

fight

MAGAZINE

A DAY IN THE LIFE

WHAT IT'S REALLY LIKE
TO BE PART OF YOUR
HEALTHCARE TEAM

WHAT YOU DON'T SEE

THE CRUCIAL
ROLES OF
SUPPORTING
STAFF

SURROUNDED BY LOVE

FINDING YOUR
WEE FAMILY



**FOCUS ON
YOUR MULTI-
DISCIPLINARY TEAM**
HOW THEY WORK
TOGETHER TO
GIVE YOU THE
BEST CARE

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Amy Jacob

Andrew Younger

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



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

Please pass on this magazine if it is no longer required, via your Urology/GPs waiting room! Many thanks.

This magazine is not intended as a substitute for the medical advice of doctors. Readers should consult their medical team in relation to their treatment.

Working to Fight Bladder Cancer

Welcome to the 12th edition of our *FIGHT* magazine.

People affected by bladder cancer need to know that they are not alone. This edition is dedicated to all the healthcare professionals who will help you in your fight.

People with bladder cancer are cared for by a team of healthcare professionals, each with their own expertise. This is often known as a multi-disciplinary team (MDT). These specialists work together to make decisions about the best way to proceed with your treatment and are there to ensure you achieve the best quality of life during treatment and afterwards. We are so thankful to all the healthcare professionals who have shared their stories with us, so you can get to know them better.

Remember that you are the most important part of your healthcare team. To get the best out of them, we encourage you and your family members to be actively involved in your own treatment and care.

We know that the ongoing effect of the pandemic is adding additional stress to an already challenging time of your lives. Fight Bladder Cancer is here to help you every step of the way. We offer free individual telephone, email and Facebook Messenger support. Our private online support forum is open 24 hours a day, and our regular Zoom support groups mean that you can share stories with other patients and carers.

Despite the challenges of the pandemic, we are delighted to be about to share with you our stories from Bladder Cancer Awareness Month, as well as some amazing fundraising and campaigning activity that continues throughout the year for Fight Bladder Cancer.

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

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

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

SUPPORT

Supporting all those affected by bladder cancer

AWARENESS

Raising awareness of the disease so it can be caught early

RESEARCH

Campaigning for and supporting research into this disease

CHANGE

Affecting policy at the highest levels to bring about change



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

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

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



fightbladdercancer.co.uk

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FBC round up

Find out what has been happening at Fight Bladder Cancer

SUPPORT



ONLINE FORUM

Our **online private forum** now has 5,187 members, and is supervised by admin and 10 moderators from around the globe 24 hours a day, seven days a week. In the past month we've had 381 posts and over 18,000 comments and reactions. Currently the most popular time for interaction on our forum is after dinner on Tuesdays.

'Welcome to this wonderful group. There will always be someone here to answer any questions you might have.' *Carol*

TELEPHONE & EMAIL SUPPORT

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

'Thank you so much for your informative reply. I've contacted quite a few places and nobody has taken the time to reply with all the helpful info as you have.' *Karen*

ZOOM SUPPORT

We now host monthly Zoom support groups. This has given us an opportunity to be in touch with people like never before. Our new virtual meetings can be attended by people from places such as Portsmouth, Yorkshire, Scotland – all at the same time. We are therefore able to offer an enhanced sense of humanity and community. Past topics have included a *Chat About Non-Muscle Invasive Bladder Cancer* with nurse Ann Moore, *Let's Talk About BCG* with Mr Hugh Mostafid, and *Springtime Activities*. For information about future Zoom support groups see our website at fightbladdercancer.co.uk or contact us at support@fightbladdercancer.co.uk

'Another great zoom session last night. It is so good to be able to see and chat about things. Well done again – good format as always. Have a great day all and Keep Fighting all.' *David*

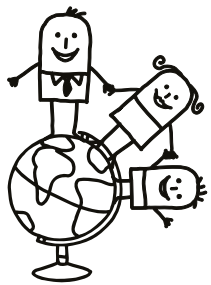
WEBSITE

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

'I wish my doctor had given me this information when she first told me that they thought I had cancer. I was on my own at the time. I had to find the Fight Bladder Cancer website myself. It has really helped both myself and my adult children with the diagnosis. I felt more confident asking questions during the cystoscopy after reading the articles on diagnostic procedures.' *Jane*

FREE FIGHT MAGAZINE

We are now offering a **digital version** of the *Fight* magazine, as well as **free posting of this magazine directly to patients, carers and health professionals throughout the UK**. We delivered the last edition to over 1,200 households. To sign up for your free digital or physical copy, please visit: fightbladdercancer.co.uk/contact-preferences



Melanie Costin



CONTACT CARDS

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



PATIENT INFORMATION BOOKLETS

Our series of **Patient Information Booklets** has been sent out to hundreds of health professionals and patients around the UK. These booklets, produced by Fight Bladder Cancer, are unique because they are large-print, full colour, full of photos of real-life survivors, endorsed by medical professionals, and filled with handy tips from others who have gone through the same journey. Healthcare professionals can order their complimentary binder at tfaforms.com/4857974



COVID-19

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

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

GLOBAL CANCER COALITIONS NETWORK

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

RESEARCH

CLINICAL ONCOLOGY

Fight Bladder Cancer published an editorial in *Clinical Oncology* on '**Bladder Preservation with Radiotherapy: The Patient Perspective**', stating that treatment decisions should be based on patient's own individual preferences and on the recommendations of a multi-disciplinary healthcare team that is experienced with all options.

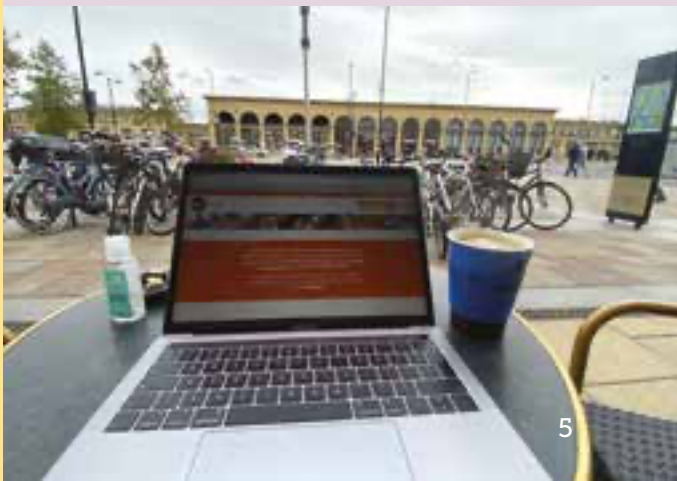


HONORARY CLINICAL PROFESSORSHIP

Fight Bladder Cancer trustee Alison Birtle was recognised for her outstanding work by being awarded the title of **Honorary Clinical Professor at both the University of Central Lancashire and Manchester University**. She will work with the Lancashire Applied Health Research Collaboration Hub and the Manchester Academic Health Science Centre to broaden and develop research horizons.

BRITISH JOURNAL OF UROLOGY INTERNATIONAL

Fight Bladder Cancer trustee Hilary Baker was a co-author of an article in the *British Journal of Urology International* on '**Recovery of health-related quality of life in patients undergoing robotic radical cystectomy with intracorporeal diversion**'. It suggested that structured rehabilitation of sexual function should be an integral part of cystectomy pathway.



COVID-19 SURVEY

We are a proud member of Cancer52 – an umbrella organisation linking charities supporting people with less common cancers – and co-created surveys about cancer patient experiences during the COVID-19 crisis.

During the most recent lockdown we found that:

- 35% of bladder cancer patients had their outpatient appointments delayed, moved or cancelled
- 26% of patients perceived themselves to be at high risk of COVID
- 90% of bladder cancer patients were confident about attending cancer services
- 66% were anxious about their cancer
- 56% were anxious about COVID

The information will be used in discussions with the government, NHS and industry to push for the best possible care and treatment.

HELP US WITH RESEARCH: If you have been affected by bladder cancer and would like to take part in research to improve services, please complete this form and we will be in touch with opportunities to take part in various studies: tfaforms.com/4875753

POLICY

EXEMPLAR

We launched the **Exemplar report** with a policy roundtable discussion, which highlighted that the lack of specialist staff leads to problems with quality of life and sexual wellbeing for bladder cancer patients. We called for more investment in the bladder cancer workforce so patients can receive the care they need and deserve.



ACCESS TO IMMUNOTHERAPY

When bladder cancer maintenance immunotherapy treatment was not recommended by NHS in England, we expressed our disappointment, called for discussions to resolve uncertainties around cost-effectiveness, and submitted an official comment.

NHS ENGLAND

Fight Bladder Cancer shared stories of the hopes and experiences of people living with terminal bladder cancer at the recent **NICE appeal of immunotherapy for untreated PD-L1-positive locally advanced or metastatic urothelial cancer** when cisplatin is unsuitable.



SCOTLAND

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

MEDICINES AND HEALTHCARE PRODUCTS REGULATORY AGENCY

Fight Bladder Cancer responded to the **Medicines and Healthcare Products Regulatory Agency consultation** on the role that patients could play in the UK's new regulation of medical devices. We reminded them that patients are the ultimate beneficiaries of many medical devices, with unique experiences and insights, and must be involved in the consultation process.



PATIENT REFERENCE GROUP

We were selected to join the **Innovative Licensing and Access Pathway Patient Reference Group**, which was established to ensure that patient views are an integral part of delivery of the Innovative Licensing and Access Pathway ambition. The Patient Reference Group will provide their expertise from the wider patient perspective, particularly in relation to the Innovation Passport designation stage, Target Development Profile stage and the specific patient engagement tool of the toolkit. The Patient Reference Group will work with the Medicines and Healthcare Products Regulatory Agency, the Scottish Medicines Consortium and the National Institute for Health and Care Excellence.

URINARY TRACT INFECTION IN ADULT WOMEN

Fight Bladder Cancer submitted feedback on the **Scottish Intercollegiate Guidelines Network's consultation on 'Management of Suspected Bacterial Lower Urinary Tract Infection in Adult Women'**. We are pleased to see that it includes the following statement: 'If symptoms do not go away within a few days, or you are distressed by more severe symptoms or have repeated episodes within a short time, then get help from your healthcare professional.'



AWARENESS



GP PACK

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

FREE CAR STICKERS

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



SCOTTISH BLADDER CANCER TRAINING DAY



Fight Bladder Cancer trustee **Param Mariappan** convened and chaired an online training day on **muscle-invasive bladder cancer**, featuring an overview of Scottish standards, Quality

Performance Indicators, interactive case studies, surgical approaches, immunotherapy and clinical trials.

EAST KENT HOSPITALS UNIVERSITY

We are thankful to East Kent Hospitals University for **signposting to Fight Bladder Cancer** on their information on transurethral resection of bladder tumour (TURBT), which was produced with and for patients.

KARGER HEALTH SCIENCE

We worked with **Karger Health Science Publishers** to share ideas for raising awareness about bladder cancer and highlighting the need for patients to have frank conversations with their medical team about the aspects of their life that will be affected by bladder cancer, including peeing, sex and body image.

WORLD BLADDER CANCER PATIENT COALITION

We were featured in the World Bladder Cancer Patient Coalition's digital world tour in May, sharing the message 'Have you ever heard about bladder cancer?', and highlighting the impact of bladder cancer in the UK.



GENESISCARE

We were featured on the GenesisCare website as one of the helpful UK organisations offering support and information for people with cancer, highlighting our helpful information on bladder cancer and patient stories.

THE SUNDAY POST

We worked with a journalist at *The Sunday Post* to produce an article highlighting the fact that **'Doctors fear young women are missing early cancer diagnosis'**. This article featured quotes from Fight Bladder Cancer patients and medical advisors, campaigning for a change in the guidelines and greater awareness of the issue.



HEALTHY WOMEN

One of our forum members was featured on Healthy Women, where she wrote: 'never be afraid of asking a healthcare provider for a second opinion. I've been quite surprised by how many people, especially younger people, are reluctant to ask. But I've found that many providers are actually quite happy to help patients who seek a second opinion.'

GUARDIAN

Fight Bladder Cancer was featured in the 2021 'Men's Health and Bladder and Bowel campaigns' inside the *Guardian*. We reminded readers that early cancer detection is likely to give them a far better outcome, and encouraged them to visit their GP if they had concerning symptoms.



MAY – 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 global activities. During the campaign period, followship increased by 10% on LinkedIn and we reached over 239,000 people via social media. See page 57 for more details!

Note from the Chair and CEO



For so many of us, COVID-19 has meant that we have been physically separated from our loved ones for over a year. We are delighted to see that the vast majority of adults have already been vaccinated against COVID-19. While being mindful of changing conditions and government regulations, we hope that as we return to cooler weather we are able to retain this strong sense of community.

This past six months have been extremely busy for the charity. We are now deeply familiar with remote working – and have organised Zooms for every occasion. We celebrated the end of the year with a Zoom trivia night, and our office manager posted out tiny fairy lights to everyone on the team to brighten up their workspace. While we have made remote working effective, we are looking forward to the day when the

Fight Bladder Cancer team can once again come together to share ideas for the future over a hot meal.

We are in the process of bringing in new trustees – including bladder cancer patients and healthcare professionals – while at the same time updating our constitution, registering with the Office of the Scottish Charity Regulator, and ensuring our governance follows best practice.

We are campaigning across England, Scotland, Wales and Northern Ireland to ensure that the TURBT biopsy is recorded as a diagnostic procedure rather than a definitive treatment, which will help to ensure that bladder cancer patients receive true treatment as soon as possible. We have written to our local parliamentary representatives about this important issue and will continue our fight to make sure that parliamentarians work with the NHS to make this change.

Every month, more and more people are hearing about



OPINION
JOHN HESTER
FBC Chair of Trustees

DR LYDIA MAKAROFF
FBC Chief Executive

Fight Bladder Cancer, and we are working harder than ever to support everyone affected by bladder cancer. We are so thankful to everyone who has volunteered for the charity – whether to increase awareness, raise funds, or help us in our daily work.

Your support has allowed us to welcome two new staff members this summer, who will help us with policy, communications, supporter care and community engagement.

As the leaves start to change and we look towards autumn, we hope that you are able to find some quiet time with your loved ones to appreciate the promise of another season, full of hope and the magic of a new beginning.

FBC by numbers

In what has been an unprecedented year for health issues, we can be rightly proud of this statistical round-up of our activities during the year 2019–20.

WEBSITE SUPPORT

32,533

users of our **website**



FORUM SUPPORT

5,059 members of our private online forum

5,864 annual forum posts

606 new forum members

127,422 forum comments

308,706 forum reactions



SUPPORT GROUPS



7 online support meetings

27 people, the average meeting attendance

74 people assigned a Bladder Buddy

TELEPHONE SUPPORT

462 support phone calls received

162 support phone calls made

401 people supported by phone



CONSTITUENT RELATIONSHIP MANAGEMENT

2,707 contacts on our system

NURSE SUPPORT

A further **39** healthcare professionals received cards with an average **250** cards per person



EMAIL SUPPORT



407 support emails received

438 support emails sent

210 people supported by email

FIGHT MAGAZINE

300 print copies of **Fight #9** magazine distributed, and **100** digital copies

923 print copies of **Fight #10** magazine distributed, and **285** digital copies



RESEARCH



9 national and international conferences attended

9 contributions to scientific papers

AWARENESS

A further **64** people were sent **free car stickers**

254 GP packs sent out

100 calendars printed and sold

Post-pandemic life

It's good to be back in the urology ward

ARTICLE
HILARY BAKER
Macmillan Lead CNS for
Uro-oncology, UCLH



What is your role?

As the Lead Clinical Nurse Specialist for Uro-oncology at University College London Hospitals NHS Foundation Trust, I provide clinical expertise and management skills across the five tumour sites, with the aim of delivering a high standard of specialist urological cancer care, whilst providing professional leadership and line-management to a team of seventeen clinical nurse specialists (CNSs) and one support worker.

Half of my time is spent carrying out clinical duties, such as acting as a patient key-worker. I am an integral member of the specialist multi-disciplinary team and provide expert nursing advice, support and

information to patients and their carers in an inpatient and outpatient setting.

With the rest of my time, I hold a leadership and strategic role within the North Central London network, which involves setting standards/guidelines and undertaking audits so we have clear and robust patient pathways across the London Cancer Alliance. This work is complemented by collaborative networked MDTs working through the professional and organisational boundaries and establishing strong communication links across the hospital sites to provide a comprehensive patient-focused service.

Were you or your staff seconded to Covid wards during 2020?

During the first wave some of my CNS team were redeployed for eight weeks to ITU, the emergency surgical wards and the covid wards to support the response to the pandemic. We maintained a core of staff to manage the service for the five tumour sites for Urology.

The Urgent Urology Unit (UUU), which is sometimes referred to as a 'hot clinic' was relocated to University College Hospital to be co-located with the Emergency Department (ED) and the wards caring for our non-elective / emergency urological patients. The CNS team worked on rotation to provide on-site cover (alongside

medical colleagues) for the services at University College Hospital looking after this group of patients.

The CNS team were also required to provide urology education at the Nightingale Hospital in London. With capacity issues and different Covid pathways, most of North Central and North East London hospitals sent their uro-oncology surgery to University College Hospital at Westmoreland Street, a designated 'green site' (Covid-19 free), to continue their cancer treatment and care.

During the second wave, only one CNS was redeployed to ITU. Much of our normal services across the five tumour sites continued, with referrals coming through from across North Central and North East London. The CNS team continued to provide cover for the UUU and provide support for our emergency patients admitted at University College Hospital. Many of the CNS team trained to become vaccinators, helping to roll out the vaccination program for staff, patients and local residents at the hospital and at other vaccination centres in Camden and Islington.

