



Your pathway

A guide to bowel cancer
treatment



Bowel CancerUK
Beating bowel cancer together

Introduction

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This booklet is for anyone diagnosed with bowel cancer and their family and friends. We hope it gives you an overview of what bowel cancer is, how it is treated, the common treatment side effects and what happens when you finish treatment.

Support for you

As well as the information in this booklet, we also have a range of other information and support that you might find useful.

Online community

Join our online community for everyone affected by bowel cancer at bowelcanceruk.org.uk/community

Ask the Nurse

Contact our nurses if you have any questions or concerns at bowelcanceruk.org.uk/nurse

Publications

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

Website

Find out more about bowel cancer at bowelcanceruk.org.uk

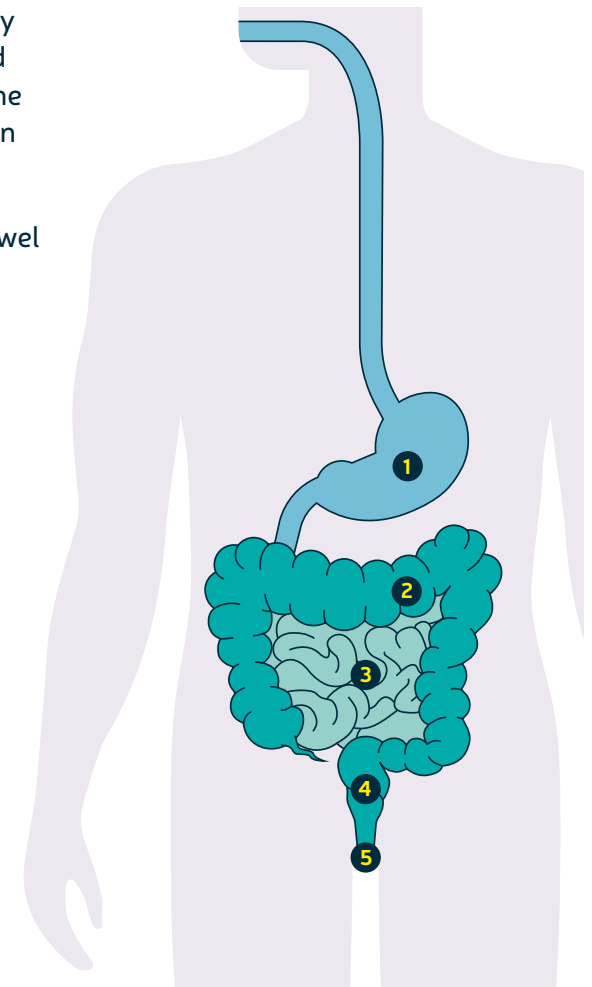
What is bowel cancer?

Bowel cancer is also called colorectal cancer. It affects the large bowel, which is made up of the colon and rectum, shown in the picture below.

The cells in your body normally divide and grow in a controlled way. When cancer develops, the cells change and can grow in an uncontrolled way.

Cancer cells can stay in the bowel or they might spread to other parts of the body, such as the liver or the lungs.

- 1 Stomach
- 2 Colon
- 3 Small bowel
- 4 Rectum
- 5 Anus



Your healthcare team

Your first appointment at the hospital will probably be with a colorectal surgeon or a specialist colorectal nurse. They are part of a bigger team of relevant healthcare professionals that look after different areas of your treatment and care. They will usually meet every week. This team is called a multidisciplinary team (MDT).

Your consultant or specialist nurse will discuss the outcome of these meetings with you. They will make sure your wishes are taken into account and that you fully understand any treatment decisions that are suggested.

Your MDT will usually include:

Colorectal clinical nurse specialist (CNS)

A nurse with specialist training in the care of bowel cancer patients. The CNS is usually your first point of contact if you have any queries or concerns.

