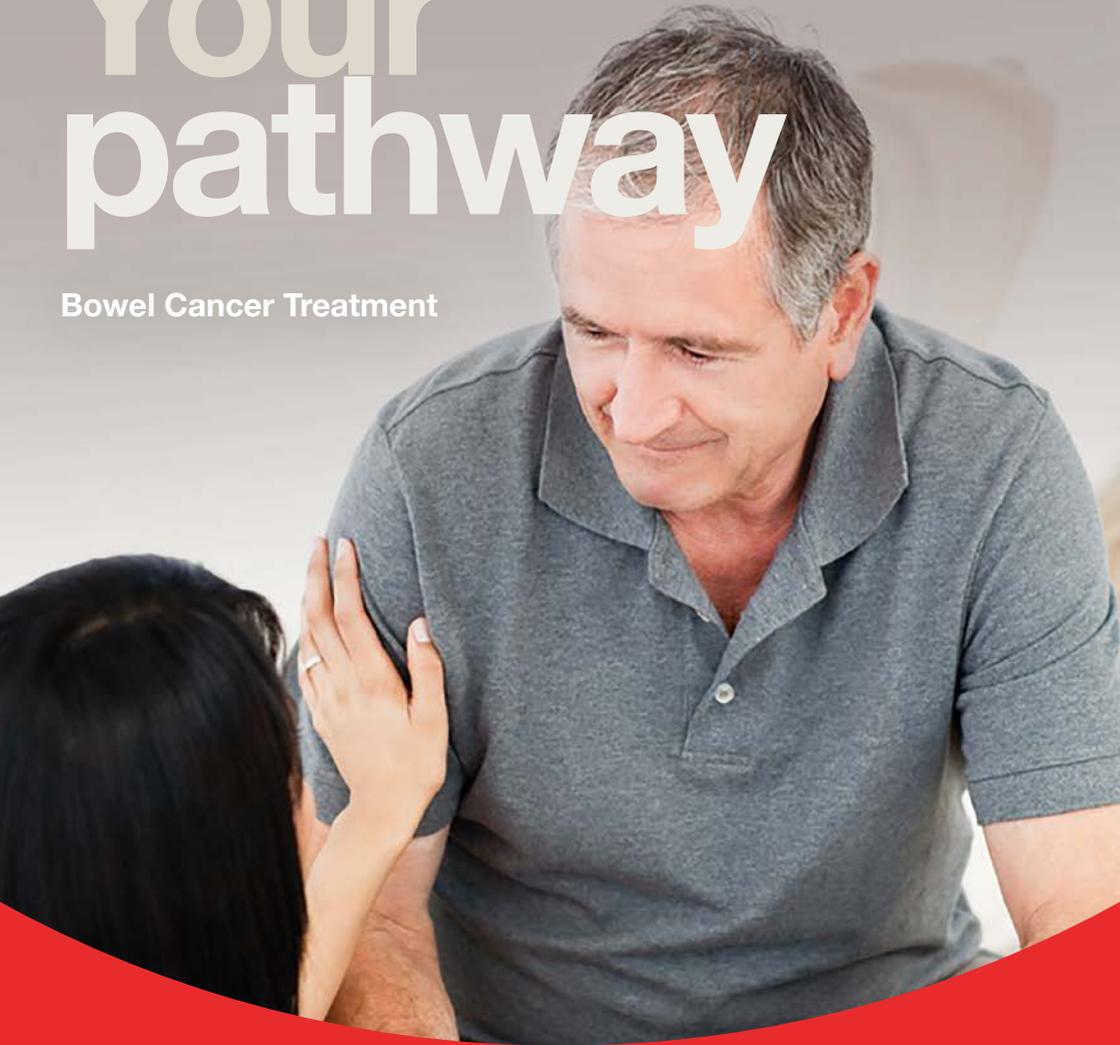


Your pathway

Bowel Cancer Treatment



Here for you
beatingbowelcancer.org



Introduction

You will have been given this booklet because you have recently been diagnosed with bowel cancer. We understand that it can be a confusing and frightening time for you and your family. We have produced this booklet to help you understand how your treatment is likely to be planned, and what your options may be, based upon the national guidelines for the diagnosis and treatment of this disease.

Even for the most positive people, being diagnosed with bowel cancer will come as a great shock. Many patients describe everything being a “bit of a blur” after they

are told. You will need to take time to consider what you have been told, and to seek advice from your hospital team, which includes your colorectal clinical nurse specialist. Your GP, your family and friends, and the Beating Bowel Cancer nurse advisors can also be an important source of support as you start your treatment.

You will also find a lively and supportive community of bowel cancer patients and relatives in our online forum at **community.beatingbowelcancer.org/forum**

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What is bowel cancer?

Bowel cancer is the general term for cancer found in the large bowel and can be divided into the following:

Colon cancer is a cancer that develops in the colon (large bowel) but excludes the rectum.

Rectal cancer is a cancer that develops in the rectum (the very last part of the bowel before the anal opening).

There are slight differences in the treatment pathway depending on whether your cancer is in the colon or rectum (see pages 12 and 13).

Your treatment options

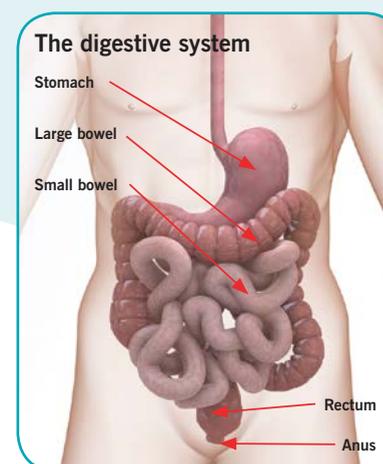
Treatment for bowel cancer is decided by:

- where the cancer is in your bowel
- how big the tumour is
- the number, size and position of any tumours outside the bowel (including lymph nodes)
- the type of cancer cells – their cell type and genetic make-up
- your general health and fitness
- your wishes as the patient.

It will also be determined by:

- the local and national guidelines for best practice in treating bowel cancer
- the availability of different treatment options within your local hospital
- the access to clinical trials available within your local hospital
- how well you respond to the treatment
- the impact of any side-effects you may experience as a result of treatment.

Everyone is different and your treatment plans will be very individual to you. Your consultant and specialist nurse will discuss the options that are available to you, including where and when your treatment will take place. They will describe to you, step by step, what each stage of your plan might involve, the likely outcomes and who will be treating you.



Your multi-disciplinary team

Your first appointment at the hospital is likely to be with a colorectal surgeon and a specialist colorectal nurse. They are part of a specialist colorectal multi-disciplinary team (MDT).

This team is led by at least one consultant and brings together all the key people involved in your care, to ensure that all the different parts of your treatment are delivered as seamlessly as possible. Your case will be presented and various treatment options will be discussed at one of the MDT's regular meetings, to ensure that you are offered the best possible care and support throughout your treatment. Your consultant or specialist nurse will let you know the outcome of these discussions.

Typically, the team will involve the following staff:

Colorectal clinical nurse specialist (CNS)

– a nurse with additional training and qualifications in the care of patients with bowel cancer, who has become an expert in this field. Nurse consultants or nurse practitioners have additional qualifications at a very advanced level. This nurse is usually your key worker, the first point of contact if you have any queries or concerns.

Colorectal surgeon – a doctor with specialist training to remove tumours in the bowel and rectum. Other specialist surgeons should be involved if the cancer has spread, for example to your liver or lungs.

Medical and Clinical oncologists – doctors who are skilled in treating cancer patients with chemotherapy and targeted therapies. Clinical oncologists also specialize in radiotherapy.

Consultant surgeons and oncologists will be supported by **specialist registrars** – qualified doctors who are gaining more experience and developing their skills within a specialist area. You may also see a **foundation doctor** (house officer) – a qualified doctor who has not yet specialised.

Diagnostic radiologist – uses X-rays and other specialised scanning machines (ultrasound, CT, PET and MRI scanners) to locate and measure the extent of a cancer.

Histopathologist – a specialist doctor who uses microscopic equipment to examine and identify samples of tissue and confirm a diagnosis.

