Living Well
Beyond Bowel Cancer

Here for you
beatingbowelcancer.org
Introduction

This booklet has been written to help you ‘live well’ beyond bowel cancer. Your return to good health will depend on many factors – the stage of your cancer, the type of treatments you have had, but also on the steps you take both physically and emotionally.

Recovery from bowel cancer is a journey with ups and downs along the way and some days will be better than others. Some people consider themselves fully recovered after a few months, while for others the process can take years. Your experience will be unique to you, but the challenges you face will be shared with the many thousands of bowel cancer survivors living in the UK today.

Having bowel cancer may have a great impact on your daily activities and your ability to do the things you did routinely before diagnosis.

The effects may be physical, psychological and/or social. Your ability to return to work may be affected, which may impact on your income. Relationships and friendships can come under strain or deepen as a consequence of your illness.

The following pages contain suggestions on ways to cope with all this change and stories from some of our bowel cancer voices on how they came through their own personal journey.

Contents

| p3  | Once treatment is over |
| p4  | Worries about recurrence |
| p5  | Patient story |
| p6  | Follow-up care |
| p8  | Emotions and feelings |
| p10 | Patient stories |
| p12 | Disturbed sleep and fatigue |
| p14 | Lifestyle choices |
| p16 | Eating well |
| p18 | Keeping active |
| p20 | Regaining bowel control |
| p23 | Altered body image |
| p24 | Intimate relationships |
| p25 | Advice for men |
| p26 | Advice for women |
| p27 | Patient story |
| p28 | Going back to work |
| p29 | Patient story |
| p30 | Useful contacts |
| p31 | Support our work |
Once treatment is over

Once treatment is over, your focus can shift to improving your general health and trying to regain a sense of normality. You will be becoming an expert in your body, developing new routines and skills to cope with the recent changes in your health. You may also have to find new ways of living and working with the side-effects of your operation, chemotherapy or radiotherapy.

A cancer diagnosis often makes people reassess many aspects of their life, and what is really important to them. This refocusing can often be a very positive and empowering experience. Many people say that living beyond bowel cancer has given them a greater appreciation of life, helped them to understand what is most important to them, or to discover strong spiritual or religious beliefs. No one can predict how things will be for you, but the more open and honest you are about how you are feeling, the easier it will be for others to support you.

“Imagine a roller-coaster. Some of you will find this an exciting and thrilling image; others of you – like me – will find it terrifying and beyond belief that anyone in their right mind would willingly subject themselves to the torment of being transported at high speed and with great discomfort in this manner. However, I have chosen this image to represent the process of the diagnosis and treatment of cancer. On a roller-coaster, you will be strapped in and sent off into the terror, knowing that there is nothing you can do about it until you emerge, wobbly and battered at the other end. You manage by getting your head down and dealing with it as best you can at the time. It is only afterwards, when you are on solid ground again, that you can look back with amazement and view what you have experienced and marvel at your courage.”

Extract from ‘After the Treatment Finishes – Then What?’ by Dr Peter Harvey, Consultant Clinical Psychologist at Leeds Teaching Hospitals Trust.
Worries about recurrence

We know that the biggest fear of many bowel cancer patients is that your cancer will come back, either in your bowel or in other parts of your body. Many people describe how they become anxious before follow-up appointments, and that going back for clinic appointments and waiting for test results can be stressful. Even visiting the hospital again can create anxiety for some people.

Your colorectal specialist team will help you to understand your individual risk of the cancer coming back, based on your original diagnosis – the type and stage of cancer at that time. The follow-up tests described on page 6 will allow your hospital team to monitor you. If anything is identified in these tests, a review at a colorectal multi-disciplinary team meeting will determine if further tests are necessary.

Any recurrence is usually picked up by routine tests, rather than any signs and symptoms you may notice yourself. However, if you do have symptoms, including those listed below, do get in touch with your GP or colorectal specialist nurse:

- continuing pain that doesn’t go away with usual painkillers
- unexplained lumps, bumps or swellings
- unexplained change in normal bowel habit that lasts for six weeks or more – especially if you are waking up in the night with loose stools
- unexplained loss of appetite, weight loss or swollen abdomen
- any new bleeding from your back passage (or in urine)
- any unexplained shortness of breath or cough which lasts more than a week
- bleeding or discharge from your wound site.
Patient story

Jim, aged 62

“In 2006 I was doing well; a healthy diet, gym, weight down and looking forward to a Panama Canal cruise with my wife Pam. I’d always had an ‘acid tummy’ and the occasional bout of piles, but they weren’t problems. Then one day I bled profusely from the bottom. My GP did a rectal examination and blood test and referred me urgently to hospital for a colonoscopy. Stage 2 bowel cancer was diagnosed – a golf-ball sized tumour in the rectum – and some polyps in the upper bowel. My consultant wanted to remove the tumour immediately, so the holiday went! The surgery was an abdominal perineal resection, with a permanent stoma formed and I was advised to have a course of 5FU chemotherapy as a safeguard.

I quickly got used to the stoma, but things went wrong after chemotherapy finished. I returned to work as an engineer, but my head was a mess. I’d easily become fatigued, stressed, have difficulty communicating and dealing with the unknown. I’d get brain ‘fog’ and tingling in my mouth and finger ends. My employers were superb. I struggled for three years, trying all kinds of medication including anti-depressants, visits to psychologists and a cognitive behavioural therapist. I finally retired on medical grounds aged 57. I’m still searching for a solution.

