

Spotlight

Bowel Cancer UK's magazine

Summer 2019



Bowel Cancer UK

Beating bowel cancer together

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Welcome

from Deborah Alsina MBE, Chief Executive of Bowel Cancer UK

I'm delighted to welcome you to what will be my last edition of Spotlight. After 11 years at the charity, 10 as Chief Executive, I will be taking up a new role as Chief Executive of Independent Age, another brilliant charity.

Working for Bowel Cancer UK has been the greatest privilege of my professional life to date. I have had the great joy of working with an incredible group of committed staff, trustees, volunteers, leading clinicians, scientists, policy makers, and a wonderful community of people affected by bowel cancer whose selfless determination to drive positive change for others has inspired and motivated me every day.

Throughout this edition of Spotlight you'll see that determination in action, from our amazing campaigners to our fabulous fundraisers. Whilst my role will be changing from staff member to active supporter, I ask you to stay with Bowel Cancer UK because it is only together, as one unified and active community, that we can drive the changes needed to save more lives in the future.

Thank you for your wonderful support over the past 11 years ☺

Bowel Cancer Awareness Month

Each year April provides a fantastic opportunity to raise awareness of bowel cancer and funds to support our work.

Thanks to supporters like you, we had our busiest Bowel Cancer Awareness Month ever. Whether you fundraised, ran a marathon or simply shared our messages on social media, we couldn't have done it without you. It's only by coming together and taking action that we can stop people dying of bowel cancer.

During the month we were thrilled to announce two new patrons – star of Netflix's Sex Education Connor Swindells and BBC's Middle East Editor, Jeremy Bowen, who joined our Chief Executive Deborah Alsina MBE on BBC Breakfast on 1 April to discuss his own bowel cancer diagnosis for the first time.

We also launched our #thisisbowelcancer campaign which shone a light on the varied and many people affected by bowel cancer. From patients to doctors, family members to researchers, hundreds of you got involved by sharing your photo and one word about yourself. We also published a powerful portrait series for the campaign taken by acclaimed photographer Sophie Mayanne ●



Deborah Alsina MBE and Jeremy Bowen on BBC Breakfast



Screening in England and the Capacity Crisis

After our big win with Screening from 50 announced last year in England, we were pleased to see this commitment reaffirmed in the recent NHS Long Term Plan, which sets out improvements to the NHS over the next ten years. It's vitally important the screening age is lowered from 60 to 50 as soon as possible as screening is the most effective method of detecting bowel cancer early, when treatment has the best chance of working.

Our work to make vital improvements to the Bowel Cancer Screening Programme (BCSP) isn't over. We'll continue to call for an optimal screening programme which includes improving the sensitivity of the new, more accurate screening test – faecal immunochemical test (FIT). If this is achieved, the BCSP has the potential to detect twice as many cancers and four times as many advanced polyps than the current test.

However, the demand for bowel cancer tests is increasing dramatically and it's estimated that at least a million more procedures a year will need to be undertaken by 2020. This is putting endoscopy and pathology services under unprecedented pressure because there simply are not enough staff to deal with this demand. That's why our Capacity Crisis campaign is calling for a fully funded long-term workforce plan which addresses these staff shortages ●



Find out more

Read about our Capacity Crisis campaign on our website at bowelcanceruk.org.uk/capacitycrisis



It's Time to Test for Lynch syndrome

Our vision is a future where nobody dies of bowel cancer and we know more people will survive the disease if those at high risk are identified.

That's why we're campaigning to improve the diagnosis and care of people with Lynch syndrome, a genetic condition that can increase the lifetime risk of bowel cancer to up to 80%.

After years of campaigning in partnership with expert

clinicians, scientists and supporters who have worked tirelessly to drive this positive change, we did it! In April Wales committed to a national system of testing all bowel cancer patients at the time of their diagnosis for Lynch syndrome – the first country in the UK to do so.