What is the situation like now?

Both the benign urology and uro-oncology services continue as the hospital is working hard to reduce the backlog of elective surgery cases, some of which were deferred due to the pandemic. As well as reducing our backlog, the team are working hard to manage a high number of new referrals. There is a pan-London team consisting of managers, commissioners, GPs and hospital clinicians working collaboratively to support the long-waiting benign urology patients across NCL and NEL.

What is it like for patients now?

Patients are being asked to attend the hospital for clinic face-to-face appointment only if it is necessary. This helps to reduce the footfall in a 'green' site hospital. All other appointments are done virtually with video clinics or telephone clinics. Following a recent survey at Westmoreland Street, many patients liked the hybrid clinic arrangements as it made them feel safer, avoided the need to travel on public transport and saved money and time.

How can patients make the most of telephone consultations?

They should receive clear communication from the hospital that their appointment is a telephone clinic. As with all appointments, patients should be ready to receive a call, which may be before or after the designated time of their appointment. It really helps if they are prepared with questions to ask at the appointment and ensure all equipment is in working order, i.e., their mobile phone is fully charged and can be put on loud speaker. A suggestion is to try to have another person with the patient to help with asking questions, conveying information and supporting the patient during the conversation.



How should patients prepare for face-to-face consultations?

As the pandemic continues, we need to maintain a limit on the number of people who can come into the hospital at any one time. At the moment we ask patients to come to their appointments on their own, with certain exceptions. They will be asked to wear a mask throughout their visit and wait in an area that allows for social distancing. It is advisable to be prepared with questions to ask and often a family member or friend can/will be asked to join on Facetime on the patient's loud speaker mobile phone or via the hospital's landline phone.



How does it feel to be back?

Covid-19 is currently very much a part of our 'normal lives' and is likely to continue to be a significant influencer of our future. The human race has an amazing ability to change and flourish at a time of crisis and with the development of a safe and effective vaccine this will be a fundamental global turning point, in determining what the future looks like. As we continue to maintain a high degree of vigilance, it is good to be able to continue services, see patients and deliver care, although most people have a degree of anxiety about the future and further pandemic waves.

Zooming into the future

When will I see you again?

While we should certainly embrace the advancing technologies that enable doctors to see more patients than ever before, should a note of caution soften the unadulterated enthusiasm for virtual appointments?

There's nothing like a global disaster to focus the mind, and the COVID pandemic did just that. As virus transmission rates soared and the NHS came under unprecedented strain, preventing all but essential human contact became the norm, and the NHS seized on various video platforms, notably Attend Anywhere, so that patients and doctors could continue to communicate without risk of contamination.

With vast investment in hardware and software, and the best advice and programming made available, specialist teams devised best practice systems and supported their implementation at an astonishing rate, so that now 99% of GP practices are able to do video consultations, enabling GPs, consultants and other healthcare professionals to see more patients than ever before.

Where next?

There is no doubt that the digital solutions established during the pandemic have a key role to play in the future of the NHS, with telephone, video and online tools helping the NHS to provide safe and effective care while reducing face-to-face appointments.

These new systems are here to stay.

- Patients get the care they need as the doctor is able to see more people.
- There is no infection risk.
- Patients can often get more convenient appointments.
- There is no need to travel to appointments.
- Patients can be accompanied.
- The system works on multiple devices for maximum accessibility.
- Healthcare professionals have found the platform easy to use and very intuitive.

Now that the outpatients systems are well established, they are spreading through other departments, including a triage system for NHS 111 calls to avoid patients having to attend A&E unnecessarily.

Health at home

Healthcare professionals are also being encouraged to find ways of introducing technologies such as video and podcasts into any aspect of their work to get the maximum potential benefit from these opportunities. Messages and videos include: how to access GP services, how to have a video consultation and how to order repeat prescriptions. Messages feature across social media channels and all partners can use the campaign toolkit on Public Health England's website to share the campaign.



PERSONAL VIEW
WENDY HOBSON
Fight editor

GROUP SUPPORT

The value of group consultations in supporting patients with long-term conditions has already been recognised, but the focus has changed to how video can be used to enable group consultations to continue.

Expressions like 'truly transformative', 'huge benefits to patients', 'embrace and engage with this change' abound in the media and this is all true. But what worries me is that no one seems to be putting forward any counter arguments and, even if we decide that they are outweighed, surely we should give them consideration.

- Not everyone has the right technology.
- Many people are spending an increasing number of their working hours at a screen, and now they are to be expected to stare at it for even longer.
- Unless a group meeting is well chaired, the loudest will prevail.
- The split-second delay between participants can make conversation stilted.
- Body language makes up 55% of communication, which is filtered by video.
- You don't have to leave your house – even if you have been cooped up there for 15 months.
- There is nothing that compares with the touch of a human hand or genuine face-to-face smile.

Let's embrace technology, by all means, but let's make sure we remain in charge of the machines.

Around the clock – we are part of your team

ARTICLE
MELANIE COSTIN
FBC Support
Services Manager

Melanie welcomes you to our FBC private support forum



Our private support forum is available at all times to its members. You can find us on Facebook (facebook.com/bladdercancersupport) where we have patients, carers, loved ones and medical professionals amongst our members. Everyone affected by bladder cancer is welcome to join us.

Some people may feel quite reticent to join a group of people and to talk about bladder cancer, but everyone gets a warm welcome and they soon relax and feel able to share their journey so far, to ask questions, (there is no such thing as a silly question!) and be able to have conversations with other people who understand their concerns.

The forum is moderated 24/7 and there's always someone to help and support you, to share experiences and news, give tips, or offer words of encouragement ... and if you want to moan or offload this is definitely a great place to do it.

There are often smiles, too, humour amongst hard times can be just what is needed!

Many of our members like to read from the sidelines without posting about themselves, as this contact is the kind of help and support they are more comfortable with. This is a great way to find out information. There is also the option of searching for a particular past topic, plus we regularly update everyone with upcoming events such as support groups and information relevant to people with bladder cancer.

Here's what some of our members have said:

'Just joined the forum and am amazed by the support flowing from everyone.'

'This forum has been like a lifeline. I've learned so much!'

'We are all better for being there for each other'

'The most awesome support group there is for people affected by bladder cancer.'

And we'll be there for you if you need us.



Your Multi-Disciplinary Team

When you are going through testing and treatment, you will be seen by specialists in many different areas.

In this special feature, we look at the key players who may be involved in your care – known as your **multi-disciplinary team** or **MDT**.

Articles by patients and practitioners will give you an insight into how this complex system works.



PATIENT VOICE
'Having educated clinical opinions from a group of different experts is of great benefit.'

PATIENT VOICE
'I felt reassured that my MDT was made up of oncologists, neurologists, radiologists (lots of ologists) and my specialist nurse.'

PATIENT VOICE
'It can make you feel as though you aren't in charge of your life any more. However, I fully trusted my team to make the best decisions for me, and I can still have a say on my treatment.'

PATIENT VOICE
'I would like to attend an MDT although that isn't possible, I don't like the idea of people making decisions about me without me being there. I've been assured that I can question my consultant about any decision made, and the bottom line is that I still can decide to consent to whatever treatment is recommended.'

GP
Your first contact if you have symptoms that need to be investigated

Scanner operators
Operators of diagnostic testing equipment from X-rays to MRI and CT scanners

Clinical nurse specialist
Your key worker and primary contact who links with all members of the team

Medical oncologist
A consultant specialising in treating cancer patients through chemotherapy, immunotherapy and targeted treatments

Clinical oncologist
A consultant specialising in treating cancer patients through drug treatments and radiotherapy

Surgical oncologist
A consultant specialising in treating cancer patients through surgery

Anaesthetist
A specialist doctor who provides anaesthesia for operations and procedures

Medical secretary
Support administrator for clinics, referrals and treatments usually working for individual consultants

Pathologist
A specialist doctor who diagnoses disease by examining cells and tissue samples

Lab technician
Supporting the pathologist, and are also involved in blood and sample testing and preparation for chemotherapy

Hospital nurses
Caring for patients on the wards and administering medication and treatment

Urology cancer co-ordinator
Co-ordinating the patient journey through all aspects of diagnosis and treatment

Physiotherapist
Helping patients through movement, exercise and manual therapy

Counsellors and psychotherapists
Supporting patients' mental health and wellbeing through their cancer journey

Stoma nurse
A specialist district nurse advising on all aspects of living with a stoma

Dietitian
Helping patients to eat healthily in order to ensure the best outcomes

Clinical trial staff
Staff involved in administering studies to test new treatments

Support group
A great part of your support will come from your family and carers, as well as your wee family on the FBC forum.

MDT meetings

MDT meetings are usually held each week, and all the relevant members of the team get together to discuss the treatment of all the patients under their care. You will not attend the meeting but your consultant will tell you what has been decided and you will have a chance to get answers to any questions.

PATIENT VOICE
'I was worried to hear my case was going to be discussed at an MDT meeting, but now I understand that it is mandatory in order to decide the next course of action.'

Remember that systems vary in different areas and on your unique cancer pathway.

YOUR GP

ARTICLE
JOHNSTONE SHAW
FRCGP FRCOG
Retired GP

It was my privilege to be a GP

'My one regret was having to retire early from the job I had loved for over 35 years.'

Holding the front line

When you think something is wrong, your GP is usually your first port of call. For the GP, dealing with that takes a lot of training and experience, not only about medical conditions, but also in good communication. So at the top of my list of training was 'learn to listen' to the ideas, concerns and expectations of the patient – both what they say and what they don't say.

Your GP is also the one who is likely to make your first diagnosis or refer you for specialist investigation. The GP's job is both busy and increasingly complex as we all get older and have multiple medical conditions which can be difficult to unravel – all in an inadequate time allocation.

Not every bladder cancer patient will walk in with an orange FBC t-shirt!

Many may have subtle or very early symptoms, masking as another condition, or may have difficulty expressing their concerns. That can be challenging with different cultural and language issues.

Fight Bladder Cancer is working with stakeholders to update guidelines to help with early diagnosis in areas such as recurrent UTIs in females and I would strongly support that (Exemplar Report 2021).

How can patients make the most of their time with their GP?

Think carefully why you need to see your GP and write down your concerns. Put the most important at the top or underline them and deal with them first. A long list may seem like something to make the most enthusiastic GP's heart sink but no matter how good a doctor, none that I know of possesses ESP, so you need to tell them what is going on. A good doctor is always looking out for the hidden agenda, too, which may include fear of cancer.

What should patients ask their GP?

After your first consultation, both patient and GP should be clear what is going to happen next. Are you going for more tests? Is there a treatment plan and are you happy with it?

What if you need a referral?

If a referral is being suggested, ask if a cancer referral is appropriate. Routine referrals can take a while (especially in a pandemic). Once a referral is made, your GP will have no knowledge of when your appointment might be, so it is reasonable to ask what you should do if there seems to be a delay that is concerning you. This might well be to contact the hospital direct.

How can patients make sure their GP takes early symptoms seriously?

Be honest. Work with your GP – they are on your side.

Make sure they know your concerns and what needs to happen if things don't resolve.

Are GPs informed of your cancer treatment?

Your cancer specialist will organise your investigation and treatment plan, informing both you and your GP of any results, including blood tests and scans etc. The GP is therefore aware of your progress but is not interpreting your results or deciding on the next steps so it is inappropriate for them to be giving you your results.

How can patients work with their GP during treatment?

These days, with time constraints and recruitment issues, it may not be possible to deal with the same doctor. That is unfortunate as it can be one of the most satisfying aspects of working as a GP. However, I would hope that most GPs have a plan in place so their cancer patients know how to make contact if issues arise.

Both your cancer team and your GP should be experienced in talking to you about difficult or embarrassing issues, such as sexual problems, symptoms that are difficult to control, or about dying.

We can't know everything

Patients are sometimes disappointed that their GP has little knowledge of bladder cancer, but remember they are unlikely to have experienced many patients with your condition. I had three in my 35 years and none of them had a radical cystectomy.

My specialist nurse is an amazing resource for most of the issues I have and gets things done or points me in the right direction. Unfortunately

What if I'm not coping well emotionally?

Your GP, and your cancer team, should be able to identify and treat underlying psychological or psychiatric illness, or they may refer you to local specialist resources.

I have really appreciated FBC support with the private forum and Zoom groups during lockdown. Knowing what others are experiencing helps enormously. In Edinburgh we have an amazing resource at the Maggie's Centre for Cancer Care, and I have recommended it to countless patients and their families with excellent feedback. Soon after the trauma of my diagnosis I plucked up the courage to go through the door and haven't regretted it for a second. Andy, the centre head, was able to transform me emotionally from a doctor into a patient, and since then I have continued to receive fantastic help from the cancer support specialists there individually and in support groups. I would strongly advise any bladder buddy to get this kind of support if you can.

some regions don't have adequate resources to provide one for every patient, which is regrettable.

Likewise, stoma nurses are my heroes and both patients and GPs rely on their specialist knowledge. Stoma prescriptions are incredibly complex and the product codes often don't match the GP-prescribing software. I admit to having been exasperated with stoma prescriptions on countless occasions. In the early days, handwriting just one easily took 30 minutes! And I'd never seen a stoma bag before I had mine, despite being able to surgically fashion a stoma!

I have a great MDT

I'm lucky in having a good GP. He should be as he was a trainee of mine many years ago! I also have a wonderful specialist team with an excellent consultant whom I trust completely, as well as a great bladder cancer specialist nurse and a fantastic stoma nurse team who don't laugh too often at all my bag questions! So I am looked after by a good multi-disciplinary team who communicate well with each other but I realise this is sadly not there for everyone.

Fight Bladder Cancer is currently working well with stakeholders in the Exemplar project, GPs included.

Doctors need to know that patients worry about all sorts of things – not only dying and sex but where the nearest toilet is!

I would have covered that in my next tutorial, I promise!



On 1 April 2019 I suddenly became the patient after being the doctor for over 40 years. Lying on the operating table after being told at my cystoscopy I had bladder cancer was not the most pleasant of experiences. Two years on, and after a radical cystoprostatectomy, I'm doing okay and trying to enjoy life – despite all the lockdowns!

Reflecting on my 40 years as a doctor and two as a patient, here are some thoughts on the role of your GP. The message I always tried to get across to medical students and trainee GPs under my care was the privilege it is to care for people from 'cradle to grave'.



Testing, Testing

Nneka gives *Fight* readers an insight into her work with this informative profile of a diagnostic radiographer

ARTICLE
NNEKA SMITH
AHP Practice
Education Facilitator



Radiographer is a protected title given to practitioners who work in diagnostic services – X-ray, CT and MRI – and in therapeutic services (delivering radiotherapy). We are classed as Allied Health Professionals (AHP) and there are 14 professions under the AHP umbrella.

Diagnostics

As a diagnostic radiographer, I use a variety of different equipment to take images that will help with the diagnosis and treatment of problems in a person's body.

You may meet a diagnostic radiographer at any stage of your cancer journey.

We are found working all over the hospital: in theatres, fluoroscopy labs, on the wards, in outpatient clinics and inpatient areas. That makes us pretty hard to miss!

Therapeutics

Therapeutic radiographers are the only health professionals qualified to plan and deliver radiotherapy treatments, and you will probably see the same team of radiographers throughout your course of radiotherapy. They use a wide range of technical equipment.

No case for mistaken identity!

Everyone's treatment is completely unique so we always ask for your name, date of birth and address before we begin any procedure – even if we know the answers!

This is an important part of our role as we are responsible for radiation protection, so we must ensure you are the right person (even if we already know you from previous sessions).

We will also check your pregnancy status and make sure you know what procedure you are about to undergo. Always ask us if you are not sure what is about to happen and we will answer any questions and explain things in more detail.

We are a friendly group of professionals and usually know our way around the hospital well so, if you are ever lost, ask a radiographer for directions.

X-rays and scans

You may be familiar with having an X-ray procedure done if you have ever broken a bone, had a procedure in theatre that required an X-ray, or if you have needed a check-up following a long period of illness caused by a chest infection. You may also have had or need a CT scan, which uses X-rays to produce a more detailed image of the area of interest. CT and X-ray are more widely used than MRI scans, although the latter may also be needed by bladder cancer patients. MRI uses magnets to produce the image and the machines are rather loud, but you will be given ear plugs or headphones. MRI scans produce a higher-quality, even more detailed image than CT scans.



Get rid of the metal

Before your imaging procedure, make sure that you remove any metal in or on the area that is going to be imaged, so you won't have to do it when you are all ready for the scan; this will help everything go smoothly and be less stressful. Jewellery and belts are obvious, but don't forget zips, bra fastenings or underwires. You may also be asked to change into a glamorous hospital gown but don't worry – it won't be for long!

Whatever scans you need, the radiographer will be there throughout to look after you and answer your questions.



PATIENT TIP:

'The contrast dye given during a CT scan gives you a warm sensation as if you have wet yourself. I was assured that nobody actually has!'

PATIENT TIP:

'An MRI scan can be long. They may ask if you would like music playing, or you may be able to take your own to help relax you.'

PATIENT TIP:

'Remember not to jiggle around to your music as you will need to stay still.'

PATIENT TIP:

'The metallic taste from contrast dye fades quickly but remember to drink plenty of water afterwards to flush it out properly.'

PATIENT TIP:

'Loose fitting clothes for scans may be ok, but remember to check for metal such as fasteners or underwires as on a bra. I also noticed that some labels have metallic threads.'

10 THINGS

you should know about your CNS

At the centre of your multi-disciplinary team is your key worker: your clinical nurse specialist, who ensures continuity of care and provides the link between all the team members and the patient.

