



**BOWEL CANCER**  
**OUR SERVICES**



**your  
support**

# welcome

**“A diagnosis of cancer turns your life, and that of your family, upside down. You will be shocked; may be feeling ill due to symptoms or the effects of an operation, and there will be more and more questions you want to ask, even though you are afraid of the answers. At a time like this, we need all the help we can get.**

Your medical team, family and friends can provide a huge amount of support. But you may find as you start this journey that sometimes you want more than anything to talk to others who are travelling the same road, people like you who have bowel cancer.

Beating Bowel Cancer can help to guide you through this land with no maps, with specialist advice, support for you and your family, and by putting you in touch with other patients.



• Alison with son Hugh

I discovered their Patient Voices network at what was a very difficult time for me - a period of remission when there was no treatment, when everyone thought I was fine, but suddenly I felt very scared and alone. It was as if the circus had left town. Meeting and talking to other patients provided a lifeline. They helped me and I found that sometimes I could help them.

That immediately made me feel better.”

**Alison Michell, Patient Voice**

## Journeywoman

I hadn't planned to go travelling  
When – without warning — they sent me  
on a journey to a land with no maps.  
Sometimes I go on foot, climbing  
slow stairs to the top of towers.  
On other days I find myself blurring  
through stations with unreadable names.

The lack of a guidebook disturbs me  
at first. I want to know my destination,  
time of arrival, will there be a bed?  
But I've grown to like the unexpected:  
a butterfly resting on a blue-painted door,  
a walk on sand and seagrass.  
Once I saw an eagle soar.

© Alison Michell, 2009 Journeywoman Poems and Alphabet

**This booklet has been produced by Beating Bowel Cancer with the generous support of Patient Voice Alison Michell, who raised money for the project through the sale of her poetry book and DVD, and of a generous donation from The Joseph Strong Frazer Trust. We would also like to thank the members of our Patient and Relative Voices group who had input into the following pages.**

# patient services your nurse helpline

Our confidential nurse helpline is staffed by friendly, trained nurses who have experience in caring for people with bowel cancer, and who are used to talking about bowels and bottoms. They can help you to find out more about signs and symptoms of bowel cancer, how it is treated, about national screening programmes and support groups in your area.

The nurses can help to reassure at any stage of your treatment pathway, whether you are worrying about symptoms and waiting for a diagnosis, or at any time if you need information or advice and are unable to speak to your local specialist nurse or doctor. Beating Bowel Cancer nurses will listen, even if you are simply just having a bad day.

If you are supporting someone else who is a bowel cancer patient, the nurses will help you to understand more about what is happening to the patient, answer your questions, clarify concerns or advise about how to get more help if needed.

T: 08450 719301

E: nurse@beatingbowelcancer.org




- The Beating Bowel Cancer patient services team

“We are so grateful to you that we had all the information we needed to go into the meeting and ask the right questions... we now have a whole network of people supporting us which we didn't have before. Thank you so much.”

**Pat, wife of Malcolm, 64**

“It's just knowing that they are there in the background, always contributing with an amazing wealth of knowledge, thinking of us and helping us through the journey we face. That is what makes a difference.”

**Michelle, 34** 

“When the nurses at the hospital gave me one of the charity's information booklets, I immediately contacted them for further support, and found instant reassurance and support at the other end of the phone.” **Rachel, 35**

# patient services ...more than just a helpline

## **Janet, a distressed patient, rang the nurse helpline.**

She had received a late diagnosis a few months previously and the cancer had already spread to kidneys, liver and lungs. After a chat with one of our nurses about all things medical, she then spoke to the patient services co-ordinator who was able to put her in touch with a Patient Voice who had also received a similar late diagnosis, but is still living life to the full.

After a few days, the nurse called Janet back to see how she was doing. Since being matched with a Patient Voice she felt that she had been given hope at a difficult time, and now felt differently about how she was going to cope with her disease.

Janet told us that, where previously she had seen no point in thinking about the future and trying to improve her quality of life, she had now decided that she had to live her life again. One of her first decisions was to see the optician, because her chemotherapy had affected her eyesight. She had also been able to go out with her family, something she felt that she could not do before. Janet told us that she now feels that she can try to help herself and that she will take all available treatment options. Her aim is to make it to 90!