We're now working hard to make sure England, Scotland and Northern Ireland urgently follow their lead to stop generations of families being devastated by bowel cancer due to Lynch syndrome. In June, we held a week-long event which saw us hand in our Time to Test petition to No.10 Downing Street and Governments in Scotland and Northern Ireland, asking for all bowel cancer patients and their families to be tested for Lynch syndrome.

It is fantastic news that the NHS in Wales is leading the way to identify patients with Lynch syndrome. It's my hope that other NHS bodies across the UK follow their example.

Tracy, campaigner in Wales

As people with this genetic condition are more likely to develop bowel cancer at a younger age, this activity forms part of our flagship Never Too Young campaign.



PIPAC clinical trial

We spoke to Consultant Colorectal Surgeon Mr Jamie Murphy about a clinical trial for patients who have bowel cancer that has spread to the peritoneum.

What is the clinical trial about?

We're studying a type of chemotherapy called Pressurised IntraPeritoneal Aerosolised Chemotherapy (PIPAC). This is given directly into a patient's tummy during an operation. We

want to see if it can shrink secondary cancers growing on the inside lining of the abdominal cavity called the peritoneum. These tumours are known as peritoneal metastases.

We don't think this treatment will cure people of their peritoneal metastases, but it may shrink the size and number of tumours. At the moment, there's not enough research to tell for sure how effective PIPAC is for bowel cancer. We hope the trial will help us answer this question.

Who can take part in the trial?

Our trial is recruiting two groups of patients. The first group are those who have only ever been treated using one type of chemotherapy. These drugs must have stopped the tumours in the peritoneum from growing for six months or more.

The second group are those who have switched to a second type of chemotherapy. Patients in this group can be considered for PIPAC surgery at any time during their treatment.

Currently, the only hospitals in the UK offering PIPAC are Imperial College London and University Hospital of Wales as part of the clinical trial.

PIPAC won't work for everyone. For example, patients who have had major surgery may have too much scar tissue inside for the treatment to be possible. Your doctor will be able to tell you if PIPAC might be suitable for you.

What does taking part in the trial involve?

Patients who take part in the trial will need to have several operations for PIPAC chemotherapy to be delivered and extra CT scans to see how well it's working. They'll also be asked to complete quality of life questionnaires.

Like all treatments there are risks with PIPAC – although rare, these could include potentially having to have a larger operation or having a reaction to the chemotherapy.

More information

Read more about the trial on our research blog at bowelcanceruk.org.uk/pipactrial

Other research news in brief:

We're delighted to be working in partnership with the Royal College of Surgeons of Edinburgh to establish Scotland's first Colorectal Cancer Surgical Research Chair. Our 'Improving Surgery, Saving Lives' appeal aims to raise £430,000 to fund this vital new post.

In May this year, we announced that we would be working with the Association of Upper GI Surgeons to fund a Surgical Specialty Lead in advanced bowel cancer. The Surgical Specialty Lead will develop new clinical trials and drive innovative research into bowel cancer which has spread to the liver.



Support for you

From diagnosis and treatment to living with and beyond bowel cancer, we provide expert information and support for everyone affected by the disease.

Publications

We work with patients and experts to produce a range of information to support anyone affected by bowel cancer. We've recently updated our booklets 'Your pathway: a guide to bowel cancer treatment' and 'Eating well: a guide to diet and bowel cancer'.

Order or download our range of free publications at bowelcanceruk.org.uk/ourpublications

Website

Visit our website for a range of information about bowel cancer including symptoms, risk factors, screening, diagnosis, treatment and living with and beyond the disease.

Visit bowelcanceruk.org.uk

Online community

Our online community is a welcoming place for everyone affected by bowel cancer, including family and friends, to ask questions, read about people's experiences and support each other. From diagnosis and treatment, to living with and beyond bowel cancer, the community is here for you at any time.

Join us at bowelcanceruk.org.uk/community

Ask the Nurse

Our nurses are here to help. They can provide you with information, and signpost you to further support.

If you have any questions or concerns about bowel cancer, visit bowelcanceruk.org.uk/nurse

Be inspired by Guy

Eight years ago firefighter Guy noticed blood when he went to the toilet and soon after, was diagnosed with bowel cancer.