Things are much better, but I still get tired and need chill time alone. Physically I lead a normal life now. I irrigate every other day, so being a colostomist really isn’t a problem. Since my operation we’ve taken several overseas trips. We’re walking a lot, going to shows and concerts and I’m doing the cooking. Love it!”

“Being a colostomist really isn’t a problem.”
Follow-up care

Regular follow-up is offered to all patients with primary bowel cancer who have had treatment to cure the cancer. This starts with a clinic visit four to six weeks after your operation. You should be offered regular surveillance which may include:

- at least two CT scans of the chest, abdomen and pelvis in the first three years
- regular CEA (blood) tests at least every six months in the first three years
- a surveillance colonoscopy at one year after initial treatment or sooner if you did not have one before surgery.

Follow-up appointments with your surgical team and then your colorectal nurse specialist are important opportunities to voice any concerns and describe ongoing symptoms if you have them. At these appointments, you may:

- discuss how you are feeling both physically and psychologically
- discuss your test results
- agree plans to investigate or treat problems with symptoms or changes in your body
- be referred to other services to help you manage other non-cancer symptoms or problems
- discuss your follow-up pathway.

At your appointment with your colorectal nurse specialist you will be able to discuss any problems and complete a holistic needs assessment (HNA) form, which will be revisited regularly to help shape your rehabilitation and recovery care plan.

A good holistic needs assessment not only gathers useful information about you and how you are feeling, but can also be therapeutic in its own right. Sometimes a conversation with the nurse will be enough to reassure you. You may require a referral for further help, for example to the local cancer centre or dietitian. The HNA form, which you should be given to complete, will ask you to identify any problems you may be having such as wound healing, pain, changes in bowel habit, diet, energy levels, sleep quality, mobility, coping with day-to-day activities, personal relationships, and any other problems or concerns.

Your hospital team will follow their local guidelines to ensure that you continue to be monitored in the most appropriate way for you.
Hospital trusts are introducing differing levels of follow-up. Increasingly, suitable patients will be given the chance to opt in to ‘self-managed’ or ‘remote’ follow-up. This means that for low risk patients there will be no face-to-face appointments unless problems arise; only patients with complex problems will be required to come back to see the hospital team.

However, if you have been diagnosed with advanced cancer, are having ongoing treatment with intensive monitoring, or lots of problems with symptoms, you will have more follow-up appointments with doctors, nurses and other healthcare professionals.

Whatever pathway you are on, you will have regular contact with your hospital team at key points, and have all the recommended standard tests to monitor for signs of recurrent disease. If issues arise between appointments, your team will want to know, so you can contact your colorectal nurse specialist or your consultant’s secretary.

Throughout your treatment, your GP will have received letters from your hospital team. Your GP is in charge of your care when you are not receiving active treatment from your surgeon, oncologist or palliative care team. Your GP is also required to carry out a cancer care review with you within six months of your diagnosis.

“Whatever pathway you are on, you will have regular contact with your hospital team at key points, and have all the recommended standard tests to monitor for signs of recurrent disease.”
Emotions and feelings

Many people talk about a feeling of ‘the circus leaving town’ in the days and weeks after active treatment finishes. As your family and friends return to their own daily routines, it may be hard for you to fit back into your old life, and you may start to look back on everything that has happened to you.

Some days you may feel that you are recovering well; but other days may be a struggle, leaving you feeling low. After the regular contact of treatment, you may feel isolated and lonely, as if you’ve been abandoned.

After the shock of diagnosis and the demands of treatment it can also be a relief to be feeling more normal and looking forward to a more comfortable and healthy future, but it can also be a time of mixed emotions. The psychological recovery process is very individual and can take much longer than the medical side of things. It helps to be patient and to be gentle on yourself.

Patience...

Everybody who recovers from treatment is always surprised at how long it takes before they feel back to their old self. Medically you may recover in a few months. Psychologically it can take longer before the fatigue finally wears off. Try to give yourself lots of time to recover. Don’t be in a hurry. You will make most of the progress early on – but give yourself time to recover fully. It’s worth having a one-year or even a two-year plan for getting back on your feet. Don’t worry yourself or rush yourself through recovery. People don’t recover quickly.

“Some of the emotions and feelings you will experience after treatment may be very powerful or unpleasant and may be new to you.”

Extract from ‘Afterwards – Recovering from the impact of cancer treatment’ by Dr Mike Osborn, Consultant Clinical Psychologist, Royal United Hospital, Bath.
Some of the emotions and feelings you will experience after treatment may be very powerful or unpleasant and may be new to you – but they are normal. On the whole people don’t talk much about the way cancer makes them feel. They can feel under pressure to be positive and not to appear low or negative. On some level, things will never be quite the same again, and it can take time to discover and learn how to live with your ‘new normal’.

Treatment for bowel cancer can put a considerable strain on your body and this can often have a profound psychological effect. Worry and fatigue can leave you feeling much more emotional than you were before; you may feel very ‘thin-skinned’. You may experience a whole range of unexpected emotions, such as feeling withdrawn, fearful or disassociated, guilt at having survived, low self-confidence, irritability, frustration, poor concentration or ‘foggy brain’.

These feelings may be fleeting, but if you feel this way for a lot of the time, it is important to seek help from your GP or your hospital team. They will be able to help by referring you to a psychologist or counsellor, or by recommending a support group you could join. Sometimes, medication is required to help with depression or anxiety.

Cancer patients often try to protect their loved ones from how bad they are feeling at times. However, it’s important to share your thoughts with someone, whether a friend or family member, a health professional, or with other people who are going through the same experiences as you.