“Since contacting Beating Bowel Cancer and being matched with a patient voice I feel safer and more in control of what is happening to me.” **Janet, 66**

“Beating Bowel Cancer has offered me a great deal of support and care all the way through my diagnosis and treatment. The website contains a significant amount of useful information and it has also been comforting to know that I can speak to a specialist nurse for advice.” **Ben, 30**

# patient services the patient voices group

**Patient and Relative Voices is our unique network of people who support the work of Beating Bowel Cancer in all kinds of ways, and who have been where you are now.**

## Patient to Patient support

Patients in the group are happy to talk to other patients about their cancer journeys, either on the telephone, by email and social networking sites or by setting up local support groups. We match you with other patients by age, geographic region, stage of bowel cancer, treatment, gender or anything else that may be specific to your needs.

## Relative to Relative support

We support relatives of people with bowel cancer in all the ways listed above and we understand that, as a partner or relative, you may have just as many questions and concerns as your loved one.

## Raising Awareness

We work hard to raise the profile of bowel cancer and to get people talking openly about the disease. If you're a patient or a relative you will already know the importance of symptom awareness and early diagnosis. Patients and relatives can help to raise awareness in many ways, perhaps by talking about their experiences to the media (newspaper, radio, TV), contacting their local MP, joining in fundraising events or becoming a Health in the Workplace presenter (see page 15).

To join the Patient Voices group, call the patient services coordinator on 020 8973 0014, email [patients@beatingbowelcancer.org](mailto:patients@beatingbowelcancer.org); or download an application form from [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org).

"Gotta love twitter, when @bowelcancer nurses ring you up for a reassuring chat - sometimes it feels like people really do care." **Lisa, 39**

"Just thought I would let you know that I gave Rachel a ring yesterday evening. What a lovely lady, she was very kind and understanding. I found our chat very helpful, we certainly have lots of similar physical problems after surgery and chemo." **Ashley, 42**



• Patient and Relative Voices get together

# patient voices in the community

Heather became a Patient Voice and started her own support group after being treated for bowel cancer herself. “Ostomistics is a support group in the Peterborough area for anyone with a colostomy, ileostomy or urostomy. Our aim is to provide a safe environment where ‘ostomists’ can pop in for a cuppa and a chat.”

Margaret and Carol are both from the Darlington area. They became Patient Voices after they too were treated for bowel cancer. They joined forces with their local specialist stoma nurses and now have a support group called “Bowel Buddies” which meets regularly, offering support, advice and a chance to meet other people living with the same challenges.

When Stuart learned that he had bowel cancer, it took him a whole year to buy a new pair of shoes, because he was thinking “What’s the point?” His first new set of footwear was a pair of walking boots, when he decided that he was going to live, and that he was going to take up the challenge of a trek... Today, he covers the length and breadth of Wales, talking to people and raising awareness of bowel cancer; providing support for people who have been diagnosed with the disease, and helping healthcare professionals to understand what the real cost of bowel cancer is from a patient’s perspective. He also supports bowel cancer support group “Footsteps” at Bangor Hospital.



• Stuart, 56



• The Bowel Buddies

# your support network

**The healthcare team looking after you while you are going through your treatment and follow up appointments will also be able to help you understand what is happening, and help you to decide which treatment options are the best for you.**

Bowel cancer is not something that should be faced alone. You will need all the support you can get from family, friends, neighbours, colleagues, and even pets. The patient services team and the Patient and Relative Voices at Beating Bowel Cancer are here to support you, too.

Make a list of all the names and contact numbers of the people who are supporting you, and keep it somewhere that is easy to access so you can find it quickly if you have any questions.

## **Your Community Team might include:**

- GP
- Practice nurse
- District nurses
- Health visitor or social worker
- Specialist cancer nurse / Macmillan nurses
- Marie Curie nurses
- Home care team
- Pharmacist
- Community therapists—physiotherapist, occupational therapist, dietician, speech and language
- Meals on Wheels, day centres and community centres
- As well as charity and voluntary services who provide practical support, e.g. community transport schemes, befriending and respite services, information and support groups.



