin.

I had always been prepared for bad news, but now I could feel tears welling up. I had to ask the doctor to repeat what he had said.

'It's gone,' he said. 'You are clear of cancer.'

Well, that was it. I burst out into uncontrollable sobbing and couldn't stop. A year of pent-up emotions came flooding out. The embarrassed doctor ushered me into a side room. A nurse came in and said, 'Sorry love, is it bad news?'. I managed a vaguely audible, 'No, it's good news!'

All clear

So now, over five years later, I am so far still clear. I am 68 and currently leading an active life with normal bladder and bowel functions. I'm enjoying my retirement. My dog keeps me active and makes sure I get up every morning. I have joined a gym to keep the old muscles active.

My wife and family have been towers of strength throughout all this and I give my sincere thanks to them and to all those who have looked after me over the past six years.

I have been monitored regularly with flexible cystoscopies and consultations with my oncologist. People still ask 'Are you cured?' I prefer to say, 'I am clear – at the moment.'



From fear and isolation to pride and joy

ARTICLE
KATIE FIRBANK,
FBC forum member

Discovering she had bladder cancer only after an early-pregnancy scan, Katie's wait for little Oscar's arrival was more than the usual roller-coaster.



Back before 2017 I had never heard of bladder cancer. I was too busy worrying about checking my boobs for lumps, booking in for a regular smear test and trying to get my five a day! – the things you're told to look out for as a 27-year-old-female.

Throughout most of my 20s, I was no stranger to UTIs; I seemed to have been battling them every couple of months for a few years. But it wasn't until July 2017 that I noticed an alarming amount of blood in my urine. Shocked and a little scared, I booked an appointment with my GP and was relieved to hear that this was just another UTI. Over the next few months I continued

to see blood in my urine every few weeks and each time I would go back to the doctors and be prescribed more antibiotics.

There has to be a better explanation

It was at this point that my fear and frustration got the better of me and that's when I first turned to Google for some answers. After typing in my symptoms, I watched in horror as page after page of bladder cancer search results came up. I was terrified. But I was young, female and a non-smoker, the exact opposite of what all the sites said were the main risk factors. At any rate, my doctors weren't worried and I was busy making the final preparations for our wedding in early November so I put everything to the back of my mind.

Fast forward a few months to January 2018. I'd been back to the doctor again, this time with painful stomach cramps and fatigue to go along with the blood that was still making regular appearances in my urine. He seemed to think all my symptoms could have something to do with endometriosis and warned us that we might struggle to have a family in the future. So imagine our surprise and delight when, in February we found out we were expecting our first baby! We were over the moon and excited to start the next chapter in our lives. Little did we know it was going to be a much bigger roller-coaster ride than we'd anticipated.

From high to low

The blood in my urine came back and now that I was pregnant that scared me more than it ever had before. We went back to the doctors and got referred for an early scan just to make sure everything was ok. It really was the most amazing feeling to see that tiny little heartbeat flashing away on the screen. We went back to the waiting room so relieved and excited.

Unfortunately our celebrations were short lived as we were called back into another room soon after. Neither of us could have predicted what was going to happen next. It was a bit like being hit with a sledge hammer as the doctor explained to us that the sonographer had found a large mass in my bladder during the scan. They couldn't confirm cancer at this stage but they weren't ruling it out either. Whatever it was they knew it shouldn't be there.

We left the hospital feeling totally shell-shocked and headed home to try and make sense of everything we had just heard.

The next few weeks were a blur of hospital appointments, scans and tests and I must confess



quite a lot of Google research. A cystoscopy at 10 weeks (pregnant) confirmed bladder cancer and I was told that surgery was the only option.

Isolated and alone

It's hard to explain the emotions that you go through when you are told you have cancer, let alone receiving that news during pregnancy. To say I felt isolated is an understatement and I can't tell you how many sleepless nights I spent searching all corners of the internet for someone who had been through the same thing as me. That's when I found the Fight Bladder Cancer forum, and reading other people's experiences has helped me no end. I also decided to write down my experiences in a blog as a way for me to process what was going on, but also just in case there was ever someone else out there in the world who was going through the same as me and felt just as alone.

What I do know is that when we were first told about the cancer I was so angry with myself. Angry that I had ignored what my body was trying to tell me and that I had carried on pretending everything was okay. By the time I knew what was going on, it wasn't just me that I had to think about; my actions were directly impacting on my unborn baby.

I feel so grateful

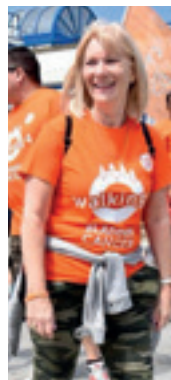
The second and overriding feeling that I feel every single day is gratitude. We are so incredibly lucky my cancer was discovered when it was still contained inside my bladder; that my baby and I were okay through the surgery and we now have a crazy little 10-month-old called Oscar to keep us on our toes. I am still going through treatment

because everything had to be put on hold until after the birth. I also know that I'll be having treatment for the rest of my life, but that's okay because I've learnt that life isn't about what you wish for, it's about what you have, and I know I can cope with anything as long as I have my two boys and my amazing family by my side.

Only you know your own body and what is normal for you. If something isn't right make sure you speak up and fight to get the treatment you need as soon as possible.



Now I *can* give something back



Susan Mullerworth's moving account of her personal battle against cancer that gave her the drive and determination to help other people.

ARTICLE
SUSAN MULLERWORTH
FBC forum member

In June this year I was asked by Fight Bladder Cancer to give a talk at the European Cancer Patient Coalition conference in Brussels. It raised very mixed feelings; I felt honoured but also saddened as I understood that our founder, Andrew, realised he would be unable to attend. The aim was to use my personal story to exemplify some of the issues met by so many bladder cancer patients. At first, I found it hard to start on my story but once I got underway, I found it very therapeutic, and I recommend that fellow cancer patients give it a go.

I am a survivor with a mission

I was diagnosed with stage 3 high-grade bladder cancer in November 2017 and I am now celebrating almost two years since my surgery.

Warning signs

I had not been in a good place either mentally or physically for some time. Personal and work issues had led to high levels of stress. I had a lot of responsibilities:

I was an end-of-life carer for my elderly mother and had a very demanding job. I worked long hours trying to keep everything going.

A colleague pointed out that I had appeared breathless after climbing a flight of stairs, even though I was physically fit. I noticed that I looked pallid but put that down to the fact that I was in my early 60s.

Initially I felt a few sharp twinges as I peed and thought it was cystitis, a common complaint, especially for women. As I was about to go on holiday, it didn't seem a priority so, rather than seeing my GP, I bought some cystitis powders and tried to treat it myself. During the holiday I felt the pain increasing but the most striking thing was that my energy levels were dropping rapidly. I never had visible blood in my pee.

At the end of August 2017, my doctor confirmed a UTI and I started on a course of antibiotics, then another, then another – none of them worked. Quite out of character, my energy levels continued to drop so that I really couldn't function. I was getting severe pain down below and had to pee frequently during the night. I was so exhausted. I knew something was wrong just when I needed to be well. Plus I was embarrassed to talk about my problems and felt very self-conscious.

In September, I was still going downhill, so my doctor organised a CT scan, which was excruciating as you must keep a full bladder. Soon after that, my GP confirmed a possible shadow on my bladder and referred me to urology for further investigations.

The European Cancer Patient Coalition (ECPC) is the voice of all cancer patients in Europe. With over 400 members, it is Europe's largest umbrella cancer patients' association, covering all EU member states and many other European and non-European countries. ECPC represents patients affected by all types of cancers, from the rarest to the most common.



It was early October by the time I went for a cystoscopy, and by then I felt so poorly I could barely walk to the consulting room. I explained exactly where I felt acute pain and described it as a 'gremlin' with its claws gripped inside me. I could feel the tumour. It was seated low down and causing dreadful vaginal pain. The urologist instantly spotted the tumour and took images. He then told me to contact a consultant urologist and get a biopsy organised as soon as possible.

Surely it can't be cancer

I was relieved that something was finally going to be done so although the cystoscopy was painful, it was quick. It wasn't until the paperwork arrived for the biopsy that my world started to collapse. The procedure was a TURBT (transurethral resection of a bladder tumour). As soon as I saw the word 'tumour', I thought, 'Surely it can't be cancer? Not me!' But I felt so ill that everything finally began to make sense.

I went in for the TURBT in mid October and stayed in hospital overnight with a catheter inserted. It was extremely painful and I felt so ill. The two weeks until the follow-up appointment seemed interminable. At the time I didn't appreciate the role of histology and pathology analysis and reporting, or the pressures on the health service.