Stoma nurse specialist – a nurse with experience and qualifications in the care and management of people with a temporary or permanent stoma (see page 14).

These healthcare professionals can offer support in the hospital or in the community:

Oncology nurse specialist – nurse with additional training and qualifications in the care and management of patients needing chemotherapy (cancer drugs).

Research nurse – nurse who helps recruit patients for clinical trials.

Palliative care specialist – doctor or nurse with additional experience and qualifications in supporting patients and families, and managing symptoms to improve quality of life for patients with very advanced cancer.

Therapeutic/radiotherapy radiographer – specialist trained to deliver radiotherapy treatments.

Pharmacist – specialist able to provide support and advice to the rest of the clinical team, and to patients, about the medicines that are being used to treat the cancer and their possible side-effects.

Counsellor – uses non-medical therapies and techniques to support you if you are struggling to deal with emotional issues and problems.

Dietician/nutritionist – supports you if you have problems with eating and/or drinking properly, or maintaining or managing your weight.

Physiotherapist – helps you to regain strength, mobility and balance after surgery.

Occupational therapist – helps you to regain your independence and cope with any physical problems which affect your home or work life; provides specialist aids and equipment.

Clinical psychologist – treats and supports you if you are having trouble coping with emotional problems.

Psychiatrist – can help you if you have problems coping with psychological or emotional issues.



Deciding your treatment

Following your diagnosis, your consultant and specialist nurse will discuss your treatment plan with you. This plan will take into account many factors, such as how much of the bowel is affected, and if the cancer has spread, what other areas or organs of the body have been affected (see bowel cancer staging on pages 10/11). The team will also assess your general health including overall fitness, current medications and if you have any other illnesses such as diabetes, heart or respiratory disease.

You should be given clear information about potential side-effects of your treatment and any potential long term consequences and what these might mean for you on a practical level.

As part of the consent process, you should be made aware that all treatments carry risks of long-term consequences which may be made more manageable if you report them quickly and they are given appropriate attention.

There will be a lot of information for you to remember and you will

naturally have lots of questions for your specialist team. You may want to take a list of questions with you so you don't forget anything, for example:

- Where is my bowel cancer, and how advanced is it?
- What are my treatment choices?
- If I need to have surgery, what kind of operation will it be and how long will I be in hospital?
- How will my bowels be affected afterwards?
- Will I need a stoma? If I do, will it be permanent (see page 14)?
- How long will I need to be off work?
- Will I need extra help at home after my surgery/treatment?
- Will my treatment have any effect on my sexual function or fertility?
- Are there any clinical trials open to me?
- Are there any other treatments available at another hospital?



Always try to take someone with you to these consultations – they can take notes for you to remind you what was said and what was decided. And don't be afraid to ask if you can record the consultation so you can play it back later.

You should be provided with a copy of the consultant's letter to your GP following any consultation. And finally, you will be given the phone number of the colorectal nurse specialist who will be your main point of contact (sometimes called your keyworker) so that you can call him / her if you think of another question later on.

“There will be a lot of information for you to remember and you will naturally have lots of questions for your specialist team.”

Second opinions

Patients sometimes choose to seek a second opinion from another consultant or hospital. This may be at the suggestion of family members keen to ensure all possible treatment options are being explored. Or it may be that patients are unhappy about their treatment pathway or decisions that have been made by their current team. We would recommend that you discuss your concerns with your GP or consultant first. It may be that talking things through can address some of your worries, allowing you to continue on your current pathway without delay.

It is possible to get a second opinion by asking your GP or your current consultant to refer you on. This can be arranged via the NHS, or privately as you wish. Asking for a second opinion can feel uncomfortable, but it shouldn't be an issue. Most doctors would prefer that you are confident in your team and the treatment being planned.

A second opinion will require all your scans and reports to be sent over to the other consultant, and your case to be discussed at their multi-disciplinary team meeting. This will quite often mean a wait of a week or two to allow all of this to happen, which can be quite stressful for you and your family.

Generally speaking, we wouldn't recommend delaying treatment in order to have a second opinion. However, some patients feel that it is worth taking the time to look at other options before starting treatment.

Patient stories



Janet, aged 63

"My screening kit arrived just after my 60th birthday. I had no symptoms at all; I was healthy, ate a reasonably good diet, didn't smoke, drank only the odd glass of wine and walked miles with my dog. How could I have cancer? However, I returned the kit and was surprised to receive a letter saying that an abnormal result had been detected. A further kit proved normal, but the third kit that they sent just to be sure was abnormal again, so I was referred to a hospital and offered a colonoscopy. Two polyps were discovered in my descending colon, one of which appeared cancerous. A CT scan was arranged for about ten days later and I was given the results about a week after that.

I was stunned to find I had bowel cancer, couldn't really think straight and just left the choice of treatment up to the experts. I was offered laparoscopic (keyhole) surgery for a left hemicolectomy. The operation was straightforward, the offending section of colon was removed and I did not need a stoma. It went so well that I was allowed to go home a day earlier than planned.

I was diagnosed with early stage 1 cancer, so did not need any chemotherapy. I think I made such a speedy recovery because the cancer was caught so early and I was healthy prior to surgery. My family have been very supportive and I have tried to keep in a positive frame of mind. I always believed that the cancer would be removed and I would be OK.

I am now three years on from my diagnosis and have had regular blood tests, MRI scans & CT scans. About six months ago the consultant announced that I was now considered cured. We celebrated with a Mediterranean cruise! I will certainly be making use of my next bowel cancer screening kit though."

Yasir, aged 27

"My family has a history of ulcerative colitis and I was on steroids and immuno-suppressants from the age of 13 to control the symptoms and was also receiving regular follow-up screening. In 2012 I had a routine colonoscopy, where polyps were removed, but not found to be cancerous. By 2013, I was starting to feel really ill again. I lost weight, was extremely tired all the time and had to use the bathroom urgently up to 12 times a day. I then developed a bad pain in my abdomen and narrower stools. I went back to my gastro-enterologist who changed my medication; my symptoms calmed down and I put back the weight I had lost, however I couldn't shake off the tiredness.

Then in late 2013, during a routine colonoscopy a tumour was found in my descending colon. My surgeon said that due to my history, he advised having my whole colon including my rectum removed and that he would fit a J-pouch [where the end of the small bowel is joined to the end of the anal canal to create a reservoir] and give me a temporary ileostomy.

Initially my surgery went well, but two weeks later I developed a high fever, very bad back pain and quickened heart rate. A CT scan showed that there were pockets of infected fluid around my J-pouch. I was given multiple antibiotics intravenously and was nil by mouth. I started to feel better after four days and was allowed home after eight days, very pleased to be able to eat proper food again.

Since then I've had regular check-ups and have been given the all-clear. My tumour was stage 1 and I did not need chemotherapy, because all 56 lymph nodes that were tested were clear of cancer.



I had my temporary ileostomy reversed nine months after the original surgery.

Before bowel cancer, I was very fit and ate well, with lots of fruit, vegetables and fibre in my diet. Since my treatment, I've had to change to refined, processed and starchy food as I couldn't handle fibre. I am anaemic, but the iron tablets I took for this made me feel sick, so I have occasional iron infusions and try to balance my nutrition as much as I can. Since my reversal, despite suffering some pouch inflammation, I have gradually resumed exercising and focused on setting myself fitness goals to push my body further. And I've got back into my other main hobby – baking cakes and pastry!"