Colorectal surgeon

A doctor with specialist training in bowel surgery. Other specialist surgeons might be involved if your cancer has spread to other parts of your body, for example to your liver or lungs.

Medical and clinical oncologists

Doctors with expertise in treating cancer patients with chemotherapy and other specialised drugs. Clinical oncologists can also give radiotherapy treatment. Medical and clinical oncologists often work together and might be supported by other doctors:

- **Specialist registrars** - qualified doctors who are gaining more experience and developing their skills in a specialist area
- **Foundation doctors (house officer) or core trainees (senior house officer)** – qualified doctors who have not yet specialised

Radiologists

Doctors with expertise in X-rays and other specialised screening machines (for example, ultrasound, CT, PET and MRI).

- **Diagnostic radiologists** use scans to locate and measure where a cancer is in the body
- **Interventional radiologists** use scans to help guide cancer treatments into a patient's body

Histopathologist

A specialist doctor who uses laboratory equipment to look at patient tissue and confirm a diagnosis.

Stoma nurse specialist

A nurse with specialist training to care for patients with a temporary or permanent stoma.

The following healthcare professionals may also be involved in your care:

Therapeutic radiographer

A healthcare professional that is trained to deliver radiotherapy treatments.

Oncology nurse specialist

A nurse with specialist training to care for patients who are treated with chemotherapy.

Research nurse

A nurse who helps recruit, manage and support patients who are taking part in a clinical trial.

Palliative care specialist

A doctor or nurse with extra training and experience to support patients (and their families) with very advanced cancer to improve quality of life.

Pharmacist

A specialist who can support and advise about the medicines being used to treat cancer and their possible side effects.

Counsellor

A professional who uses non-medical therapies and techniques to support people to deal with emotional issues and problems.

Dieticians and nutritionists

Professionals who support you if you have problems with eating and/or drinking, or if you need help with managing your weight.

Physiotherapist

A professional trained to help you regain strength, movement and balance after surgery.

Occupational therapist

A professional trained to help you regain independence and cope with home or work life after surgery or other treatment.

Clinical psychologist

A professional trained to treat and support you if you are having trouble coping with emotional or behavioural problems.

Psychiatrist

A doctor trained to treat and support you if you have problems coping with psychological or emotional issues.

GP

Your GP is also likely to be involved in your care throughout your diagnosis, treatment and beyond.

We've included space for you to add contact details of the healthcare professionals involved with your treatment and care.

Name:

Tel:

Email:

Name:

Tel:

Email:

Name:

Tel:

Email:

Deciding your treatment

Every bowel cancer patient is different and not all treatment options will be suitable for you. Making a decision about which treatment to have can be difficult, but your healthcare team will support you and answer your questions.

It is important that you understand and are happy with the treatment suggested for you and any possible side effects. Treatment decisions depend on lots of different things including:

- Where the cancer is
- How big the tumour is
- If the cancer has spread outside your bowel
- The type of cells that make up your bowel cancer
- Whether your bowel cancer has changes (mutations) in certain groups of genes
- How well you respond to the treatment
- Any treatment you've already had
- Any side effects you have as a result of the treatment
- The local and national guidelines for treating bowel cancer
- Your general health and fitness

- If you have any other illnesses or are taking any other medicines
- Whether there are any suitable clinical trials for you



“

My consultant explained that he would like to operate and remove a section of my bowel. Being able to take the time to absorb everything empowered me to make the right treatment decision for me.

Stuart

”

Meeting your specialist team

You might find it useful to take a list of questions with you when you meet with your specialist team. Here are some examples:

Where is my bowel cancer?

Will treatment affect my sexual function or fertility?

How advanced is my bowel cancer?

Are there any clinical trials suitable for me?

What are my treatment choices?

Are there any other treatments available at another hospital?

How will my bowels be affected after treatment?

After your appointment, your consultant will send a letter to your GP. You will also be given a phone number of your colorectal nurse specialist who you can call if you have any more questions.

Will I need a stoma?