Shaken, sad and alone ... but not for long

When I went for the results, I was quite blasé and in denial. I knew I was ill but I was still not admitting the real cause. The consultant was to the point: 'You're not very well are you?' Then he went straight in. 'I'm afraid it's bad news. It's cancer of the bladder.' My diagnosis was stage 3, high grade and I was given various treatment options. I felt shaken, sad and alone. Although I could have opted for BCG treatment or another TURBT to perhaps remove more of the tumour, I knew how ill I was. I remained in so much pain and because of where the tumour sat, I really knew my only option was life-changing surgery and a radical cystectomy. I informed my family of the diagnosis and everyone rallied round to support my road to recovery.

Acceptance is the hardest thing

Despite a lifetime of associations with other people's cancers – family members and friends – I have always been the carer, not the patient. And despite my knowledge of other cancers, I never

knew you could have your bladder removed. Acknowledging that I have succumbed to cancer has been one of the hardest parts of my battle.

But this was not the lowest point. When I went back to see the consultant and he described the detailed operation, things started becoming even more surreal. I was rapidly becoming knowledgeable in an area that I felt uncomfortable, intrusive and embarrassing. I found it very challenging and I had no time to absorb what my future held. I knew that I must put my house in order and be practical in case I didn't survive either the surgery or for how long afterwards?

What had caused my cancer?

Also, I was frantically trying to process exactly how I had got this cancer and started to research desperately. Could these factors have caused my cancer?

- I had a severe car accident many years ago and damaged my bladder.
- After childbirth I had a prolapsed bladder.
- I had dyed my hair for years.
- I had smoked briefly in my teens.
- Was it hereditary? I was unaware of any relatives who had been diagnosed.

I began to Fight and found I was not so alone

I was so lucky that my consultant put me in touch with Fight Bladder Cancer UK, and that I live near their HQ in Chinnor, Oxfordshire. I went on the FBC website and the next day I went straight to the offices. Immediately I felt safe and welcomed among people who understood. I met Andrew and we spoke in great detail about what was going to happen to me and how I needed to prepare. I had so many questions. Andrew became my mentor and gave me hope that you can survive.

I had an agonising wait for my operation. I wish it could have been done sooner but I now understand the challenges to assemble a team of medics and co-ordinate hospital facilities and an MDT (multi-disciplinary team).

In between, rather sadly, I also had to cope with an unfortunate and untimely set of personal circumstances. My sons informed me that their father, my ex-husband, had been found dead. My mother also passed away and therefore as a family we had two funerals to arrange swiftly, ahead of my surgery date.

On 27 November 2017 I had my radical cystectomy. For those not familiar with this procedure, it is a major operation, often involving the removal of other organs and lymph nodes as well as the bladder itself. In men, removing the entire bladder typically includes removal of the prostate and seminal vesicles. In women, it also involves removal of the uterus, ovaries and most of the vagina.

The operation and recovery processes are lengthy and complex, usually involving further hospital stays; and often numerous infections and challenging setbacks. I succumbed to sepsis, infections and painful bowel blockages.

During my recovery I have found it so hard to come to terms with anxiety and the acceptance of cancer. I wake everyday hoping that it has been a bad dream and yes – as so many cancer patients – wishing we could turn the clock back.

Were my lifestyle choices a contributory factor?

I strongly believe that aspects of my lifestyle contributed to my cancer diagnosis; basically, I didn't look after myself, putting myself under far too much stress and constantly rushing around.

I didn't have visible blood in my wee, but I didn't empty my bladder properly. I had also been an insomniac for several years and was taking prescribed sleeping tablets (Zopiclone, a strong benzodiazepine). They are known to cause bladder retention and therefore a build-up of chemicals, perhaps causing my UTIs and kidney infections. Research has also shown that prolonged use of Zopiclone may cause cancer (affecting the brain, lung, bowel, breast and bladder). This is documented on the Internet and I believe it to be factual. There are published papers written about Benzodiazepines but I want to call for further research into this theory.

What now?

I am now thankfully able to be relatively active and continue to do as much as possible, although I have to be mindful of my condition. I understand the need to keep fit, to eat healthily, to sleep and rest. I constantly have setbacks that require a visit to hospital, and I keep a supply of antibiotics.

My continuing daily challenge is to avoid setbacks. I desperately want to live, and I have so much to live for. I enjoy my life immensely. I get fed up with physical pain as some part of my body always hurts. My energy levels are depleted,

and I must rest and listen to my body. However, the mental pain and subsequent anxiety is just something else. I do have a very strong positive mental attitude, but people don't see what goes on inside the head of a cancer patient. The period after my operation was horrendous; everything is stripped from you. You have nothing, you're running on empty and you must FIGHT and FIGHT like hell to survive. I fully appreciate why patients may opt for BCG treatment, but I have no regrets. I am so thankful to be alive.

Back to life

Three months after my operation I returned to work, and I am determined to live my life as normally as possible, even with a stoma – a bag for life. I am truly indebted to all urologists and their teams who have made this solution to life and survival possible. But it is life-changing. I can't have anything reversed; and I can't even take the bag off other than for a quick change. It can fill up quickly and it can leak, so I must plan the day around facilities.

Specifically, with bladder cancer following a radical cystectomy, the challenge of resuming intimacy will test a relationship. Sexual dysfunction in both male and female survivors is common. Naturally sexual desire disappears as we lose hormones and the position of the tumour can determine closure of the vagina and, for men, erectile malfunction.

Outwardly I will tell you that I have a very positive mental attitude. However, inside I am so angry for what's happened to me. However, I **can** give something back and I **can** assist medical research, and that is the reason I am sharing my story with you.



Back in the saddle

Derek tells how his plans for retirement had to be put on hold – but only temporarily

ARTICLE
DEREK SILVESTER,
Bladder cancer survivor



Like so many other people, I looked forward to retiring at 70 and having time to carry on my hobbies of photography, cycling and fell walking in the Lakes. That turned out to be somewhat complacent.

In the summer of 2014, I noticed blood in my urine. At the time I thought I would just monitor the situation, but the blood returned intermittently. In August we went on holiday as everything seemed fine. But on our return, I found that I was going to the toilet to pass urine more frequently than usual. I made an appointment and went to see the doctor on the Monday, and he told me it was old age. By Thursday of the same week, though, I had quite a quantity of blood in my urine so I phoned my GP again and he arranged an appointment at the Westmoreland General Hospital the following week for a flexible cystoscopy. I then had an appointment to see the urologist, who explained what the problem was. It was obviously clear to him that we did not fully understand everything he was telling us, so he asked if we would like to see a Macmillan nurse, to which we agreed.

This was the first time cancer had been mentioned even by association.

Making difficult decisions

The Macmillan nurse explained my situation with the aid of an excellent booklet. I then had an appointment to see the oncologist at the Lancaster Hospital where I was told I had a Grade 3 aggressive bladder cancer. We went through the choices of the treatments involved and I was recommended to go and see the surgeon at Blackburn Hospital to discuss his views and see the right way forward for me. One way was to have the bladder and other parts completely removed. After serious consideration of all the facts, I decided on the second option: chemotherapy and radiotherapy.

Coping with treatment

During the chemotherapy and ongoing CT scans it was discovered I had blood clots around both lungs. My first follow-up cystoscopy had to be postponed for six months whilst I had Clexane injections every day at 6pm. At the final chemo session, I had a Hickman line fitted to my arm and into my chest – a way of delivering the necessary drugs – that stayed in for a week, combined with the radiotherapy. This was going to be repeated two weeks later but my white blood cells were very low so the chemotherapy was stopped at that point, and I carried on with 34 sessions of radiotherapy.

Throughout the chemotherapy, although at times it was gruelling, there were sufficient drugs to help combat any side-effects, plus the chemo nurses were always there at the end of the phone line with help and reassurance 24 hours a day. As for the radiotherapy, I found that quite

easy to deal with, the only side-effect being that it left me feeling really tired in the afternoon after each session, and I needed to go to bed for two to three hours.

The staff at the Preston Rosemere Centre, where I was treated, were very welcoming and easy to talk to. They always explained everything that was going to happen and took good care of me. After treatment I looked forward to coffee and cakes and a chat with the volunteers at the Rosemere café.

Always look on the bright side

We are a very positive family who always look on the bright side of life. After much deliberation I am pleased I went down the chemo and radiotherapy route as opposed to having my bladder removed. As you can probably imagine, it was a difficult decision, but it was the right one at that time, and I now have a fully functioning bladder, with no sign of cancer.