After a friend of his was also diagnosed with the disease, Guy and the Oxfordshire Fire and Rescue Service decided to fundraise for us during Bowel Cancer Awareness Month.

"After hearing about my friend's diagnosis, I organised an event for support staff from the Oxfordshire fire service to climb Mount Snowdon. It was a really momentous challenge to take on.

To help the team fundraise, I issued a challenge to the 25 stations across Oxfordshire to take part in a virtual 24-hour mountain climb on a treadmill. 21 stations got involved, running day and night outside their stations, in town centres and even outside Blenheim Palace!

We smashed our original fundraising target and raised over £16,000 which is incredible and

it was a fantastic event for everyone to get involved in. My friend is doing really well as am I – early diagnosis has meant our treatment has been effective. The day we climbed Snowdon was my friend's birthday, so we raised a toast in celebration!"

If you would like to follow in Guy's footsteps, take a look at page 20 for some fundraising inspiration ●



The Moondance Bowel Cancer Project

Wales faces significant challenges around bowel cancer with consistently poor outcomes which compare unfavourably with the rest of the world.

This is why we've joined forces with other motivated partners across the bowel cancer community in Wales, aiming to lay foundations to transform five year bowel cancer survival rates in the country within a decade. This has only been made possible with a generous £1million donation from the Moondance Foundation.

Working with leading NHS clinical colleagues, Bowel Screening Wales, The Royal College of Surgeons, community pharmacy colleagues and teachers and children in secondary education, the Moondance Bowel Cancer Project will deliver a series of activities to improve all areas of the patient pathway.

Lowri Griffiths, Head of Wales for Bowel Cancer UK said: "This project recognises that radical new approaches are needed to achieve the step change required to dramatically improve outcomes. That's why over the next 18 months this exciting



Our pharmacist training session

programme of work will challenge all aspects of the patient pathway.

At the end of the 18 months we will have tested new and innovative approaches, from increasing screening uptake and fast tracking training for a new endoscopy workforce, to laying the foundation for the way we deliver surgery." ●

More information

Find out more at
bowelcanceruk.org.uk/moondance

Working with companies

Our corporate partners play a powerful role in helping us raise awareness and vital funds. There are so many ways that companies can support us, but here are just a few:

Charity of the Year

Does your workplace have the option to have a Charity of the Year that they support? If so, why not nominate us? We could work to boost your company's profile and give staff, customers and suppliers the chance to help ensure a future where nobody dies of the disease.

Cause-related marketing

Adding a donation or a percentage of the sales from one of your products or services is a really easy way to make the most of an association with us, which could also increase your brand profile and attract new customers.

Make a corporate donation

A corporate donation could have a transformational impact on our work. It shows your customers that you're a responsible business and could create positive PR, whilst helping everyone affected by bowel cancer.



Star of Hope pin badges

Could you sell some of our Star of Hope pins at your till point or reception desk? We'd love to share how you're supporting us with our networks and across our social media channels.

To find out more about our corporate partnerships programme please contact Lyndsay Dixon on 020 7940 1760 or email lyndsay.dixon@bowelcanceruk.org.uk



Eating well

The food you eat can affect how you feel during and after your treatment for bowel cancer. After treatment you may find you can't eat the same foods as you did before. These changes may be temporary or longer-lasting.

Vegetables and fruit

Aim for at least five portions of vegetables and fruit each day, ideally more vegetables than fruit. These are a good source of fibre, which helps keep your digestive system working well. You might need to follow a low-fibre diet during and after treatment. Your healthcare team will give you information on how to include enough vegetables and fruit in your diet.

Starchy carbohydrates

Starchy carbohydrates are a good source of energy. You should eat some carbohydrate every day. You can get carbohydrate from foods like bread, pasta, cereals, rice and grains, and starchy vegetables like potatoes and sweet potatoes. Choose wholegrain

varieties, unless your healthcare team has advised you to follow a low-fibre diet.