Some people find it useful to take someone with them to their medical appointments to help them take notes and remind them what was discussed.

How long will I need to be off work?

Will I need extra help at home after treatment?

Bowel cancer staging

Staging a cancer involves describing its size, where it is and whether it has spread. Knowing the stage of your cancer will help you and your doctor decide on the best treatment.

You might have one or more of the following tests:

- CT scan
- MRI scan
- Ultrasound scan
- PET-CT scan

Staging systems

TNM

There are different ways of staging bowel cancer. The most common is the TNM (tumour, node, metastases) system.

- **T (tumour)**: how far the tumour has grown through the bowel wall. T stage ranges from T1 (where the cancer is in the inner layer of the bowel) to T4 (where the cancer has grown through the outer lining of the bowel wall)

- **N (node)**: has the cancer spread to nearby lymph nodes
 - **NO**: no lymph nodes contain cancer cells
 - **N1**: there are cancer cells in up to three nearby lymph nodes
 - **N2**: there are cancer cells in four or more nearby lymph nodes
- **M (metastases)**: has the cancer spread to other parts of the body. M0 means the cancer hasn't spread to other parts of the body, M1 means it has.

You will sometimes see the TNM staging report written with a lower case letter in front of it.

- **cTNM** means the report is based on the clinical findings on scans and biopsies before the start of treatment
- **pTNM** means the report is based on the full findings of both the pre-treatment investigations and confirmed by a pathological assessment (of tissue under the microscope) following surgery

Number staging

Information from the TNM staging report can be used to give a number stage from 1 to 4. See [page 12](#) for more information about number staging.

Dukes' staging

Doctors sometimes also use the Dukes' system to describe the stage of the cancer. This system uses the letters A, B, C or D to describe bowel cancer stage. Dukes' A means the cancer is in the inner lining of the bowel. Dukes' D means it has spread to another part of the body.

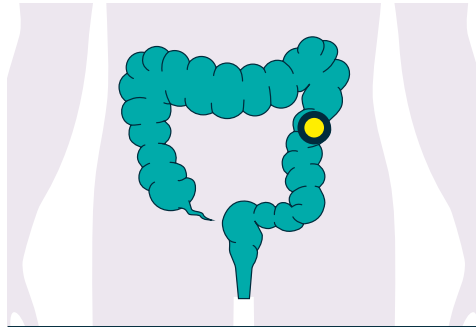
Grading

You might also hear your doctor talk about the grade of your cancer. Grading the cancer helps you and your doctor understand how quickly it may grow and spread. A low grade cancer may grow more slowly and is less likely to spread than a high grade cancer.

- **Low grade** – the cancer cells look similar to normal cells
- **Moderate grade** – the cancer cells look more abnormal
- **High grade** – the cancer cells look very abnormal

Treatment pathways

Number staging



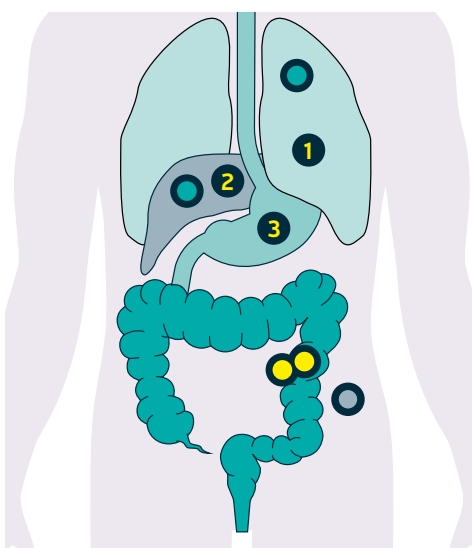
Stage 1: T1 or T2, N0, M0
The cancer hasn't spread outside the bowel wall



Stage 2: T3 or T4, N0, M0
The cancer has grown into or through the outer layer of the bowel wall



Stage 3: Any T, N1 or N2, M0
The cancer has spread to nearby lymph nodes



Stage 4: Any T, Any N, M1
The cancer has spread to other parts of the body

Key

- Tumour
- Nodes
- Metastases
- 1 Lungs
- 2 Liver
- 3 Stomach

Your treatment will depend on lots of different factors, including where in the bowel the cancer is and whether or not it has spread anywhere else in the body.