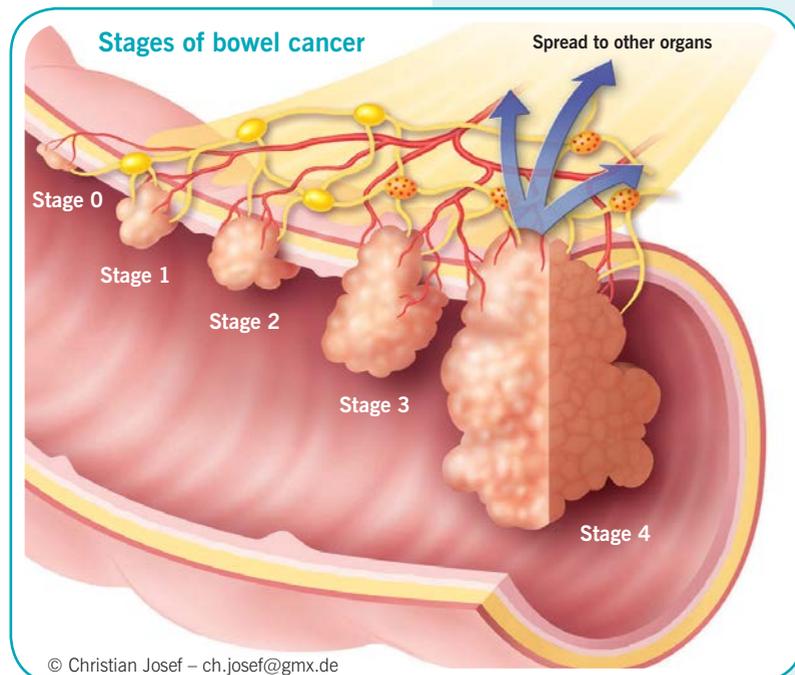
Bowel cancer staging

In order to determine the best treatment for your particular bowel cancer, you will have various tests to find out the size and position of the cancer and whether it has spread. This process is called 'staging'. You will have a CT scan and possibly further scans (such as MRI or PET) to show the size and location of the tumour, and an ultrasound and blood tests to get more information about the cancer.

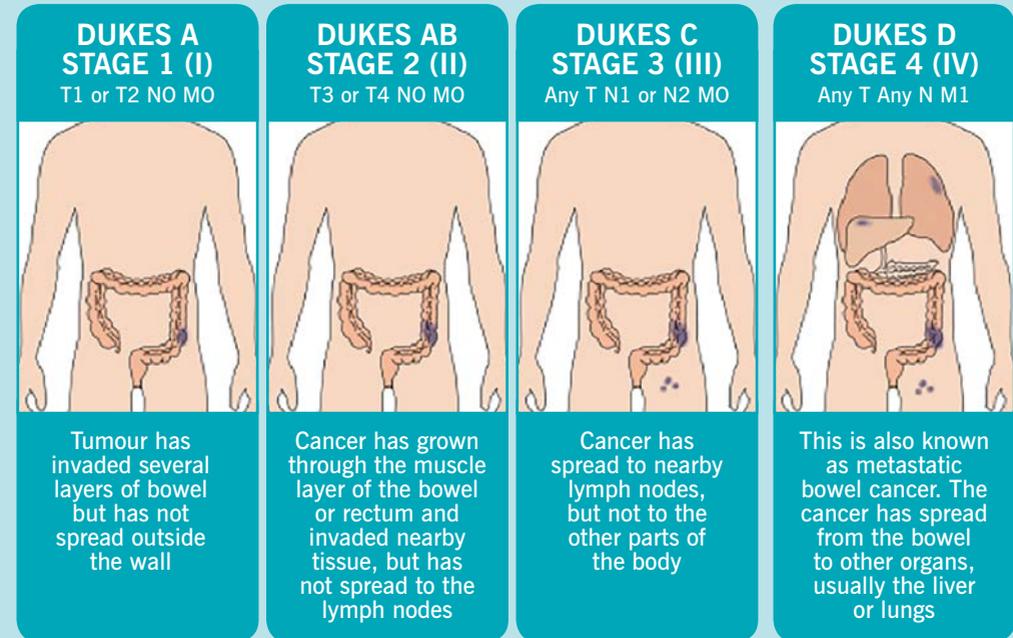
The stage of your bowel cancer can be described as stage I-IV (or 1-4). This international system is increasingly being used when talking to patients. The original Dukes' staging system is also still used (Dukes A, B, C or D). You will sometimes see the TNM (Tumour, Node, Metastases) staging report written with a lower case letter in front of it.

A cTNM means that it is based on the clinical findings of your scans and biopsies before you start your treatment. A pTNM classification is based on the full findings of both the pre-treatment investigations, and confirmed by a pathological assessment (of tissue under the microscope) following your surgery.

Stage 0 or 'carcinoma in situ' means that the cancer cells are contained in the inner lining of the bowel and there is very little risk of any cancer cells having spread.



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TNM (Tumour, Node, Metastases) is a shorthand description of the staging classification, which helps the specialists to understand very quickly what your cancer looks like.

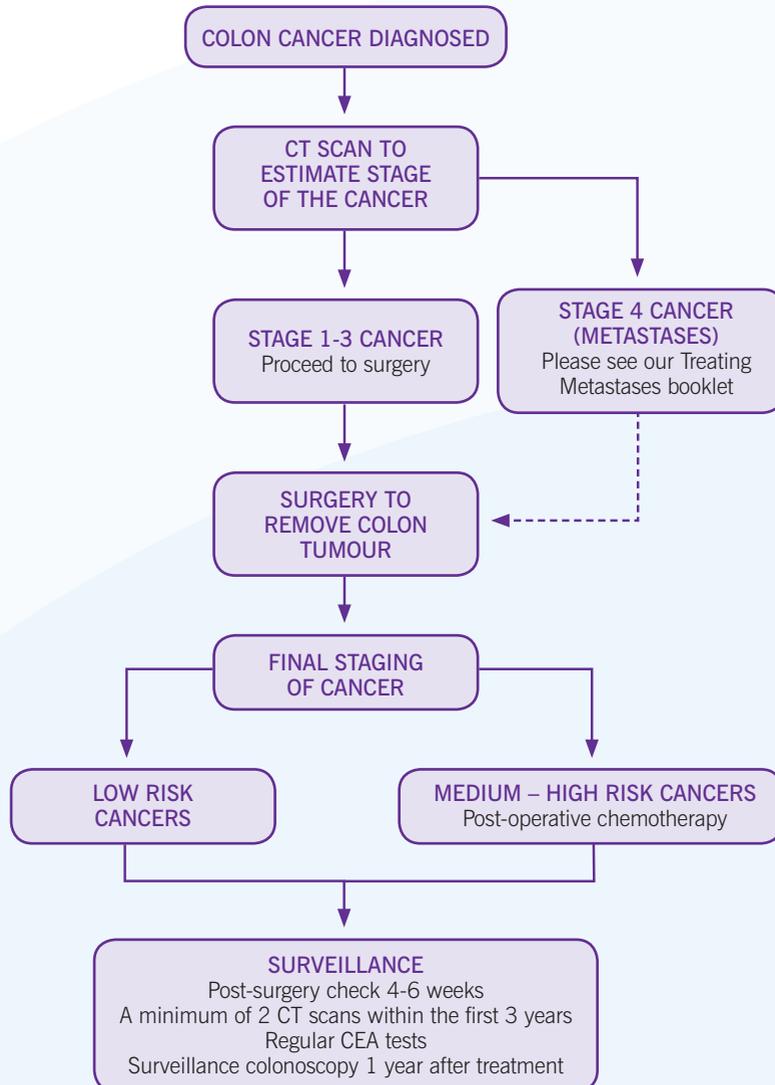
T: describes tumour size and how far it has grown into – and through – the bowel wall, using a scale of T1 to T4.

N: describes lymph node involvement – from NO which means that no lymph nodes are affected, to N2 where there are four or more lymph nodes affected.