I am now 77 years old, fit, healthy and enjoying cycling again. I would like to thank my wife and family for their support throughout my battle with cancer. Also my very good friend Robin who helped transport me to Rosemere at Preston, which is an 80-mile round trip. Lastly I would like to thank Dr Alison Birtle, a trustee of Fight Bladder Cancer, for her excellent diagnosis and treatment, and her entire team for the way I was looked after; I could not have wished for anything better. I believe Dr Birtle's treatment saved my life.

FIGHT BLADDER CANCER

joins the advanced cancer movement

Fight Bladder Cancer is excited to announce that we have joined forces with a number of UK charities to become part of the Advanced Cancers Coalition (ACC). The coalition is focused on addressing the unmet needs of those living with advanced cancers and we look forward to being part of this important movement.

The Advanced Cancers Coalition is a coalition of UK cancer patient groups with a shared interest in delivering improvements in care for people with advanced cancer. After forming early last year, the group held three meetings in 2018 to agree their ambitions and discuss future plans.

Together, the Advanced Cancers Coalition aims to raise awareness of the unique needs of people living with advanced cancers in order to improve the level of care and support for this patient group.

ARTICLE
RICHARD COUSINS,
MHP Communications
ANNE MACDOWELL,
Corporate Partnerships FBC



What is the Advanced Cancers Coalition doing to help?

The Advanced Cancers Coalition mission is to raise awareness of the unique needs of those living with advanced cancer, in order to improve the level of care and support available to this patient group. We have produced several guides, including "A guide for talking about advanced cancer" and "Your rights, your choices: A guide for people living with advanced forms of cancer". The Advanced Cancers Coalition is also currently formulating plans that will aim to drive discussion in Parliament, raise the profile of this group and its unmet needs via the media, and build resources to support people living with advanced cancer.

Why has FBC joined the Advanced Cancers Coalition?

The landscape for advanced cancer patients is changing. Whilst treatment options were once very limited, there are now ways to live longer and manage the disease better. Data from England's national cancer registry, for example, has revealed that at least 17,000 people have lived for two years or more after being diagnosed with stage 4 cancer.¹ In addition, according to Cancer Research UK, 10% of people with stage 4 bladder cancer survive for five years or more after diagnosis.²

However, living for longer with an advanced stage of the disease often poses new challenges. In light of this, it has emerged that there is currently an imbalance of focus and support between those living with early stage cancers and those living with advanced cancers.³

The *No Patient Left Behind* report, which summarises the discussions of a round table attended by patient groups, shows the real effect these factors have on the quality of healthcare provision.³ For example, one discussion group raised concerns that those with advanced cancers were far less likely to have a clinical nurse specialist, whilst another noted that improvements in communication with healthcare professionals could help patients to feel better supported.

The report also highlights the lack of focus on the short-term needs of advanced cancer patients, embodied by NHS England's *Achieving World-Class Cancer Outcomes: Taking the strategy forward*⁴, which places an emphasis on recovery and long-term quality of life. In order to address this imbalance, the needs of advanced cancer patients must feature more prominently in the debates surrounding government policy.

DISCLAIMER

The meetings of the Advanced Cancers Coalition are funded by Roche Products Limited. The Secretariat for the Advanced Cancers Coalition is provided by MHP Communications, and Virgo Health supports the Advanced Cancers Coalition with their external communications, both of whose services are also paid for by Roche Products Limited. Members of the Advanced Cancers Coalition receive no payment from Roche Products Limited for attending meetings, except to cover appropriate travel costs.

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Fight Bladder Cancer in Scotland

Earlier this year, Lydia Makaroff (our CEO) and I visited Edinburgh and Glasgow to meet members of the Fight Bladder Cancer network in Scotland and learn about the experiences of patients, carers and healthcare professionals and to talk about the future of Fight Bladder Cancer in Scotland.

ARTICLE
AMY RANDALL,
FBC Research Lead



Maggie's centres

During our trip, we visited two Maggie's centres based in Edinburgh and Glasgow hospitals to provide emotional and psychological support for anyone affected by cancer. There are Maggie's centres across England, Scotland and Wales, all of which provide free practical, emotional and social support to people with cancer and their families; including bladder cancer support groups and individual counselling.

Our discussions covered all aspects of the bladder cancer experience, the challenges faced by support services and health care professionals and how Fight Bladder Cancer could further support their work in Scotland.

Support groups and social activities

Both patients and carers talked about the importance of support services, including Fight Bladder Cancer's Fight Clubs (face-to-face support groups) and our online forum. They felt it is important for people to have a space to ask questions and receive advice from people who have gone through something similar in an environment in which they feel comfortable.

However, they also highlighted the barriers to people engaging in support groups. It is often difficult for people to travel long distances to get to a support group, especially if they live in rural Scotland. It can also be hard for some people to talk about personal issues or feelings within a group setting.

Some people we spoke to said they did not want to attend social activities aimed solely at people with bladder cancer. A condition such as bladder cancer can have a major impact on identity and self-esteem. One person we spoke to said they did not want to attend support groups as they just 'want to feel normal'.

Some people noted that bladder cancer support-services are often

targeted at older men. As a result, women and younger people with bladder cancer can feel 'out of place' in support groups. They suggested developing some activities specifically for women or young people with bladder cancer and their families, in order to remind them that they are not alone.

Peer mentoring, such as our Bladder Buddies service, was also highlighted as a positive approach to providing support for both carers and people with bladder cancer, in order to provide a more flexible



approach to emotional and practical support – either on the phone or in person – from someone who has been through something similar.

Public awareness

Most people we spoke to were frustrated about the lack of public and GP awareness about bladder cancer and its symptoms. Most of them were unaware of bladder cancer before they were diagnosed and many were unfamiliar with the risk factors. One person we spoke to reported that their GP had told them there were 'too young for bladder cancer' before they were diagnosed. A lack of signposting was seen as a major barrier for people receiving the support they need, although there were different experiences of signposting. The crucial factor seemed to be that if key members of the clinical staff were advocates for support services, such as Fight Bladder Cancer and Maggie's Centres, then information was more readily available.

We met with doctors and nurses around Scotland, and encouraged them to tell their patients about all the

different kinds of support services that Fight Bladder Cancer can offer.

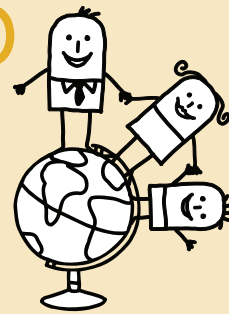
The commonality of experience was abundantly clear, and it was obvious to us that our meetings had laid the groundwork for more co-ordination and communication between Fight Bladder Cancer in England and Scotland.

We were also delighted to see our *Fight* magazine in many of the urology waiting rooms and Maggie's centres throughout Scotland. If you would like this magazine delivered to your local waiting room or Maggie's centre, please contact us at info@fightbladdercancer.co.uk.



Fundraising round up

September – November 2019

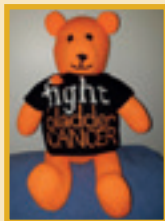


Personal donations and fundraising are the mainstays of the income here at Fight Bladder Cancer. We would not be able to do what we do to support people affected by bladder cancer – raise awareness, support research and campaign to get policy change at the highest level – without all of your help.

We are SO grateful and absolutely love working with you. We like to use this spot to feature some of your stories – it's not possible to include them all – but we also do our best to promote your activity on our Facebook page and send you lovely messages of thanks and support. If you don't hear from us, please pick up the phone to Emma and Sophie, or send them an email at fundraising@fightbladdercancer.co.uk. They also LOVE hearing your ideas, catching up and also getting your feedback. If you'd like us to feature your fundraising activity and send a big shout out to your supporters, please email fundraising@fightbladdercancer.co.uk.

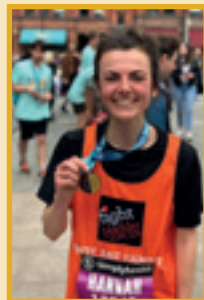


A massive thanks to **Kerry Michaels** and her boyfriend **Sam** who travelled 2,000 miles across Asia, raising awareness of the charity and raising just under £1,000! What a fantastic experience!



Long-standing supporter of the charity, **Ros Bruce**, organised another of her amazing teddy raffles to celebrate her eighth anniversary post-RC and raised a whopping £510!

Hannah Layland took part in the Great Manchester 10k race in support of her Dad, raising £420 for Fight Bladder Cancer.



Deb Wyatt and **Mark Burrell** have raised over £1,200 for the charity through competing in a number of marathons and organising the football shirt for one of our BCAM auctions – thank you!