Whether your cancer is in your colon or rectum can affect the treatment you have, so we have provided separate pathways for each. Treatment is individual for each patient, but these flowcharts can help give you an idea of what to expect.

Colon cancer

Colon cancer diagnosis



Staging

You will be offered a CT scan to work out the stage of your colon cancer. Staging looks at the size of the cancer, where it is and whether it has spread.



Surgery

Surgery is the most common treatment for bowel cancer. Most people with early stage bowel cancer will have surgery.



Treatment after surgery

Some people will be offered treatment after surgery. This is sometimes referred to as 'post-operative' or 'adjuvant' treatment. This will usually be chemotherapy.



Follow up

After treatment has finished you will have regular follow up visits. This is to check that the cancer hasn't come back or spread.

Rectal cancer

Rectal cancer diagnosis



Staging

There are a range of tests that are used to work out the stage of your rectal cancer. You are likely to have a CT scan. You may also be offered an MRI scan and/or an endorectal ultrasound. Staging looks at the size of the cancer, where it is and whether it has spread.



Treatment before surgery

Some people will have treatment before surgery. This is sometimes referred to as 'pre-operative' or 'neoadjuvant' treatment. This could be chemotherapy, radiotherapy or both (chemoradiation). Not everyone will have treatment before surgery.



Surgery

Surgery is the most common treatment for bowel cancer. Most people with early stage bowel cancer will have surgery.



Treatment after surgery

Some people will be offered treatment after surgery. This is sometimes referred to as 'post-operative' or 'adjuvant' treatment. This will usually be chemotherapy.



Follow up

After treatment has finished you will have regular follow up visits. This is to check that the cancer hasn't come back or spread.

Advanced bowel cancer

If you have stage 4 colon or rectal cancer that has spread to other parts of the body such as the liver or lungs, there may be different treatment options or combinations of treatment available to you. This could include chemotherapy and surgery.

You may also be able to have other types of treatment such as targeted therapy, which helps your body control the way cancer cells grow. Read more about targeted therapy on [page 28](#). Your medical team will tell you if this is suitable for you.

Find out more

Read more about treatment for advanced bowel cancer on our website bowelcanceruk.org.uk/aboutbowelcancer

Surgery

Surgery is the most common treatment for bowel cancer. Your healthcare team will help you decide the best treatment for you. Not everyone can have surgery. Your medical team will be able to discuss with you whether surgery is suitable for you.

Types of surgery

The type of surgery you have will depend on where your cancer is and whether it has spread to other parts of the body. The information on this page is about surgery for cancer in the bowel.

You might be offered open surgery or keyhole (laparoscopic) surgery. If you have open surgery, the surgeon will make one opening to try and remove the cancer.

If you have keyhole surgery, the surgeon will make several small openings in your stomach area. They will put a long, thin tube with a light and camera through one of the openings and use surgical instruments to remove the cancer through the other openings.

If you have a very small, early stage cancer, the surgeon may remove it from the lining of the bowel in an operation called a local resection.

Surgery to remove part of the colon is called a colectomy. The type of colectomy you have will depend on where in the colon the cancer is.

If you have rectal cancer, the most common type of surgery is called total mesorectal excision. This is where part or all of the rectum is removed, together with surrounding tissue.

Emergency surgery

Sometimes cancer can block the bowel and stop poo from passing through. This is called a bowel obstruction. If this happens you will need to have an operation as soon as possible. You might have emergency surgery to form a stoma or to insert a colonic stent. A stent is a temporary way of unblocking the bowel before more surgery is planned.