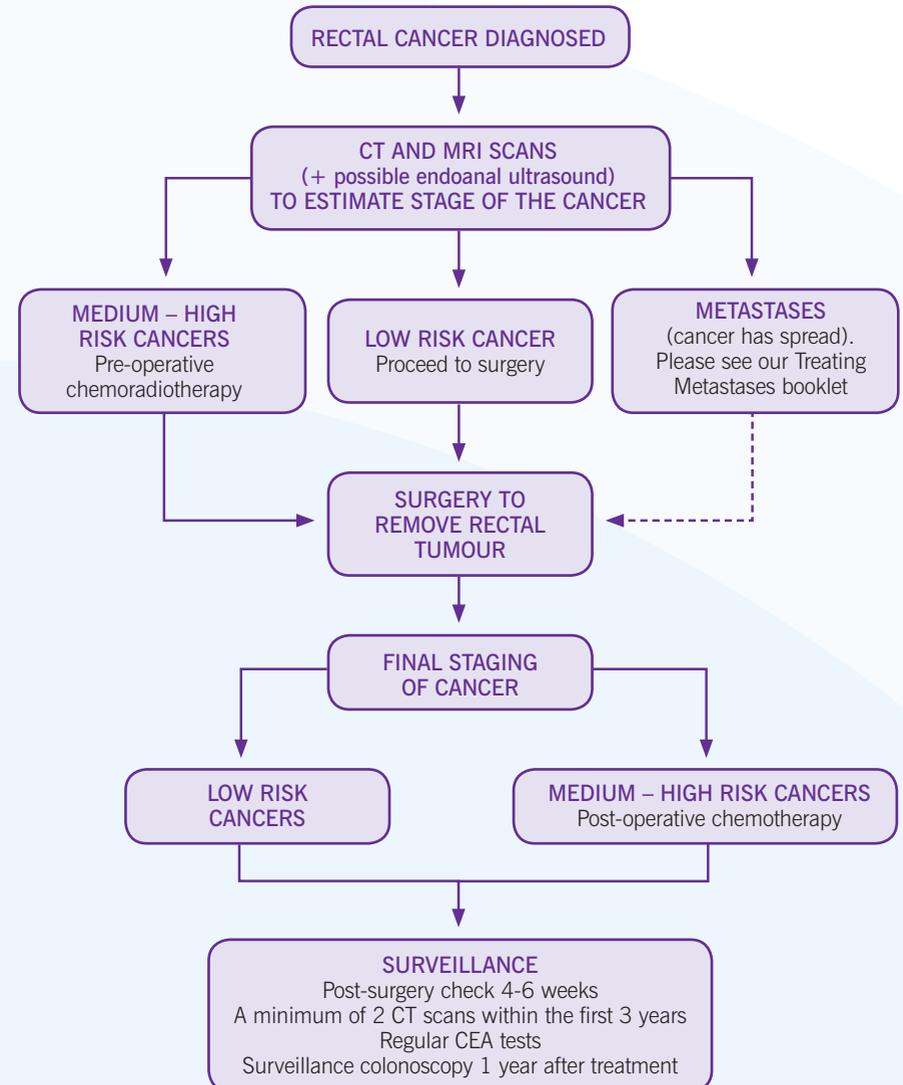
M: describes whether distant metastases (secondary tumours in other parts of the body) are present or not. MO means that there is no evidence of the cancer having spread, while M1 means that there is.

Within any category of the TNM scoring system, the use of an X score means that it has not been possible to assess the presence of cancer within the area described.

Treatment pathway colon cancer



Treatment pathway rectal cancer



Planned surgery

Surgery is the standard treatment to remove bowel cancer. Once you have had staging investigations to discover the location and size of your tumour, your multidisciplinary team may recommend surgery to remove the cancer. They may also decide to give you other treatment such as chemotherapy and/or radiotherapy to shrink the tumour before the operation and to reduce the risk of the cancer coming back.

During this operation, the surgeon will aim to remove the tumour and a small section of healthy bowel from both sides of the tumour called the 'surgical margin'. This is very important, to ensure that all of the cancerous cells have been removed. After the part of the bowel containing the tumour is removed, the two ends of the bowel will be joined back together, rather like a piece of plumbing.

Sometimes, particularly in the case of rectal tumours, your surgeon may want to give the join time to heal and will form a temporary stoma. A stoma is a piece of bowel that is brought out through your abdominal wall so that waste can be collected in a bag. The stoma is usually reversed a few weeks or months later, however in some cases it will be permanent.

Histology results

Following the operation, the piece of bowel removed and the tissues around it (known as a biopsy) are sent to the laboratory. This is to look for cancer cells present in the lymph nodes and/or blood vessels, and give the final staging for the cancer. The results (known as a biopsy) will help your specialist team decide if further treatment is required.

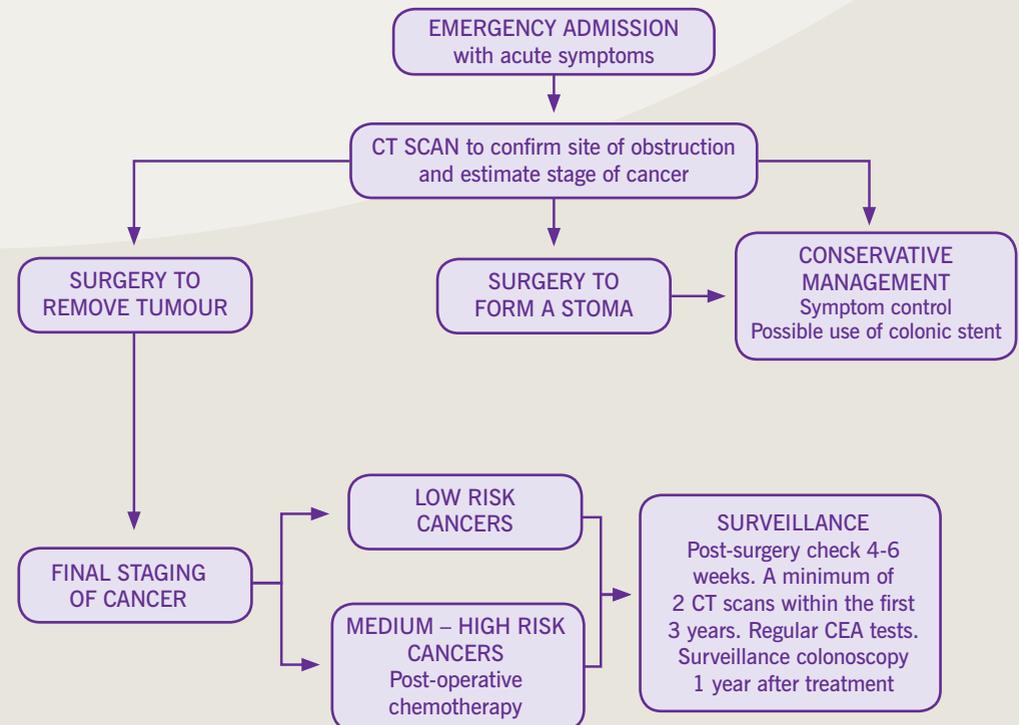
The location of the tumour in your colon or rectum will affect the type of surgery you have. Ask your doctor to explain the operation, and perhaps to draw you a picture of what they will be doing, and how your bowel will look after the operation. This can also help you to understand how the surgery may affect your bowel habit, the position of any scar tissue and where a stoma might be formed.

For more comprehensive information, please see our **'Bowel Cancer Surgery – Your Operation'** booklet, our **'Stoma Reversal'** factsheet, or visit our website beatingbowelcancer.org/surgery

Emergency surgery

While many patients have time to plan for their surgery, some patients are diagnosed with bowel cancer following emergency admission to hospital with abdominal pain or other severe symptoms. In these cases, the doctor will perform exploratory surgery which is always done as an open (not keyhole) procedure, and will depend upon your symptoms when you are admitted.

If it is not possible to rejoin the two ends of the bowel immediately, the surgeons will form a stoma, which may be reversed later on. In cases where patients are admitted as an emergency, with a blockage in the bowel caused by a tumour, the surgeon may choose to insert a colonic stent as a temporary way of unblocking the bowel, so that more extensive surgery can be planned. For more information, please see our **'Colonic Stenting'** factsheet.



Recovery after bowel surgery

Bowel surgery is a major operation. It can take several weeks or even months to fully recover (often reflecting how long your operation took). While you are recovering, your care will be shared between the hospital and your GP.

Side-effects of surgery are common, but will affect people in different ways. Many effects are short lived and will settle with time. Other effects may last for several months, or longer, depending on your general health and the type of surgery you had.

Some of the most common side-effects of surgery may include:

- pain and reduced mobility – especially immediately after surgery
- a change in bowel function (diarrhoea, urgency or constipation)
- nausea and/or vomiting
- loss of appetite or bloating
- tiredness and a lack of energy.