## Your Hospital Team might include:

- Colorectal specialist surgeon
- Colorectal specialist nurse
- Radiologist
- Pathologist
- Oncologist
- Chemotherapy nurse
- Phlebotomist
- Radiotherapist
- Pharmacist
- Stoma nurse
- Dietician
- Speech and language therapist
- Physiotherapist
- Occupational therapist

**Your multi-disciplinary team (MDT), which meets weekly and will regularly review your case, will include several of the specialists in this list. If you have secondary (metastatic) disease, you can ask to have your case reviewed by an experienced specialist consultant, eg:**

- Liver surgeon
- Thoracic (chest) surgeon
- Neurologist (brain) surgeon
- Orthopaedic (bones) surgeon
- Gynaecologist
- Genito-urinary surgeon
- Specialist clinical oncologist

**Specialist treatment for advanced cancer is usually only available at larger hospitals across the UK and you may have to travel in order to access the services of specialist teams.**

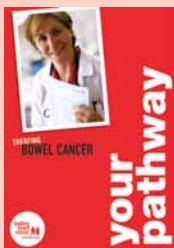
# patient services publications

**Beating Bowel Cancer has a range of free publications, which are regularly updated and can be downloaded from [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org) or ordered by phone.**

## **Booklets:**

### **Treating Bowel Cancer - Your Pathway\***

A detailed booklet for people embarking on the treatment journey, including information on the bowel cancer staging system, surgery, chemotherapy and monoclonal antibodies, radiotherapy and clinical trials, as well as patient case studies and further references.



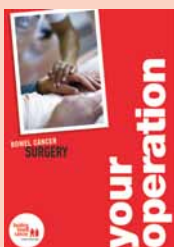
### **Advanced Bowel Cancer - Liver Treatment**

Detailed information on the treatment options for patients whose bowel cancer has spread to the liver, including a variety of patient stories. It covers the various tests you may undergo, surgery, radiotherapy, chemotherapy, monoclonal antibody therapy and other recent developments in treatment.



### **Bowel Cancer Surgery - Your Operation\*\***

Clear information on the different forms of surgery available to bowel cancer patients, tips on preparing for hospital and advice to aid recovery.



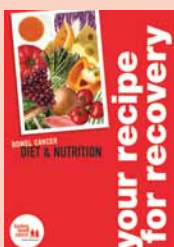
### **Accessing Treatment – Your Options**

An information pack to help patients campaign for access to a recommended drug or treatment which is not available on the NHS.



### **Bowel Cancer Diet & Nutrition - Your Recipe for Recovery\***

Advice for bowel cancer patients on what to eat or avoid to cope with specific problems after surgery, due to a stoma or stoma reversal or as a result of the side effects of chemotherapy.



### **Coming soon:**

Beyond Bowel Cancer \*\*

Bowel Cancer - A Carer's Handbook \*\*

\* New / updated in 2010

\*\* New / updated for 2011

# patient services publications

## Factsheets

These 4 titles provide signposting to organisations which can help you with the non-medical consequences of a cancer diagnosis:

- **Emotional support**
- **Practical support**
- **Employment support**
- **Financial support**

- **Clinical trials**

What clinical trials are, the different phases and what happens if you are invited to take part

- **Returning home after surgery \***

Advice on how to look after yourself once you have been discharged from hospital

- **Colonic stenting**

Explanation of this procedure to relieve pressure which has built up due to a blockage in the bowel

- **K-RAS**

This gene test is designed to test the likelihood of a patient responding to certain treatments for secondary bowel cancer

- **Stoma reversal**

Clear advice on the possible consequences of having a temporary stoma reversed, the effect on your bowel function and ways to overcome any problems

- **Regaining bowel control**

Advice and exercises to help overcome bowel leakage or incontinence following surgery

- **Anal cancer\***

Factsheet on the treatment of anal cancer, which is a rare form of bowel cancer, treated by a specialist team