Stomas

Some people will need to have a stoma. This is where a section of bowel is brought out through an opening on your stomach. This part of the bowel then empties into a stoma bag which is stuck onto your skin. Some stomas are temporary to let your bowel rest after surgery. Some people may need a permanent stoma if the ends of the bowel can't be joined back together after surgery.

More information

Learn more about surgery and stomas on our website bowelcanceruk.org.uk/aboutbowelcancer



Further staging and grading

You might have been given a stage based on the results of scans and biopsies before the start of your treatment. After your operation, your surgeon will have more information about the size and spread of your bowel cancer. This gives a better idea of the stage of the bowel cancer (known as pathological stage). A doctor called a pathologist will also look at the cancer cells under a microscope to see how normal or abnormal they look to give your cancer a grade.



Take all the help going from your stoma nurse. They know the road you're on and what you may experience. Allow yourself time to get well and recover. It can be hard at first, but I now do all that I did before and more.

Neil



Recovery after surgery

After your operation your healthcare team will help you to get out of bed and start moving around as soon as possible. They will show you some leg and breathing exercises to help prevent any complications.

Pain relief

Painkillers will help you get up and move around after your operation. You should let your medical team know if you feel your pain is not controlled.

Stomas

If you have a stoma, your stoma care nurse will visit you on the ward. They will show you how to look after your stoma and can give you advice on what food to eat.

Food and drink

You will usually be allowed to eat and drink soon after you return to the ward. You will start off eating small portions of food and gradually build this up.

Side effects

All surgery carries a possible risk of side effects. Your surgeon will explain all the risks of your operation during the consent process. Your healthcare team should also give you written information about the possible side effects of your surgery. They won't be able to tell you in advance which ones you will get or how long they will last.

Surgery can cause changes in how your bowel works. Most side effects get better a few weeks after you finish treatment. But some people might have side effects that last longer or may get new side effects later on.

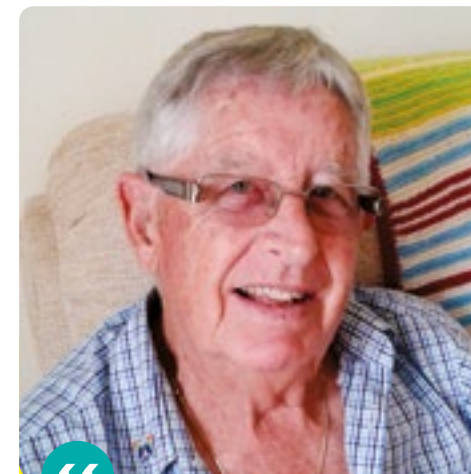
Possible long term and late side effects of surgery include:

- tiredness
- bowel problems
- bladder problems
- sexual problems
- infertility

Speak to your healthcare team if you have any concerns or unexpected symptoms.

Going home

You will usually go home a few days to a week after you've had surgery. You will be given a follow up appointment to talk about next steps for your treatment.



To help my recovery after surgery I returned to my love of oil painting, to express my feelings through my art. I now enjoy a healthy lifestyle, full of outdoor and indoor activities like motor-homing, oil painting, reading and gardening.

Reginald



Radiotherapy

Radiotherapy is a possible treatment for rectal cancer. It is not usually used to treat cancer in the colon. You may have radiotherapy together with surgery or chemotherapy (chemoradiation). If your cancer can't be cured, you might have radiotherapy to help your symptoms. This is called palliative radiotherapy.

How is radiotherapy given?

External radiotherapy is delivered from outside the body by a machine and only takes a few minutes.

Internal radiotherapy (also known as brachytherapy or contact radiotherapy) is delivered from inside the body. It means a high dose of radiation can be given to the cancer and limit damage to the tissues and organs around it.