Rachel Panther, dear friend of the **Nicol and Ray family**, completed a number of races for Fight Bladder Cancer and raised an amazing £1,031!



In memory of his best friend, **Andrew Lewis**, **Dean Howells** completed the Tour de Gwent, raising huge amounts of awareness in South Wales and £915 for the charity.



Liz and Neil Lewis walked 200 miles of the Camino de Santiago in northern Spain during May, raising both awareness and funds for the charity – £1,379!

Friend of Fight Bladder Cancer, **Rudy Ike**, took part in the Velo 100 in Birmingham and raised a brilliant £806 for us!



Bladder cancer patient **Susan** and her husband **Matt Mullerworth** joined us on the Wee Walk in Chinnor, raising over £830 for Fight Bladder Cancer through sponsorship!



Matthew Edwards and family organised the second year of the Brian Panton Bladder Cancer Cup and raised a wonderful £725 for the charity. He already has plans for the third year in 2020!

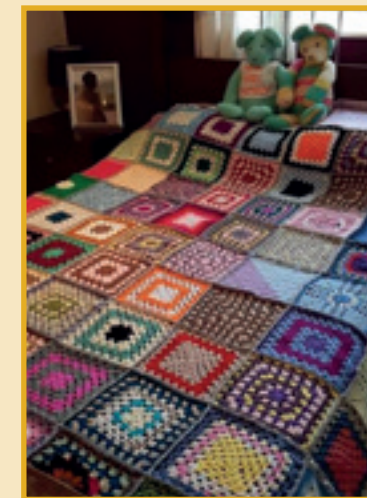


Richard Roberts walked to the top of the Gibraltar Rock on his Wee Walk for Fight Bladder Cancer, raising £413 for the cause!

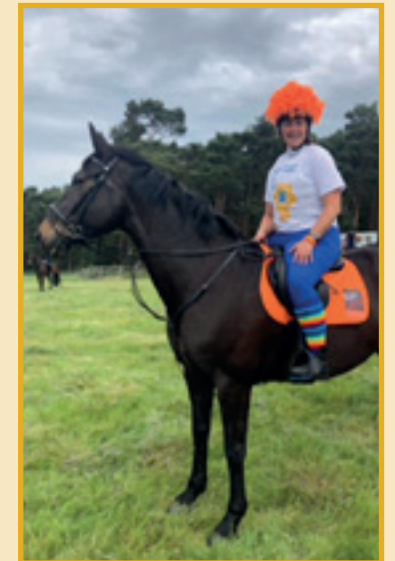
Melanie Askew organised a street sale outside her shop as part of Lostfest in Lostwithiel, Cornwall and raised an amazing £658!



Alison Crellin organised her band of merry knitters and crocheters to produce a number of beautiful blankets that were then raffled off – thank you for raising £660 for Fight Bladder Cancer!



Chris Illingworth and fiancé **Helen** organised a Barn Dance at his farm and so far have donated £2,300 as proceeds from this great evening.



Huge thanks to **Helen Bealby**, friend of **Chris Illingworth**, who organised the Osberton Charity Ride and raised over £2,200 for Fight Bladder Cancer.

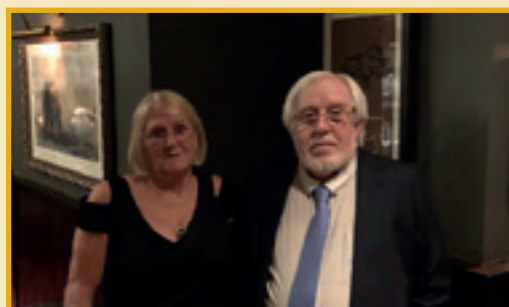
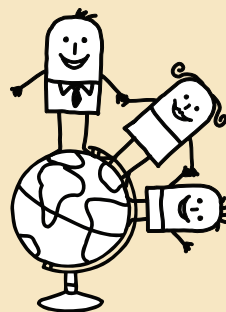


Christine Rooney organised a quiz night and supper in Castle Douglas and raised a fantastic £527 for Fight Bladder Cancer!

Alison Young and the **Stepford Singers** kindly chose Fight Bladder Cancer as the charity to support at their Summer Concert, raising both awareness and £519.



Dear friend of the late **Clive McGhie**, **Jim Burns**, cycled from London to Amsterdam proudly wearing his Fight Bladder Cancer top and raising more than £1,300 for the charity.

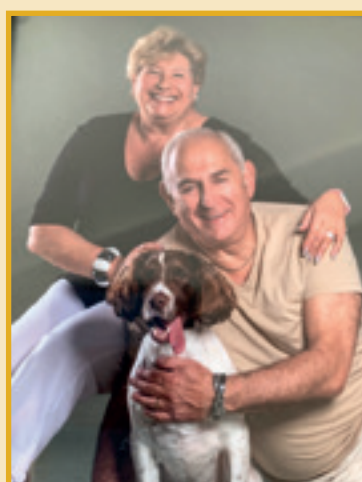


Thank you to **Sandra and Tony Massey** who asked friends and family to help them celebrate their 50th wedding anniversary by donating to Fight Bladder Cancer.



Massive thanks to **Vicki and Jim Thompson**, family and friends who organised a Clay Pigeon Shoot and a Table Top sale in Hawes. These two events, combined with donations from their local restaurant, The Board Inn, mean their fundraising exceeds £10,300!

Jan Southwell from St Albans & District Bowling Association proudly presented the charity with a cheque for £1,947 following their year of fundraising.



Dennis Vangeen asked that friends and family donated to Fight Bladder Cancer instead of presents for his 70th birthday in April and raised more than £1,100!



Many thanks to **Chris and Jen Marr** from Edinburgh who asked for donations to Fight Bladder Cancer, instead of gifts, at their wedding at Hearts Stadium in July.



We are incredibly grateful to the **Chinnor 1st Beavers group** for raising £374 for the charity from their sponsored readathon in February and March.

Raise some money & have some fun!

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

You can download our fundraising ideas booklets from our website

www.fightbladdercancer.co.uk/downloads



WHY WE NEED YOUR SUPPORT

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

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

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



Our fundraising promise to you

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

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

We can help you fundraise!

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

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

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

BladderPath study:

Re-designing the current diagnostic and management pathway for bladder cancer



ARTICLE

ANA HUGHES,
Senior Trial Co-ordinator, Cancer Research UK;
Clinical Trials Unit, Institute of Cancer and
Genomic Sciences; College of Medical and
Dental Sciences, University of Birmingham

We are still looking for better ways to diagnose bladder cancer. The last major improvement was a 'rapid diagnostic service for patients with haematuria' in Birmingham (UK) in 1994 – what we now generally know as 'haematuria clinic'. The launch of the European Association of Urology guidelines for bladder cancer in 2002 also united the approaches to the diagnosis and treatment of the disease, and likely contributing to improved outcomes through the dissemination of evidence-based best practice.

At present, all patients suspected of having bladder cancer in an outpatient haematuria clinic undergo transurethral resection of the suspected bladder tumour in the operating theatre some days or weeks later. Known as TURBT, this involves using a telescope or endoscope to remove the bladder tumour piece by piece, and was first described in 1910. However, in the 100+ years since then, there has been a technical revolution in diagnostic imaging – initially with CT scanning (the first patient scanned in Wimbledon in 1971), and then with MRI scanning (the first scans in Nottingham in 1976). Since then, CT and MRI have developed considerably with 'spiral' CT and 'multi-parametric' MRI.

For virtually every other human cancer, the diagnosis and staging of the disease is achieved by taking a small biopsy, or sample, of the suspected tumour followed by imaging the suspected tumour by ultrasound, CT or MRI scanning. And so why not apply this approach to bladder cancer?



What is the background of the study?

The treatment and outcomes for bladder cancer have not changed significantly in the last 30 years. The current standard therapy across the NHS and in most major centres worldwide for the initial assessment for bladder cancer involves a flexible cystoscopy, where the bladder is inspected by inserting a small cystoscope via the urethra. If a bladder tumour is seen, the patient then proceeds to removal of the tumour by TURBT.

The removed tumour is assessed to decide if it is confined to the bladder lining (non-muscle-invasive bladder cancer or NMIBC) or invading bladder muscle (muscle-invasive bladder cancer or MIBC).

For non-muscle-invasive bladder cancer, the TURBT should successfully remove all the tumour; nonetheless further drug treatment into the bladder is usually given to reduce the risk of recurrence.