- **Palliative care\***

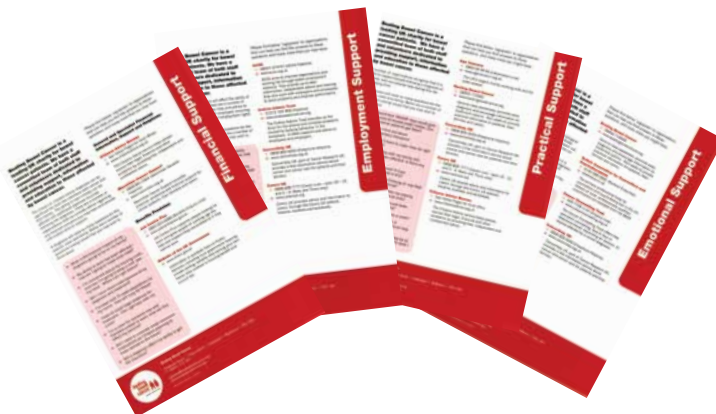
A summary of the care of patients with advanced bowel cancer, the treatments and support available

- **Lung metastases \*\***

- **Complementary therapies \*\***

\* New / updated in 2010

\*\* New / updated for 2011



# real life stories

“My wife Sheila was diagnosed with Bowel Cancer in 2003 and immediately started searching the internet for information on the disease. Coming across the charity Beating Bowel Cancer, we found them very informative, helpful and understanding at a time that was frightening and stressful for us both. Through the charity, we met with other bowel cancer sufferers and found this a great comfort in understanding what was happening and what to expect. As Sheila’s treatment progressed, she felt she could give something back from her experiences and decided to become a Patient Voice. When she died in 2009, I was determined to continue what she had started.

Giving other bowel cancer sufferers the benefit of Sheila’s experience and how she dealt with life as a cancer patient, has given them hope, an understanding of how to cope with this terrible disease but also advice on where to go to for help. I don’t know all the answers and am certainly no professional, but I can offer my experiences as a carer who has watched a loved one in their daily fight for life and feelings of inadequacy at being unable to alleviate their condition. If in some small way I can support others who face this terrible situation and help them through the feelings of desolation and isolation, then it is worthwhile and a tremendous legacy to my wife who fought so much to show that you can live with cancer and every day is worth fighting for.”

**Goff, 64**



**Journeywoman—Poems and Alphabet (2009) is available to buy in both book and audiobook format. To order, please call Beating Bowel Cancer or visit our website shop.**

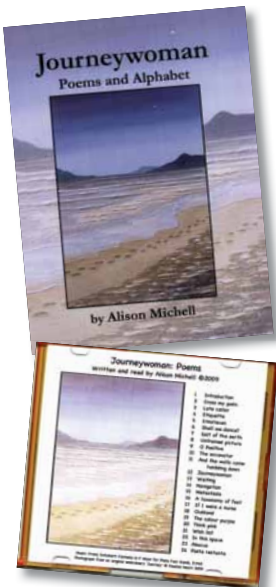


"I was diagnosed with bowel cancer that had spread to my liver in 2002 when I was 56. Surgery to remove the primary tumour and a diseased ovary was followed by chemotherapy and my first liver resection.

This brought three years of remission. There was a blip after two years when I needed a second liver resection to remove an unrelated tumour, before the cancer recurred in 2006. Since then I've had a third liver resection, further courses of chemotherapy (72 doses of assorted drugs so far) and several Radio Frequency Ablation (RFA) procedures. Treatment continues in the hope that RFA may be possible again. I am not giving up.

After my initial diagnosis I started writing seriously and then took on the challenge of an MA in Creative Writing and continued even when the cancer recurred during the second year of the course. I wrote about my experience of living with cancer, and this led in 2009 to the publication of a collection of poems, 'Journeywoman', as an unusual way of raising funds for Beating Bowel Cancer. If I hadn't got cancer, I might never have started writing. Makes you think, doesn't it!"