Contact your hospital team straight away if you develop any unexpected symptoms, or suddenly feel less well. They will be able to talk through anything that concerns you and advise and reassure you as appropriate.

Taking your prescribed pain killers **regularly** and trying some gentle exercise are both important parts of your recovery. Drinking plenty of water, and eating small, light meals frequently will also help.

Please see our **'Returning Home after Surgery'** factsheet and **'Eating Well'** booklet for more detailed advice.

You will see your surgeon a day or two after the operation, to get an idea of how he/she thought the operation went, and what the outcomes are likely to be. A follow-up appointment is also arranged, for around 3–6 weeks after the operation, to consider your options. By then, the results of your pathology tests will be back and your case will have been discussed at the multidisciplinary team meeting.

Patient story



John, aged 56

"In 2011 I had noticed an on-going change of bowel habits along with stomach pain for about six months, but I didn't think it was anything serious. However we were on holiday in France when I had an episode of obvious bleeding from the bottom. On our return I went to the GP, who did a rectal examination then referred me for a colonoscopy and scans. The doctor told me I had a tumour at the junction of the colon and the rectum. I would need chemotherapy and radiotherapy to shrink the tumour before it could be removed.

I had initial surgery to have a temporary ileostomy created and then a course of capecitabine and five weeks of radiotherapy, prior to more surgery to remove the tumour. My cancer was diagnosed at stage 3 with one lymph node involved; the tumour had grown through to the outer layer of the bowel wall. I had a further course of chemotherapy with oxaliplatin, and a third operation to reverse the ileostomy nearly a year later.

I found the hardest part in all this was telling my children and my parents. Cancer still has the power to scare, but once I accepted my predicament I was determined to be strong physically and mentally. I retired after 30 years in the Fire Service in the middle of my treatment and whilst disappointed not to have finished my career by attending one last fire, I accepted that my long-term health was the priority.

My wife Estelle has been a massive support. She suggested I start writing a 'blog', which I found helped me deal with my emotions. We are both Catholic and although not devout, I found this also helped me rationalise my situation.

My last CT scan was all clear. I think I am coping well now that surgery and treatment have ended. I had some residual neuropathy symptoms in my hands and feet (see page 27), but they are reducing all the time. Now that I have my fitness back, I volunteer for a local charity that clears woodland, as I find being in the open air helps my mood."

Radiotherapy options

Radiotherapy is the use of controlled, high-energy radiation, usually X-rays, to destroy cancer cells. It is only used in rectal or anal cancer. Some specialised techniques may be used in advanced colon and rectal cancer (see our 'Treating Metastases' booklet for information).

The treatment doesn't make you radioactive and it's perfectly safe to be with other people during your treatment. Radiotherapy can be used at several different stages of treatment:

Before surgery (neo-adjuvant)

This is given for rectal cancer to shrink the tumour to make it easier to remove and reduce the risk of the cancer coming back. This treatment is usually given with a low dose of chemotherapy to make the radiotherapy more active (chemo-radiation).

Chemo-radiotherapy can also be used on its own to kill cancer cells as an alternative to chemotherapy and/or surgery. Whether you have external or internal radiotherapy, there will be a period of time between the radiotherapy treatment ending and your surgery.

This delay is intentional, as the radiotherapy continues to shrink the tumour for several weeks after the end of treatment.

After surgery (adjuvant)

If you have not had radiotherapy before your surgery, you may be advised to have radiotherapy with chemotherapy after surgery, to destroy any cancer cells that may be left behind. This might be because the tumour is difficult to remove, or has grown through the wall of the rectum or spread to nearby lymph nodes.

Palliative radiotherapy

Lower doses of radiotherapy, over a shorter period of time, can also be given if surgery is not an option to relieve symptoms or slow the spread of the cancer.

External radiotherapy

This is delivered from outside of the body by a machine and only takes a few minutes. For this type of radiotherapy you will often need a CT scan 7-10 days before treatment to help plan how to give it.

Internal radiotherapy

Also known as brachytherapy or contact radiotherapy, this involves positioning radioactive sources near to or inside the tumour.

This treatment delivers a high dose of radiation directly to the cancer while limiting damage to surrounding tissues and organs. It is currently only available at some specialist cancer centres.

The Papillon technique is an example of contact radiotherapy for rectal cancer. It is performed at Clatterbridge Hospital in Liverpool, Castle Hill Hospital in Hull, Nottingham City Hospital and St Luke's in Guildford. It may be used where appropriate as an alternative to surgery on tumours which are fairly low in the rectum, less than 3cm diameter and where the cancer is at an early stage (T1 or T2). Patients who are not medically fit for other treatments may particularly benefit from this technique. However the conventional treatment for rectal cancer is with external radiotherapy followed by surgery.

Intensity modulated radiotherapy (IMRT)

Is radiotherapy where both the radiotherapy beam and the dose within the beam are shaped to match the tumour's shape and thickness. IMRT gives less radiotherapy to normal tissues compared to standard radiotherapy and research is starting to show that it causes less severe side-effects.

Doctors are now also looking at a new type of IMRT called volumetric modulated arc radiotherapy (VMAT). This is where the radiotherapy machine rotates around the body, continuously reshaping and changing the intensity of the radiotherapy beam.



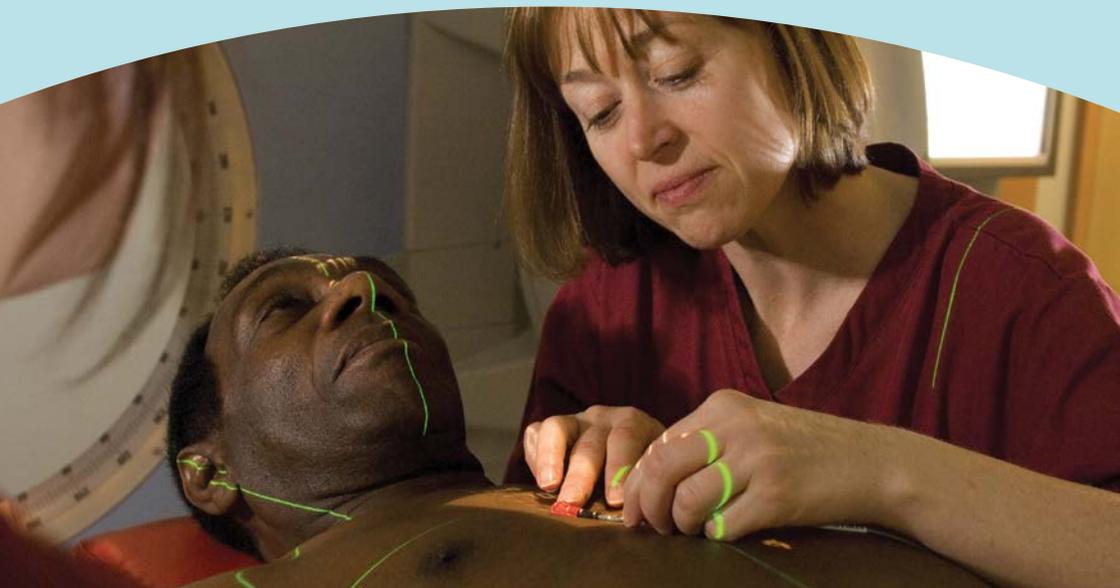
Side-effects of radiotherapy

Side-effects will vary depending on length and intensity of treatment you have. It will affect the bowel and other tissue close to the tumour, including your skin. This can cause temporary pain, discomfort, and a change to your bowel habit. Long-term problems may include chronic inflammation of the bowel (pelvic radiation disease). This can be difficult to cope with initially, but there are specialist treatments available which may help.

Pelvic radiation disease often needs very careful monitoring and changes to diet and lifestyle to manage successfully. The formation of scar tissue after treatment is common, and can cause narrowing of the vaginal wall in women and impotence in men. Your radiotherapy team will be able to advise you on how to minimise and cope with any problems or side-effects associated with your treatment.

Radiation proctitis is the term used to describe inflammation of the rectum caused by radiotherapy. Symptoms which include, diarrhoea, urgency, faecal incontinence and rectal bleeding may occur during or immediately after treatment or several months or years after treatment.