ARTICLE

HILARY BAKER, Lead CNS for Uro-oncology, UCLH & Fight Bladder Cancer Trustee



NURSE OF THE YEAR

We are delighted to congratulate Hilary on being chosen as one of the *British Journal of Nursing Nurses of the Year 2020*.

1 The pivotal point of the team

When you are in treatment for something as serious as bladder cancer, you don't see just one doctor, you are cared for by an entire multi-disciplinary team (MDT) of specialist doctors and healthcare professionals, all with urology expertise (NICE 2015). The rock at the centre of that team is the CNS, who is the hub around which care and support is provided.

2 Clinical expertise

Every CNS is a registered nurse who has studied to degree level and who is expected to be working towards masters level. They are all clinical experts within their tumour speciality and nursing practice.

3 Continuity of care for the whole journey

Their role is to provide specialist care, support and information throughout the patient's cancer journey, from diagnosis through treatment to, in some cases, end-of-life care. Equally important is that they ensure continuity of patient care – co-ordinating the various agencies and providing the vital link between them and the patients.

4 There for everyone

They are not only there for the patient, but can also signpost relatives to national information, support services, self-help groups and associated urology-specific support.

5 Holistic approach with emotional support

Everyone's experience of cancer is personal, so the CNS ensures that care is delivered that responds to the individual needs – physical, emotional and practical – which are identified at key milestones of the cancer pathway. The single fact that every patient has one constant reference point provides a huge degree of reassurance and emotional support.



6 Point of contact between patient and hospital

Following the introduction of NICE's Manual for Cancer Services for Urology, the CNS is named as the key worker who, since 2004, has been responsible for organising and navigating the patient through their care at a practical level. They are the point of contact between hospital and patient to provide support, advice and onward referral.

7 Provide quality assurance

The key worker is also a requirement for the National Cancer Peer Review Program, which is a quality assurance programme aimed at reviewing clinical teams and services to determine how they perform compared with national measures. The CNS provides the information necessary to carry out this assessment of quality aspects of clinical care and treatment.

8 Influence effective patient care

Being an advocate for the patient and a link between patient and professionals, at the centre of the treatment with key access to the urology multi-disciplinary team, means that the CNS is able to influence effective patient care and experience across the whole of their pathway.

9 Seamless transitions

As the patient passes through various stages of their cancer journey, they may be transferred to a different hospital trust or to another care provider. When this happens, the CNS is responsible for providing medical notes and all the information for a seamless handover.

10 We journey together

Immensely challenging at times, being a CNS is also truly rewarding as we journey with our patients, each along their unique cancer pathway.

Patient Information Books

Your CNS will explain the details of your cancer and the proposed treatments to you but it is helpful to have information you can take home and read in your own time.

Your CNS will be able to show you the Fight Bladder Cancer Patient Information Booklets that are appropriate to you and order copies for you, either print or digital.

Find more information on the back cover.



ENDORSED BY

The British Association of Urological Surgeons

British Association of Urological Nurses

British Uro-Oncology Group



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

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

A clear head & a warm heart



ARTICLE

JOANNA WHALLEY
Medical Secretary, Lancashire
Teaching Hospitals Trust

After liaising with their secretaries, my consultant and our bookings team to gather the test results – scans, bloods, pathology, etc. I organise the first appointment and inform the patient, who then comes under our care.

Call me

I make sure patients know that I am always there to answer queries or deal with concerns. If I can't answer a question, I can direct them to the correct person who will be able to answer medical queries, or give advice or results over the phone.

But it's not just the patients who have my number! Phone queries come in from other members of the wider oncology team, from GPs and other hospitals. The mundane ones – like checking an appointment – only take a couple of minutes to sort out; others need investigation but I don't give up until I have an answer.

Maintaining the routine

With such a varied workload, there isn't a typical week, although the common factor is that we are always busy! Prioritising is crucial. There is a daily routine of dealing with incoming and outgoing mail, answering the phone, arranging appointments, typing letters, and recording medical notes, revolving around the consultants' schedules.

Excellent organisational skills, accurate typing and a keen eye for detail may be vital, but they are not the only qualities required of our medical secretaries. Joanna gives us an insight into what her work at the Rosemere Cancer Centre involves.

My primary role is to provide administrative support for the consultant clinical oncologists specialising in urological cancers, plus the registrars and CNSs. That calls for a clear head and an organised mind.

But I also act as a conduit between the patients, the consultant and the rest of the team so it is essential to have empathy and understanding in order to deal sensitively with patients and their families.

First contact

My initial contact with new patients begins with the receipt of the letter from the referring clinician.

My inspiration

Cancer patients battle one of the hardest and most difficult medical situations. Those who inspire me are the ones who rise above adversity with a 'beat it' attitude and a zest to live life to the full. Many spend their time and energy raising money for cancer charities, including FBC. They have a vital role in research into pioneering surgery, medication and radiotherapy, or providing support, , holistic alternatives for wellness and monetary help to cancer patients.

One such patient was a young woman who lived for eight months after diagnosis, although she was given only weeks. She spent those months selling Rosemere merchandise to anyone who looked her way and thinking about how to improve facilities for those who would come after her.

Even now, 18 years later, this woman is still inspiring others through the Rosemere Cancer Foundation, with an award in her name. This young lady was my sister, Emily.



Questions, questions

It is perfectly normal for your mind to go a complete blank when you are first told by your consultant you have bladder cancer, and you will simply not hear another word. Use these notes to help you.

DEALING WITH QUESTIONS

- Write down any questions before the next meeting and take your notes with you.
- Take someone with you to all your consultations (COVID permitting) and ask them to write notes on what is said. A hardback notebook is better than paper in case you have to rest it on your lap.
- Record the meeting on your phone if everyone attending finds that okay.
- Keep jotting down questions between appointments as you think of them.
- If in doubt, ask your Clinical Nurse Specialist (CNS).
- If you don't understand the answer, ask again.
- Tell the consultant how much detail you want to know – they can't read your mind, and everyone is different.

Don't be afraid to ask the big questions or the detailed ones; nothing is off limits.

If you are diagnosed with advanced bladder cancer, most people want to know whether their condition is terminal and, if so, how long they might have. Your consultant will have heard all these questions many times before and will answer as best they can.

Ask your CNS for the FBC Patient Information Booklet that is most suitable for you, or download it from fightbladdercancer.co.uk. This will give you a greater understanding of the answers you may get from your consultant.

QUESTIONS TO ASK YOUR CONSULTANT WHEN YOU ARE FIRST DIAGNOSED

- What kind of bladder cancer do I have? Is this a common type?
What grade and stage is the cancer?
You will be told if you have non-muscle-invasive or muscle-invasive bladder cancer, determined by whether or not the cancer has spread beyond the bladder lining. The grade tells you how fast the cancer is growing, and the stage tells you how far it has spread. There is a very fine line between the different stages so don't be surprised if your diagnosis changes.
- What are my treatment choices? Which treatments do you recommend and why?
Your medical team will decide what treatment they believe is best for you but there may be options. They will all have pros and cons so consider the information carefully before you make your choice.
- What are the risks and possible side-effects of each treatment? Will the treatment affect my normal activities or my sex life?
- Can I speak to a patient who has had this treatment?
The FBC private forum is a good place to talk honestly about your worries and hear the first-hand experiences of patients who have been through similar treatments. This can help you make a more informed decision.
- What is my prognosis?
There is no definitive answer, but the consultant will give you as much information as possible from professional knowledge and experience.
- What can I do to make my treatment as successful as possible?
You may be given advice on general health, diet, exercise and giving up smoking, if you are a smoker.

Keep asking questions throughout your treatment. Generally speaking, your CNS is the first person to ask.

Medical oncology & bladder cancer

Rob Jones looks at the rapid advances in drug treatments for cancer

ARTICLE
ROB JONES
 Professor of Clinical Cancer Research, Consultant in Medical Oncology, Beatson West of Scotland Cancer Centre, Glasgow



One of the most important developments of the late 20th century in UK cancer care was the multi-disciplinary team, whereby a cohesive group of specialists work together to manage patients. Whilst many patients may not see more than one member of this team, it's only as part of it that I can perform my role.

Medical oncology, using drugs to treat cancer, is a relatively new speciality which has grown exponentially since I started in the mid '90s.

It is only in the past decade that a significant number of medical oncologists have been treating bladder cancer, alongside prostate and kidney cancer.

When I was appointed as a consultant in 2006, I was the first medical oncologist to get involved in bladder cancer in Scotland and one of only a handful in the UK. Some centres still have no medical oncologists in this field, the role lying with clinical oncologists, who also deliver radiotherapy where appropriate.

When treating bladder cancer, clinical and medical oncologists have more similarities than differences; we often brand ourselves as just 'oncologist'. So don't worry if you've never knowingly seen a medical oncologist – the most important thing is that you are getting the advice you need. However, if you think you may benefit from speaking to a medical oncologist, ask your urologist (or existing oncologist).

Suitable for drug treatments

My patients are predominantly those for whom drugs are considered the main initial treatment.

In bladder cancer, this includes patients with muscle-invasive disease who need chemotherapy before planned cystectomy or radical radiotherapy (neo-adjuvant chemotherapy), and patients with disease that has spread to the extent that they are not suitable for these treatments.

In the first group, I'll deliver chemotherapy but it is equally important that the patient gets the best radical treatment after that. For some, there is a clear medical preference; others need to see the radiotherapist and the urologist to make an informed choice about surgery or radiotherapy.

For the second group, the patient and I will work together to make the best choices regarding palliative treatments for what, unfortunately, is a disease we cannot cure. Often these choices include chemotherapy or immunotherapy, and many patients will have more than one type of treatment at different stages of their journey.



Risk and benefit assessment

If you need to see a medical oncologist, then it's really important that you consider drug treatments carefully: it is unusual for there to be only one treatment option (even if one is considered more effective). For example, the choice to start chemotherapy in cancer which has spread and cannot be cured, is always a balanced one: the benefits are often quite modest and side-effects can sometimes be worse than the disease itself. And each patient is different: some will have other medical conditions which make some treatment options riskier, others will have clear priorities as to how they choose to spend what is, sadly for many, limited time.

So, it's really important that you clearly understand and take time to consider what is involved with drug treatment and what the side-effects are.



Understandably, we all want to start cancer treatment quickly, but a rushed decision can sometimes turn out to be the wrong decision – another week or two rarely makes a difference in outcome, so take your time.

You also need to ask what the other options are: sometimes (but not often in bladder cancer) there is more than one choice of drugs, but sometimes a period of watchful waiting is an option, or some patients might choose not to have drug treatment, preferring to focus on optimising symptom management. You should also be able to speak to a clinical nurse specialist, so ask if you think this would be helpful.

A lot of my bladder cancer patients cannot be cured even at the point of initial diagnosis. It is one of the greatest privileges to be involved with these patients and those close to them at such a time in their lives – and, together, we are now finding ways of improving and prolonging this time.



Clinical trials are advancing cancer care

My own interests also include clinical trials.

In the past five years there has been an unprecedented growth of new drug treatments for patients with incurable bladder cancer – indeed it is this constant improvement that makes medical oncology such an exciting speciality.

These developments happen because there are new scientific breakthroughs creating new drugs, but also because we have a systematic process for demonstrating that the new drug really works – a process that is founded in clinical trials.

Clinical trials are a form of experiment where patients choose to undergo treatment with these new drugs whilst undergoing measurements of safety, side-effects and effectiveness. Some trials happen very early in the development of a new drug – these are called phase I trials and typically only involve a few dozen patients. The purpose of these trials is mainly to learn more about side-effects and work out the best dose to use.

Others, phase II trials, are designed to establish whether the drug is effective at all and, again, usually have less than 100 patients, typically all of them receiving the new drug.

Phase III trials are bigger – often many hundreds of patients – and are designed to show that the new drug is better than standard treatment. These trials are randomised – so some patients will be chosen at random to have standard treatment and some will be chosen to have the new drug. If the phase III trial is a success, then the drug becomes the new standard, often on a global scale.

Radiotherapy for bladder cancer

For those considering radiotherapy treatment, Dr Mohini Varugheese looks at the role of the clinical oncologist who specialises in administering bladder radiotherapy within the MDT.



I am a clinical oncologist based at the Royal Devon and Exeter Hospital in the South West of England. I have been a consultant specialising in the management of bladder cancer since 2009, having completed my clinical oncology training in London. I deliver both drug therapies and radiotherapy. I also work with medical oncologists who specialise in delivering drug therapies.

Chemotherapy and immunotherapy are drug treatments currently used for bladder cancer that are usually delivered as an infusion. Radiotherapy is targeted X-ray treatment, and in bladder cancer this is usually delivered to the whole bladder in daily treatments over a set period of time.

MDT meetings

I am also a core member of the uro-oncology MDT. At our regular meetings, a team of specialists discusses patients and makes treatment recommendations based on history, pathology and radiology findings. We also consider relevant clinical trials. Either a urologist will ask for an oncology opinion or the oncologist will identify patients that they need to see.

ARTICLE

DR MOHINI VARUGHESE
Consultant Clinical Oncologist,
Royal Devon and Exeter
Hospital NHS Foundation Trust

Making choices

Patients are referred to me once initial tests have been completed confirming muscle-invasive bladder cancer. If the patient is appropriate for drug therapy they may see either a medical or a clinical oncologist.

Following the NICE guidance, patients who have been diagnosed with muscle-invasive bladder cancer that has not spread, should be given the chance to see a clinical oncologist and also a urologist who specialises in cystectomy. This ensures patients can find out both what each procedure entails and any potential side-effects, which are very different in each case.

Patients with severe urinary symptoms are less suitable for radiotherapy because such inflammation can worsen symptoms, during and shortly after treatment. Patients with inflammatory bowel disease (Crohn's disease or ulcerative colitis) are also not suitable for radiotherapy due to risk of long-term effects of radiotherapy on their bowels.

There is no clear evidence that radiotherapy or surgery have better outcomes. Patients must make their own decision after full consultation. The risk of cancer spreading is also the same, whether or not the bladder is removed.

Radical radiotherapy

This is radiotherapy given with the hope of curing the patient, in a course over four or six and a half weeks. Also known as curative intent radiotherapy or bladder preservation treatment, it offers patients an alternative to a major operation and the need for stoma bags, whilst maintaining sexual function and body image. Patients with muscle-invasive disease that has not spread beyond the bladder are suitable for consideration.

Clinical trials have shown that radiotherapy is more effective when given at the same time as radio-sensitising drugs, which make the cancer cells more sensitive to the radiation; this is now best practice. These drugs are known as concurrent radio-sensitisation agents.

After this treatment, patients will be given regular cystoscopies to monitor any recurrence.

Side-effects

Radiotherapy creates a degree of inflammation where the X-rays travel through the tissues, and this results in side-effects, typically transient urinary or bowel problems. These build up during the course of radiotherapy, are worst at the end and for several weeks, and then tend to settle within six weeks after completion of treatment.

Mapping and planning

The first appointment for a radiotherapy patient will be for 'mapping and planning'. After fully emptying their bladder, the patient is given a CT scan, which provides the radiotherapy team with full 3D information on the bladder and surrounding structures. Tattoos (pin-prick-size marks) are made on the skin for positioning.

It will take a couple of weeks for the clinical oncologist to define the area they wish to treat and then our physics colleagues design and calculate a radiotherapy plan that provides the optimal treatment dose to the bladder whilst minimising the dose to normal structures. Technical aspects have advanced significantly in the last decade and many centres can offer volumetric arc radiotherapy (VMAT) or intensity modulated radiotherapy (IMRT), which can 'curve' the dose tightly to minimise dose to normal areas.

Radiotherapy treatment

For treatment, the patient lies in the same position as for the scan, using the tattoos and lasers to confirm accuracy. A CT scan confirms the position of the internal organs and the treatment plan is matched to their position on the day, using image-guided radiotherapy techniques, such as cone beam CT.



A radical external beam radiotherapy plan using volumetric arc radiotherapy, which shapes the dose around curved structures. Treatment dose is delivered to the bladder and a margin of normal tissue (red area above), and then rapidly falls off.

High-dose palliative radiotherapy

If a patient is not suitable for curative intent treatment, then alternatives can be considered. High dose palliative radiotherapy is delivered once a week over six weeks, and is used for patients with muscle-invasive disease who would struggle to attend hospital daily. Where patients are very symptomatic – with bleeding or pain – and the focus of care is on improving quality of life, then shorter courses of radiotherapy are used; typically a single dose, or three treatments on alternate days.

Don't be afraid to ask

Patients should feel empowered to ask questions of their specialists and CNS and to express their priorities for treatment. The amount of information can seem overwhelming, but patients can review clinic correspondence in their own time, and use charities and validated websites (such as FBC or Cancer Research UK) to demystify complex jargon in order to help them make an informed decision.

Excellent cancer care is hallmarked by MDT teams that give unbiased, honest information coherently while always holding the patient's priorities at the heart of decision-making.

Sweet dreams

The best experience with an anaesthetist is one you won't remember a thing about!

ARTICLE
SREYASHI SEN
Anaesthetist, Leeds
Teaching Hospitals



It was a pleasant surprise when I received an offer from Lydia to write a piece for the *Fight* magazine. I am honoured to be able to accompany you in this journey.

My name is Sreyashi and I am an anaesthetist working in Leeds Teaching Hospitals. I am what you commonly regard as the 'sleep doctors'. You will meet me during your preassessment before surgery to discuss your general health and if you have had any previous issues with anaesthesia.

On the day of surgery, you will come to hospital in the morning. The surgeon and I will talk you through the events of the day and answer any questions.