**Alison, 64**



# living with, and beyond bowel cancer

**From the initial waiting for confirmation of your diagnosis, through every treatment and into the follow up phases, this life-changing experience will have a profound effect on you, and on your family and friends. There is so much new information to take in – each test and scan anticipated with hope and worry in equal measure, each success cherished as another personal challenge overcome.**

Those patients treated for early disease may think of themselves as “survivors”, or that they are cured and can move on. Others with more advanced disease may prefer to think of themselves as “living with” bowel cancer. There is no right or wrong way, and you will need time, support and practical help and advice from a whole range of different sources to help you and your family achieve an optimum quality of life.

Reassessing priorities and looking for new opportunities can be the key. Small goals and pride in personal achievement can also be a great boost, and treats are important too – experimenting with a new look or hairstyle, arranging a trip, trying a new activity for the first time. The most important thing is to do what feels right for you.

People often talk about how their diagnosis has highlighted what is important. Some talk about how their animals have helped them to cope. Faith also seems to play an important role for many. Everyone will be different, but it is good to talk to family, friends and colleagues too. Let them know how they can help and reassure them, just as they can go on reassuring you.

Support from other people going through a similar bowel cancer journey can be invaluable. The Patient Voices group is a great example of patients and families supporting each other through the darkest times, and celebrating the good times with you, too.



I'd rather you didn't claim that I'll be fine  
just because I'm being so positive.

Be wary of saying how well I look –  
my complexion owes its bloom to blusher.

Please stop giving me pink ribbons –  
my breasts are fine, the problems lie elsewhere.

Resist the temptation to quiz me  
about side effects – I'm not a prize exhibit.

Trust my protocol for scans – I'm a gladiator  
alone in the ring. I'll tell you if the thumb was up.

Bear with my grumpy moments – on good days  
let me dance or scrub the kitchen floor.

Don't ask 'How *are* you?' with that droop  
of the voice which shows you think I'm doomed.

Talk to me instead about the holiday you're planning,  
how your novel is progressing, your new cat.

Bring me soup, or cake. Send silly postcards  
and parcels from unlikely places.

When I want company, come with me to a movie.  
Buy me shoes with unsuitably high heels

or walk with me up the track through the pine woods  
till we reach the top and that view

of the cove where we shared our first picnic  
and afterwards went skinny dipping in the sea.

And don't make me into a hero – I'm no braver  
than you, just getting on with my new job.

© Alison Michell, 2009 Journeywoman Poems and Alphabet

# patient voices in action

**Our Health in the Workplace initiative allows us to visit organisations up and down the country to give short talks aimed at raising awareness of bowel cancer. The talks are all given by trained volunteers who are members of our Patient and Relative Voice group – all of whom have reached a point where they want to be able to give something back to the community. Hearing these individuals talk about their experiences in an open and honest way means that important messages about symptoms and risk factors resonate strongly with the audience to maximum effect.**

“I have been involved in the Health in the Workplace programme since 2005. These presentations are always well received by the organisations we have been invited to visit and the feedback has shown there are many people with little or no knowledge of bowel cancer or the symptoms of this disease. Some people already have symptoms, but had not realised the importance of seeking medical advice. I am convinced this programme has saved many lives as it is vital to get treatment early.

I suffered with bowel cancer in 2004 so I am walking evidence that if you take action as soon as you suffer with any of the symptoms, you can be cured. I gain great satisfaction from knowing that I can help others survive bowel cancer.”

Sue, 63



• Patient Voices at a presenter training session

**The support Beating Bowel Cancer provides to patients and those affected by the disease is always free, but we can only continue to do this because of the generosity of our supporters.**

**Phil:** I was diagnosed with bowel cancer in 2005 at just 48 years old. Following my stoma reversal in 2006, I took on my first challenge, trekking up Mount Kilimanjaro.



- Phil (4th from right) and Dick (2nd from right) in Peru

**Dick:** “I had bowel cancer when I was 48, some seventeen years ago. After all the treatment was over, I decided that I wanted to get fitter, do more to help Beating Bowel Cancer and see more of the world – so it made perfect sense to do a trek. I have now completed three, and I can promise you that it is definitely a positive and life-changing experience; a great sense of fun and shared challenges that create lasting friendships between the trekkers.”