Beating Bowel Cancer supports a lively community of patients, survivors and relatives at community.beatingbowelcancer.org/forum, and local Facebook groups where you can get in touch with other bowel cancer patients in your area.
Mary, aged 65
“\textquote{I was diagnosed with bowel cancer in 2008 and classified as Dukes C, Stage 3, which meant that the cancer had spread into my lymph nodes. I had surgery, which was an anterior resection, and fortunately didn’t need a stoma or have any problems with bowel control.}

I was then given six months of chemotherapy – capecitabine and oxaliplatin. I struggled with the side-effects; cold sensitivity, severe fatigue, nausea and throat spasms after only a few cycles. I couldn’t complete the last three cycles due to developing neuropathy* in both hands and feet.

When first diagnosed, I was reluctant to plan things too far ahead and worried about how well I would be when my first grandson was born. On bad days I wondered if I would even be around at all.

Two years later I had a recurrence in my liver so I had to have a liver resection, but needed no further treatment. I was still clear after three years, but when my consultant said I would only need annual scans I was rather apprehensive. We agreed that I could ask my GP to do blood tests every six months and then phone the oncologist’s office to check that she had seen the results, which was reassuring.

The lasting effects of neuropathy mean that I find standing or walking for long periods difficult, especially on hard surfaces such as in the supermarket. I’ve had to learn to manage the symptoms and I go swimming regularly, which helps.

I came across Beating Bowel Cancer’s online forum and read many of the threads. I thought it was a fantastically supportive place and eventually plucked up courage to write a post and received some great responses from people. A few years ago I was thrilled to be asked to become a patient moderator.”

* Please see our ‘Peripheral Neuropathy’ factsheet for information on managing this side-effect.
Guy, aged 50

“I had surgery to remove a T2 tumour in 2011, during which most of my rectum and 10 inches of colon were removed. There was no evidence that the cancer had spread, so I did not need further treatment.

When I went home, I wasn’t prepared for my weakness, and having to rely on other people. I’m accustomed to being very self-reliant and capable; in fact I’m more of a carer by nature, so it was really hard to ask for help. As well as my wife, Rachel, I have to thank three extraordinary friends who chopped wood, washed, vacuumed, shopped and did whatever everyday tasks I couldn’t manage, as well as providing company and cheerful support. They made a huge difference to my life after surgery.

All the same I felt incredibly tired and feeble, and worst of all I began to become obsessed with the way my bowels worked. Because bowel movement was so important in my recovery, but could also take a long time, it became difficult to ‘go’ anywhere but at home in a safe environment, where people wouldn’t be knocking on the door, either to go themselves, or to ask if I was OK. This delayed my return to work, and isn’t the joke you might think, as it played a significant part in how I felt about myself and how safe I felt in other environments.

During my first follow-up colonoscopy in 2012, the new join in my bowel caused a few problems and a scrape of the bowel wall. I went home, but went into shock and had to be readmitted to the colorectal unit for five days of observation (and starvation!).

It’s now been five years since my surgery, so I have been discharged by the colorectal team. However, as polyps were found during my follow-up, I will be given a colonoscopy every two years for the foreseeable future.”
Disturbed sleep and fatigue

Illness, treatment and surgery can all take their toll on your energy levels, making you feel very tired and lethargic. Worry and uncertainty associated with your cancer diagnosis are likely to have given you several sleepless nights, and spending time in hospital can often disrupt your sleeping patterns.

It’s not unusual to find that this can be the start of longer-term problems with insomnia, low energy levels or a really deep fatigue that can last for many months after treatment finishes. Tiredness may be linked to other problems, untreated symptoms like pain or anaemia, or other changes in your body. Stress and anxiety can also take their toll and make it difficult to get to sleep, or cause you to wake up again in the small hours of the morning.

If your bowel cancer diagnosis is causing you so much anxiety that you just cannot sleep, it’s worth talking to your GP about self-help strategies or complementary therapies. If necessary, they can refer you to a counsellor or mental health professional, or prescribe medication.

As we get older, sleep can be disturbed by a need to use the toilet and this can be a particular problem after bowel cancer treatment. If you find frequency or urgency of bowel movements during the night is disturbing your sleep, you may wish to talk to your GP about medication such as loperamide to slow your digestion down. Please see our ‘Eating Well’ booklet for more tips.

The worry that you are not getting enough sleep can itself be a problem. If you find yourself awake in the night, tell yourself that relaxing can be as refreshing as sleep. Lie quietly and don’t keep looking at the clock. Allow your thoughts to drift away and focus on things that make you feel happy. A relaxation or meditation CD or podcast can be a way to take your mind off the fact that you are not sleeping and you may actually drift off.

Good sleep habits

- Avoid caffeinated drinks (coffee, tea, cola) for at least four hours before bedtime – try a cup of herbal tea instead.
- Avoid smoking or drinking alcohol close to bedtime (or give up completely).
- Be consistent with your bedtime routine.
- Only go to bed when you feel sleepy.
- Don’t eat or watch TV in bed, but make it a place only for relaxing or sleeping.

For advice on sleep problems please visit: www.nhs.uk/LiveWell/sleep
Fatigue is the feeling of lacking energy and finding everyday tasks exhausting. It can affect the way you feel, and make it more difficult to enjoy even relaxing activities such as reading or watching TV. It can affect your mood and your relationships, so you find yourself getting impatient with yourself and others, or upset and tearful over small things. You might find that you avoid spending time with friends or family, because it just feels too exhausting. It’s not unusual for fatigue to last for many months after treatment is over. In some people, it may last for a year or two.