The operating theatres are located in a dedicated area. My assistant and I will meet you in a room outside the operating theatre where my assistant will attach some routine monitoring devices, like a blood pressure monitor, ECG and

oximeter. Sometimes I may offer you an epidural injection for pain relief as well. I will then give you some oxygen to breathe through a face mask followed by some medicines through your drip that will slowly drift you off to sleep.

I will be with you while you are asleep throughout the surgery to monitor your progress. When surgery is complete and it's time to wake up, I will take you to the recovery area. There you will be looked after by a nurse until you are ready to go to the ward.

Though my interaction with you will be brief, I will ensure this part of your journey is worth remembering – and that means remembering nothing but going to sleep and waking up!



Up close & PERSONAL



Among the most important members of your team are your partner, friends and family, who are all vital in helping you through difficult times.

When you are undergoing cancer treatment, there will be ups and downs, good days and bad, times when you just want to be alone with your thoughts and others when you want to share your experiences with others.

There may also be days when your energy levels are okay and you want to get on with things, but others when the best you can manage is a doze on the sofa.

That's when those closest to you can be the most vital members of your team, when they can make you a cuppa, do some shopping or tempt you with a little something nice to eat.

Tell them how they can help

Don't turn away offers of help because you will need your energy for your cancer battles and those closest to you are only too keen to do what is necessary to support you. But unless you tell them what would be most useful, they can only guess and if they guess wrong – and who can blame them when you don't always know what you want yourself! – it doesn't help anyone. So keep a list of things you would like. Someone may think you'd like them to do the shopping when you'd really rather they hoovered round, played with the kids for half an hour, or just stopped by for a chat.

They all have skills that will contribute to your MDT.



HOW DO YOU KNOW what type of cancer you have?

ARTICLE

DR LYDIA MAKAROFF
CEO Fight Bladder Cancer

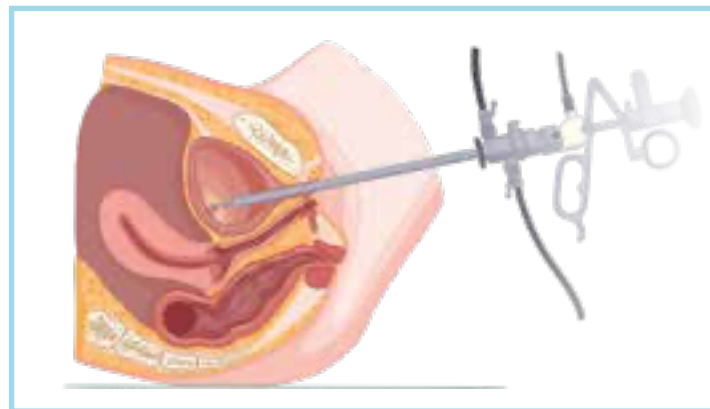
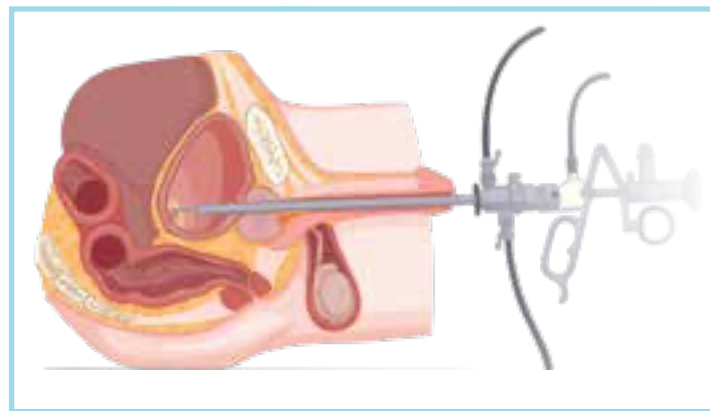
The small samples of your cancer tumour that are sent to pathology are key to finding out all about your cancer so that the doctor can make decisions on appropriate treatment. Lydia gives us an insight into the person who examines those samples: the pathologist.



A pathologist is a doctor who diagnoses disease by looking at urine, blood, cells and small pieces of the cancer. They work in a laboratory and you are unlikely to meet them face to face.

The urologist will remove a piece of the cancer from your bladder by inserting a tube through your urethra during a TURBT (transurethral resection of bladder tumour) procedure, and then give this sample to a pathologist, who will perform various tests.

The pathologist will help your medical team answer questions like these about your cancer.



TURBT procedure for men (above) and women (below)

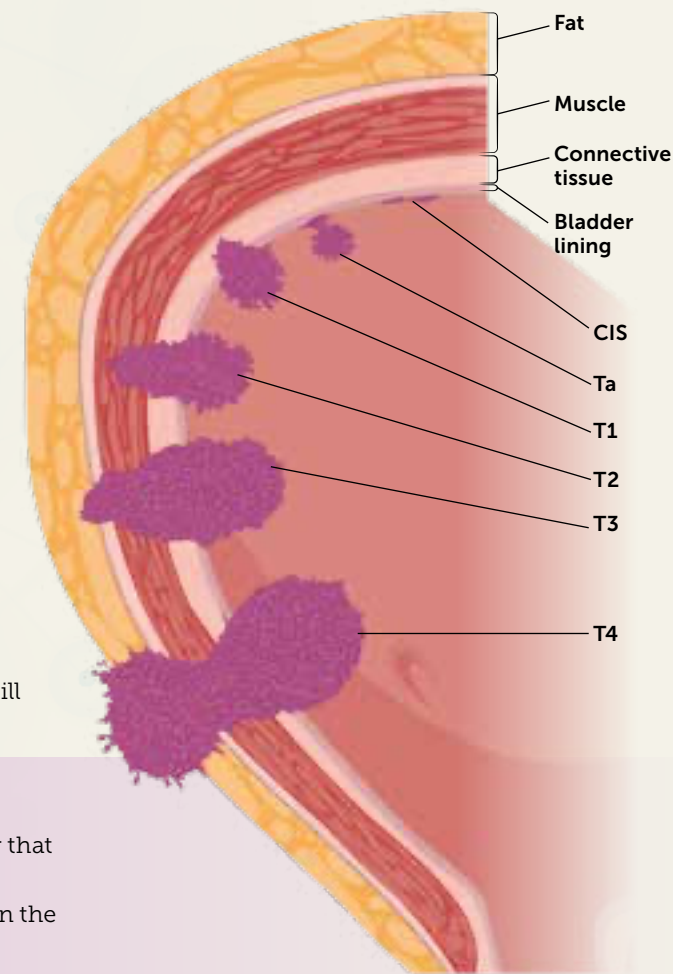


Is this non-muscle-invasive bladder cancer or muscle-invasive bladder cancer?

The pathologist will put a tiny piece of the tumour on a glass slide and look at the slide through a microscope. The pathologist will examine the cancer cells to see if the cancer tumour is sitting on top of the bladder cancer muscle (non-muscle-invasive bladder cancer) or if it is sitting inside the bladder cancer muscle (muscle-invasive bladder cancer).

Based on what they see through the microscope, they will give your cancer one of the following indicators:

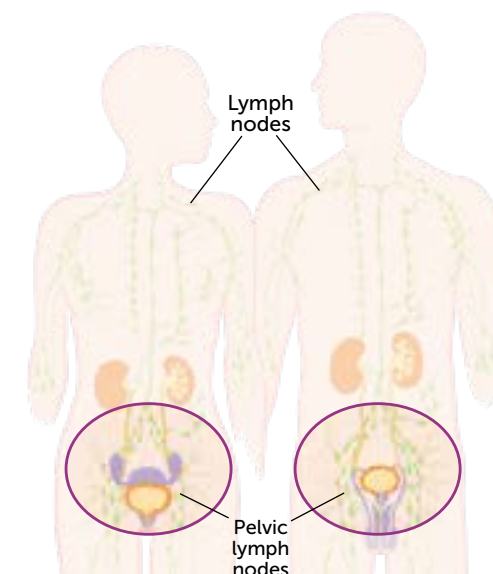
- T0:** no tumour
- TIS (CIS):** carcinoma in situ, a flat, fast-growing tumour that spreads across the inner layer of the bladder
- Ta:** papillary, mushroom-shaped, tumour that is only on the innermost layer of the bladder
- T1:** tumour has started to grow into the connective tissue
- T2:** tumour has grown through the connective tissue into the bladder muscle
- T3:** tumour has grown through the layer of muscles into the surrounding fat layer
- T4:** tumour has spread outside the bladder into other organs such as the prostate or uterus



Is there cancer inside your lymph nodes?

The surgeon might also remove some of the lymph nodes in your pelvis and other regions for examination on a glass slide under a microscope. The pathologist will look at the cells inside the lymph nodes to see if there are any cancer cells, and give your cancer one of these indicators:

- N0:** there are no cancerous cells in any of your lymph nodes
- N1:** there are cancerous cells in one of the lymph nodes in your pelvis
- N2:** there are cancerous cells in two or more of the lymph nodes in your pelvis
- N3:** there are cancerous cells in one or more of the lymph nodes (known as common iliac nodes) deep in your pelvis



What grade is your bladder cancer?

The pathologist will look at your cancer cells under a microscope, count the number of tumours, and then give your cancer a grade. The grade refers to the number and what the cancer cells look like under the microscope compared to healthy tissue and indicates how aggressive the cancer is and how likely it is to spread.

To classify bladder cancers, the World Health Organisation established one system in 1973, and then established a slightly different system in 2004.

In the 1973 grading system, grades are expressed as a number; the higher the number, the less the tumour resembles a normal cell and therefore the more aggressive it is.

- G1 / low grade
- G2 / intermediate grade
- G3 / high grade

Alternatively, your doctor may simply refer to the grade of your tumour as low, intermediate or high.

In the 2004 system, the categories are:

- PUNLMP (Papillary Urothelial Neoplasm of Low Malignant Potential)
- low grade
- high grade

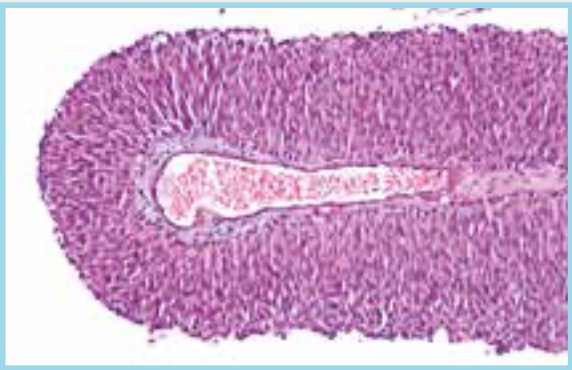
You can see from the diagram below that the boundaries of the three sections are not the same. It's like comparing UK and European shoe sizes; a size 7 can be a 40 or a 41.

PUNLMP	Low grade	High grade	2004 WHO
Grade 1	Grade 2	Grade 3	1973 WHO

Stratification of tumours according to grade in the WHO 1973 and 2004 classifications



PUNLMP (Papillary Urothelial Neoplasm of Low Malignant Potential), magnified. User: Nephron / Wikimedia Commons / CC-BY-SA-4.0



Low grade bladder cancer, magnified. User: CoRus13/ Wikimedia Commons / CC-BY-SA-4.0



What is the best treatment for your advanced bladder cancer?

If you have advanced or metastatic bladder cancer, your medical team will decide on the best treatment for you based on the following factors:

- how well your kidneys function
- how active you are in your day-to-day life
- if your cancer cells have a protein called PD-L1
- if your cancer DNA has a pattern called NKTR
- if your cancer DNA has a pattern called FGFR

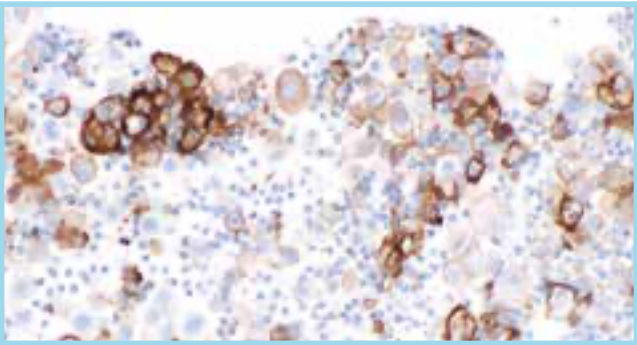
If your kidneys function well, and you are fairly active in your day-to-day life, your medical team is likely to suggest that you have a mix of chemotherapy drugs that includes cisplatin.



If your kidneys don't work as well as they used to, or you are not as active as you used to be, then your medical team will talk to you about your treatment options. They might also do some tests on your cancer cells to help decide which treatments are most likely to work best for you.

PD-L1

The doctor will give the pathologist a piece of your tumour, the pathologist will take a small bit and put on a special dye that will turn brown if the cancer cells have a protein called PD-L1 on their surface.



The centre of the cells are stained blue and the PD-L1 protein on the outside of the cancer cells is stained brown.

PD-L1 positive: If your cancer cells have a protein called PD-L1 on their surface, your medical team might suggest an immunotherapy called atezolizumab to fight your cancer.

PD-L1 negative: If your cancer cells do not have PD-L1 on their surface, your medical team might suggest a mix of chemotherapy drugs that includes carboplatin to fight your cancer.

FGFR & NKTR

Your medical team also might look inside the DNA of your cancer to help them decide the best type of treatment for you to have. Your doctor will take a piece of your cancer tumour and the pathologist will look at the DNA inside the cancer and see if your cancer cells have particular patterns in their DNA.

The pathologist will look for patterns in your tumour called NKTR and FGFR.

NKTR positive: If the pathologist finds an NKTR pattern in your cancer tumour's DNA, they might give you a targeted treatment called entrectinib or larotrectinib to fight your cancer.

NKTR negative: If your cancer tumour's DNA does not have an NKTR pattern inside it, your medical team might suggest a mix of chemotherapy drugs that includes carboplatin to fight your cancer.

FGFR positive: If your cancer tumour's DNA has an FGFR pattern inside it, your medical team might suggest enrolling you in a study to use the targeted treatment erdafitinib to fight your cancer.

FGFR negative: If your cancer tumour's DNA does not have an FGFR pattern inside it, your medical team might suggest mix of chemotherapy drugs that includes carboplatin to fight your cancer.

Remember the final decision about treatment is up to you and your loved ones. Your medical team will discuss all your treatment options with you, give you an update on your prognosis, and go through the advantages and disadvantages of each of the treatment options, including potential side-effects and best supportive care.

No such thing as A TYPICAL DAY for a nurse

ARTICLE
CHARLENE DOWDALL
Staff nurse on Ward 20 at
Arrowe Park Hospital

On any given day, nurses can see people at their weakest and most vulnerable, or at their strongest and most resolute. They witness the results of career-ending (and life-ending) injuries and illnesses alongside heart-warming recoveries. Here's Charlene's first-hand account of just some of the things hospital nurses cope with on a daily basis.



Ward 20 is the dedicated urology ward at Arrowe Park Hospital, where we provide acute and elective services for patients with urological diseases. It is a mixed, 29-bedded unit with a newly refurbished TWOC lounge (for checking that patients can pass urine without a catheter).

Our dedicated and professional nursing team has specialist skills and works closely with our consultants to provide an unrivalled level of care. The ward sister is involved with the smooth and efficient running of the ward and under her guidance there are various roles such as the deputy ward sisters, staff nurses, health care assistants, ward housekeeper, ward clerk and the domestic team, all of whom play an important role in ensuring standards are maintained and the patients receive exceptional care.

A TYPICAL DAY?

It is almost impossible to portray a typical day – it varies depending on patients' needs every day and every shift! But I've done my best to give you an idea of what a 12-hour shift might be like for a hospital nurse.

It is all guided by a routine that allows nurses to anticipate and prepare for every situation, and to spend a lot of time guiding patients and teaching them about preventative care.

6am: Often up before the sun, many nurses are out of bed, showered and eating breakfast before other professionals hit the snooze button. Patients are woken up around 6am, before the day shift starts, for vital observations and morning medication rounds. This is also time for breakfast – for the patients, that is!

Despite popular belief, a hospital ward is not a place to get much rest as vital observations are carried out on many patients every four hours, with post-op patients needing hourly or two hourly observations overnight.

7am: Most day-shift nurses begin by conferring with their night-shift colleagues, so they are up to date on any changes in the patients' status, any overnight admissions, or other matters they should be aware of. Then

the whole team meets for a safety huddle at the patient board; this is to highlight any safety matters, such as patients at high risk of falls, patients with pressure ulcers who require repositioning, patients with special food charts or fluid balances. The ward manager also draws attention to any areas requiring improvement.

Morning: Mornings are the busiest time for nurses on the ward. First, they deal with anything that requires immediate attention, then it's time to check in with each patient within their team. The nurses carry out a medication round, checking any lines and attachments, examining each patients' pressure areas and recording their vital observations. They also attend ward rounds and take note of any task they may need to carry out. Plus the nurses and the clinical support workers help the patients with their normal daily activities.

Afternoon: It could be time for discharge of some patients, a process which starts with the doctors' ward round. It is not uncommon for the doctors who discharge the patients to forget to tell them that can only happen once they have the results of blood tests, pharmacy checks for take-home medications and a clinical discharge letter. Nurses are used to having to explain this to patients who are keen to get home that it can take time, depending on how busy the ward pharmacist team is on that shift.

Of course, with some patients leaving, more patients need to be admitted and settled into the ward,



with nurses administering any medications and catching up with charting.

Nurses need to answer new patients' questions on their care plans and ensure both patients and their family members have understood everything they need to absorb. They soon build up excellent people skills.

Handover: Before going home, staff have to ensure that everything has been properly documented, checking and double-checking the patients' charts and the information the night staff will need. When the night shift arrive, the day shift carries out handover, then the cycle begins all over again.