For muscle-invasive bladder cancer, removal is generally incomplete and further treatment is required. This may involve cystectomy (to remove the bladder) or radiotherapy with or without chemotherapy.

A major concern with the current treatment pathway is that TURBT delays the definitive treatment for patients with muscle-invasive bladder cancer – in the UK the typical delay is over 100 days. TURBT may also spread tumour cells into tissues around the bladder or into the bloodstream. The prolonged nature of the pathway, and potentially unnecessary TURBT, may contribute to the comparatively poor outcomes seen with muscle-invasive bladder cancer.

Modern MRI approaches now have the ability to accurately stage bladder tumours and so the platforms already exist to improve patient pathways, potentially leading to improved outcomes.

The ideal pathway would therefore separate non-muscle-invasive bladder cancer from muscle-invasive bladder cancer early, with treatment tailored more appropriately and rapidly according to disease stage.

What are the study aims?

The aims of the BladderPath study are to evaluate whether it is possible to expedite definitive treatment for patients with muscle-invasive bladder cancer using an MRI scan rather than TURBT to diagnose and more accurately and rapidly stage their cancer. We hypothesise this may improve outcomes from muscle-invasive bladder cancer by reducing the time from diagnosis to definitive treatment.

Who can participate?

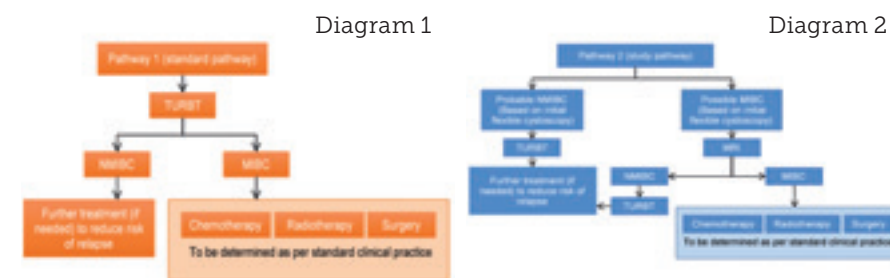
Patients aged 18 or over given a diagnosis of suspected bladder cancer.

What does the study involve?

Participants are randomly assigned 1:1 to be treated either by the current standard pathway (Diagram 1) or according to the research study pathway (Diagram 2).

- In the current standard pathway, TURBT removes most/the entire tumour and if the tumour is found to be muscle-invasive bladder cancer, then chemotherapy, radiotherapy or cystectomy will follow.
- In the research study pathway, patients with probable non-muscle-invasive bladder cancer will undergo TURBT in the usual way. Patients with possible muscle-invasive bladder cancer will have an MRI scan instead of TURBT to distinguish muscle-invasive bladder cancer from non-muscle-invasive bladder cancer; if the MRI shows non-muscle-invasive bladder cancer, then TURBT will follow as per the current standard pathway but if the MRI shows muscle-invasive bladder cancer, treatment with chemotherapy, radiotherapy or cystectomy will be started.

The time taken to receive definitive treatment (chemotherapy, radiotherapy or cystectomy) and the clinical progression-free survival after two years' follow-up will be measured in both groups.



What are the possible benefits of participating in this study?

There may be no immediate clinical benefit from taking part in this study. However, the information obtained from this study may result in changes in the future diagnosis, treatment and follow-up of patients with bladder cancer.

The purpose of the study is to find out if by using an MRI scan early in the management pathway, we can identify patients with disease invading the bladder muscle (MIBC) and move directly to definitive treatment without the need for a TURBT.

If the MRI scan correctly identifies the involvement of the muscle then there are two immediate advantages:

- Avoiding TURBT and the subsequent risks of this operation.
- The definitive cancer treatment could be given much sooner, meaning that the cancer will have less time to progress before treatment is given.

Where is the study run from?

Twelve centres around the UK will take part in this study. Currently the study is open at:

- Arrowe Park, Wirral
- Derriford Hospital, Plymouth
- Glan Clwyd Hospital, Rhyl
- Maelor Hospital, Wrexham
- Manchester Royal Infirmary
- Morriston Hospital, Swansea
- Northwick Park, London
- Nottingham University Hospitals
- Royal Oldham Hospital
- Sheffield Teaching Hospitals NHS Foundation Trust
- University Hospitals Birmingham NHS Foundation Trust
- University Hospitals Coventry & Warwickshire NHS Trust

When is the study starting and how long is it expected to run?

The first patient was recruited in June 2018 and we are expecting to reach the recruitment target of 950 patients by May 2021.

Who is organising and funding the study?

The study is sponsored by the University of Birmingham and is co-ordinated by the Cancer Research UK Clinical Trials Unit (CRCTU) at the University of Birmingham. The research is approved and funded by the National Institute for Health Research Health Technology Assessment programme (project number 14/08/60).

For further information please go to the study website: www.birmingham.ac.uk/research/activity/mds/trials/crctu/trials/Bladder-Path

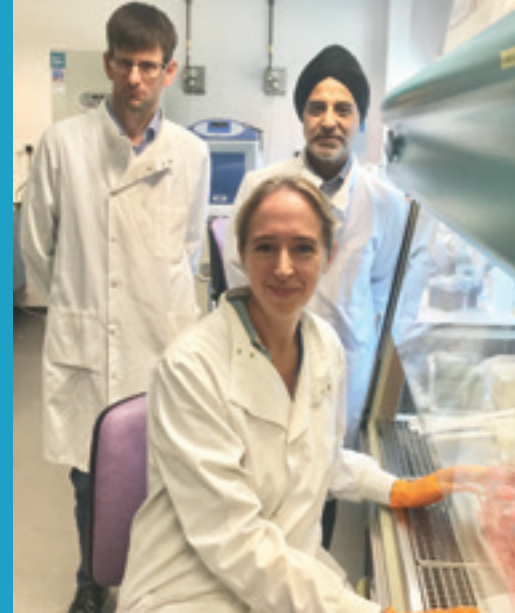
or e-mail the study office at bladderpath@trials.bham.ac.uk

HOPE

for a new treatment

New research suggests that a new kind of therapy using a specially selected virus could help those with non-muscle-invasive bladder cancer

ARTICLE
NICOLA ANNELS,
Senior Research Fellow,
Department of Clinical
and Experimental Medicine,
University of Surrey



While surgery, Bacillus Calmette-Guérin (BCG) therapy and chemotherapy can dramatically slow the progress of non-muscle-invasive bladder cancer (NMIBC), these treatments don't work for everyone. The recent CANON trial has demonstrated the potential of using a specially selected virus as a future treatment option for this kind of bladder cancer.

What are oncolytic viruses?

Cancer-killing (oncolytic) viruses are viruses that target, infect and kill cancer cells without harming the normal tissues. Because the normal protection mechanisms against viral infection are impaired in the majority of cancer cells, most viruses can infect and reproduce to a much greater extent in cancer cells than in normal cells. Eventually the infected tumour cell can no longer retain the multiple copies of the virus and the tumour cell bursts. The dying cancer cell releases materials, called tumour antigens, that allow the cancer to be recognised by the immune system.

A long lead time

As long ago as the 1800s, doctors observed that some cancer patients went into remission after a viral infection, and more recent developments in the field of cancer-killing virus therapy have demonstrated the important role the immune response plays in the outcome of this therapy. This was shown by the first cancer-killing virus to receive Food and Drugs Administration approval, talimogene laherparepvec (T-VEC), used as a treatment for melanoma. Injecting this genetically engineered cancer-killing herpes virus into skin tumours resulted in shrinkage or complete remission of tumours even in distant tumour sites that had not been injected, suggesting that not only can T-VEC activate the immune system locally, it also generates a

'memory' in the person's immune system to have an effect at distant, non-injected tumours.

The transfer to bladder cancer

The fact that the bladder is hollow means it provides an ideal environment for the administration of cancer-killing viral therapy. Local delivery to the isolated environment of the bladder can be achieved easily and directly via a catheter, allowing the tumour to be exposed to large doses of virus with complete control of the length of exposure and sequencing of repeat doses. It is also possible to use in combination with other treatments, such as BCG. An added benefit is that this can be accomplished with limited exposure to the rest of the body and consequent reduced toxicity.

University of Surrey research

In the CANON clinical trial led by our group of oncologists and scientists at the University of Surrey, UK, we studied the tolerability and safety of escalating doses of the cancer-killing virus, Coxsackievirus A21, a specially selected strain of the common cold virus. This virus binds to a molecule called ICAM-1 which is over-expressed on the surface of many human cancer cells, including bladder cancer. In this window-of-opportunity study, 16 people with untreated non-muscle-invasive bladder cancer received Coxsackievirus A21 alone or in combination with chemotherapy (mitomycin C) before undergoing their scheduled transurethral resection of bladder tumour (TURBT).