Fatigue can show itself in other ways. You may find yourself wanting to spend longer and longer in bed in the morning, but still have problems sleeping. You may have difficulty accomplishing the smallest tasks and find that you are short of breath doing even light activities. Poor concentration or memory loss might also be a problem. You might find that you have lost all interest in sex, even though you have recovered physically from your surgery.

Ways to manage fatigue
- Regular exercise, perhaps a gentle walk, some stretching or a beginner’s yoga class, can help.
- Try to get some fresh air and gentle exercise every day even if you don’t really feel like it and gradually increase your time/distance, but allow time to rest afterwards.
- Take an afternoon nap if you need to, but get up again for the evening.
- Meditation, acupuncture, massage, reflexology, aromatherapy, music therapy or reiki can help reduce stress and anxiety.
- Keep to a routine – try not to stay in bed in the morning after you’ve woken up.
- Eat as healthy a diet as possible to boost your energy levels (see our ‘Eating Well’ booklet).
- Drink water, squash, diluted juice or herbal tea regularly to keep you hydrated.
Lifestyle choices

There is plenty of evidence that lifestyle choices can have a direct impact on our health and wellbeing, and affect our risk of developing certain diseases and illnesses. Having had treatment for bowel cancer, you may feel that you want to do as much as you possibly can to improve your general health and to reduce the risk of your cancer coming back.

The lifestyle choices mentioned here may help reduce your personal risk. You may wish to incorporate some of them into your routine to a lesser or greater degree, depending on your personal circumstances and your budget.

General health advice

- Reduce the amount of processed foods in your diet, especially refined ingredients, with a high fat and/or sugar content, and high levels of preservatives.
- Avoid reheating fats and oils.
- Avoid super-heated snacks such as crisps, chips and cheap breakfast cereals.
- Reduce your intake of smoked, barbequed or burnt foods.
- There is evidence of a link between excessive consumption of red meat (beef, lamb, pork) and bowel cancer, so we recommend that you aim for less than 500g (cooked weight) a week. The research linking processed meats (e.g. bacon, ham, salami) with bowel cancer is even stronger, so we recommend cutting down on these as much as possible.
- If consumed at all, alcoholic drinks should be limited to two small drinks for men and one for women a day. For cancer prevention, the best recommendation is not to drink any alcohol at all.
- There is evidence that long-term smokers are more likely than non-smokers to develop bowel cancer. Giving up smoking will have many health benefits, including reducing your risk of cancer.

There's more detailed information and evidence at these websites:
www.cancernet.co.uk
www.cancerresearchuk.org
www.wcrf-uk.org
There is much debate about which environmental factors may cause cancer. In the meantime, you might like to take control by taking steps to avoid some possible causes.

**Pesticides, herbicides and fertilisers**

You can reduce your exposure to these if you:

- soak lettuce leaves and herbs in water, then dry before eating (use a salad spinner)
- wash fruit well before placing in the fruit bowl
- wash vegetables well before cooking
- buy organic foods if possible.

It’s not always possible, but you could try limiting your exposure to other potentially harmful substances which occur in everyday products:

- petrol and diesel fumes, paraffin
- cosmetics, shower gels and deodorants that contain parabens
- polycarbonate plastic bottles (use glass where possible).

And these are a few easy ways to limit your exposure:

- have leafy plants and ferns around the house to help absorb environmental pollutants
- do not reuse plastic water bottles
- rinse soap and detergents thoroughly from crockery and cutlery
- don’t store food in plastic food containers or plastic film
- if you like burning candles go for soy or beeswax varieties.
Eating well

As you recover from bowel cancer treatment, it’s important to keep eating regularly. Smaller portions eaten throughout the day may suit you better than three bigger meals, especially if you are still experiencing problems with an unpredictable bowel pattern and poor appetite. Drinking two litres of water a day will help prevent constipation and dehydration.

Along with regular exercise, a healthy, nutritious diet that includes a wide range of fresh vegetables, fruit, whole grains, pulses, good quality protein and healthy oils is an integral part of your recovery, and a key factor in preventing future ill health.

It is important to remember that excessive intake of any vitamin or mineral can have harmful effects. Do speak to your oncologist, clinical nurse specialist or GP before taking any supplements.
Ensure an adequate intake of these foods, vitamins and minerals in your diet:

- fruit
- fibre
- vegetables
- berries, nuts and seeds
- healthy fats, found in fish, olive oil, avocados
- vitamin A, found in dairy foods, fish, carrots and spinach
- vitamin C, found in citrus fruits, apples, cherries and exotic fruits
- vitamin D, found in nuts, fish oils, eggs, vegetables, grains and cereals (can also be topped up by sensible exposure to sunlight)
- vitamin E, found in wheat germ, nuts and seeds
- trace minerals such as selenium, zinc and calcium.

However, many of these foods in their natural form cause problems for people recovering from bowel surgery, with or without a stoma. Incorporating some of these foods into blended soups and smoothies may be a way to ensure a good intake.

If you have trouble digesting fruits and vegetables, you might like to consider taking your vitamins and minerals as a supplement. If you take them in capsule form, bear in mind that if you have an ileostomy and the capsules are ‘time release’, they may not have been absorbed by the time they reach your stoma.

Polyphenols (also called phytochemicals) are plant chemicals with health benefits. Research is emerging that some polyphenols have anti-cancer and anti-oxidant properties, protecting the cells in your body from damage.