THE BIGGEST CHALLENGES

Some of the bigger challenges include workload (as is the case for all of us) plus being able to separate work from home. There is always at least one patient who occupies some of my thoughts when I'm not actually at work but I am okay with this as I feel it comes with the territory.

I am aware that my role is a privileged one in that I see patients who are dealing with one of the biggest challenges they will ever face and I actually am fortunate in that these patients have taught me a great deal in how to face such huge challenges.



Communication IS THE KEY

Robyn talks about the delights and challenges of being part of the cancer hub.

My base is the cancer hub at Broadgreen Hospital, where I co-ordinate the support for patients with bladder cancer (as well as those with prostate, renal and testicular cancers) with a view to making sure every patient is closely tracked throughout their treatment.

I work alongside a designated cancer clerk, a prostate support worker, 2 MDT co-ordinators and a team of CNSs. We work simultaneously with effective communication, making and chasing up appointment dates – including diagnostic, outpatient and inpatient appointments. The inpatient surgical waiting lists are managed by the secretaries with whom I liaise for updates on patient admission (TCI or to come in) dates. We work closely to streamline the entire pathway.

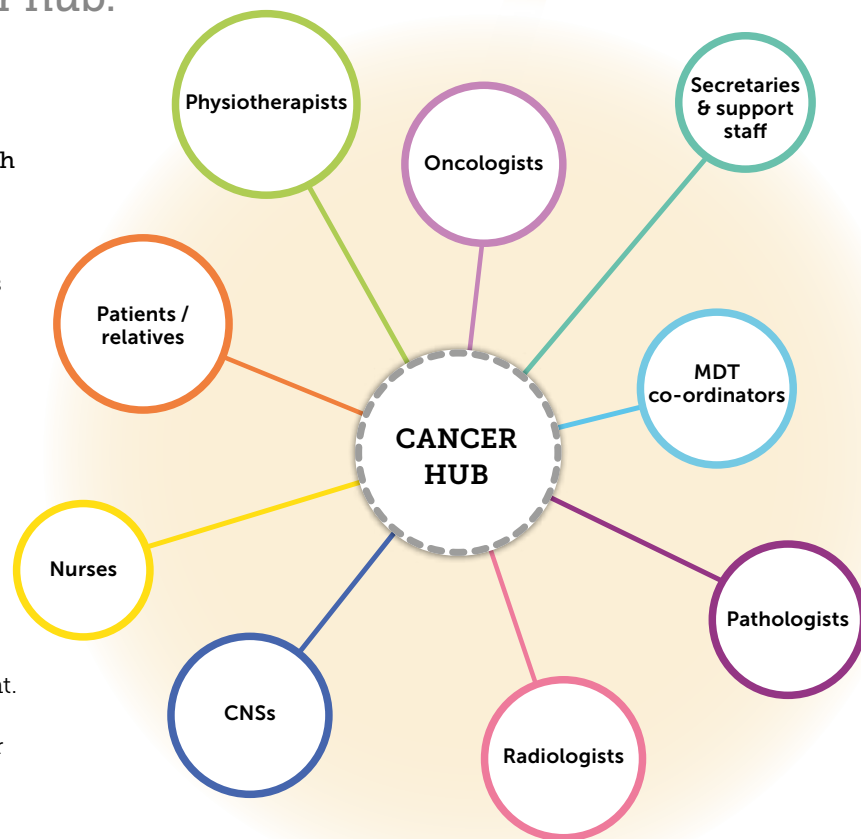
Where does it start?

From a GP referral, the cancer clerk books a telephone assessment with a CNS for the patient. I then communicate frequently with radiology until we have scan dates, then either the cancer clerk or I book the relevant appointment.

Being involved right from the start means I have not only been able to utilise my clerical experience to support the clerk, but I am also continually developing my own knowledge of urology.

TROUBLESHOOTING

Part of my job is also to flag any capacity issues up the hierarchy. I then work with the team to find solutions – such as setting up extra clinics – in an attempt to ensure our patients are diagnosed in line with the NHS targets – or pathway milestones.



Making improvements

I was appointed to this brand new role in June 2020 in an effort to improve the services provided for patients and I am delighted to say that the beginning of the pathway has improved greatly.

Working closely with our radiology colleagues, we have been able to secure allocated ultrasound slots four days a week, so patients can attend a one-stop service for an ultrasound and flexible cystoscopy and given their results on the same day. This is reassuring for patients, who then have fewer queries for us, freeing up admin staff for useful monitoring rather than progress chasing.



ARTICLE
ROBYN TENNANT
Early Diagnostic Cancer
Support Worker for Urology,
Liverpool University Hospitals

For patients needing an initial CT scan as part of their diagnostic journey, this is requested by the CNS during the telephone assessment and I then track the date for these patients, often chasing up if they do not get a date within a couple of days. A flexible cystoscopy is then booked seven days later, either by the cancer clerk or by me. We are currently in the process of setting up allocated slots for CT scans – this will enable us to give patients a date over the phone for their scan, and also their flexible cystoscopy.

A co-ordinated approach

The clinical questions we can't answer ourselves are passed on to a CNS or consultant. The team also takes all the CNS calls and passes on their messages, so their clinics are not interrupted.

Patients can phone me direct with any queries.



Future challenges

Going forward, fortunately my role has been extended for a further 12 months and during this time I hope to further my clinical knowledge. This will include me shadowing the team in clinic, meeting patients face to face, helping them put a face to a name, as they usually only speak to me over the phone.

Bladder cancer support group

With one of our CNSs, Nicky Bermingham, I have also been integral in setting up a support group for bladder cancer patients in conjunction with the local Maggie's Centre. Nicky and I visited the centre to discuss how best to cater for individual patient's needs within a group setting.

I also loved fundraising for Fight Bladder Cancer's Bladder Cancer Awareness month in May, where we held a bake sale in the department, raising an amazing £211.62; in addition I also participated in the 12,000 steps for 12 days challenge, raising a further £154!



I absolutely love working with the public and I really feel as though I'm making a difference to patients. Every day, I feel happy to leave the office having achieved something or learned something new. I am proud to be part of such a fantastic team.

WELLBEING

it's about the reasons we want to be alive

'Wouldn't it be just fab if people had more access to psychological support services everywhere!'

Before 2016, there was no specialised psychological support for cancer patients in North Devon – only private therapy, the cost of which ruled out most patients. But that all changed when Jess was tasked the fantastic opportunity of setting up a cancer service under a Macmillan initiative called the Recovery Package. Jess told us all about it.

The ethos of the Recovery Package is particularly exciting as it works towards a new way of treating cancer. Rather than just focusing on the physiological process, it looks holistically at each person's unique needs and how we can work to improve overall quality of life for those living with and beyond cancer. This joined up way of working reminds me of a fantastic quote by Atul Gwande.

'We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But it's really larger than that. It is to enable wellbeing. And wellbeing is about the reasons one wishes to be alive.'



ARTICLE
JESS FRENCH
North Devon Cancer Care
Counselling Services

This approach is vital to the work we do because receiving a cancer diagnosis and undergoing treatment can be such a complex process for individuals to navigate.

Cut adrift

When they get to the end of their treatment, many patients feel isolated and cut adrift when all their regular treatment appointments come to an end. It can feel like their safety net has been snatched away. That's at a time when people begin to work out what their 'new normal' looks like and it is then that many people seek support from our service.

Sometimes after treatment people may be left feeling like parts of their identity have been stripped away. Possibly they are no longer able to do things they previously enjoyed or carry out roles they previously had, like being the main breadwinner or the one in the family who cares for other people. The experience of needing help from others can be particularly challenging and upsetting for some. We may think we only experience grief when someone we love has died, but that's not so.

We can also feel very intense grief for the way our life used to look or for interrupted future hopes and plans and the loss of bodily functions.

Health anxiety is a problem for some: difficulty planning for the future, feelings of panic and an inability to cope with stressors in daily life. Although these feelings are exceptionally uncomfortable, I tend to view them as a normal reaction to an experience that has been particularly frightening and physically and emotionally challenging. Patients have told me time and again that they feel a tremendous sense of guilt when they are unable to move on with life in the way they want to, or feel bogged down by grief, fear and anxiety.

Tools and strategies to cope

In North Devon, support in the form of one-to-one counselling and psychotherapy is available for anyone who has received a cancer diagnosis and is living with and

beyond cancer to help them process what has happened and explore coping tools and strategies. Sometimes the best way to support cancer patients may be to provide support for their families as well, as a cancer diagnosis can affect the whole family, so we also offer one-to-one counselling and psychotherapy to the partner and children of cancer patients.

Alongside our one-to-one work we offer a number of support groups for patients and carers, supervision support for the chemo nurses and a six-week Macmillan course called HOPE (helping to overcome problems effectively), all run in our new, purpose-built cancer wellbeing centre, the Fern Centre, which offers counselling and psychotherapy plus a wide range of holistic support, including complementary therapies like reflexology, massage and Reiki, specialised wig fitting facilities, exercise classes suitable for people living with and beyond cancer and site-specific information.

If you are living with and beyond cancer and feel like you may benefit from some emotional support why not speak with your CNS or GP to find out what is available in your local area.

A PATIENT'S VOICE

'I have been so fortunate to have a counsellor like Jess beside me on my journey. When I was diagnosed with cancer, I felt like no one understood me at all. Counselling with Jess has been life-changing.

'To have a special connection with someone who is there for you to talk with, who you can trust and confide in and to be able to share the most painful feelings of shock knowing you are terminally ill has been such a huge support to me. I was able to access counselling when life had suddenly sent me on a road

I was not expecting to travel and I didn't know where to turn. Having a counsellor alongside me has made a massive difference, knowing I have a person just for me, to talk to about my feelings and fear of what is happening to me. It is a space and time given to me that has made my life feel more worthwhile.

'A counsellor in my opinion is one of the most important services I could have accessed and we are fortunate to have this opportunity on offer to us. It helped me to come out of the darkness that this

experience had thrown on me and made me feel like everything had come to an end.

'The combination of creative exercises we did and the relationship that we have built has helped me see the light at the end of the tunnel. Jess challenged me to see other perspectives and has given me comfort and hope and a view of the bigger picture. I no longer feel on my own and I can see why I am here and my purpose in life.

'Thank you.'

Bladder cancer & exercise



TenClinical
Physiotherapy and exercise are likely to be a part of your cancer care. TenClinical specialise in cancer rehabilitation and this feature gives advice on how exercise can benefit cancer patients. A team of exercise physiologists, TenClinical supports patients through individual exercise programmes to manage the side-effects associated with cancer treatments, enable patients to do more and thereby improve quality of life. They work with patients both face-to-face and online.

Despite the diverse types of cancer treatment, when patients ask if they are allowed to exercise while receiving chemotherapy or radiotherapy, the answer is always the same. Yes! Exercise is highly recommended and encouraged – even if you can't do much, it is better than nothing at all.



Work in the guidelines

Exercise is not intended to make you feel drained or wiped out when you are a cancer patient, it is aiming to do the opposite and make you feel a little more energised, so it is important that the type and intensity of the exercises are suitable for you. During an exercise session, you should be working within a comfortable range and up to 'somewhat hard' – certainly not 'extremely hard' – using the Borg scale to assess how someone is feeling. The Borg scale is widely used to give a unique assessment for each patient.

Quality of life

Regardless of the type of cancer treatment, exercise has various positive effects on the body, including affecting common quality-of-life indicators important to bladder cancer patients, such as a positive body image and sexual interest.¹ This means that those who are more active report a higher

quality of life than those who are more sedentary. It is also well documented that cancer patients who complete some form of exercise report lower levels of depression and anxiety, while seeing increases in social function.²

Reduced side-effects

Research has also highlighted that those who exercise during and after their cancer treatment experience reduced side-effects. This can include decreased pain and fatigue, as well as enhanced physical function, and hence, body composition (the balance of fat and muscle a person has).³ Improving body composition in relation to bladder cancer is important as there is a direct correlation between bladder cancer progression/recurrence and obesity. Improved body composition is also linked to a decreased risk of other conditions, such as heart problems or type 2 diabetes.

THE BORG RATING OF PERCEIVED EXERSION (RPE)

6 No exertion	11 Light	17 Very hard
7 Extremely light	13 Somewhat hard	19 Extremely hard
9 Very light	15 Hard	20 Maximal exertion

STOP if you feel any of these symptoms:

- fever or infection
- nausea, vomiting or diarrhoea
- dizziness or fainting
- unusual sudden muscular weakness
- bleeding from any source
- persistent headache
- Chest, arm or jaw pain
- discontinuation of chemotherapy due to low blood level count
- irregular heartbeat

What type of exercise should I do?

Exercise comes in many different forms and can be any type of planned movement! When looking to start exercising, it is important to consider a type which will engage you the most and that you will enjoy otherwise you won't keep it up. Do not forget daily activity is a form of exercise so why not start by dancing around the room to your favourite songs?

We typically break our exercises up into three forms:

- **Cardiovascular training – like walking, cycling or dancing:** Low to high levels of activity that exercise the heart, lungs and associated blood vessels, as well as the muscles that such activity uses.
- **Resistance training – using hand weights or resistance bands:** Activity that involves work against a resistance to improve muscular strength, tone, mass and endurance.
- **Mobility training – stretching or foam rolling:** Activity that aims to increase flexibility and range of movement at a given joint.

What is stopping you?

There are many barriers to exercise that people face during their cancer journey, and you are not alone in facing them. Some barriers include:

- exercise not being a priority
- fatigue or lethargy
- lack of interest
- lack of time
- not having the equipment⁴

We can help with all these issues, so go to fightbladdercancer.co.uk/exercise and download our pdf. It will help you to understand the importance of exercise to those living with bladder cancer, and also provides safe exercises with varying levels of difficulty. And don't use equipment as an excuse! Get creative: two cans of beans or bottles of water will do just as well as a set of hand weights.

ARTICLE
TOMMY MARSHALL
Exercise physiologist/clinical trainer

Why exercise helps

There is no one reason why exercise is good for cancer patients – there are plenty! Here are just a few things exercise can do for you:

- release endorphins (the body's happy hormone), which reduce pain and improve mood
- regulate insulin which, when present in the blood in high quantities, can increase risk of type 2 diabetes, cardiovascular disease and some forms of cancer
- boost the immune system and decrease inflammatory blood markers linked to cancer recurring
- decrease body fat and the amount of fat in the blood, which in turn reduces the risk of cancer development and cardiovascular disease
- decrease cancer mortality and incidence in over 25 types of cancer, including bladder cancer.⁵⁻⁶ Research from 2017 saw a 47% decrease in bladder cancer death in individuals who reported any form of exercise compared to those who reported no exercise at all.⁷

Remember: Exercise is a safe tool to help improve mental and physical wellbeing before, during and after cancer treatment. Some form of exercise is always better than nothing at all!

For more information, please go to: ten.co.uk/clinical or contact clinical@ten.co.uk



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Eating well can help your healing



I am a Registered Specialist Oncology Dietitian at Milton Keynes University Hospital (MKUH). Registered dietitians are regulated by the Health Care Professionals Council (HCPC) and are governed by an ethical code to ensure we always work to the highest standards.

My role at MKUH was created to coincide with the opening of the new Cancer Centre in March 2020. I work closely with the onsite Macmillan support team which includes dietitians and allied health professionals, specialist nurses, doctors and consultants. I support patients during and after cancer treatment, but generally see those who have been admitted to the hospital for acute clinical care. My involvement with the Macmillan team is crucial as it allows continuity of care.

My daily work

Nutritional support during the cancer continuum is associated with improved quality of life, and maintenance of muscle mass and functional status. Optimising your nutrition status also helps improve tolerance to treatment, resulting in better outcomes. The patients I see are generally experiencing symptoms related to their disease, or from side-effects brought on by treatment. I help them navigate through symptoms such as nausea, vomiting, gastrointestinal disturbances, appetite loss, mucositis and lethargy. I also assist with eating problems created by difficulty swallowing, addressing the need for feeding tubes if deemed appropriate.

Many of the patients I see find it challenging eating the right way on a day-to-day basis. I help relieve any anxiety they might feel around eating by providing tools that empower them to manage their health, and take back some control through diet.

With so much conflicting information out there, it can be difficult knowing where to turn or what to do.



The dietitian in a MDT

The process of including nutrition into patient-centred care requires all members of the multi-disciplinary team (MDT). On the ward I work alongside the consultants, members of the surgical team, clinical nurse specialists and other health professionals. MDT working helps identify at-risk patients early in the process, ensuring malnutrition does not become an overlooked, under-recognised and undertreated problem.

One of the key benefits of working within an MDT is that it maintains continuity of care for the patient. Having a professional team in close proximity is invaluable for support and guidance, and offers reassurance to patients that any issues will be dealt with promptly.

As a team we gather daily to review the schedule and address any concerns, ensuring a team approach with good communication that avoids repetition from different professionals. It also ensures everybody, including the patient, is aware of current priorities. Our collaborative care planning also minimises the potentially overwhelming number of professional visits the patient could encounter on a day-to-day basis.

Another advantage of being a dietitian based within an MDT is that there is reassurance that nutrition is always being advocated for within the caseload. It has also allowed me to understand barriers that other clinicians experience when screening for malnutrition or providing first-line advice.

Working with other professionals ensures the best care for all our patients. It is an aspect of the job that I really enjoy, as we all bring our own specialities and work together.

ARTICLE
AMANDA ALLEN
Dietitian



Caring in the COMMUNITY

There's plenty of support to help you get used to managing your stoma

Bernadette has been a stoma care nurse specialist since 2002. Having moved to England from Ireland in 1992 to complete her nurse training, she went on to specialise in neuro surgical nursing and worked on a colorectal and urology surgery ward, where her love of stoma care nursing was born. Here Bernadette tells us about the support available for stoma patients.