The papillon technique is an example of contact radiotherapy for rectal cancer. It can sometimes be used in people who can't have surgery. At the moment it is only available at some specialist cancer centres. Your medical team will discuss this with you if it's suitable for your cancer.



“

Make sure to ask any questions you have and chat to the nurses about how you feel. During the treatment itself, I didn't really like the noises of the machinery, so I tried out mindfulness and breathing techniques. It was really useful and helped me stay calm.

Sima

”

Radiotherapy side effects

All treatments carry a risk of side effects. Your healthcare team should give you written information about possible side effects, but they won't be able to tell you in advance which side effects you will get or how long they will last.

Short term side effects might include problems with your bowel, bladder and skin close to the tumour. These side effects often get better in the first few months after you finish treatment.

Some symptoms might be more long term. You might notice changes in the way your bowel works, such as loose or runny poo (diarrhoea), having to go to the toilet more or less often, being woken up from sleep to poo, having less warning to get to a toilet or being unable to control your bowel and having accidents.

Radiotherapy can also damage the bones in your pelvis (the area between your hips), irritate your bladder and affect your sexual function.

Remember

Tell your healthcare team as soon as possible if you have any new or ongoing side effects. You may need to have some tests to find out what is causing them. Your healthcare team may be able to give you treatments to help.

Chemotherapy

Chemotherapy uses drugs to kill cancer cells. You may have chemotherapy on its own or together with other treatments.

Who has chemotherapy?

If you have very early stage bowel cancer (stage 1), you will not normally need any chemotherapy.

Some patients with stage 2 bowel cancer will have chemotherapy after surgery to help reduce the risk of the cancer coming back. This isn't needed for all patients with stage 2 bowel cancer.

Most patients with stage 3 bowel cancer will be offered chemotherapy after surgery to help reduce the risk of the cancer coming back.

If you have advanced bowel cancer that has spread to other parts of the body (stage 4), you might have chemotherapy before or after surgery or in combination with other types of treatment.

Read more about bowel cancer staging on [pages 10–12](#).

When is chemotherapy given?

Neo-adjuvant

Treatment given before surgery to shrink the cancer is called neo-adjuvant chemotherapy.

Adjuvant

Treatment given after surgery to help stop the cancer coming back is called adjuvant chemotherapy.

Palliative

If your cancer has spread to other parts of the body, you might have treatment to keep the cancer under control or ease symptoms. This is called palliative chemotherapy. Some patients have such good responses that the cancer can be removed.

How is chemotherapy given? **Chemotherapy drugs**

You will have chemotherapy as an injection, drip or infusion into your vein (intravenous) or as a tablet (oral).

Chemotherapy into your vein

You might be given chemotherapy directly into your bloodstream. This could take a few minutes, hours or days in some cases. There are a range of ways the treatment might be given:

- **Cannula** – a thin flexible tube that goes into the back of your hand or arm each time you have chemotherapy
- **Central line** – a longer flexible tube that goes into a vein in your chest. This can stay in place for many months
- **PICC line** – a longer flexible tube that goes into the upper part of your arm. This can stay in place for many months
- **Portacath** – a small chamber that sits under the skin

Common chemotherapy drugs for bowel cancer include:

Fluorouracil (also known as 5FU)

Fluorouracil is one of the most common chemotherapy drugs. You usually have fluorouracil together with a drug called folinic acid (leucovorin), which makes the chemotherapy work better. You will have this drug into a vein as an infusion.

Capecitabine (Xeloda®)

Capecitabine is taken as tablets twice a day. The body absorbs the drug and converts it to fluorouracil (5FU). You may take capecitabine before or after surgery or to treat bowel cancer that has spread to other parts of the body.

Oxaliplatin (Eloxatin®)

Oxaliplatin is taken as an injection or drip into a vein. You may have oxaliplatin after surgery or to treat bowel cancer that has spread to other parts of the body.

Irinotecan (Campto®)

Irinotecan is taken as an injection or drip into a vein. This drug treats bowel cancer that has spread to other parts of the body.