Foods known to have a high polyphenol concentration include:

- **Green vegetables** cabbage, spinach, broccoli, leeks, onions
- **Salad** dark green lettuce leaves (rocket), celery
- **Fruits (especially ripe)** pomegranates, kiwis, plums, apples, lemons, apricots, plums, pears, oranges, nectarines, strawberries, bananas, grapes
- **Mushrooms** white and wild varieties
- **Dried fruits** raisins, prunes, apricots
- **Berries** cherries, blueberries, blackberries, cranberries, goji berries
- **Legumes** beans, lentils, chick peas
- **Nuts** hazelnuts, peanuts, cashews
- **Herbs and spices** garlic, parsley, mint, coriander, thyme, rosemary, turmeric
- **Tea** green and black tea

For more information about diet after bowel cancer, please see our ‘Eating Well’ booklet.
People recover much more quickly and have fewer complications from their treatment if they think positively about their health and keep active throughout the day, rather than spending long periods of time sitting or lying still.

The physiotherapy team may already have given you some exercises to help strengthen your pelvic floor muscles and the muscles in your abdomen and lower back. These exercises are important for regaining bowel control and increasing your strength and stamina. Housework and other more strenuous physical activities can be gradually re-introduced into your daily routine, however driving and lifting heavy objects can strain healing muscles and skin.

Once you have had your post-operative follow-up appointment, you can start to think about increasing your exercise. Whatever exercise you choose, a little bit of advance planning can be useful.

This includes knowing where the toilets are, or taking some spare clothing with you in case of unexpected accidents.

**The benefits of exercise**

Regular exercise increases the sense of self-empowerment for both you and your family if they choose to join you. It makes you feel good about yourself and can restore your confidence after cancer treatment has finished. There is strong evidence that exercise has major benefits on many of the symptoms and side-effects associated with cancer treatment, including fatigue, nausea, constipation, sleeplessness, joint and muscle pain. It can improve your brain function, prevent weight gain, lower cholesterol levels, reduce anxiety and depression and improve your memory.
Introducing exercise into your routine
The trick with exercise is to do it regularly – keeping an exercise diary may be helpful. This can be as simple as walking briskly for 20-30 minutes every day. Buy a comfortable pair of training shoes so you are ready to go. If you can’t get to a gym or an organised class, you could invest in an exercise bike, treadmill or rowing machine to use at home. There are plenty of second-hand ones online!

You can build exercise into your day by walking instead of using the car or bus for short journeys, or get off the bus one stop earlier. Use the stairs instead of a lift or escalator. If you are watching TV, get up and have a walk around every half hour. Take a 10 minute walk before dinner every evening. If you are at work and desk-bound, make a point of getting up for a walk round the office every half hour and make time for a walk at lunchtime.

Exercising in a group is a great way to get out and meet people and if you really enjoy the activity you are more likely to stick with it. Look out for dance, fitness, tai chi or yoga classes in your area.

There are many excellent rehabilitation and exercise programmes available. Your GP, specialist nurse, your local sports centre or swimming pool will have more information about exercise referral schemes, support groups and exercise classes.

Joining a walking group is an effective and sociable way of getting back to good health:

England
www.walkingforhealth.org.uk
Scotland
www.ramblers.org.uk/scotland
Wales
www.ramblers.org.uk/wales
Regaining bowel control

Diarrhoea, constipation, unpredictable bowel patterns, wind and problems with stomas (both permanent and temporary) are the most common questions posted on our patient forum at beatingbowelcancer.org/forum

Your bowel habit is unlikely to return to what it was before surgery, and it will take time to adapt to your ‘new normal’. Many changes in bowel habit are caused by a change in the length and shape of your colon after surgery. A shorter bowel means less time for water to be reabsorbed from the faeces (poo) as it travels through, so bowel movements can seem very loose and watery. Over time, however, the body can adapt to these changes, and so it is often only a temporary problem.

Other problems are caused by the bowel’s ability to hold the poo once it reaches the end of the bowel, especially if the rectum has been removed or affected in some way by surgery or radiotherapy.

Some of the nerves that help to control the movement of the bowel and the muscles of the anus and bladder can be affected during surgery and this can cause problems with leaking of urine and soiling. This may only be a short-term issue for you, but in some cases, it can become a longer-term problem and may need professional help and treatment to manage effectively.

Pelvic floor exercises, relaxation, regular activity and avoiding sitting still for long periods can all help to improve the strength and control of the muscles in your abdomen and pelvis. Controlling your diet and taking medicines to change the consistency of the poo can also help to make bowel movements more predictable and comfortable to manage.

However if you are really struggling, do seek advice on how to manage and minimise your symptoms.
Q: I have been having problems with constipation since my treatment.
A: Constipation can be caused by not drinking enough water or by not eating enough food to help keep the bowel moving. It can also be caused by not getting enough gentle exercise every day, and spending long periods of time sitting still. Increasing the amount of fibre in your diet from fruit, vegetables and whole grains or gentle medicines can also help to keep the stools soft and comfortable to pass. Speak to your specialist nurse or doctor about this if you are worried.

Q: I've got a new stoma but I am still passing mucus from my bottom and feeling like I need to go to the toilet.
A: This sensation is normal, as the bowel below the stoma is still producing mucus to keep it healthy. Sit on the toilet and allow anything in your rectum to empty out when you feel the need, but avoid pushing or straining. This symptom should gradually settle down, but if it doesn’t, or if you start to notice any fresh bleeding or increase in amounts of mucus, speak to your specialist nurse as soon as you can. There may also be some faeces left in the lower bowel from before your operation (especially if you had emergency surgery). It may be that you need some intervention to remove it, so do let your hospital team know, as the problem can be quickly resolved (although it will recur in some people).