Your consultant may want to perform an examination to look at the area and possibly take a biopsy to confirm the diagnosis.



Patient story

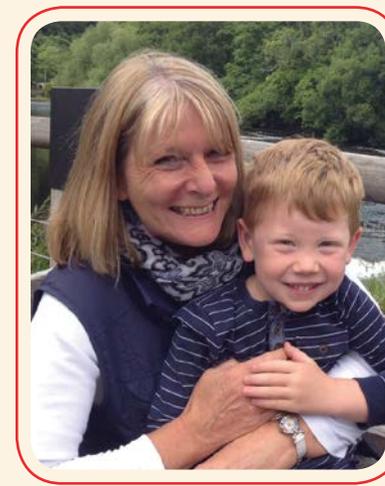
Jackie, aged 60

"In 2010 I noticed a change in my bowel habit, but I put it down to the stress of helping my daughter organise her wedding. Gradually the symptoms got worse and I was also bleeding and so I went to the GP, who examined me and referred me for blood tests, but these came back normal. My symptoms persisted and worsened so I went to see a different GP some months later, who referred me for a sigmoidoscopy.

The tumour was in my rectum, so I was given a week of radiotherapy to shrink the tumour to make it more operable. I was sent for tattooing; three permanent marks were strategically placed in order to target the tumour accurately. I found the radiotherapy relatively painless, just intense having to stay absolutely still during the treatment. My side-effects included tiredness and nausea, and my legs ached. It was a very long journey to and from the Cancer Unit five times a week and this added to my tiredness. The radiotherapy also brought on the menopause, which I was not concerned about except all the symptoms came almost overnight!

My surgery took place directly following the radiotherapy. It was an anterior section, so part of my rectum and sigmoid colon was removed. I was given a temporary loop ileostomy (a stoma I referred to as Buddy!) to allow the join to heal. I struggled with poor absorption of minerals and vitamins during this time, so despite being given dietary advice I lost a lot of weight and condition and became anaemic. Fortunately, once I had the stoma reversed, these problems subsided very quickly and I was able to stop taking the nutrient tablets.

My tumour was graded as stage 3 because it was close to perforating the bowel wall, but no lymph



nodes were affected and I did not need follow up chemotherapy.

I did suffer from depression and anxiety during my treatment and I tried counselling. It was very hard to readjust to life after cancer and I couldn't find a local support group at the time here in North Wales. I just didn't know anyone who had ever had this disease. I stumbled onto Twitter and found lots of people with bowel cancer who have become great friends.

I had regular follow up appointments, initially 3-monthly then 6-monthly and now yearly. I am scheduled another CT scan this year and a colonoscopy mainly because my brother was found to have polyps in his bowel, which has confirmed a family link. My 5 year check-up is November this year and I will technically be 'cured'. Bring it on!"

Chemotherapy explained

Chemotherapy is the use of 'anti-cancer' drugs to destroy cancer cells in the body.

If you have stage 0 or 1 bowel cancer, it should be possible to remove the cancer by surgery and chemotherapy will not be required.

If you have stage 2 bowel cancer – where there is no evidence that the cancer has grown through the bowel into the pelvis or lymph nodes – you may not need to have chemotherapy. However, where the tumour is larger or invading deeper within the bowel wall, chemotherapy may be offered to 'mop up' any cancer cells that may be left in the body, which the surgeon could not see. One large study has shown that having chemotherapy for stage 2 bowel cancer could reduce the risk of the cancer returning by 4%. There is no strong evidence to suggest that this is beneficial for everyone and it should be considered carefully on an individual basis.

If you have stage 3 bowel cancer, surgery to remove the cancer and nearby lymph nodes is usually followed by a course of chemotherapy to help prevent the cancer returning.

If you have stage 4 (advanced) cancer, symptoms can be controlled and the spread of the cancer can be slowed using a combination of surgery, chemotherapy, radiotherapy and targeted therapies as appropriate.

Chemotherapy is used at different stages of treatment:

Neo-adjvant – to shrink the tumour before surgery to reduce the risk of the cancer recurring in the future.

Adjuvant – to destroy any microscopic cancer cells that may remain after the cancer is removed by surgery and reduce the possibility of the cancer returning.

Palliative – to relieve symptoms and slow the spread of the cancer, if a cure is not possible.



Chemotherapy drugs can be given in several different ways:

Oral – drugs available as capsules to be taken at home every day.

Intravenous (IV) infusion – the treatment is given directly into a vein. This could be a small injection over a few minutes, a short infusion of up to 30 minutes, or longer infusions over the course of a couple of hours or even a couple of days. IV chemotherapy can be given via different methods, depending on how often you will need treatment to be given:

Cannula – a small tube inserted into a vein in the back of your hand, or your arm at each chemotherapy session.

Central line – a thin, flexible tube inserted through the skin of the chest into a vein near the heart, which can stay in place for many months. Hickman® or Groshong® lines are common types.

PICC line – thin, flexible tube passed into a vein in the bend or upper part of your arm and threaded through until the end of the tube lies in a vein near the heart. PICC lines can stay in place for many months.

Portacath – this is a small chamber which lies completely under the skin with a thin, flexible tube that goes into a vein in your chest or arm.

Your oncologist will discuss the best treatment plan options with you; you may be prescribed one drug or a combination of drugs. Depending on the stage of your bowel cancer, you may also be recommended treatment with targeted therapies (see page 32). The chemotherapy drugs licensed for treatment of bowel cancer in the UK are: 5FU (5-fluorouracil), capecitabine, oxaliplatin, irinotecan, tegafur-uracil and raltitrexed (for people who cannot tolerate 5FU).

A combination of two or more drugs is common, for example:

- **FOLFOX** – 5FU and leucovorin with oxaliplatin
- **FOLFIRI** – 5FU and leucovorin with irinotecan
- **FOLFOXIRI** – 5FU and leucovorin with both oxaliplatin and irinotecan
- **CAPOX** or **XELOX** – capecitabine with oxaliplatin
- **CAPIRI** or **XELIRI** – capecitabine with irinotecan
- **DeGRAMONT** – 5FU and folinic acid.

Patient stories

Lynda, aged 61

"I was diagnosed with rectal cancer in late 2009 and had surgery, resulting in a temporary ileostomy, which was reversed in 2010. I was treated with oxaliplatin and capecitabine via the SCOT clinical trial [now closed] which compared the effects of 12 weeks' treatment against 24 weeks. I suffered with very bad sickness, so my treatment was delayed for a month and they attached an anti-sickness syringe driver to me. I also had anorexia and extreme tiredness at times during the treatment. It was quite a blow, as I had started to feel really well again after my surgery. My main chemo was tablets which required hospital treatment one day every three weeks. I did everything the medical staff told me – to the letter – and was especially careful when on chemo not to go into crowded places.

Once the treatment was over I began to regain strength really quickly, with lots of rest and healthy nourishing food. I have been really careful since my cancer to look after my health. I've just had

Dalair, aged 62

"I was diagnosed with stage 2 colon cancer in 2005. I had been feeling more tired than usual and had back pain and constipation for a couple of years, but the diagnosis was a huge shock, as a man full of life ambitions and dreams faced with this news. Breaking this news to my family was something I found near enough impossible. I underwent surgery, but due to complications with the procedure I then had to undergo a second operation just days later, after which I was in intensive care for several weeks.

I gave it a lot of thought before I decided not to have any chemotherapy when it was offered to me, because I felt I had already been through so much. Ten years on, I have been very lucky, I am much better, and still enjoy my golf. I am now grateful for every minute of my life and spend as much of it as I can with the most precious people in my life, especially my grandchildren."



my last hospital visit to sign off on the SCOT trial and they now don't need to see me again. Everyone at the NHS from my GP surgery to the surgical team, chemo team and colorectal team have all been fabulous, dealing with not only the physical but also the emotional."

5FU and capecitabine

5FU or capecitabine, both fluorouracil based drugs, are currently one of the main first line treatments recommended for treating bowel cancer, at all stages of the disease. They are usually used in combination with oxaliplatin or irinotecan, and have been shown to increase the potential to extend overall survival and improve symptom control, even in advanced disease. Fluorouracil and capecitabine can also make radiotherapy treatments more effective, when given in combination before surgery.