When I was working as a junior sister in the hospital, there was no specialist stoma nurse service. Patients were supported by the ward staff and on discharge were then referred to the community stoma nurse, which left a big gap in the day-to-day support that stoma patients received.

Developing a new approach

After my specialist training and with the support of my manager, I went on to complete my Foundations in Stoma Care Course and subsequently was given the opportunity to develop a stoma care service within the hospital. I have since completed the advanced level qualification. We established our stoma care support service for patients and their families within the hospital, clinic and community environments, resulting in seamless support that patients could rely on throughout their stoma journey.

My role evolved to lead and provide constantly updated stoma care education to ward staff, students, community carers and colleagues from various departments.

I also developed a teaching package on stoma care for GPs on the GP Training Programme.

Moving into the community

In 2014 I decided to leave the NHS to move full time into the community, settling in a role with Hollister Incorporated, an independent, employee-owned company that develops, manufactures and delivers healthcare products and services worldwide.

We are a team of 38 nurses based throughout England providing a highly clinical service both in hospital and community stoma care, working in partnership with the NHS. We have accreditation with the Royal College of Nursing (RCN) and with the Care Quality Commission (CQC). In 2018 I took on additional training to become an independent prescriber, and I continue to provide stoma care reviews to all patients.

In addition I provide support and education to GPs, district nurses, care homes and home carers. In my role as a nurse manager, I also

ARTICLE
BERNADETTE AMBROSE
Hollister Stoma Care
Nurse Manager



provide support and leadership to a team of five nurses across the south, who provide stoma care in hospitals and the community.



How the system works

As part of my service, all patients are reviewed following our Secure StartSM pathway. This is a clinically proven pathway in which every patient is reviewed on discharge from hospital, and then continues to receive regular visits throughout the first year and then annually.

Clinically I support West Suffolk community one day a week, seeing around six patients per day for scheduled appointments. Of course, patients can contact the service at any time if they are having any stoma-related problems. We have also added a weekend nurse-on-call support line to our Secure StartSM service, open Sat/Sun and bank holidays for patients wishing to speak to a stoma nurse.

How we help patients

The role of the stoma nurse is to provide clinical support and guidance on a wide range of practical issues within stoma management, starting with choosing the right equipment. As a qualified stoma nurse specialist, I can make sure the patients have a choice of stoma bags and supplies that best suit their needs from the wide variety available. With a comprehensive, holistic review looking at their stoma, skin health, lifestyle and independence, I advise patients on the most clinically suitable pouch for them. It is essential that the chosen pouch fits well so that it works efficiently and allows them to maintain healthy peristomal skin.

Straight after surgery, there is a period of adjustment which may require that they try different pouches as the stoma and skin settle.



There are many suppliers of stoma products and most companies provide additional help and support to patients. You can find out more on their websites or by asking your stoma nurse or CNS.

Then they need to learn how to fit, empty and change the pouch, and care for the stoma and surrounding skin.

Always ask questions

Patients tend to ask me a range of questions including things like

- 'How long am I going to be in hospital?'
- 'Will my stoma bag leak?'
- 'Will it smell?'

I can give them both practical advice with the benefit of my knowledge and experience, along with care and reassurance to help them overcome their worries.



The impact of COVID-19

Throughout this period of Covid-19 measures and restrictions, we have continued to provide stoma care in the community, using all the appropriate PPE needed during these times. We have constantly risk assessed, reviewed and re-structured our practices in line with local and national guidelines.

Through telephone and video consultations, we have been able to use these alternative methods of reviewing patients where they were unable to have a home visit.

Stoma patients can be reassured that that a knowledgeable team is on hand to support them as they learn to deal with their new situation.

A trip to Theatre

Jaimin Bhatt told us about the journey of bladder cancer patients in his hospital, and introduced us to the key people in his team who form a strong circle of care around their patients.



ARTICLE
MR JAIMIN BHATT
Consultant Urological and
Robotic Surgeon at the
Queen Elizabeth University
Hospital, Glasgow

As the son of a bladder cancer survivor and a consultant urological surgeon with a specialist interest in pelvic urologic oncology (treating patients with bladder and prostate cancer), Jaimin Bhatt has personally been on both sides of the line. That makes him extremely passionate to ensure the best outcomes for his patients.

The first people most patients meet when they come to us are our expert team of clinical nurse specialists (CNS), who perform a diagnostic flexible cystoscopy, which only takes a few minutes. Patients found to have a bladder tumour are then counselled about the next steps of a CT scan, if not already done, and an operation known as TURBT, in which a bladder tumour is removed endoscopically under a general or spinal anaesthetic. Most patients are in hospital for a couple of days after the procedure.

Treatment decisions

At the weekly multi-disciplinary team meeting, urological surgeons, oncologists, radiologists, pathologists, CNSs and other experts discuss the results of the TURBT and scans and recommend the best treatment options for each patient, based on disease factors and their general health, and using evidence-based guidelines.

Most patients are recommended regular checks and occasionally medications in the bladder given via a catheter, such as a full course of Mitomycin or BCG, depending on the grade and stage of their cancer. However, some patients with more advanced disease will need a radical cystectomy or external beam radiotherapy; others may need chemotherapy or immunotherapy. The test results and the decisions of the MDT are passed on to the patients.



Radical cystectomies

As a bladder cancer surgeon, I perform radical cystectomies on patients with high-grade or muscle-invasive bladder cancer. This is a major operation with multiple steps in which the patient's bladder with the cancer is removed, usually together with adjacent organs (prostate in men, womb and sometimes ovaries in women), as well as the pelvic lymph nodes.

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

For more details on all the procedures mentioned here, ask your CNS for the relevant copies of our Patient Information Booklets or order them from fightbladdercancer.co.uk/patientinfo

The first consultation

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

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

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



The second consultation

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

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

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

GETTING BETTER FASTER

Patients need to be as fit as they can for the operation as we emphasise it's not unlike running a marathon or climbing a mountain. Like all high-performance athletes, the first ingredient of success is having the right attitude and mental stamina. This requires self-motivation and positivity, which I have always found in abundance in all my patients. I have also found a great deal of satisfaction from patients with this strategy, as not only does this empowerment get them fitter for their operation, but suddenly their focus shifts from their cancer to something they feel they can control – their wellbeing.

Key steps

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

BEFORE SURGERY	AFTER SURGERY
A = Attitude (positive), Action	A = Attitude (positive)
B = Breathing exercise	B = Breathing exercise
C = Cease smoking, being in Control	C = Chewing gum, Changing stoma bag, Catheter flushes
D = Dietary build-up	D = Diet, DVT prevention, Discharge planning
E = Exercise aiming for 1h or 10k steps/day	E = Energy requirements, Expected follow up
F = Fight Bladder Cancer booklets	F = Footsteps of recovery

The operation

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

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

During the COVID pandemic, when patients' families were not allowed to visit, our teams in the ward worked even harder to ensure that patients were looked after, and their families kept up to date.

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

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

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

As a wise person once said:

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

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

YOUR RESEARCH NURSE

New therapies that bring new hope

Maria talks about working to make advances in the treatment of bladder cancer

'Hello, my name is Maria, and I will be your research nurse for the clinical trial you are now participating in.' This is how I briefly introduce myself to the new patients taking part on the clinical trials that I run. Unfortunately, I am not able to read minds, but it is often noticeably clear to me that this is a completely new concept for them.

The role of a research nurse is extraordinarily complex and varied. Probably the best way to explain my role is by taking you through the different steps of a typical clinical trial.



ARTICLE
MARIA LAPUENTE
Research Nurse



Identification

Research nurses identify potential patients who would benefit from participating in clinical trials via multi-disciplinary team (MDT) meetings or clinic consultations alongside the medical team. Once identified, the clinician gains the patient's consent to participate in the trial.

Screening

The screening process is probably the most difficult stage for the patients to understand because so much information and so many tests are required. A lot of clinical history and information is needed to enrol the patient in a clinical trial, and often additional tests are needed as part of the screening process, such as CT scans, blood and urine tests, physical assessment, and so on. This is why the screening process takes on average 28 days to complete.

Eligibility

When all the tests and data are collected, they are meticulously reviewed by a clinician who certifies that the patient is eligible for the trial and fit to proceed with therapy according to the trial protocol. A trial protocol is the document that describes how the clinical trial is to be conducted and it is followed by the trial team to ensure the patient's safety and data integrity are maintained. The protocol outlines the inclusion and exclusion criteria, and there are times when patients do not meet the criteria. Abnormalities on blood results, for example, may make them unsuitable for the trial.

Education

The randomisation of eligible patients then takes place. This process randomly assigns each patient to a treatment option from the various choices available. Some trials are not randomised if just one therapy is being studied, in which case randomisation is not needed.

It is then the job of the research nurse to make sure each patient is fully informed about the treatment they are receiving. Patients will have already been seen by a clinician, but it is when they meet the research nurse that they feel comfortable to talk more freely and ask questions. As research nurses, we act as 'translators', making sure the patients understand the science behind their trial by explaining it in plain English. We will make sure the patient knows what is going to happen and give clear recommendations on potential treatment side-effects. Throughout the trial, we remain the patient's main point of contact.

Co-ordination

Now our patient understands the goal of the new therapy, how it works and the potential side-effects. The next step will be the co-ordination of the trial where the research nurse will make sure the patient complies with the schedule of assessments, ensuring that blood tests, physical examinations or urine tests are performed in accordance with the study design. Every trial is different, and the intensity of activities varies in terms of patient participation throughout the duration of the study.



During the co-ordination of the trial is when we get to know the patients and their families. Patients might be required to come to hospital every two, three or four weeks. We talk about the weather, their last holiday, or the new baby in the family. We also talk about friends they have lost or COVID-19.

We have celebrated together their highs and lows of cancer. We become what I like to call a 'trial family', a team that wants to make a change together, from sponsors and investigators to research nurses and patients.

Clinical trials are currently playing a key part in the field of oncology. Research is essential to improve detection and prevention of cancer and to determine if new therapies or new regimes are safe and effective for patients. Through trials, we prolong and improve the quality of life of patients living with cancer.

There is a very extensive team involved in clinical trials, but as a research nurse my role is to ensure patients are comfortable, informed and supported, not only when they make the decision to participate, but throughout the whole trial. It can be a difficult decision deciding to take part in a trial where therapies are new and developing but with support from the research team, we hope to make these discoveries together in a safe and caring environment.



ARTICLE
ANDREW YOUNGER
FBC Forum Member

Immunotherapy gave me my life back

When Andrew Younger was given only months to live, he sought a second opinion. Enrolling on to Professor Thomas Powles' trials of Atezolizumab gave him hope – and four years on, he's still looking forward to the future.

It all started way back in late 2015, shortly after being diagnosed with low-risk prostate cancer. I noticed blood in my urine and mentioned this to my urologist who immediately ordered more tests, aware, no doubt, that I might have further problems.

I had an MRI scan in the following February as part of my prostate cancer 'active surveillance programme', and my urologist suggested an exploratory examination as my kidney function required checking, although my prostate condition appeared unchanged.

The doctors found that my left kidney only had 9% function and that

there appeared to be a tumour, they thought, confined within my left ureter and they would have to take a sample for testing, a procedure that took place in April. Some agonizing weeks later I was diagnosed with an uncommon but aggressive form of urothelial carcinoma, which was deadly and required removal and so my left kidney and left ureter were removed in an operation in May.

First surgery, then the chemo

Although the surgery had been successful, my surgeon stressed that I was not cured and recommended a course of chemotherapy, which I

began in July 2016. I was still working at the time (to take my mind off my condition) and started to put my home, financial and work affairs in order.

At the start, I was highly fatigued and was mildly nauseated but tolerated the drug infusions quite well. But as the weeks went on – I think the course of treatment was about 12 to 15 weeks – I became more debilitated and by August I was suffering from tinnitus and then peripheral neuropathy, as a result of the chemotherapy treatment. The chemotherapy caused damage to my nerves which resulted in pain, numbness and weakness in my fingers and toes. However, the healthcare team seemed to think it was worth the effort as I received the good news that I was 'all-clear' of the disease when I had my scan in November 2016.

But there was a shock in store

I was so relaxed following the successful scan in November that, following my three-monthly scan in February 2017, I attended my oncologist appointment on my own. It's a day I'll never forget. I was given the terrible news that my tumour has metastasised and they had found further tumours in my abdomen, lung and neck! The final blow was that they were inoperable.

They gave me a few months, perhaps a year or so, to live.

In a state of total shock and feeling alone and numbed, I brought my wife and two daughters in later in the week to see my oncologist and discuss the next stage in my treatment. My treatment options were a drug trial, which had many awful side-effects, or treatment with Immunotherapy. I didn't know which of these options would be best, so with the help of my daughter Amie I sought a second opinion. And that was when I met Professor Thomas Powles who was running Immunotherapy trials with patients with my condition.

By the time we went for the appointment, my disease was progressing very quickly; I was less mobile and angry, tired, in pain, unable to eat, losing weight rapidly and quite frankly terrified!

Confidence and reassurance

I know doctors have different ways of delivering information to patients but with a background of research, Professor Thomas Powles and his hard-working team at Bart's Hospital in London gave us great confidence, reassurance and hope, despite the dire situation we found ourselves in. They were focused and direct, and even offered options for treatment and a coherent immunotherapy treatment plan. I'll never forget Professor Powles telling us calmly that my condition was of 'medium severity' and we should know in three cycles if the treatment would work. If it didn't, we'd try something else. That was his approach. The attitude of all the staff

there was exemplary. One of the nurses said to me: 'It's all new to us and we want to be part of it'.

Eager to start treatment

My first treatment with Atezolizumab was on 20 April 2017 and I was hoping that the effect of the drug would slow the progress of my cancer long enough for me to walk Amie, my younger daughter, down the church aisle on her wedding day. The night before the wedding – after only the third treatment – my wife, Caroline, noted that I ate a whole pizza, needed less pain relief and started getting stronger – so from being so desperately ill things were turning around!

By the autumn of 2017, my scans showed the numbers on the three large tumours that were being measured starting to come down ... 80% – 60% – 50% These were from a baseline figure given to me later in 2019 of tumour sizes between 28mm and 32mm. There are ongoing side-effects but they are nothing compared to what I endured with chemotherapy.

What a 'complete response' feels like

By 2019 I felt that I had been given my life back and I'm so thankful and feel very privileged to be alive!

When you get to the point that you are sure you are going to die, you realise just how important life is and how important everybody around you is – your partner, children, family, doctors, nurses and the scientists who have worked for years perfecting these drugs. I, for one, am very, very thankful to them all for their love and support during what has been a difficult journey over the past few years!

This drug was my last chance – there was no two ways about it. And, thankfully, almost four years later, it continues to work well for me, and to give me hope for the future.



Getting a second opinion

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

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

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

The bladder cancer unit specialises in:

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

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

This second opinion is FREE under the NHS.

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



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

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

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

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

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

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

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



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

If you like orange, you'll love it here

Come along to fightbladdercancer.co.uk/our-shop and take your pick of our range of merchandise to support your fundraising and awareness for **Fight Bladder Cancer**

Future plans for FBC

Fight Bladder Cancer is currently a registered charity but discussions are under way to convert it to a Charitable Incorporated Organisation (CIO).

The objectives of the new Charitable Incorporated Organisation would be the relief of sickness and the preservation of health amongst people affected by bladder cancer, in particular, but not exclusively by:

- a) the provision of support and assistance to patients diagnosed with bladder cancer, their families, friends and carers
- b) the provision of information on the subject of bladder cancer, its symptoms, range, treatments and aftercare needs
- c) promoting awareness campaigns regarding the causes, symptoms, treatments and aftercare to the public and within the medical profession
- d) supporting research into the nature, causes, diagnosis, prevention, treatment and cure of bladder cancer
- e) promoting and advocating for effective policies for the prevention, care, treatment and support for people affected by bladder cancer

The main benefits of the change are that the charity would have a legal personality, which means that it can enter contracts and hold property in its own name, rather than in the name of its trustees. It also means that its trustees have limited liability. CIO status is conferred by the Charity Commission on application by a charity, whether new or existing. Almost any existing charity, including charitable companies, can convert to a CIO.

Currently, Fight Bladder Cancer is registered with both Companies House and the Charity Commission, and both of these have their own regulations and requirements. In contrast, a Charitable Incorporated Organisation only needs to register and file accounts and returns with the Charity Commission, which will reduce bureaucracy for FBC.

Once the Charity Commission for England and Wales confers CIO status on FBC, we will file a request with Office of the Scottish Charity Regulator to be registered as a cross-border charity.

Fundraising round up

Without the amazing exploits of our wonderful supporters, we would not be able to provide our essential services, so we say a big **THANK YOU** to everyone who has contributed, run, baked, blown bubbles or burst them, or helped us raise valuable funds in any other ways.

Welcome and well done!

We are delighted to welcome Amy Jacob, our new Supporter Care & Community Engagement Officer. After years of volunteering with various charities, Amy joined FBC to help with our fundraising efforts. Her responsibilities involve offering support and guidance to our fundraisers. Reach Amy at amy@fightbladdercancer.co.uk. Welcome to the Wee Family!



Sophie Maggs has now left FBC and we wish her all the best for the future.

Spring 2021 – Autumn 2021

THREE GROUPS BEAT THE THREE PEAKS – AND THERE'S MORE!



Janire and friend Sarah wanted to raise the profile of bladder cancer by climbing Pen-y-Ghent, Whernside and Ingleborough in just 10 hours! They raised a fantastic £310.

We are hugely grateful to you both – thank you!