Easy access to public toilets
You can buy a specialist RADAR key for a national network of secure public toilets and a map from www.disabilityrightsuk.org
T: 020 7250 8191

You can buy a Just Can’t Wait toilet card to help you gain access to toilets from www.bladderandbowelfoundation.org
T: 01536 533255

For more information on changing bowel habits, see our ‘Regaining Bowel Control’ factsheet.
Regaining bowel control

Q: I had a tumour removed from my rectum six weeks ago and I am still having problems with controlling my bowel motions. This can be very embarrassing and I am frightened to leave the house.
A: Unfortunately you may be suffering from anterior resection syndrome, which is a collection of symptoms patients have after undergoing removal of part of their rectum (the last 6–8 inches of the large bowel). Those most at risk are people who have had radiotherapy or chemotherapy before surgery or those with a tumour very low in the rectum. It is normal for your bowel function to be erratic and difficult to control for several weeks or even months.

Some people find that their symptoms resolve over time, while others may continue to have problems, in which case you should talk to your GP or colorectal nurse about being referred to a continence service. The symptoms may include pain, incontinence, frequency or urgency of stools, clustering of stools (numerous bowel movements over a few hours) and/or increased wind.

Ways to control these symptoms:
• loperamide is an over-the-counter medication that helps to slow down your bowel function
• chew foods thoroughly and try small, frequent meals (5–6 per day)
• add new foods one at a time to determine the effect on your bowels
• drink plenty of fluids; avoid caffeine, alcohol and sorbitol (an artificial sweetener)
• in the first 6–12 weeks it can help to eat a low-fibre diet, gradually introducing fibre as your bowel settles down
• carry a survival pack of wet wipes, protective ointments and loperamide.

Q: I am still having problems with diarrhoea and wind since my treatment.
A: Diarrhoea and wind are common after having a large part of your large bowel (colon/rectum) removed, as less water is reabsorbed from the poo as it travels towards the anus. Some foods or medicines can also make the problem worse, e.g. caffeine in tea and coffee, gas in fizzy drinks, and chemicals in some beers and wines. Eating quickly, not chewing your food thoroughly and swallowing air when you are eating all lead to problems with wind, cramping or bloating.

Further information:
www.stmarkshospital.nhs.uk/patients-visitors/patient-information-leaflets (click on ‘Loperamide’)
Beating Bowel Cancer’s ‘Eating Well’ booklet and ‘Regaining Bowel Control’ factsheet
Altered body image

Treatment for bowel cancer such as surgery, radiotherapy and chemotherapy can take its toll on you emotionally, psychologically and physically. Changes to your body can be a constant reminder of your cancer diagnosis and treatment.

Wounds heal, leaving scars that often only you and your partner will see. There may be changes in how your body looks and behaves that you have difficulty accepting. These unexpected feelings can leave you feeling anxious or vulnerable, especially when on holiday or in an intimate setting. Surgery can change the shape and function of your body; hernias can often protrude a little and stoma bags can form shapes under your clothing.

These days there is pressure via the media on both men and women to have a perfect body – an unrealistic ideal which can cause anxiety, regardless of whether you have had cancer or not. Like many others, you might also be worrying about how other people see you. You may feel unable to talk openly with people about your cancer experience because of their own fears or assumptions.

Some common worries include:
• concerns that others will no longer find you attractive
• worries that you will be unable to form new relationships
• embarrassment over physical changes, a new stoma or scar
• noises or smells your body may now make
• loss of confidence and self-esteem.

Whether you are in a long-term relationship, single or dating, there may be body image issues for you and your partner that you might want to talk to a professional about. It can be quite daunting to consider discussing such sensitive and personal issues with someone else, but it is important to remember that healthcare professionals are used to talking about such issues.

Do talk to your medical team about how you are feeling. Your colorectal nurse or GP can refer you to specialist therapists and support services who can work with you on a one to one basis if you feel it would help.
Intimate relationships

Sex can be a sensitive subject for people under ordinary circumstances, let alone after a cancer diagnosis. Many people who have had bowel cancer find that they have problems with both lack of interest in sex and performance as a consequence of their diagnosis and treatment.

There is also the potential for difficulties and anxiety around intimate relationships and sexual intercourse which, if not addressed early, can undermine your recovery and this may lead to other problems with personal relationships.

There may be physical issues such as lack of energy, physical discomfort after surgery, and/or the fear that you may do more harm than good! There may also be more complex psychological problems that can affect how you feel about initiating sexual activity.

Talking to your partner about how you might still be able to enjoy an intimate relationship without full intercourse may help, if this is a problem for either of you. You can have fun making small changes to favourite positions or finding other ways of giving pleasure without putting pressure on newly healing wounds or a stoma. Experimenting with low lighting and keeping on some clothing may also help, if you are self-conscious about scars, a stoma or unpredictable leaks.

Surgery, some chemotherapy drugs and radiotherapy can affect the tiny nerve endings and blood vessels around the pelvis, causing local inflammation and swelling, changing the sensations you can feel. This is often only a temporary problem that will gradually settle down, but occasionally there may be some longer-term loss of sensitivity or numbness in and around the pelvis and genital area.
Advice for men

As a result of surgery or radiotherapy, you might find that you are having problems achieving or keeping an erection. This is again much more common than you might expect, and happens as a result of inflammation and damage to tiny nerve endings and blood vessels in the area around the pelvis. These side-effects of treatment are often short-lived and gradually disappear over the course of a few weeks or months, but occasionally it can become something that remains a problem.