The trial allowed us to take photographs of the tumour inside the bladder before and after virus therapy. We saw evidence of anti-cancer activity in resected cancer, including one complete response in one of the three patients receiving the highest

dose of Coxsackievirus A21 alone. Tumour tissue samples obtained after surgery also confirmed that the virus was highly selective, targeting only the cancer cells and leaving all normal cells unharmed. Urine samples taken from patients on alternate days following virus administration detected 'shedding' from the virus, indicating that once virally infected cancer cells had died, the newly replicated virus continued to attack more cancerous cells in the organ.

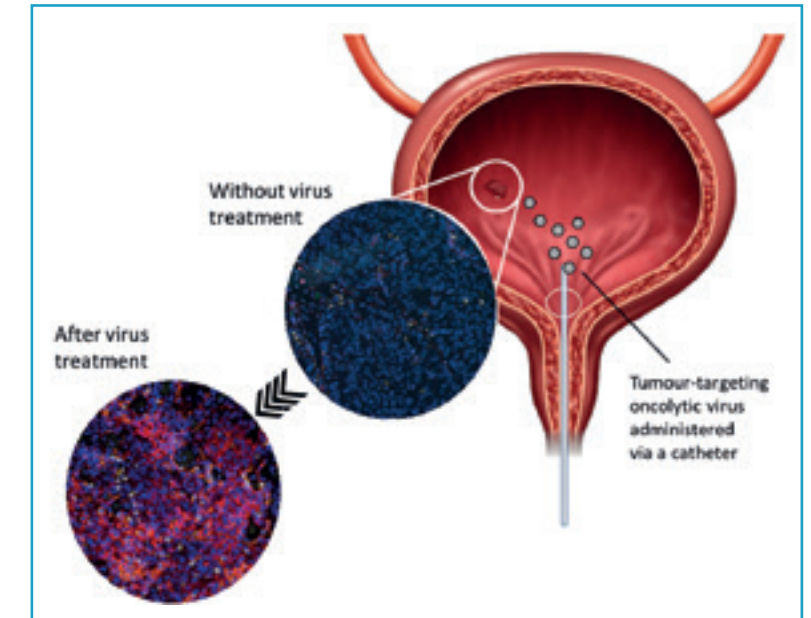
Fighting the cancer cells

One of the main aims of cancer-killing virus therapy is to stimulate a person's immune system to fight the cancer cells. This study showed that Coxsackievirus A21 was able to do this. By performing a detailed analysis of the immune cells within the virus-treated tumour tissue we took out of the bladder, we observed a high level of immune cells and immune markers within the bladder tumours. This finding was in contrast to untreated bladder tumours, which are generally known to have low levels of these immune cells. Thus the use of a virus to treat bladder cancer makes the cancer look foreign, triggering an immune response which wouldn't normally be activated by the tumour itself.

Importantly, we also observed an increase in the genes that can slow immune responses within the bladder tumours after the virus treatment. Whilst this might initially seem to be a negative side-effect of this type of treatment, the usefulness of cancer-killing virus therapy is expected to improve further when combined with immunotherapy drugs. The idea here is that treatment of a tumour with a virus will increase the number of immune cells, and then the immunotherapy drugs can work to keep the immune cells fighting the cancer.

Future potential

The CANON trial demonstrated the ability of a cancer-killing virus to reduce tumour burden in people with non-muscle-invasive bladder cancer. Intravesical Coxsackievirus A21 therapy was extremely well tolerated with minimal toxicity, and was highly tumour-selective. Cancer-killing viral therapy, alone or in combination with immunotherapy drugs, may one day offer an alternative to BCG therapy, but without its limiting toxicities.



The therapeutic administration of an oncolytic ('cancer-killing') virus into the bladder promotes a strong immune response in the tumour which will sensitise tumours to the therapeutic effects of immune checkpoint inhibitors.

How does it work?

The virus acts by seeking out and attaching itself to a protein that is highly expressed on the surface of many cancer cells. Once attached to this protein, the virus is then able to insert itself into the cancer cell, replicate, and burst the cancer cell apart, a process known as lysis. Thousands of viral progeny then can spread and replicate this cycle of destruction. During this process, tumour cell fragments are released, which can potentially activate the body's own immune system by identifying the cancerous tumour cells as foreign.

The results from the CANON clinical trial (CANON: CAVATAK in non-muscle invasive bladder cancer) were published in the medical journal *Clinical Cancer Research*, 4 July 2019 DOI:10.1158/1078-0432 and show the potential of oncolytic virus therapy as a future treatment option for bladder cancer.

Patient surveys

Discussions on a world stage



ARTICLE
JOSIE ELLIOTT,
FBC Volunteer Researcher

In early April 2019, I set off for the International Kidney Cancer Coalition 2019 Summit in Lisbon to share the conclusions of the World Bladder Cancer Survey we organised in 2018*.

We had already won the runner-up award for Best Patient/Public Poster at the Public Health England Cancer Services, Data and Outcomes conference in June 2018 for FBC, outlining the preliminary results of the survey, so it was exciting to share our experiences in an international setting with many patient advocacy groups – some of which had conducted their own surveys for kidney cancer.

Contributors to the conference came from many countries and interest groups: patient advocacy groups, researchers, clinicians, pharmaceutical companies and, of course, patients. The scope of the discussions was equally varied, from liquid biopsies and cutting-edge research for kidney cancer diagnoses, to how to run a successful global campaign. What a fantastic opportunity this was, not only for Fight Bladder Cancer to be recognised for their research in patient surveys at the international level, but also to learn from other patient advocacy groups – and I learnt a lot!

Why are patient surveys so important?

The only way to find out about patients' experience is to ask them, so patient surveys are absolutely crucial in determining the best way to provide optimum care and support for cancer patients. Via Menti.com, participants to the workshop submitted their opinions online. This is what they concluded.

Patient surveys are vital because they are a great way to:

- identify what is important to patients
- highlight gaps where support is needed
- understand the challenges faced by patients
- help to establish clinical initiatives and direct clinical research
- learn more about the community
- gain perspective on the situation as a whole
- provide important patient data within HTA submissions
- enable patients to have a voice and set the agenda for care and research
- provide feedback on improvements implemented or in discussion

My top tips from patient advocacy workshop

Here are the top tips I learnt from the discussions in the workshop I mediated.



1. Collaboration

Patient advocacy groups all share a common goal: to put the needs of patients first and give patients a voice. Patient surveys play a huge role in this both by providing a platform for patients to give feedback on their own diagnoses and treatment pathways, and also giving patient advocacy groups the data they need to take action based on these results. By collaborating with other national and international cancer patient groups, we can share what works well and what to avoid when conducting further patient surveys. Collaboration also offers an opportunity to reach more patients on a global scale and compare a wider range of responses.

2. Keep the survey short and relevant

Despite knowing their value, some cancer patients admitted that they felt pressured into completing too many patient surveys. This highlighted the need for surveys to be specific in what they address and not ask unnecessary questions that prolong the completion time. Overly-long surveys tend to be abandoned unfinished, leading to incomplete data that may not best represent the true nature of patients' experience.

3. Plan your timing

During the conference, one patient spoke about her own experience of being in remission from her cancer, but still having imaging every few years to confirm that the cancer was still in remission. It would take about two weeks to get the scan results and for those two weeks she felt all the anxieties and stress she had whilst her cancer was active, worrying and waiting to hear the results.

She felt that patients in remission might not want to complete patient surveys and be reminded of those difficult times. One way to target those people without creating additional stress would be to offer the survey while the patient is in the hospital awaiting their scan – perhaps on an iPad – at a time when their cancer would already be in the forefront of their mind.

4. Avoid medical jargon

A patient survey cannot be truly accurate if patients do not understand what is being asked of them, so the language should be clear and direct. Any medical language needs to be translated into text that anyone can understand. Only essential medical words should be included, followed by a brief explanation of what they mean.

5. Tailor the survey for each country to make it as accessible as possible

Surveys should be tailored to the needs of specific countries.

Different countries access surveys in a variety of ways so it is important to organise for the survey to be completed on the most common input device. For example, we were interested to learn how, in many low-income countries, like Ghana, most people consider a smart phone essential – indeed, some people go to university without a laptop, using just their mobile. Obviously, it's vital that any surveys can easily be completed on a smart phone.