Protein

Protein is important for cell growth and repair and for helping your body recover after cancer treatment. Good sources of protein include chicken, fish, eggs, nuts and seeds. Nuts and seeds contain lots of nutrients but have high levels of fat, so keep to a modest handful each day. They are also high in fibre, so don't eat too many if you have been told to follow a low-fibre diet.

Dairy

Dairy foods are important sources of protein, calcium and vitamins. Examples include milk, cheese, yoghurt and butter. Eat some dairy foods each day and choose low fat, unsweetened varieties.



“

I made sure I still could have vegetables by removing the skin when cooking and making blended soup for tasty lunches. Don't be afraid to experiment, some things will work and some won't.

Mike

”

Fat

Our bodies need fat for energy, brain function and as a source of vitamins. We only need small amounts of fat in our diet. Unsaturated fats are healthier and are found in foods such as oily fish, smooth nut and seed butters, seeds and seed oils, olives and olive oil, and avocados.

Fibre

A diet rich in fibre (wholegrains, pulses, vegetables and fruit) is important for bowel health. Healthy adults should eat at least 30g of fibre a day. Your healthcare team will explain how much fibre you need to include in your diet. Add fibre to your diet gradually to avoid wind, bloating and stomach cramps. After treatment you may find it hard to digest high-fibre foods like bran, nuts or seeds. Over time, you should be able to gradually increase the amount of fibre you eat ☺



More information

Find out more about diet during and after bowel cancer treatment in our newly updated booklet 'Eating well: a guide to diet and bowel cancer'. Visit bowelcanceruk/ourpublications

Royal College of GPs endorse our symptoms diary

Earlier this year we collaborated with one of our supporters, Beth Purvis, to launch a symptoms diary for people that are worried about their bowel habits. We're delighted to announce it's been formally endorsed by the Royal College of General Practitioners (GPs).

Beth was diagnosed with stage 3 bowel cancer at 37 years old. Her GP thought it might be Irritable Bowel Syndrome (IBS) as the symptoms were similar,

but it was difficult to reach a diagnosis without access to a symptoms diary or formal diagnostic tests in the community.

The symptoms diary, pioneered by Beth and supported by Coloplast, aims to help keep track of a person's symptoms before they visit their GP. This will give a good indication to their doctor whether they need further tests. Patients may not remember all their symptoms during the short appointment so having something written down can be useful.

Beth says: "I spoke to my GP two years before my diagnosis but was told that it was probably IBS and to come back if my symptoms got worse. I was in so much pain I went to A&E and was diagnosed with stage 3 bowel cancer.



I had surgery to remove the tumour followed by chemotherapy for six months, but suffered from severe damage to my nerves, which has still not gone away. The following year a routine scan revealed spots on my lungs and I'm now diagnosed at stage 4 and have been told I'm considered incurable.

I've had surgery on my lungs to remove the tumours and I'm back on chemotherapy in the hope that the treatment will prevent further spread and keep the cancer at bay to extend my life.

I'm absolutely delighted that the diary has been formally endorsed by the Royal College of GPs. I hope it will help to either rule out bowel cancer or that a person will be diagnosed with the disease early when treatment has the best chance of working." ☺

Download it

Download the symptoms diary shown below on our website at bowelcanceruk.org.uk/symptomsdiary

Symptoms diary



Supported by  GSK

Bowel Cancer UK

Bowel cancer symptoms

-  Bleeding from your bottom and/or blood in your poo
-  A persistent and unexplained change in bowel habit*
-  Unexplained weight loss
-  Extreme tiredness for no obvious reason
-  A pain or lump in your tummy

Most people with these symptoms don't have bowel cancer. Other health problems can cause similar symptoms. But if you have one or more of these, or if things just don't feel right, go see your doctor.

Find out more at bowelcanceruk.org.uk

How to use this diary

-  Use this diary to help you keep track of your symptoms before you talk to your doctor.
-  Tick the relevant boxes each day you experience a symptom. Use the free text box to record any extra details, such as how often or severe your symptoms are.

-  Keep a record of your symptoms for at least three weeks and take your diary with you when you visit your doctor.