Almost half of all men who have had treatment for bowel cancer find that they have problems associated with both interest in sex and performance as a consequence of their diagnosis and treatment, so you are not alone.

If you experience long-term difficulties or have concerns about intimate issues, there are things that can be done to help, with the support of your GP, specialist nurse, or a genito-urinary specialist or psycho-sexual therapist.

There are medications, and other techniques that can help to strengthen and sustain an erection, and many practical tips and advice to help cope with these new challenges and find new ways to achieve satisfaction and intimacy with your partner.

“I was 53 when I was diagnosed with bowel cancer. Now at 70 I still have an active and intimate life in all aspects. I married my partner, Rose, just eight months after my surgery. We built on our new relationship in all the ways we could and the intimacy is still as important now as it was back then. At the time it wasn’t easy, but we strove on regardless. We built upon trust and the help of a ‘little blue pill’ through a doctor’s prescription – you can have four a month! Body image is still so important and trusting your body with confidence is key as well as the continued acceptance from your partner. Last summer we strolled happily along a lovely beach in Spain, soaking up the sun and without a care in the world. As I use colonic irrigation I only needed to wear a small plug which is very discreet.” Tim, 70
Advice for women

Almost half of all women who have had treatment for bowel cancer find that they have problems associated with both intimacy and sex as a consequence of their diagnosis and treatment.

Being self-conscious about how your body looks after surgery (with or without a stoma) is only natural and there may be practical reasons such as low energy levels and discomfort from scar tissue that can affect how you feel about wanting to have sex.

If you have had radiotherapy, there is an increased risk of vaginal dryness and tightening, which can make penetration and vaginal examinations uncomfortable or painful. This can be eased in a number of ways, by using intimate lubricating gels or creams to help moisten the vagina and gently massaging the area with your finger to keep it supple. Natural lubricants, such as ‘Sylk’ or ‘Yes’, are available on NHS prescription.

Using vaginal dilators, which are also available on NHS prescription, can help prevent tight bands of scar tissue forming, and keep the vagina ‘open’ after your treatment has finished. There is specialist help available if you need it from gynaecologists, genito-urinary specialists or psycho-sexual therapists, to talk through worries or to help find solutions to practical problems or concerns. Your GP or specialist nurse can make the referral for you.

More information from:
Sexual Advice Association
T: 020 7486 7262
www.sexualadviceassociation.co.uk

“When I first got my stoma I was worried about how sex would be and if I would still be seen as attractive. Also would I need to cover my stoma bag up or was it OK to have it just on display. I also wondered if sex and the pleasure of it would be affected because of the operations. I had only just met my partner when I got my ileostomy so he didn’t know me any differently, but I was still nervous.

I decided the best thing was just to ‘get on with it’ and it was fine. The bag didn’t leak, fall off or flap about as I had feared and it’s just the same and as fun as it always was. Having sex with the bag on has become second nature and I got used to it very quickly. I don’t feel the need to cover up with underwear or clothing; it’s just part of who I am. And as for my partner, well it certainly doesn’t bother him or stop him from finding me attractive!” Cheryl, 35
**Patient story**

I retired from my post in 2014 due to ongoing bowel issues and the need to have toilets near to hand. However, I continue to work as an education consultant, inspector of schools and chaplain.

My follow up scans have been clear ever since and my physical needs have stabilised. However, the emotional and psychological effects that came along with my diagnosis and treatment caught me by surprise. It took me some time to realise that people around about me were just as susceptible as I was.

What I eventually learned is that an emotional response is allowed; we all need time to adjust and come to terms with everything. I’ve come to accept that ‘not dying’ does not mean that I am ‘really well again’. All my ongoing issues continue to need emotional and psychological resilience, but I manage to live a good and meaningful life.

My advice, whatever stage you’re at, is not to suffer in silence. Let your voice be heard, because only then will you learn about and receive help and support, and you might just help educate those around you into the bargain!”

---

**Brian, aged 61**

“I was diagnosed with Dukes C bowel cancer in 2011. I was 56 at the time and working as an assistant director of education looking after over a hundred schools. I had surgery, a right hemi-colectomy and, due to a wound infection, was in hospital for three weeks. I then had eight cycles of capecitabine and had a bad reaction after cycle six, with a septic rash and severe hand and foot syndrome. Most of my side-effects have gone, but I still have problems with my fine motor skills and my saliva glands no longer work well, so I have to use an artificial spray.

Let your voice be heard, because only then will you learn about and receive help and support.”
Going back to work

Work helps us remain financially independent, gives us a sense of purpose and self-worth; it brings structure to our lives and is a source of social interaction and friendship. It can be a lifeline back to normality and well-being. However, many cancer patients of working age struggle to return to their job, dealing with the side-effects of treatment, which can include pain, fatigue, and loss of bowel control, but perhaps also depression and a lack of self-confidence.

There is legislation in place to support cancer patients who wish to return to work. The Equality Act 2010 and the Disability Discrimination Act 1995 protect you from discrimination at work and employers must not treat you less favourably for any reasons relating to your cancer. This includes recruitment, promotion, training, pay and benefits. Your employer must make ‘reasonable’ arrangements to help you return to your job. ‘Reasonable’ depends on the type of work you do and will take into account cost, practicality and how much any arrangement will be effective in helping you perform your role.