In India, on the other hand, one delegate explained that cancer patients there rarely had internet access, so instead of doing an online survey, she set up more than 200 phone calls to interview patients. Although more time-consuming for the researcher, there are benefits to this form of interview as questions and answers can be clarified.

Making your survey as accessible as possible gives the best possible results, as it avoids biases in missing important participants. For example, if an older population is unable to access an online survey, you will miss a huge wealth of knowledge of this demographic.

6. Be careful with translations

Language is complex and fluid, so translations must be undertaken with the utmost care. A word, phrase or expression in one language does not necessarily translate exactly, as the International Kidney Cancer Coalition demonstrated when their final checks of their own survey, translated into Turkish, revealed that 'Turkey' the country had been translated as 'turkey' the bird. All surveys should be checked by a native speaker, and ideally undergo a pilot trial.

7. Take action

Once the results of a survey have been analysed and the outcomes determined, act on this data to campaign to make changes for the better! We have already seen the huge impact patient advocacy groups can have on policy through the 'Blood in Pee' campaign last year.

The work **Fight Bladder Cancer** is doing throughout the world is increasing our knowledge all the time so that we can expand our work in reaching out to people affected by bladder cancer and best serving their needs.

* in collaboration with the European Cancer Patient Coalition, the Norwegian Bladder Cancer Society (*Blærekreftforeningen*), the Italian Bladder Cancer Society (*Pazienti Liberi dalle Neoplasie Uroteliali*), Bladder Cancer Canada, Action Bladder Cancer, the Bladder Cancer Advocacy Network USA (BCAN), Bladder Cancer Support Group France (*Les Zuros*), the Hellenic Cancer Federation Greece (ELLOK), and the Association of Cancer Patients in Finland (*Suomen Syöpäpotilaat ry*).

NEW TREATMENTS for bladder cancer

ARTICLE
DR LYDIA MAKAROFF
FBC CEO

Exciting times as new treatments for bladder cancer show potential

There are quite a few exciting scientific discussions about new clinical trials of immunotherapy and targeted therapy drugs in bladder cancer.

Clinical trials usually go through three phases. Phase 1 studies are the first time that people receive the drug, and they look at the safety and side-effects. Phase 2 studies are the first to look at how well the drugs work. Phase 3 studies directly compare new drugs with existing treatments. A drug cannot be made available on the NHS until the phase 3 results have been released, and it has been authorised by the European Medicines Agency.

Immunotherapy drugs are synthetic antibodies which effectively 'alert' our immune system to cancer.

The European Medicines Agency has authorised three immunotherapy drugs to treat advanced bladder cancer: atezolizumab (Roche's Tecentriq), pembrolizumab (MSD's Keytruda) and nivolumab (BMS's Opdivo).

In England, there are two immunotherapy drugs on the NHS England Cancer Drugs Fund for bladder cancer – atezolizumab (Tecentriq) and pembrolizumab (Keytruda) – however, these drugs are currently only allowed to be used in people with advanced bladder cancer after they have tried chemotherapy, or if they are not healthy enough to have chemotherapy.

In Wales and Northern Ireland, pembrolizumab (Keytruda) and atezolizumab (Tecentriq) are also available, but also currently only allowed for people with advanced bladder cancer after they have tried chemotherapy, or if they are not healthy enough to have chemotherapy.

In Scotland, pembrolizumab (Keytruda) and atezolizumab (Tecentriq) are available under the NHS, but only for people with advanced bladder cancer after they have tried chemotherapy. It is not available for people if they are not healthy enough to have chemotherapy in the first place.

Targeted therapies are drugs that block the growth of cancers by acting on specific proteins in cancer cells.

There are currently no targeted therapies authorised by the European Medicines Agency for bladder cancer.



Immunotherapy and chemotherapy in people with advanced bladder cancer who had not previously been given chemotherapy

Combining traditional chemotherapy with an immunotherapy drug called atezolizumab (Tecentriq) increased survival by several months in advanced bladder cancer patients in the phase 3 IMvigor130 study. The cancer shrunk or disappeared in 47% of patients, and the signs of cancer disappeared completely in 12% of patients. This is the first positive study testing a chemotherapy-immunotherapy combination in people with advanced bladder cancer who had not previously been given chemotherapy.

If immunotherapy can be used sooner, at the same time as chemotherapy, then this could mean that many advanced bladder cancer patients live longer and healthier lives.

Immunotherapy in people with non-muscle-invasive cancer in people who had tried BCG

The phase 2 KEYNOTE-057 study looked at using pembrolizumab (Keytruda) in people with non-muscle invasive cancer in people who had tried BCG.

102 patients were tested, and the cancer shrunk or disappeared in 42 people. After two years of treatment, 19 people still had no signs of cancer or cancer that had shrunk. No one developed muscle-invasive or metastatic disease while receiving the treatment. We will have to wait a few more years to see how this treatment works in the long term, but the initial results are very exciting.

Immunotherapy in people before bladder removal

Giving pembrolizumab (Keytruda) to people with muscle-invasive bladder cancer before their radical cystectomy (bladder removal) was associated with complete response (disappearance of all signs of cancer) in 42% of patients in the phase 2 PURE-01 study. Similar results were seen with atezolizumab (Tecentriq) in the phase 2 ABACUS study.

Targeted therapy for advanced FGFR bladder cancer

A recent phase 2 study looked at giving a new drug called erdafitinib to people who had advanced bladder cancer, who were positive for the FGFR test, and who had previously been treated with chemotherapy. The cancer shrunk or disappeared in 40% of people.

Targeted therapy and immunotherapy in people with advanced bladder cancer who were not healthy enough to receive chemotherapy

The phase 1 EV-103 study looked at giving a new drug called enfortumab vedotin together with pembrolizumab (Keytruda) to people with advanced bladder cancer who were not healthy enough to receive chemotherapy. The cancer shrunk or disappeared in 71% of patients. These are very early results, but very promising.

TREATMENT AND RESEARCH GLOSSARY

Atezolizumab (Tecentriq): An immunotherapy drug approved to treat some kinds of cancer. Currently only allowed to be used in people with advanced bladder cancer after they have tried chemotherapy, or if they are not healthy enough to have chemotherapy.

Combination treatment: Two or more types of treatment given at the same time.

Enfortumab vedotin: A targeted therapy drug currently being tested. It is not yet authorised by the European Medicines Agency for bladder cancer treatment, but is available in clinical trials in the UK.

Erdafitinib: A targeted therapy drug currently being tested. It is not yet authorised by the European Medicines Agency for bladder cancer treatment, but is available in clinical trials in the UK.

European Medicines Agency: The agency that is responsible for ensuring that all medicines within the European Union are high quality, safe and effective.

FGFR test: Laboratory test to see if the drug erdafitinib is likely to work.

Immunotherapy: Drugs that increase the ability of our own body's white blood cells to fight cancer. Immuno-oncology drugs can help keep cancer cells from hiding from the body's white blood cells.

Muscle-invasive bladder cancer: Cancer that has spread from the lining to the muscles of the bladder.

Nivolumab: An immunotherapy drug approved to treat some kinds of cancer. Approved in Europe for locally advanced or metastatic bladder cancer following prior chemotherapy, but not available on the NHS.

Non-muscle-invasive bladder cancer: Cancer that has not spread from the lining to the muscles of the bladder.

PD-L1 test: Laboratory test to see if the drugs atezolizumab or pembrolizumab are likely to work.

Pembrolizumab (Keytruda): An immuno-oncology drug approved to treat some kinds of cancer. Currently only allowed to be used in people with advanced bladder cancer after they have tried chemotherapy, or if they are not healthy enough to have chemotherapy.

Targeted therapy: Drugs that block the growth of cancers by acting on specific proteins in cancer cells.

Tumours: Abnormal masses of tissue that result when cells divide more than they should or do not die when they should. Tumours may be benign (not cancer) or malignant (cancer).

UK bladder cancer clinical trials

For more information about all current bladder cancer trials head to Cancer Research UK's dedicated portal at www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/. There you will find further information about the studies and which hospitals are taking part.

Suspected bladder cancer

IDENTIFY

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

ClinicalTrials.gov ID: NCT03548688

Newly detected or recurrent bladder cancer

ANTICIPATE X

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

ClinicalTrials.gov ID: NCT03664258

Non-invasive bladder cancer

PemBla

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

ClinicalTrials.gov ID: NCT03167151

POTOMAC

This study is for people with non-muscle-invasive bladder cancer. Patients will receive BCG treatment, with the possible addition of durvalumab. This is a study looking at how well durvalumab works in people with non-muscle invasive bladder cancer.