This document/resource has been formally endorsed by the Royal College of General Practitioners.

Visiting your doctor

To give your doctor as much detail as possible, it might also be useful to think about and note down answers to the following questions:

- When did you first notice your symptoms?
- Are your symptoms come and go?
- Are you going to the toilet more or less often than usual?
- Do you have any pain when you go to the toilet?
- Have any members of your family had cancer? If so, roughly how old were they and what type of cancer did they have?
- Have there been any changes in your life recently e.g. change in diet, medicines or any recent travel abroad?

About Bowel Cancer UK

Bowel Cancer UK is the UK's leading bowel cancer charity. We're determined to save lives and improve the quality of life of everyone affected by the disease.

This diary was pioneered by Bethany Purvis, who was diagnosed with advanced bowel cancer at 37 years old. Bethany is passionate about improving early diagnosis for patients with bowel conditions.

Beating bowel cancer together

Symptoms	Week 1: _____ Date _____	Week 2: _____ Date _____	Week 3: _____ Date _____	Other symptoms or details you would like to jot down
 Bleeding from your bottom and/or blood in your poo	M T W T F S S	M T W T F S S	M T W T F S S	(for example if you notice any mucus in your poo, a sensation of wanting to go to the toilet without being able to, or changes in the colour and consistency of your poo or the number of times you're going to the toilet): _____ _____ _____ _____ _____
 A persistent and unexplained change in bowel habit*	M T W T F S S	M T W T F S S	M T W T F S S	_____
 Unexplained weight loss	M T W T F S S	M T W T F S S	M T W T F S S	_____
 A pain or lump in your tummy	M T W T F S S	M T W T F S S	M T W T F S S	_____
 Extreme tiredness for no obvious reason	M T W T F S S	M T W T F S S	M T W T F S S	_____

*Change in bowel habit means anything that isn't normal for you, for example looser poo or going to the toilet more or less often

Symptoms	Week 1: _____ Date _____	Week 2: _____ Date _____	Week 3: _____ Date _____	Other symptoms or details you would like to jot down
 Bleeding from your bottom and/or blood in your poo	M T W T F S S	M T W T F S S	M T W T F S S	(for example if you notice any mucus in your poo, a sensation of wanting to go to the toilet without being able to, or changes in the colour and consistency of your poo or the number of times you're going to the toilet): _____ _____ _____ _____ _____
 A persistent and unexplained change in bowel habit*	M T W T F S S	M T W T F S S	M T W T F S S	_____
 Unexplained weight loss	M T W T F S S	M T W T F S S	M T W T F S S	_____
 A pain or lump in your tummy	M T W T F S S	M T W T F S S	M T W T F S S	_____
 Extreme tiredness for no obvious reason	M T W T F S S	M T W T F S S	M T W T F S S	_____

Have you listened to our new podcast?

During Bowel Cancer Awareness Month in April, we launched our podcast series hosted by BBC's George Alagiah.



Matthew Wiltshire, George Alagiah,
Deborah Alsina MBE, Andrea Robson,
Lisa Allison and Stacey Heale

We published three episodes called 'In conversation with George Alagiah: A Bowel Cancer UK podcast', which saw George interviewing supporters and leading experts on the disease, as well as discussing his own treatment and diagnosis.

In the first episode George interviews Matthew Wiltshire, from Surrey, who has stage 4 bowel cancer, and the charity's Chief Executive, Deborah Alsina MBE, about living well with advanced bowel cancer. The second episode sees George interview Andrea Robson, from London, who has stage 2 bowel cancer and a stoma, along with her stoma nurse Lisa Allison, Clinical

Nurse Specialist in Pouch Care at Northwick Park and St Mark's Hospital, London, on managing a stoma.

Lastly in the third episode George interviews Stacey Heale, from Southampton, whose husband has stage 4 bowel cancer, together with our Chief Executive, on caring for someone with bowel cancer •

Listen now

Download our podcast on
iTunes, Spotify, Audioboom,
and Castbox or visit
bowelcanceruk.org.uk/podcast



Meet Julie

We caught up with Julie to find out why she supports our work.