When **Sid Parkin** decided he wanted to raise awareness of bladder cancer, he had no idea that the original date for his Virtual Three Peaks Challenge would move back not once, but twice! Finally completing the challenge in April, he was joined by personal trainers Andy and Kerim, and they each climbed the equivalent of



the Three Peaks on treadmills and Stairmasters. They've raised more than £2,500 and we are so grateful!

In memory of their stepdad Kev, brothers **Sam and Matthew Jonas**, with five of their friends, climbed the Three Peaks in relentless weather in May. With 23 miles of walking, 81k steps and 10k calories burnt, Sam, Matt, Jack, Hannah, Jon, Laura and Jodie completed their challenge.



Raising money for FBC along with three other organisations, each charity has received just over £1,350. Thank you all!

Tia Caswell asked friends and family to donate loose change found in strange and funny places. She raised £50 in support of her mum who is living with bladder cancer. What a great idea!

Facebook fundraisers

Facebook is a great way to raise money for Fight Bladder Cancer. The page is super-quick to make and you can share the link to all of your contacts really easily. Facebook don't charge anything for processing donations, so 100% of the money raised comes directly to the charity.

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

Huge thanks to the friends and family of **Abdul** who supported his birthday fundraiser earlier this year. Abdul lost his father to bladder cancer in 2019 and he wanted to help raise funds for the charity, in his memory.



In support of her Dad after his diagnosis with bladder cancer, **Vicky Atkinson** used her love of long-distance running to benefit FBC by running 51 miles over 12 hours. She has raised an amazing £621 – thank you!

Huge thanks to the **Bay Medical Group** in Morecambe, who hosted an Easter egg decorating competition and raised £140 for FBC!



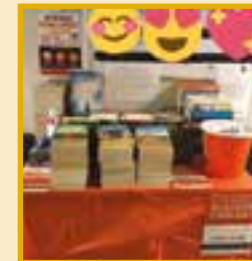
BLADDER CANCER AWARENESS MONTH

We're so grateful to **Poppy Bermingham-Byrne** of Holy Family High School for raising £170 at her Krispy Kreme fundraiser!

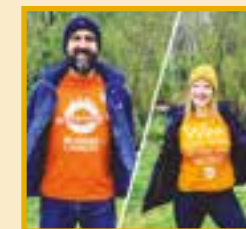


Don and Dorothy Markham organised a Wee Walk in Fife, followed by a picnic under a huge canopy. A total of 26 people (and 12 dogs!) enjoyed the event and we're so grateful for the £180 that they've raised!

Huge thanks to **Jen Marr**, from Niddrie Mill Primary School who raised a fab £80 by hosting a book sale.



John & Rachel Parker joined the BCAM Big Step Challenge and walked 12,000 steps a day for 12 days, following John's diagnosis with bladder cancer. They raised over £1,000, including a donation from their employer's Community Cashback Scheme.



When **Steve and Eve** decided to host a 'Cuppa and a cake' event for BCAM, they had no idea that the wind and rain would be one of the biggest challenges! Huge thanks to them for the fantastic £290 they raised.



Helen Tabor lost her dad to bladder cancer in 2017 and has raised money for us ever since. This year, her family got creative and raised £245 by making orange butterfly jelly, painting butterflies for the windows and blowing bubbles in a hot tub wearing orange bandanas. Even the dog got involved!

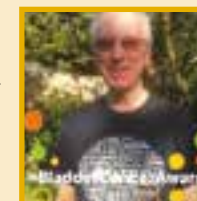


Huge thanks to **Robyn, Nicky, Lesley, Juliet, Michelle, Carla, Louise, Nicky, Beth, Andrea, Colette, Linda** and **Laura** from the Urology dept at **Broadgreen Hospital, Liverpool** – they turned the whole Urology department orange! We are incredibly grateful to Robyn and Nicky for arranging it all



Anthony Tapsell raised more than £88 with a dress-down day. Thank you so much for choosing to support us.

Long-time supporter of the charity, **Tom Gamble**, started the 12k steps for 12 days challenge, but kept going, walking 12k steps for 19 days straight. He raised nearly £290 – well over his target of £120. Thank you Tom!



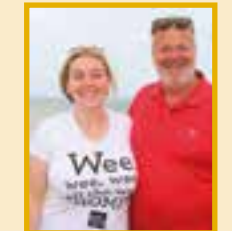
Bladder cancer patient advocate **Danielle Marr** hosted an online Wee Couples Quiz. Questions included 'who is the funniest?' and 'what is their hidden talent?' She raised over £68 at a very enjoyable night!

In support of her friend Gemma, **Sharlene Taylor** walked 12,000 steps for 12 days in May. She raised £265 and we are so grateful to her for putting on her trainers and going out in all weathers to complete this challenge!

Iain McGregor walked 12 straight days with more than 12,000 steps per day for a total of 248,165 steps to raise over £200. Iain, you've earned another big bowl of porridge!



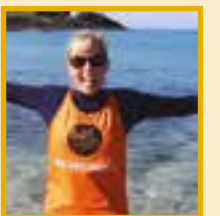
To support her dad, **Francesca Cosway** took the challenge of walking 10,000 steps a day for the whole of May. She raised an impressive £552!



Huge thanks to **Param Mariappan** from **Western General Hospital Edinburgh** for sharing information about FBC with his colleagues. He encouraged them to wear orange and his wife **Kokila** held a Wee Walk, together they raised over £3,700.



Nurse **Tanya Lord** ran a mile or more every day in May, and raised £1,900. We love to see all those orange t-shirts!



You can see more about our **Bladder Cancer Awareness Month** activities on page 57.



Following his wife's diagnosis in 2020, **Gordon Morrison** climbed Ben Nevis to raise funds and awareness for FBC. We are so grateful to him for raising nearly £4,000 – thank you to everyone who supported his challenge.

After Sarah's father was diagnosed with bladder cancer, **Sarah and Gemma** wanted to fundraise for us by running the Leeds 10k race. Together they've raised an amazing £671 – thank you!



In Memoriam

Giving to charity when someone dies is an amazing way to honour their memory. We are immensely grateful to those who choose to remember loved ones who have died by giving a gift to Fight Bladder Cancer.

When **Patricia O'Sullivan** died in January, daughters Claire, Olivia and Julie set up a tribute page to their wonderful mum. Thank you to the friends and family who have now donated more than £3,000 to Fight Bladder Cancer in Patricia's memory; this will go directly to supporting others who have been affected by the disease.



Fight Bladder Cancer is honoured to have received gifts totalling £273 given in memory of bladder cancer patient **Paul Kelly**, husband to Bev.

Mini Heroes



Maisie Hoggins participated in the FBC Mini Hero 12 Chore Challenge to support her sister, who was diagnosed last year. Maisie worked hard all May on her chores and raised over £270. Very impressive!



Rebecca Lilley was a Mini Hero and completed 12 chores over 12 days. She began by cleaning her bedroom and raised £76! Great work Rebecca!



Kearney, Kerensa, and Kallen completed chores around the house and garden to raise £179. Amazing! They celebrated with a well-deserved trip to the park.



Arnav Bhatt is 12 years old – the same age as FBC! He started a fundraiser to celebrate his dad's awesome work as a bladder cancer urological surgeon, and to celebrate his grandmother's success in her fight against bladder cancer. He raised over £1,350!



At 22 months, **Murray McArthur** was our youngest fundraiser this year. The great-grandson of a bladder cancer patient, this Mini Hero raised £29.

Raise some money & have some fun!

WE NEED YOUR SUPPORT



FBC is committed to:

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

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

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

We can help you fundraise!

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



BLADDER CANCER AWARENESS MONTH

Wee Are Family!

ARTICLE
DR LYDIA MAKAROFF
CEO Fight Bladder Cancer

May is Awareness Month

Throughout May, Fight Bladder Cancer collaborates with patients, carers, family members, healthcare professionals, community groups and businesses to highlight the impact of bladder cancer, promote awareness of the symptoms and urge improvements to policy.

Sharing stories of hope, optimism and love in May for **Bladder Cancer Awareness Month!**



Awareness Month in 2021 was certainly a challenge as we continued to face the effects of the pandemic. In line with the World Bladder Cancer Patient Coalition's global campaign, our chosen theme and central topic for change was 'have you heard about bladder cancer?'. We shared patient stories – including Gareth's and Melanie's positive and encouraging messages for others in the bladder cancer community – and launched a new video highlighting the signs and symptoms of bladder cancer.

We created a special feel by developing a **Bladder Cancer Awareness Activity Calendar** to cover the 31 days of May. Concepts included:

- updating your social media picture with a **#BladderCancerAware** frame
- wearing a Fight Bladder Cancer wristband
- displaying a car window-sticker
- sharing a photo of an orange sunset
- baking an orange cake
- taking a Wee Walk



We worked hard to maintain our activities, which included:

- wearing orange – sharing orange selfies, doing Zoom calls in teams wearing orange
- sharing our social media posts on LinkedIn, Twitter and Facebook
- thanking nurses on 12 May – International Nurse and Midwife Day
- taking up challenges – as listed in the 31 Days of May Calendar
- blowing bubbles – we focused on bubble blowing on 31 May and remembered the anniversary of the death of our dear founder, Andrew Winterbottom





Awareness Month Support Group

We encouraged all the patients and family members attending our virtual support group in May to wear orange and make a noise about bladder cancer. It was wonderful to hear about everyone’s awareness-raising activities, and share tips and tricks about how we were spreading the word about bladder cancer.

Craft and creativity

Throughout May we encouraged our friends and supporters to get creative during lockdown – with an orange theme, of course! Butterflies featured heavily in our design theme for 2021 – we felt their colour and beauty represented hope, optimism and warm energy. Crafts shared with us at Fight Bladder Cancer headquarters included jewellery making, baking, orange bunting, and face coverings! Finally, gardening images of multiple shades of orange and yellow from our supporters showed us just how much thought went into Bladder Cancer Awareness Month in 2021.



Support from medical professionals

We were disappointed not to be able to run our Urology Team Fundraising Challenge this year, or to go on tour at UK hospitals to host Fight Bladder Cancer information stands. We were, however, thrilled to be supported by medical professionals all over the country who wore orange, sent us emails, shared our social media messages, and worked in partnership with us to reassure patients and support Awareness Month.



Media spotlight during Awareness Month

Despite the ongoing pandemic, we were delighted to see that the 2021 Bladder Cancer Awareness Month received mentions in traditional and social media. During the campaign period, followship increased by 10% on LinkedIn, and Fight Bladder Cancer was mentioned 351 times by other stakeholders on Twitter, and we reached over 239,000 people via our social media channels. Our top mention on Twitter was Monzo’s virtual art gallery that included a hand-drawn version of the Fight Bladder Cancer logo.

Bubbles for bladder cancer

31 May is a special day for the Fight Bladder Cancer wee community. We blow bubbles to remember all those affected by bladder cancer and those we have lost. We were bowled over by the number of people who took part in blowing bubbles with us this year, and we created a map to visualise the bubbles that were blown across the region. THANK YOU for joining with us.

It was particularly moving, as we shared our memories of our dear founder Andrew Winterbottom on the anniversary of his death. We shared a video of our co-founder Tracy’s reading of a special poem, remembering Andrew with love:

*My body’s gone but my soul is here,
please don’t shed another tear,
I am still here. I’m all around,
only my body lies in the ground.
I am the snowflake that kisses your nose,
I am the frost, that nips your toes.
I am the sun, bringing you light,
I am the star, shining so bright.
I am the rain, refreshing the Earth,
I am the laughter, I am the mirth.
I am the bird, up in the sky,
I am the cloud, that’s drifting by.
I am the thoughts, inside your head,
I am the cuddle, in your bed.
I am the bubbles blowing up in the sky.
Remember me in laughter,
and that way, I’ll never die.*



Get in touch with the Fight Bladder Cancer team if you have ideas for ways to raise awareness as well as urgently needed funds in May 2022. Please call Amy on **01844 351621** to share your ideas, or email **fundraising@fightbladdercancer.co.uk**. We love to chat with our supporters and are keen to hear your stories and work together to make next year’s Awareness Month even bigger.

THANK YOU

We remain humbled and grateful to every single patient, carer, family member, friend, nurse, doctor, researcher, business partner and organisation that got behind Fight Bladder Cancer during May 2021 to participate in Bladder Cancer Awareness Month. Given the challenging times we were overwhelmed by the good wishes, support and energy that people gave to us.

THANK YOU ALL.

Choose Fight Bladder Cancer as your **Charity of the Year**

Do you work for a company that has a Charity of the Year opportunity? Are you in a position to choose what charity support your business or your employer gives to the community? Are you interested in learning how Fight Bladder Cancer works with the business community?

Fight Bladder Cancer is committed to improving the quality of life and the treatment outcomes for bladder cancer patients, and supporting anyone affected by the disease – partners, carers, families and friends. At FBC, we work hard to raise awareness, support and influence medical research, and campaign to affect policy at the highest levels to bring about change in bladder cancer treatment.

We rely on our supporters' brilliant fundraising efforts, which make a huge difference to what we are able to do to help bladder cancer patients and those caring for them.

Over the past couple of years, companies such as Big Bear and InHealth have chosen FBC as their Charity of the Year, which is a great way to raise awareness of bladder cancer and to raise much-needed funds for FBC.

How you can help us

Why not suggest to your company that they choose Fight Bladder Cancer as their Charity of the Year? Or perhaps you'd liked to explore a partnership?

If you have a connection with a company that you think would like to partner with FBC, then we would LOVE to hear from you. Partnership and support from your company would make a massive difference to FBC. Fundraising support from employees, suppliers, stakeholders, and customers is very welcome – as is your company's help with signposting patients and carers to FBC.

We are also keen to explore opportunities to raise awareness about bladder cancer in partnership so that more people learn about the symptoms and how early diagnosis can improve survival. This could include putting posters on the back of toilet doors or including links to us on your website or on other communication platforms.

How does the company benefit?

It's not just a one-way street! Charity link-ups are recognised as being great for staff and for the company:

- it brings people together who would not normally work together
- increases brand, reputation and credibility: 84% (C&E Barometer)
- engages and retains employees: 88% (Charities.org)
- fulfils the expectation of the workforce : 67% of millennials expect their employers to support causes (KPMG)
- 81% of consumers are more likely to buy a product associated with a cause they care about (Business in the Community)

'Charitable activities really do bring everyone together and, in our case, many different teams of people who wouldn't normally come together, worked alongside each other to fundraise. I believe all businesses should support a charity as this type of partnership is mutually beneficial – and above all it's a lot of fun!'

Zosia Hedges, Head of Brand and Communication, InHealth



There are multiple business benefits and value to be reaped from working in partnership with Fight Bladder Cancer. These include:

- **Profile Raising:** A 'Charity of the Year' partnerships gives year-long visibility with Fight Bladder Cancer's stakeholders – the key names in the bladder cancer space.
- **Developing Publicity and Brand Affinity:** Exposure through sharing communications platforms with the UK's patient and carer-led charity for people affected by bladder cancer and those working with the disease.
- **Patient-facing:** A unique opportunity to position the business brand as an engaged provider of products and services within the bladder cancer health space.



Partnership, values and terms and conditions

The core values and ethos of a Fight Bladder Cancer corporate partner will need to closely mirror the charity's – a process that will be overseen by one or more Trustees and the charity Chief Executive. The spirit of partnership and collaboration will be the essential ingredient for the effective delivery of the Charity of the Year commitment. Any Charity of the Year partner is expected to comply with the Fight Bladder Cancer's Ethical Collaboration Policy.

By working together to Fight Bladder Cancer we can achieve more for patients, help to improve their lives & increase their chances of survival.

If you have an idea or a connection that could help develop a company partnership with Fight Bladder Cancer – then get in touch with us today. All ideas and suggestions are welcome. Please call Amy on **01844 351621** or email her at amy@fightbladdercancer.co.uk



'I felt that the charity's values clearly resonated with Great Bear's and was inspired by their passion for the cause... For us, the biggest benefit of collaborating with Fight Bladder Cancer was that, at a time when we all had to work remotely, fundraising for the charity united us in a common goal ... Not only was this a great way to collectively do a sponsored walk and raise money, it also incentivised the team to get out walking and keep active.'

Lindsey Morham, Great Bear Healthcare



Give us a call on **+44 (0)1844 351621** or email getinvolved@fightbladdercancer.co.uk to find out more. It could be the best thing you do this year.

What exactly are clinical trials?

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

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

Why trials are essential for patients

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

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

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

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

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

How clinical trials work

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

Phase 1

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

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

Phase 2

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

Phase 3

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



Current open bladder cancer trials

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

Suspected bladder cancer

CIS-013

This trial is for people undergoing a transurethral resection of bladder tumors (TURBT). It will test the visualization performance of a single-use flexible endoscope with a portable high resolution monitor compared to a reusable rigid scope or resectoscope.

Locations: Addenbrooke's Hospital, Royal Hallamshire Hospital

ClinicalTrials.gov ID: NCT04190641

UROX BIOMARKER

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

Location: East and North Hertfordshire NHS Trust

ClinicalTrials.gov ID: NCT03973307

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.

Locations: Royal Surrey County Hospital, Sunderland City Hospital

ClinicalTrials.gov ID: NCT03664258

Non-invasive bladder cancer

CHECKMATE 7G8

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

Locations: Glasgow, Bebington,

Bournemouth, Coventry, Manchester, Sheffield, Stoke-on-Trent.

ClinicalTrials.gov ID: NCT04149574

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.

Locations: Plymouth, Chelmsford, London, Southampton, Lancaster
ClinicalTrials.gov ID: NCT03519256

CREST

This study is for people who have high-risk non-muscle-invasive bladder. Patients will receive BCG, with the possible addition of the immunotherapy sasanlimab. This is a study looking at how well sasanlimab works together with BCG in people with bladder cancer.