ClinicalTrials.gov ID: NCT03528694

CheckMate 9UT

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

ClinicalTrials.gov ID: NCT03519256

NCT03091764

This project will develop and evaluate a patient-reported symptom index to assess the impact of treatment for non-muscle invasive bladder cancer on patient burden, toxicity, symptoms and side-effects. The symptom index will provide a method for assessing treatments from the patients' perspective; help healthcare professionals make better informed treatment decisions, and provide a method to be able to effectively evaluate treatments for non-muscle invasive bladder cancer.

ClinicalTrials.gov ID: NCT03091764

iROC

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

ClinicalTrials.gov ID: NCT03049410

Advanced or metastatic bladder cancer

BladderPath

This study is to redesign the management pathway for patients with muscle-invasive bladder cancer by using an MRI scan rather than doing a transurethral resection of a bladder tumour (TURBT), to diagnose

and more accurately and rapidly stage their cancer. We hypothesise this may improve outcomes for these patients by reducing the time from diagnosis to definitive treatment. isrctn.com International Standard Randomised Controlled Trial Number: ISRCTN35296862

NCT02516241

This study is for people who have inoperable advanced or metastatic bladder cancer. Patients will receive chemotherapy, with the possible addition of the drugs durvalumab and/or tremelimumab. This is a study looking at how well these drugs work in people with bladder cancer.

ClinicalTrials.gov ID: NCT02516241

PIVOT-02

This study is for people who have advanced or metastatic bladder cancer. Patients will receive drugs called nivolumab and NKTR-214, and perhaps another drug called ipilimumab. This is an early study looking at the safety and ideal doses of the drugs.

ClinicalTrials.gov ID: NCT02983045

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

EV-301

This study is for people who have locally advanced or metastatic bladder cancer. Patients will receive either chemotherapy (docetaxel, vinflunine or paclitaxel), or a new drug called enfortumab vedotin. This is a study looking at how well this drug works in people with bladder cancer.

ClinicalTrials.gov ID: NCT03474107



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

RAIDER

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

ClinicalTrials.gov ID: NCT02447549

NCT02599324

This is a study for people with advanced bladder cancer. Patients will receive chemotherapy (paclitaxel), along with a new drug called pemigatinib. This is a very early study looking at the safety of the drug and what is the ideal dose.

ClinicalTrials.gov ID: NCT02599324

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 JNJ-63723283, as well as to test their safety and how well they work.

ClinicalTrials.gov ID: NCT03473743

NCT03390504

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

ClinicalTrials.gov ID: NCT03390504

FIGHT-201

This is a study for people with metastatic or inoperable bladder cancer who test positive for one of the FGF/FGFR biomarkers. Patients will receive a drug called pemigatinib. This is a very early study looking at the safety and ideal dose of the drug.

ClinicalTrials.gov ID: NCT02872714

CheckMate 274

This is a study for people who have had their bladders removed after being diagnosed with bladder cancer, and who have a high risk of the cancer returning. Patients receive standard follow-up care, with the possible addition of a drug called nivolumab.

ClinicalTrials.gov ID: NCT02632409

JAVELIN Medley

This is a study for people with locally advanced or metastatic bladder cancer. Patients receive a drug called avelumab, with the possible addition of the drugs PF-04518600, PD 0360324, or PF-05082566 + PF-04518600. This is a study looking at how well these drugs work to treat people with bladder cancer.

ClinicalTrials.gov ID: NCT02554812

NCT03317496

This is a study for people with locally advanced or metastatic bladder cancer. Patients receive best supportive care with the addition of a drug called avelumab. This is a study looking at the safety of avelumab, as well as how well avelumab works to treat people with bladder cancer.

ClinicalTrials.gov ID: NCT03317496

NCT03523572

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

ClinicalTrials.gov ID: NCT03523572

NCT03955913

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: NCT03955913

NCT03782207

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

ClinicalTrials.gov ID: NCT03782207

MORPHEUS mUC

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

ClinicalTrials.gov ID: NCT03869190

NCT03096054

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

ClinicalTrials.gov ID: NCT03096054

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

FBC glossary

ACC Advanced Cancer Coalition

adjuvant after initial treatment to prevent secondary tumours

angiogenesis the development of a blood supply to a tumour

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

antiemetic a drug to counteract nausea and vomiting

B-cell response a natural immune response

basal relating to the base

baseline starting point for comparison

BAUN British Association of Urological Nurses

BAUS British Association of Urological Surgeons

BC bladder cancer

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

BCQS Bladder Cancer Quality Standards

biomarker something by which the disease can be identified

biopsy a sample of tissue taken for examination

BLC blue light cystoscopy

BPH benign prostate hyperplasia

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

carcinogenic cancer-causing

carcinoma malignant growth or tumour

catheter a thin tube

CCG clinical commissioning groups

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

chemoradiation combination treatment of drugs and x-rays

chemotherapy treatment with drugs

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

duration 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

endoscopic an illuminated tubular device used to look inside the organs

enhanced recovery pathways methods of improving recovery times and experience

eosinophils a leukocyte or blood cell lacking haemoglobin

ER enhanced recovery

expressed active

FDA Food and Drugs Administration (US)

FGFR fibroblast growth factor receptor

fMRI functional magnetic resonance imaging

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 treatment using the body's immune responses, also called immune oncology therapy

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

intolerable toxicity the point at which the treatment becomes more painful 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 the bladder

lymph nodes small glands that store the white blood cells that help to fight disease and infection

lymphangiogenic originating in the lymphatic system

macrophages specialist cells in the blood vessel walls

MDT multi-disciplinary team

metaplasia conversion from normal to abnormal tissue

metastatic a cancer that has spread to an unrelated organ

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 from the lining to the muscles of the bladder

mutagenic an agent that changes genetic material

MVAC chemotherapy treatment involving methotrexate, vinblastin, doxorubicin and cisplatin

narrow band imaging imaging enhancement to aid diagnosis during a cystoscopy

NCRAS National Cancer Registration and Analysis Service

NCRI National Cancer Research Institute

NED no evidence of disease

neoadjuvant chemotherapy chemotherapy given before surgery

neoantigens newly formed cells not recognised by the immune system

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

PDE5 inhibitors drugs that block the negative action of chemicals in the muscles that prevent blood flow

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

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 cytology

PHR patient-held record

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

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

polyuria frequency of urination

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 feverish

QoL quality of life

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

radiotherapy treatment with radiation

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

RCTs randomised control trials

refractory resistant

resection surgical removal

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

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

squamous scaly

stoma an artificial opening from the bladder (or other organ)

surrogate markers a reliable substitute for the disease

T-cell a cell that can attack a cancer cell

tachycardia abnormally fast heart rate

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 microenvironment the cellular environment in which the tumour exists

TURBT transurethral resection of bladder cancer: a surgical removal 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, or artificial opening for the bladder (or other organs)

urothelial of the urinary tract

UTI urinary tract infection

visceral of the nervous system

WBCPC World Bladder Cancer Patient Coalition

You can help us fight bladder cancer!



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

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

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

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

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

Darren Roberts, aged 50

Main bladder cancer drugs

These are the generic drug names you are most likely to encounter, with some of their most common brand names.

alprostadil Vitaros®

atezolizumab Tecentriq®

avanafil Spedra®

avelumab

AZD1775

AZD4547

AZD9150

BMS-096205

cabazitaxel Jevtana®

cabozantinib

carboplatin Paraplatin®

cavaject

cisplatin

docetaxel

doxorubicin Adriamycin®

durvalumab

enfortumab vedotin

erdafitinib

evalumab

finasteride

gemcitabine Gemzar®

Ibhibizone™

ipilimumab

JNJ-63723283

MED14736

methotrexate Maxtrex®

minocycline

mitomycin Mitomycin C Kyowa®

NKTR-214

nintendanib

nivolumab Opdivo®

olaparib Lynparza®

paclitaxel Taxol®

PD-0360324

pembrolizumab Keytruda®

pemigatinib

PF-04518600

PF-04518600,

PF-05082566

rifampin

RO7198457

rogaratinib

selumetinib

sildenafil Viagra®

SRA737

tadalafil Cialis®

tremelimumab

varafenafil Levitra®

vinblastine Velbe®

vinflunine

vistusertib

vofatamab

Bladder cancer grading & staging

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

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

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

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

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

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

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

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

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

INTUITIVE.

What's right for my fight?

Understand your options

If you and your doctor decide that surgery is right for you, be sure to ask about all of your options.

Skilled robotic-assisted keyhole surgeons offer patients a minimally invasive surgical approach that may be right for your fight.



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

fightbladdercancer.co.uk