Raltitrexed (Tomudex®)

You might have raltitrexed if you can't have fluorouracil or capecitabine. It is taken as an injection or drip into a vein.

Trifluridine-tipiracil hydrochloride (Lonsurf®)

Trifluridine-tipiracil hydrochloride is taken as tablets twice a day. It is used to treat bowel cancer that has spread to other parts of the body.

Folinic acid

Folinic acid is not a chemotherapy drug, but is often given as part of treatment.



“

For me, the thought of chemotherapy was far worse than the actual treatment. It's a great leap into the unknown, and whilst sometimes unpleasant, my side effects were well managed. I felt nauseous in the first few days of every cycle but I was never actually sick, and I never lost more than a few strands of hair.

Catherine

”

Chemotherapy combinations

You might be given more than one chemotherapy at the same time. Some common combinations used to treat bowel cancer include:

FOLFOX:

- Folinic acid
- Fluorouracil
- Oxaliplatin

FOLFIRI

- Folinic acid
- Fluorouracil
- Irinotecan

FOLFOXIRI

- Folinic acid
- Fluorouracil
- Oxaliplatin
- Irinotecan

CAPOX or XELOX

- Capecitabine
- Oxaliplatin

De Gramont

- Fluorouracil
- Folinic acid

Chemotherapy side effects

Each chemotherapy drug or combination has its own side effects. Most side effects can be easily controlled by medicines. Not everyone will have the same side effects. Your healthcare team will give you information about the side effects that are most likely to affect you. You might find it helpful to keep a note of any that you experience.

Common chemotherapy side effects include:

- Diarrhoea
- Increased risk of infection
- A sore mouth
- Feeling and being sick

Talk to your medical team about any side effects you have. They will be able to help you control or manage them.

Risk of infection

Chemotherapy can reduce the number of white blood cells called neutrophils, which help fight infection. If you have a low number of these cells it's known as neutropenia.

You can help to protect yourself from infection by washing your hands regularly and avoiding contact with people who have an infection such as a cold or flu.

You should be given information about infections by your chemotherapy team. If you think you might have an infection, you should contact your medical team as soon as possible.



Side effects related to specific chemotherapy drugs

Oxaliplatin

You might have tingling or numbness in your hands and feet. This side effect is known as peripheral neuropathy, because it only affects the nerve endings in the extremities of your body. Peripheral neuropathy is a common side effect of the chemotherapy drug oxaliplatin. Talk to your medical team if you have these symptoms.

“

I carried a pair of gloves with me at all times when I was on oxaliplatin and wore extra thick slipper socks to keep the tingling/burning sensation at bay during cold weather.

Gemma

”

Capecitabine

Some people who take the chemotherapy drug capecitabine have a skin reaction on their hands and feet called hand-foot syndrome (also known as palmar-plantar syndrome). Your medical team can help you treat and control this.

Irinotecan

Some people have a reaction within 24 hours of taking the chemotherapy drug irinotecan. This is referred to as 'acute cholinergic syndrome'. Symptoms include diarrhoea, stomach pain, producing a lot of saliva and sweating more than usual. These symptoms can be easily treated. Tell your medical team if you have any of these symptoms.

Fluorouracil

Having fluorouracil (or fluorouracil based drugs) can sometimes affect the way your heart works. You might have tests to check how your heart is working. If you have any existing heart problems you should let your medical team know. If you have any chest pain or tightness contact a doctor as soon as possible.

Get support

Tell your doctor or nurse about any side effects you have. They will be able to help you manage your symptoms. You might find keeping a note of these helpful. If you're feeling very unwell or have a high temperature, you should contact a doctor or nurse straight away.

Targeted therapies

Targeted therapies (also known as biological therapies) help your body control the way cancer cells grow. This type of treatment could be used on its own or together with chemotherapy to treat advanced bowel cancer that has spread to other parts of the body.