Locations: Barts Health NHS Trust, Charing Cross Hospital
ClinicalTrials.gov ID: NCT04165317

KEYNOTE-676

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

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

Muscle-invasive, advanced or metastatic bladder cancer

BL13

This study is for people with muscle-invasive bladder cancer. This study is looking at whether a type of immunotherapy drug called durvalumab

can be safely administered after initial treatment. This study is to determine whether durvalumab given after standard trimodality therapy (maximal transurethral resection of the bladder tumour (TURBT) followed by concurrent chemotherapy and radiation) improves disease-free-survival when compare to surveillance alone.

Locations: Royal Cornwall Hospitals NHS Trust, The Christie NHS Foundation Trust, The Royal Marsden NHS Foundation Trust – Sutton, University Hospital Southampton NHS Foundation Trust.
ClinicalTrials.gov ID: NCT03768570

BLADDERPATH

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

Locations: University Hospitals Birmingham NHS Foundation Trust, University Hospitals Coventry & Warwickshire NHS Trust, Sheffield Teaching Hospitals NHS Foundation Trust, Glan Clwyd Hospital, Derriford Hospital, Arrowe Park Hospital Birkenhead, Morriston Hospital Swansea, Manchester Royal Infirmary, Northwick Park Hospital Harrow, Royal Oldham Hospital, Nottingham City Hospital, St James's University Hospital Leeds, Norfolk & Norwich University Hospital, Royal Stoke University Hospital, New Cross Hospital Wolverhampton.
Number: ISRCTN35296862

FIDES-02

This is a study for people with advanced bladder cancer who test positive for the FGFR biomarker. Patients will receive either a drug called derazantinib, or both derazantinib and another drug called atezolizumab. This is a very early study looking at the safety and ideal dose of derazantinib.

Locations: Barts and The London, The Sarah Cannon Research Institute London, University College London Hospitals, The Royal Marsden NHS Foundation Trust, Sutton
ClinicalTrials.gov ID: NCT04045613

IGNYTE

This study is looking at the drug RP1 alone and then RP1 in combination with nivolumab. This trial needs participants with advanced and/or refractory solid tumours. This a phase 1 and phase 2 trial and is being done to determine the maximum tolerated dose and recommended dose of the drug. It is for a range of cancers and includes bladder cancer.
Locations: University of Leeds- Teaching Hospital, Oxford University Hospitals NHS Trust, Beatson West of Scotland Cancer Center Glasgow, The Clatterbridge Cancer Centre NHS Foundation Trust Bebington, Royal Marsden Hospital London
ClinicalTrials.gov ID: NCT03767348

IMVIGOR011

This is a study for people with high-risk muscle-invasive bladder cancer and who have had a cystectomy. Patients will be followed up closely after their cystectomy and may receive the immunotherapy atezolizumab. This is a phase 3 study looking to see if atezolizumab can improve disease-free survival.
Locations: Belfast City Hospital, Addenbrookes Hospital, Western General Hospital, St James Hospital, Barts Hospital, University College London NHS Foundation Trust, Derriford Hospital, Royal Preston Hospital, Weston Park Hospital, Southampton University Hospitals NHS Trust, Royal Marsden Hospital (Sutton).
ClinicalTrials.gov ID: NCT04660344

KEYNOTE-866

This study is for people who have muscle-invasive bladder cancer. Patients will receive a drug called pembrolizumab along with chemotherapy and bladder removal, or chemotherapy and bladder removal without pembrolizumab. This is a study looking at how well pembrolizumab works together with chemotherapy and surgery in people with bladder cancer.
Locations: Aberdeen Royal Infirmary, Torbay Hospital, Kent and Canterbury Hospital, Lister Hospital, The Royal Marsden Foundation Trust, Imperial College Healthcare NHS Trust, Norfolk & Norwich University Hospital NHS Foundation Trust, Royal Cornwall Hospital.
ClinicalTrials.gov ID: NCT03924856

KEYNOTE-905/EV-303

This study is for people who have muscle-invasive bladder cancer, and who are not eligible for cisplatin-based chemotherapy. Patients will receive either surgery alone, pembrolizumab plus surgery, or enfortumab vedotin plus pembrolizumab

plus surgery. This is a study looking at how well pembrolizumab and enfortumab vedotin work together with surgery in people with bladder cancer.
Locations: Kent and Canterbury Hospital, Lister Hospital, Barts Health NHS Trust, The Royal Marsden Foundation Trust, Imperial College Healthcare NHS Trust, Western General Hospital, Royal Cornwall Hospital
ClinicalTrials.gov ID: NCT03924895

KEYNOTE-992

This study is for people who have muscle-invasive bladder cancer. Patients will receive chemoradiotherapy, and might also receive a drug called pembrolizumab. This is a study looking at how well pembrolizumab works together with chemoradiotherapy in people with bladder cancer.
Location: South Devon Healthcare Foundation Trust
ClinicalTrials.gov ID: NCT04241185

LEAP-011

This study is for people who have advanced or metastatic bladder cancer, and who either test positive for the PD-L1 biomarker or who are not eligible for chemotherapy. Patients will receive a drug called pembrolizumab, and perhaps another drug called lenvatinib. This is a study looking at how well these drugs work together in people with bladder cancer.
Locations: Queens Hospital Romford, Lister Hospital Stevenage, Kent and Canterbury Hospital, Royal Preston Hospital, Saint Bartholomews Hospital London, University College London Hospital NHS Foundation Trust, Imperial Healthcare NHS Trust Charing Cross Hospital London, Nottingham University Hospital NHS Trust, Derriford Hospital Plymouth, Weston Park Hospital Sheffield, Royal Stoke University Hospital
ClinicalTrials.gov ID: NCT03898180

MORPHEUS MUC

For people who have advanced or metastatic bladder cancer, who have progressed during or following chemotherapy. Patients will receive a drug called atezolizumab, and perhaps one of the following drugs: enfortumab vedotin, niraparib, Hu5F9-G4, isatuximab, linagliptin or tocilizumab.
Locations: Barts and The London, The Christie NHS Foundation Trust Manchester, Churchill Hospital Oxford, Royal Marsden NHS Foundation Trust Sutton
ClinicalTrials.gov ID: NCT03869190

NCT03096054

For people who have advanced or metastatic bladder cancer. Patients will receive a drug called LY3143921. This is an early study looking at the safety and ideal doses of the drug.
Locations: Belfast City Hospital, Western General Hospital Edinburgh, Beatson West of Scotland Cancer Centre Glasgow, Northern Centre for Cancer Care Newcastle Upon Tyne
ClinicalTrials.gov ID: NCT03096054

NCT03170960

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

NCT03289962

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

NCT03473743

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

NCT03661320

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

Locations: Chelmsford, York, Glasgow, Lancaster, London, Oxford
ClinicalTrials.gov ID: NCT03661320

NCT03782207

This study is for people who have advanced or metastatic bladder cancer, who have been previously treated with chemotherapy. Patients will receive a drug called atezolizumab. This is a study looking at how well this drug works in people with bladder cancer.
Locations: Barnet Hospital, Royal United Hospital Bath, Clatterbridge Cancer Centre Bebington, Heartlands Hospital Birmingham, East Lancashire Hospitals NHS Trust Burnley, Addenbrookes Hospital Cambridge, Velindre Cancer Centre Cardiff, Diana Princess of Wales Hospital Grimsby, Royal Surrey County Hospital Guildford, Northwick Park Hospital Harrow, Huddersfield Royal Infirmary, Hull Royal Infirmary, Airedale General Hospital Keighley, Royal Marsden Hospital Kingston upon Thames, St Bartholomew’s Hospital London, Royal Free Hospital London, Guys and St Thomas Hospital London, Queen Elizabeth Hospital London, St George’s Hospital London, Royal Marsden Hospital, Fulham London, Hammersmith Hospital London, Charing Cross Hospital London, Maidstone Hospital, The Christie Manchester, James Cook Hospital Middlesbrough, Freeman Hospital Newcastle upon Tyne, Nottingham City Hospital, Churchill Hospital Oxford, Royal Preston Hospital, Weston Park Hospital Sheffield, Royal Stoke University Hospital, Royal Marsden Hospital Sutton, Torbay Hospital, Royal Cornwall Hospital, Pinderfields General Hospital Wakefield, Great Western Hospitals Wiltshire, New Cross Hospital Wolverhampton, York Hospital
ClinicalTrials.gov ID: NCT03782207

NCT03934827

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

NCT03955913

The purpose of this observational study is to identify participants with bladder cancer and selected FGFR aberrations through molecular testing of their archival tumour tissue.

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

NCT04069026

In this study researchers want to gather relevant information regarding the safety of BAY2416964 and how well the drug works in participants with a type of solid tumours that cannot be cured by currently available drugs. Researchers want to find the highest dose of BAY2416964 that participants could take without having too many side-effects, how the drug is tolerated and the way the body absorbs, distributes and gets rid of the study drug.
Locations: Royal Marsden NHS Trust Surrey, Beatson West of Scotland Cancer Centre Glasgow, Christie Hospital Manchester
ClinicalTrials.gov ID: NCT04069026

NCT04197986

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

NCT04316689

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

NCT04349280

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

NCT04389632

This trial will look at a drug called SGN-B6A to find out whether it is safe for people

who have solid tumours. It will study SGN-B6A to find out what its side effects are. It will also study whether SGN-B6A works to treat solid tumours.
Location: The Royal Marsden Hospital Surrey
ClinicalTrials.gov ID: NCT04389632

NIAGARA

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

PLUMMB

This study is for people with muscle-invasive or advanced bladder cancer. Its aim is to determine the safety, tolerability and effectiveness of an immunotherapy drug used in combination with radiotherapy. It is a phase 1 clinical trial, and will start with pembrolizumab prior to starting a course of radiotherapy.
Location: Royal Marsden NHS Foundation Trust
ClinicalTrials.gov ID: NCT02560636

THOR

This is a study for people with advanced bladder cancer who test positive for the FGFR biomarker. Patients will receive either chemotherapy, a drug called erdafitinib, or a drug called pembrolizumab. This study will test how well these drugs work in people with bladder cancer.
Locations: University Hospitals Bristol, St Bartholomew’s Hospital London, Sarah Cannon Research Institute London, Charing Cross Hospital London, The Christie NHS Foundation Trust Manchester, Derriford Hospital Plymouth, University of Sheffield, Southampton General Hospital, Royal Marsden Hospital Sutton
ClinicalTrials.gov ID: NCT03390504

WAVE

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

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
bladder preservation treatment see radical radiotherapy
BLC blue light cystoscopy
BPH benign prostate hyperplasia
cannula a thin tube inserted into a vein in the arm or hand
carcinogenic cancer-causing
carcinoma malignant growth or tumour
catheter a thin tube
CCG clinical commissioning groups
checkpoint inhibitors drugs that prevent cancer cells from disabling protective T-cells
chemoradiation combination treatment of drugs and X-rays
chemotherapy treatment with chemicals toxic to the body's cells
CIS carcinoma in situ or flat tumour
CNS clinical nurse specialist
confocal laser endomicroscopy an advanced imaging technique for diagnosis
CT computerised axial tomography, a scan that uses a series of X-ray images to create cross-sectional views of the body
curative intent radiotherapy see radical radiotherapy
cystectomy removal of the bladder
cystoprostatectomy surgical removal of the bladder and prostate
cystoscopy a procedure to examine the inside of the bladder
cytokines cells that communicate an immune response
DAT device assisted therapy
DNA deoxyribonucleic acid
durable response rate the length of time a response is observed
DVT deep-vein thrombosis, a blood clot in a deep vein in the body
dysplasia abnormal development
dysuria painful or frequent urination
EAU European Association of Urologists
EBRT external beam radiotherapy
EBUS endobronchial ultrasound test for lung cancer
ECPC European Cancer Patients Coalition
ED erectile dysfunction
EMA European Medicines Agency, responsible for ensuring that all medicines within the EU are high quality, safe and effective
endoscope a medical instrument that is made to see inside parts of a person's body
enhanced recovery pathways methods of improving recovery times and experience
eosinophils white blood cells that fight off certain parasites and infections
ER enhanced recovery
expressed active
FDA Food and Drugs Administration (US)
FGFR fibroblast growth factor receptor
FGFR test laboratory test to see if a cancer has a mutation in a gene that could potentially be treated with erdafitinib

fMRI functional magnetic resonance imaging
gene forms of DNA, a collection of chemical information that carries the instructions for making the proteins a cell will need; each gene contains a single set of instructions
GI gastrointestinal
haematuria blood in the urine
HCP healthcare professional
HDU high-dependency unit
Hickman line is a hollow tube inserted into a vein in the chest to deliver medication
histology the microscopic examination of cells
histopathological microscopic examination of tissue to identify disease
HNA Holistic Needs Assessment
HrQoL health-related quality of life
HSE Health and Safety Executive
ICER incremental cost effectiveness ratio
ileal conduit see urostomy
immune component part of the immune system
immunotherapy also called immune oncology therapy, treatment that stimulates the body's white blood cells to fight cancer; these drugs can help keep cancer cells from hiding from the body's white blood cells
IMRT intensity modulated radiotherapy treatment, a modern radiotherapy technique that enables doctors to target radiation doses at the tumour and minimise dose to normal areas
inhibitory pathway a situation in which defensive cells are prevented from attacking foreign cells
intolerable toxicity the point at which the treatment becomes more harmful than the disease
intra-vesicle installations treatments administered directly into the bladder via a catheter
ITU intensive therapy unit
KW key worker

lines [of treatment] treatment regimens
luminal relating to the hollow inside an organ such as a blood vessel or an intestine
lymph nodes contain white blood cells, and are found all through the body
lymphangiogenic originating in the lymphatic system
macrophages white blood cells found within tissues
MDT multi-disciplinary team
metaplasia transformation of a tissue from one type of tissue to another type of tissue
metastatic cancer that has spread from its original place to another part of the body
MIBC muscle-invasive bladder cancer
MRI magnetic resonance imaging, a method of scanning using a magnet and radio waves
muscle-invasive bladder cancer cancer that has spread to the muscles of the bladder
mutagenic an agent that changes genetic material
neoantigens newly formed proteins that have not been previously recognised by the immune system, often as a result of tumours.
NMIBC non-muscle-invasive bladder cancer
OCT optical coherence tomography, a medical imaging technique
ODP operating department practitioner
oncolytic cancer-killing
palliative radiotherapy treatment designed to improve quality of life in advanced cancer care
PALS Patient Advice and Liaison Service
PCT primary care trust
PDD photodynamic diagnosis – a technique where a special liquid is placed in the bladder before operating, so the surgeon is able to distinguish tumour cells from normal cells
PDE5 inhibitors drugs that help erection with sexual stimulation, and are used in the treatment of erectile dysfunction. Viagra is a PDE5 inhibitor
PDL-1 inhibitor an antibody that helps T-cells recognise cancer cells

PD-L1 test laboratory test to see if the drugs atezolizumab or pembrolizumab are likely to work in people who are not able to have chemotherapy
penile prosthesis/implant malleable or inflatable rods inserted within the erection chambers of the penis
PET positron emission tomography
Peyronie's disease a disorder of the penis resulting in bent or painful erections
PFS progression-free survival
photodynamic diagnosis BLC or blue light cystoscopy
PHR patient-held record
PICC line peripherally inserted central catheter, a hollow tube inserted into a vein in the arm to administer medication
platelets disc-shaped cell fragments in the blood responsible for clotting
polyuria excessive urination – greater than 2.5 litres over 24 hours in adults
priapism a persistent penile erection not necessarily associated with sexual arousal
primary endpoint answers to the primary questions posed by a trial
PROMs patient-reported outcome measures
proteases enzymes that break down protein
pyrexial having a body temperature above the normal range
QoL quality of life
radical cystectomy (RC) surgical removal of the bladder and lymph nodes, as well as the prostate in men
radical radiotherapy also known as curative intent radiotherapy or bladder preservation treatment, radiotherapy designed to destroy cancer cells
radiotherapy treatment with radiation
radio-sensitisation agents drugs given to patients at the same time as radiotherapy, which make the cancer cells more sensitive to radiation
randomised trial a controlled trial in which people are randomly assign to different groups to test a specific drug, treatment or intervention; neither the participants nor the healthcare professionals know to which group each patient belongs

RCTs randomised control trials
refractory resistant
resection surgical removal
sensitivity a measure of the percentage success rate of a test on patients with a disease
specificity a measure of the percentage success rate of a test on patients who do not have a disease
squamous scaly
stoma an artificial opening on the abdomen that can be connected to either your digestive or urinary system to allow wee or poo to be diverted out of your body
surrogate markers a reliable substitute for the disease
T-cell a cell that can attack a cancer cell
tachycardia abnormally fast heart rate
targeted therapy drugs that block the growth of cancers by acting on specific proteins in cancer cells
TNM system (TNBM) tumour node metastasis, a way of defining the size, location and spread of a tumour
transitional cell cancer (TCC) most common urinary cancer
tumour abnormal masses of tissue that result when cells divide more than they should or do not die when they should; tumours can be benign (not cancer) or malignant (cancer)
tumour microenvironment the cellular environment in which the tumour exists
TURBT transurethral resection of bladder tumour – a surgical removal of part or all of a tumour
urethra the tube connecting the bladder with the outside of the body
uropathy a disease of the urinary tract
urostomy a surgical procedure to create a stoma
urothelial of the urinary tract
UTI urinary tract infection
visceral referring to the internal organs of the body, specifically those within the chest or abdomen
VMAT volumetric arc radiotherapy, a modern radiotherapy technique that enables doctors to target radiation doses at the tumour and minimise dose to normal areas
WBCPC World Bladder Cancer Patient Coalition

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