Q Tell us about yourself

A I'm 53 and live in Newport with my husband Tim and our three cats. I work for an Assembly Member in the Welsh Assembly and she supports my volunteer work for Bowel Cancer UK.

Q What's your connection with bowel cancer?

A My very good friend Sam Gould was diagnosed with bowel cancer two years ago, aged 33. I still remember so clearly when he called me to tell me he had bowel cancer. He died six weeks later.

Q How have you been supporting the charity?

A I'm a volunteer and give talks about the symptoms of bowel cancer. I've been campaigning too, with a highlight being an event at the Senedd (National Assembly Building in Wales) in 2018. It was Sam's idea so I'm proud to be carrying on his legacy. I also give a monthly donation, because I know how important it is for the charity to have regular income to keep their amazing work going.

Q Why should other people support the charity?

A Because bowel cancer has to stop, I don't want anybody else to go through the pain of losing someone they love ●

Support us

You can help save lives too by setting up a monthly donation at bowelcanceruk.org.uk/donate

- £5 a month could help us campaign for better testing
- £10 a month could help us give advice to someone after a diagnosis
- £20 a month could help us fund lifesaving research

Fundraise for us



© Brendan Foster Photography

Walk Together is back

Walk Together is a series of five mile sponsored walks that bring people together to show support for those undergoing treatment, remember loved ones and help us to stop people dying of bowel cancer. Join us in Edinburgh, Belfast, London or Cardiff, or if you can't attend one of these events, you can organise your own in your local area or choose our virtual option and walk five miles spreading the mileage out through the month. You can also volunteer for

the day and help marshal the route and cheer from our refreshment stop, all help is greatly welcome! Learn more at bowelcanceruk.org.uk/walktogether

Event dates

Edinburgh	Sunday 1 September
Belfast	Saturday 7 September
London	Saturday 14 September
Cardiff	Saturday 28 September



Take part in The Big Jump

There really is no better way to take on a skydiving challenge than to join our Big Jump team and raise vital funds for our work. The fundraiser takes place on Saturday 5 October at Black Knights Airfield in Lancaster. If you can't attend this location, we can support you to organise your own jump closer to home on the same day.

Sign up now [bowelcanceruk.org.uk/
thebigjump](http://bowelcanceruk.org.uk/thebigjump)



Thank you

We want to say a big thank you to all of our fundraisers who have raised an incredible amount for us so far this year – you're all amazing and we couldn't do everything we do without you!

Back in April, our incredible team of runners took part in a sunny Virgin Money London Marathon. A huge thank

you to everyone who ran and made the event such a huge success; the team have raised over £250,000 so far which is amazing.

Inspired to take on a challenge or do your own thing? Find out more about our fundraising events at bowelcanceruk.org.uk/fundraise

Events diary

To find out more about any of these events or other ways you can get involved, visit bowelcanceruk.org.uk

August

- 18 Kiltwalk Dundee
- 25 Lap the Lough, Northern Ireland
- 25 Simplyhealth Great Aberdeen Run
- 30–1 Ring O' Fire Ultra Marathon and Firelighter, Wales

September

- 1 Walk Together Edinburgh
- 1 Cardiff 10K, Cardiff
- 7 Walk Together Belfast
- 8 Simplyhealth Great North Run
- 14 Walk Together London
- 15 London to Brighton Cycle
- 15 Edinburgh Kiltwalk
- 22 Belfast Half Marathon
- 28 Walk Together Cardiff
- 28–29 Bank of Scotland Great Scottish Run, Glasgow
- 29 Mine to Mountain, Snowdon



October

- 5 The Big Jump (various locations)
- 6 Cardiff Half Marathon
- 6 Loch Ness Marathon
- 7–13 Brew Together – pop the kettle on this October and hold a Brew Together event
- 13 Royal Parks Half Marathon
- 27 Dublin Marathon

November

- 8–10 Supernova Run, The Kelpies
- 29 Belfast Carol Concert

December

- All Decembeard – Grow your month beard this December, raise awareness and vital funds