5FU is given as an infusion into a vein via a cannula. You may also be given a slow infusion over a few days, in which case you will be fitted with a central line or PICC line (please see page 23) and sent home with a pump. 5FU is combined with folinic acid (leucovorin), a vitamin which boosts the effects of the chemotherapy. Each cycle is typically given every two or three weeks.

Capecitabine is taken as tablets. They are normally taken twice a day with a glass of water with a meal or within half an hour of eating, as the drug works best when digested with food. The doses should be regularly spaced so after breakfast and then after your evening meal are the best times. You usually have several cycles of capecitabine over a few months and each cycle takes 21 days (14 days of tablets and 7 days rest). Capecitabine may be given on its own, or with other chemotherapy drugs.

The potential side-effects of these fluorouracil based chemotherapy drugs may include: diarrhoea, nausea and vomiting, weight loss, abdominal pain and generalised weakness, mouth ulcers, a drop in white blood cells affecting natural immunity, or hair thinning.

Skin soreness, swelling, redness and dry, cracked skin on the soles of feet and palms of hands (hand-foot syndrome) are particularly common with capecitabine. You can help reduce the symptoms by keeping your hands and feet cool, avoiding very hot water, avoiding tight fitting gloves or socks, and keeping your skin well moisturised with a non-perfumed medical (not cosmetic) moisturiser.

These drugs can cause angina, chest pain and very rarely a heart attack. If you do have any existing heart problems you need to mention this to your oncologist.

Raltitrexed may be prescribed for people who cannot tolerate 5FU or capecitabine or who have a previous history of coronary heart disease. Raltitrexed is given as an infusion into a vein, usually once every three weeks.

About one in ten people will experience a temporary drop in the number of red and white blood cells, which can cause an increased risk of picking up an infection, anaemia, or nosebleeds, bruising and sore gums.

Irinotecan

Irinotecan can be used to treat bowel cancer that has started to spread, either in the first line setting or as a treatment option for recurrent disease. It can be given in combination with other chemotherapy drugs, including 5FU/capecitabine, oxaliplatin, and also with targeted therapies (see page 32).

Irinotecan is usually given as a slow intravenous infusion in cycles of two to three weeks. Side-effects can include increased sweating and saliva production, stomach cramps and diarrhoea – a recognised syndrome that can be very successfully treated with other medications.

Other common side-effects are nausea and vomiting, delayed diarrhoea, muscle weakness, lethargy and tiredness, bruising, bleeding gums or nosebleeds, hair loss, and a drop in the blood cells responsible for your natural immunity.



Oxaliplatin

Oxaliplatin is used where the bowel cancer has spread, locally into lymph nodes or into other distant organs. It can be given in combination with either 5FU or with capecitabine as either a first-line treatment, or subsequent treatment regimes. It is also compatible with targeted therapies (see page 32).

Oxaliplatin is usually given as a slow intravenous infusion which is repeated at regular intervals, every two or three weeks, depending on the treatment pathway you have been prescribed. Side-effects from oxaliplatin may include nausea, vomiting, and diarrhoea, and it can affect normal blood clotting, leading to bleeding gums, nose bleeds and bruising.

Peripheral neuropathy is a significant side-effect of oxaliplatin. This is a collection of symptoms, including numbness or tingling, especially in the hands or feet, because it affects delicate nerve endings throughout the body. You may wish to avoid oxaliplatin if a loss of sensitivity in your fingertips would prevent you carrying out your job or favourite hobby. It can also affect nerve endings in the neck

or throat, causing a feeling of tightness or temporary shortness of breath. They can come on after one treatment, or may become more obvious as you receive repeated doses of the drug. The symptoms usually improve once treatment stops, although you may find that they do not completely disappear.

These symptoms can be triggered by anything cold, so you should avoid iced drinks and wrap up warmly in the cold weather. It is important to report any symptoms to your oncologist who may consider reducing the dose of the drug if the symptoms are severe.

For detailed information on this side-effect please see our **'Peripheral Neuropathy'** factsheet.

“I am just over six months post chemo, oxaliplatin and 5FU. I think that it is only now that I can say that my body has recovered, I still get tired though! The longest lasting side-effect was the peripheral neuropathy in my hands and feet. I also had ‘Lhermittes sign’ – every time I put my chin down my whole body jolted from the top of my spine down towards my feet. Very frightening at first until I realised it was all part of the neuropathy. Fortunately it was the first side-effect to disappear, about two months after chemo finished, followed by my hands returning to normal, then my feet which took much longer. I am now ‘tingle free’ with just the faintest sign of numbness left, but I’m still hopeful that will go eventually.”

Extract from our patient forum at <http://community.beatingbowelcancer.org>

CINV and diarrhoea

Chemo-induced nausea and vomiting (CINV)

Nausea and vomiting are two of the most common side-effects of cancer treatment. About 50% of people who have chemotherapy for bowel cancer suffer from nausea and vomiting, which might also cause dehydration, fatigue, loss of appetite and difficulty concentrating. Some patients are more vulnerable to CINV than others. These include women (even more so if they experienced these symptoms during pregnancy), people under 50, and patients who have received previous chemotherapy treatments. Other risks include a personal history of motion sickness, or problems with anxiety.

Many new medications are available to control CINV and it can now be prevented in most people by carefully assessing your risk of developing these side-effects before you start treatment.

Ways to manage CINV

- avoid eating solid foods immediately before and after treatment (although please note that capecitabine tablets do need to be taken with food)
- avoid caffeine and alcoholic drinks
- sip clear liquids such as sports drinks, ginger ale, lemon-lime sodas, or diluted, unsweetened fruit juices (avoid grapefruit juice)
- start with bland foods such as dry toast or crackers, then gradually build up to small, frequent meals throughout the day
- avoid spicy or greasy foods
- avoid favourite foods on days you are sick so they don't become nausea triggers
- avoid strong smells that may upset your stomach such as cooking odours, smoke, or perfume
- avoid lying flat for at least two hours following meals - a short walk may also help
- contact your specialist team if vomiting is severe or if you cannot keep anything down
- complementary therapies such as yoga, self-hypnosis, guided imagery, progressive muscle relaxation, acupuncture, or acupressure may also help.

Diarrhoea

Diarrhoea is also a fairly common side-effect of chemotherapy and in most cases is relatively mild and easily managed. However if you are having more than 5 or 6 episodes of diarrhoea a day do tell your consultant or chemotherapy nurse. Diarrhoea is often best managed with anti-diarrhoeal drugs such as loperamide, but ensure that you discuss this with your medical team first in case there are any reasons why you should not take it.

Increased risk of infection

Chemotherapy can reduce the number of blood cells made by the bone marrow, including white blood cells, which fight and prevent infection. If the number of your white cells is low you are more likely to get an infection. The main white cells which fight bacteria are called neutrophils, so when they are low you are described as neutropenic.

Your resistance to infection is usually at its lowest 7–14 days after chemotherapy. The number of your white blood cells will then increase steadily and usually return to normal before your next cycle of chemotherapy is due. If you get an infection as a result of the side-effects of chemotherapy – when the body is already compromised – it is considered to be a medical emergency and you may need hospital admission for treatment with antibiotic intravenous (IV) infusions.

You can manage your personal risk actively by taking these precautions:

- always wash your hands thoroughly after using the toilet and before preparing food
- stay away from crowds and from people who you know have an infection, such as a cold
- make sure your food is thoroughly cooked, peel fruit before you eat it and avoid 'risky' foods such as unpasteurised cheeses and shellfish
- wash your hands after handling animals and avoid litter trays and cages.

Who is most at risk?

The people most at risk of developing this serious problem are often older patients who also have poor general health and other underlying health issues with heart, kidney or other problems with major organs. People who have a low white blood cell count as a result of previous chemotherapy

treatments or current chemotherapy in high doses may also be at risk.