If adjustments are needed at your workplace, the Access to Work scheme might be able to provide grants for equipment and can sometimes help with the cost of taxis to work. Visit [gov.uk/access-to-work](http://gov.uk/access-to-work)

Your human resources manager or occupational health team should be able to support you in gradually getting back to your full hours. They can also advise you about what will happen if your changed personal circumstances have affected your ability to continue in the role you had previously.

For signposting to information on employment rights, welfare benefits and much more, please see our ‘Financial & Employment Support’ and ‘Practical & Emotional Support’ factsheets

You may wish to discuss:

- taking on light duties or temporarily reduced hours
- flexible working
- working from home on certain days
- allowing extra breaks if you are experiencing fatigue
- allowing time off for hospital appointments
- availability of toilet facilities.
Patient story

The second challenge was all the other side-effects. Peripheral neuropathy meant I couldn't hold a normal pen; my ‘chemo brain’ meant I was often stuck for words or forgot dates – not helpful when you're trying to remember which meetings you are supposed to be at, the names of the colleagues you're meeting, and whose birthday parties the children are meant to be at this weekend.

I felt very frustrated that I was supposedly well, yet still not back to normal. My company was very helpful and provided things to help (special thick pens!). Meanwhile a team of specialists, including a neuro-psychologist to help re-train my brain, helped put me back together.

Three years post-chemo, and most of the challenges seem to have been conquered with a combination of being frank and open with work colleagues and doctors, making the most of what help my employer and my oncologist could offer, and a lot of patience and time. There are still follow-up tests, which are disruptive and worrying for everyone, particularly for the children as they get older and understand more, but we manage.”

Emma, aged 41

"I was living a normal, if somewhat hectic, life as a working mother with two small children when I was diagnosed with bowel cancer at the age of 37. A lower anterior resection swiftly followed, then the further blow that the cancer had reached Stage 3 and I would require chemotherapy. Following a course of oxaliplatin and 5FU, I have been in remission since May 2013.

Once I realised there might be life after cancer, returning to work was an important part of getting back to normal for me. The first challenge was the exhaustion. Putting even half a day's work in, on top of family life, meant I needed to sleep for the other half of the day! Gradually this got better, and with a staged return to work I built up again to full time over a five-month period."
Useful contacts

If your clinical nurse specialist does not run a bowel cancer support group, there may be other local cancer support groups that meet regularly. This website gives a list of local cancer support centres, such as Maggie’s and other charities: www.macmillan.org.uk/in-your-area

If a face-to-face group is not convenient for you, then why not join us online at community.beatingbowelcancer.org/forum where you can chat to patients and relatives at all stages of a bowel cancer journey.

We also help nurses and patients to set up local and regional Facebook groups. Please see our website for details of existing groups, or why not consider setting up a new one?

Other useful contacts

Colostomy Association
For people with a colostomy
T: 0800 328 4257
W: colostomyassociation.org.uk

IA Support Group
For people with an ileostomy or j-pouch
T: 0800 0184 724
W: iasupport.org

NHS Information
Advice on healthy living
W: nhs.uk/livewell
W: nhs.uk/change4life

Pelvic Radiation Disease Association
Support for the effects of radiotherapy
T: 01372 744338
W: prda.org.uk

Gary Logue Colorectal Nurse Awards
These awards were set up in memory of our nurse advisor, Gary Logue, who passed away in 2014. Bowel cancer patients are warmly invited to show recognition of the fantastic work that nurses do by nominating their colorectal cancer nurse specialist for an award. Each year, two nurses will receive £500 each towards their personal development.

Please visit beatingbowelcancer.org/nurse-awards and tell us why your nurse deserves this special recognition.
Support our work

We provide practical and emotional support
• We provide specialist support and information to anyone affected by bowel cancer.
• We run the UK’s only nurse-led specialist helpline for bowel cancer. Patients call it a ‘lifeline’ and often build up long-term relationships with our nurses over many years.

We campaign for the highest quality treatment and care
• Everyone affected by bowel cancer, no matter who they are or where they live, should get the best possible support, care and information. We campaign nationally and locally to make sure governments and health services do better by providing the highest quality care and treatments, and by making beating bowel cancer a priority.

We bring people with bowel cancer together
• Bowel cancer affects people physically and emotionally and a problem shared can make a world of difference.
• We connect people through the power of our website, social media and major events such as our Patient Days.

We promote early diagnosis
• 9 in 10 people with bowel cancer will survive if they’re treated early. That’s why we work tirelessly through innovative campaigns to promote greater awareness of symptoms, and the key message that bowel cancer can be beaten.

We raise money to fund our vital work
• We need you to help us continue our work that provides such vital support for people with bowel cancer.
• We are a charity that relies entirely on voluntary donations and gifts in Wills and by giving a donation you will help fund a range of vital services that give people with bowel cancer help, hope and reassurance.

Please join us and together we can beat bowel cancer.

To make a donation please visit beatingbowelcancer.org/donate or call 020 8973 0000.
Beating Bowel Cancer is the support and campaigning charity for everyone affected by bowel cancer.

We provide vital practical and emotional help – on the phone, digitally and face to face. We’re proud to run the UK’s only nurse-led specialist helpline for bowel cancer which patients call a ‘lifeline’.

We bring patients together to share invaluable experience and support, through our website, social media and major events.

Our high impact campaigns have led to the introduction of the bowel cancer screening programme, which is helping save lives, as well as new funding and greater patient access to life-changing cancer treatments.

If you have any questions or comments about this publication, or would like information on the evidence used to produce it, please write to us, or email info@beatingbowelcancer.org

Contact our nurse advisors
T: 020 8973 0011
nurse@beatingbowelcancer.org