There are many innovative ways our supporters have chosen to help us. Our newsletters are full of stories about the personal achievements of patients like Dick and Phil. People from all walks of life have used our support services and continue to help us through their own events, like cake sales and quiz nights, car boot sales and ticketed parties.

Fundraising events, regular monthly donations and gifts from a will; all help to secure a long term future for the charity. If you would like to know more about how you can get involved, call our fundraising team on 08450 719 300 or visit [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org).

# further help

You can get more information from your local specialist nurse, from Beating Bowel Cancer (see back page) or from organisations such as:

## Ileostomy Association

T: 0800 0184 724  
www.info@iasupport.org

## Colostomy Association

T: 0800 328 4257  
www.colostomyassociation.org.uk

## Age UK

T: 0800 196 6565  
www.ageuk.org.uk

## Macmillan Cancer Support

T: 0808 808 00 00  
www.macmillan.org.uk

## Marie Curie

T: 0800 716146  
www.mariecurie.org.uk

## Young Carers

T: 0844 800 4361  
www.youngcarers.net

## In this space

People ask me what I do.  
I am waiting, I reply,  
in that pause between  
fact and uncertainty.  
We see the past, inspect  
its weights and measurements –  
and some think they can  
foresee the future.

I used to think so too,  
before the random division  
of cells intervened.  
So I wait, in this space  
which is my place.  
That is what I do.

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# supporting us

## I would like to support the work of Beating Bowel Cancer

(registered charity number 1063614)

I wish to make a monthly donation of £5  or £10  or my own choice £

### Standing Order Mandate:

To the Manager (Bank name and address).....

.....

.....

..... Postcode .....

Please pay Beating Bowel Cancer £..... each month/quarter/year\* starting on \_\_/\_\_/\_\_ until further notice. *\*(delete as appropriate)*

Please debit my account number \_ \_ \_ \_ \_ Bank sort code \_\_/\_\_/\_\_

Name of Account Holder: ..... Please pay Barclays Bank plc (sort

Signed: ..... code 20-72-17) for the credit of

Date: ..... Beating Bowel Cancer account

number 10799831

### I wish to make a single donation

I enclose a cheque/postal order for £.....made payable to Beating Bowel Cancer

Or please debit my Switch/Visa/Mastercard/Delta (*minimum £10*) for the amount of £.....

Card number \_ \_ \_ \_ \_ Expiry Date \_\_/\_\_/\_\_

Name on card ..... Switch issue number.....

*Please note – you can also donate online by visiting [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)*

### Gift Aid Declaration:

I am a UK taxpayer and I want Beating Bowel Cancer to treat all donations I have made up to four years prior and all donations I make from the date of this declaration as Gift Aid donations, until I notify you otherwise. Signed ..... Date .....

*By ticking the Gift Aid box we can reclaim tax you have paid on your donation, meaning we can increase the value of every £1 you give to £1.28 at NO cost to you. To qualify for Gift Aid, what you pay in UK income tax and/or capital gains tax must at least equal the amount we will claim in the tax year.*

This donation is not eligible for Gift Aid.

### My contact details

Mr/Mrs/Miss/Ms.....

Address ..... Postcode .....

Daytime Telephone ..... Email Address .....

Preferred method of contact:  Post  Email

I am a:  Patient  Relative of Patient  Health Professional  Other

**YES/NO** Add me to your mailing list and send me a free copy of your newsletter (3 times a year)

**Please return this form to the address overleaf.**

PSOS

**Beating Bowel Cancer is a leading registered UK charity for bowel cancer patients, working to raise awareness of symptoms, promote early diagnosis and encourage open access to treatment choice for those affected by bowel cancer. The charity was founded in 1999, and through our work we aim to help save lives from this common cancer.**

**We provide a wide range of support services for patients, and deliver numerous awareness and education campaigns aimed at both the general public and healthcare professionals. We are very grateful to everyone who supports our important work. If you would like to get involved, or to make a donation, please visit our website or complete the form overleaf.**

#### **Chief Executive**

Mark Flanagan

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Registered Charity Number 1063614

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This booklet was first published in August 2008  
Revised September 2010