How your hospital team can help

Prior to each cycle of chemotherapy you will have your blood levels checked and be carefully assessed for any signs and symptoms of infection. Your chemotherapy team should give you a special card with the signs and symptoms to look out for, and an emergency contact number that is active 24 hours a day. Where your personal risk is considered to be high, medications can be prescribed to increase the production of white blood cells, to help you recover more quickly from chemotherapy.

Chemotherapy toxicity

Chemotherapy is a toxic treatment and each person's ability to deal with this varies. All precautions are taken to reduce the risk of the treatment to you. Very occasionally it is necessary to carry out certain blood tests to see if you are particularly at risk prior to starting treatment. Your oncologist will discuss the possible risks to you and allow you time for questions.

Getting the most from your chemo

- **Be positive** – it can be easy to focus on the negative aspects of chemotherapy, particularly the side effects, but remember it's there to help you! It could make you feel worse initially but this is a short term thing with the potential to get you back to health. Try and picture YOUR chemo as YOUR friend, coming in to beat the cancer up for you.
- **Keep a diary** – chemo affects everyone in different ways. This includes the side-effects you may experience, as well as when they may occur. If you keep a diary your team will be able to assess how well you're tolerating the drugs and you will get to know when your good and bad days are likely to be.
- **Diet** – if you're thinking about starting a special diet or taking supplements while on chemo, it's important to discuss this with your nurse or doctor first in case there are any potential interactions.
- **Don't worry about dose** – your doctor will often start at a high dose with a view to reducing it to a level that you can tolerate. So a dose reduction doesn't mean things are failing, quite the opposite, it means you're getting the treatment tailored for you so you can get the most out of it.
- **Be gentle but don't hide away** – this is your balancing act! Your body is going through a lot during chemo and you're likely to be quite tired on occasions. Listen to your body and take it easy when you need to, but do try and get out at least for a walk each day for some fresh air and a bit of exercise.
- **Take your meds** – you may be given lots of other medicines to help support you, for example to help stop you feeling sick, or anti-diarrhoea tablets. They really can make all the difference, but if they aren't working for you then tell your chemo nurse as there may be other medicines and advice they can give you.
- **Don't suffer in silence** – if you are worried or feeling really ill then call your chemo unit; they will want to hear from you and will be able to give you good advice.
- **Travelling abroad** – so long as your doctor is OK with it and you are feeling fine then there is no reason you shouldn't travel during chemo. It's worth organising travel insurance and getting a letter from your doctor stating that you are cleared to travel and listing any medications. Pack your medicines in your hand baggage just in case your checked bags get lost!

Patient story

Steve, aged 52

"In 2013 I was diagnosed with bowel cancer. At the time I was fit and healthy, I trained six days a week in the gym, did 10k races and practiced yoga and mixed martial arts.

My symptoms were very subtle. I had started to go to the toilet more often – eventually up to 12 times a day, however there was no pain, only a very little blood occasionally. I then started to feel tired all the time so I went to my GP for the first time in seven years. I was sent for a colonoscopy and a scan after which my gastroenterologist told me I had bowel cancer and it had spread to my liver and lungs. I was so shocked, but my doctor was very positive. He really gave me confidence because he immediately talked about what they were going to do to tackle it and how aggressive they could be with treatment because I was so healthy and fit.

I had surgery to remove a large tumour from my lower bowel (recto sigmoid junction) and following six weeks of recovery, I went to see my oncologist. The original scan showed dots on my liver and lungs, but a new scan showed the lung lesions had grown significantly – each was 2-3cm in size. I was put on a six months course of Avastin plus FOLFIRI chemotherapy.

After three months I had another scan. It was magical – my liver was completely clear and the tumours on my lungs were at least 50% reduced. After six months even the tumours on my lungs were reduced so much that the planned surgery was cancelled. I am now on

maintenance chemo for life (Avastin plus capecitabine). Initially I had a few problems with this, especially with the hand and foot syndrome and diarrhoea. I then found Beating Bowel Cancer's forum, where I was given lots of practical advice and support by people who had gone through the same thing and that really helped.

I've now got a real balance to my life despite being on lifetime chemotherapy – I work, exercise, walk my dog and travel the world. Officially I'm classed as 'incurable' and am therefore on a form of palliative care. However, I don't view this as the end, it's my stimulus to make the most of things and enjoy my life."



Targeted therapies

The development of targeted therapies, also known as personalised or biological therapies or monoclonal antibodies, is an exciting development in the treatment of advanced cancer, as it may be possible to destroy cancer cells without damaging other, healthy cells. New drugs are being developed which act in different ways. They may: stop cancer cells from dividing and growing; seek out cancer cells and kill them; encourage the immune system to attack cancer cells; or alter the growth of blood vessels into the tumour.

Combinations of chemotherapy and targeted therapies are increasingly successful ways of treating a greater number of patients with stage 4 bowel cancer (metastases in the liver and elsewhere) before and/or after surgery.

RAS and other biomarker tests

Knowing the genetic type of your bowel cancer can help your oncologist select the most effective treatment for you. This may also avoid giving you treatments which are unlikely to work. Currently the most common test looks at the RAS family of genes (KRAS and NRAS). If your bowel cancer has spread to other parts of your body, then you should have a RAS test done.

The biomarker tests are done on cancer cells from the tumour or biopsy that was removed during your operation or endoscopy. Even if the test is not done immediately, samples of the cancer will have been preserved and stored in the hospital laboratory.

Your medical team will arrange for the tissue sample to be tested and, once the sample has been located, the test results typically take 5-14 working days to come back to your oncologist.

Which therapies are available for bowel cancer patients?

Up to 50% of bowel cancer tumours tested have normal, wild type genes which may respond to the targeted therapies cetuximab (Erbix) or panitumumab (Vectibix).

The other 50% of bowel cancer patients have one of the genes mutated and are unlikely to benefit from these drugs. If this is the case, you may still benefit from drugs which work in a different way such as bevacizumab (Avastin). Unfortunately, with effect from November 2015 this drug is not currently available on the NHS in the UK.

Access to targeted therapies is an ever-changing situation with different criteria being used in England, Wales, Scotland and Northern Ireland. For the current status, please refer to our website: beatingbowelcancer.org/access-targeted-therapies.

When treatment has finished

Many hospitals have adopted a 'Recovery Package' which includes a number of steps designed to improve the coordination of care for people living with and beyond cancer:

- a Holistic Needs Assessment (to establish how confident you feel about managing your own recovery) carried out at two key points in your treatment
- a Treatment Summary to be completed by the multi-disciplinary team at the end of each treatment phase, which is sent to both you and your GP
- a Cancer Care Review to be completed by your GP or practice nurse six months after your cancer diagnosis, covering post-treatment support, possible late-effects of cancer and other important Information
- a patient education and support event which will include advice on a healthy diet and lifestyle, and how to get help if you are not coping as well as you might.

If you are not offered any of these, ask your GP or hospital team about them.

There is more information on life after treatment finishes in our '**Beyond Bowel Cancer – Living Well**' booklet and our '**Managing Your Follow Up**' factsheet.

Your colorectal nurse may be able to recommend a local support group or you will find a lively community of bowel cancer patients and relatives at community.beatingbowelcancer.org/forum

In addition, Beating Bowel Cancer organises Patient Days every year, currently in London and Manchester, where you and your family can meet others affected by bowel cancer.



Who else can help?

Beating Bowel Cancer has a range of resources and a dedicated patient services team. We can answer your questions and offer information and signposting if you have any concerns relating to symptoms or the treatment and management of bowel cancer.

You can contact our **Specialist Nurse Advisors** and get further information in several ways:
T: 020 8973 0011
E: nurse@beatingbowelcancer.org

Online forum for patients and relatives at community.beatingbowelcancer.org/forum

Download or order booklets at beatingbowelcancer.org

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

Pelvic Radiation Disease Association

Support for the effects of radiotherapy
T: 01372 744338
W: prda.org.uk

NICE Guidelines

Guidance from the National Institute for Health and Care Excellence on the management of colorectal cancer
W: nice.org.uk/guidance/CG131/informationforpublic

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 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 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 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: **08450 719 301** or

T: **020 8973 0011**

nurse@beatingbowelcancer.org

For more information visit www.beatingbowelcancer.org

Beating Bowel Cancer is a registered charity

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