Who can have targeted therapy?

Targeted therapies won't work for everyone. If you have been diagnosed with advanced bowel cancer, your specialist might offer you a 'biomarker test'. This is to see whether there are any targeted therapies that might be suitable for you and which ones won't work. The tests look for specific changes (mutations) in your cancer cells. Speak to your doctor to see if this sort of test is appropriate for you.

RAS genes

The most common biomarker test for bowel cancer patients looks at a group of genes called RAS genes. If the cancer has a normal RAS gene, it is known as RAS wild type. If it has a change or mutation, it is called a mutated RAS gene. If you have a RAS wild type gene, you might be able to have the drugs cetuximab or panitumumab.

BRAF gene

BRAF is another gene which can be mutated in bowel cancer. If the cancer has a mutated BRAF gene, the drugs cetuximab and panitumumab are unlikely to work. Research studies are currently looking into new ways to treat patients with BRAF mutated bowel cancer.

Mismatch repair genes

Some bowel cancers develop due to mutations in the genes that usually repair DNA (known as mismatch repair genes). These bowel cancers often have a high number of mutated genes. This is referred to as deficient mismatch repair (dMMR) or MSI-High. If you have this type of mutation, you might be able to have the immunotherapy drugs nivolumab or pembrolizumab.

Targeted therapy drugs for bowel cancer include:

- Cetuximab (Erbix®)
- Panitumumab (Vectibix®)
- Bevacizumab (Avastin®)
- Aflibercept (Zaltrap®)
- Regorafenib (Stivarga®)

Cetuximab and panitumumab work by blocking messages that tell cancer cells to grow. Bevacizumab, aflibercept and regorafenib interfere with the way cancers grow their own blood supply.

Immunotherapy drugs for bowel cancer include:

- Nivolumab (Opdivo®)
- Pembrolizumab (Keytruda®)

Nivolumab and pembrolizumab are a type of immunotherapy known as immune checkpoint inhibitors. These drugs stimulate the immune system to kill cancer cells.

Access to targeted therapies

Not all targeted therapies are available on the NHS in England, Scotland and Wales, or the Health and Social Care service in Northern Ireland. If your doctor thinks you might benefit from this type of treatment, they will discuss it with you. Your cancer specialist can apply for funding for a treatment if you both agree that you would benefit from it. This can be a difficult process and it's not always successful.

More information

Speak to your doctor if you have any questions about targeted therapy.

After treatment

When your treatment has finished, you are likely to be coming to terms with lots of changes. Your focus might shift to improving your general health, rebuilding your confidence and trying to regain a sense of normality.

Many people say they don't feel confident to manage the impact of side effects on their everyday life. There is a range of support and information to help. If you are finding it difficult to cope, contact your GP or medical team for further support and advice.

Our support services

We have a range of support and information services you might find helpful. Read more on [page 34](#).

Recovery package

Many hospitals offer a 'recovery package', designed to support people living with and beyond cancer. Ask your medical team for more information. A recovery package includes:

Holistic needs assessment

These help to find out what practical, physical, emotional or spiritual needs you have. Your healthcare team may refer you to other local services, if you need them. Your specialist nurse can tell you if these assessments are available in your area.

Treatment summary

A treatment summary gives details about the treatment you have had, tests or investigations you may need and symptoms and side effects to be aware of. A copy is sent to you and your GP.

Cancer care review

This is an opportunity to discuss any concerns or questions you have, talk about the information and support available in your local area and other useful information about living with and beyond bowel cancer.

Health and wellbeing events

Some hospitals offer health and wellbeing events. You can find out more about health and wellbeing after treatment and get support to make lifestyle changes. You will also get the chance to meet other people affected by cancer.



“

One of the first things I did after my treatment was to try and reclaim both my fitness and independence. I started walking round the block, trying to go a little further each time. I now feel strong enough that I can walk a few miles on my own on a good day.

Tania

”

Follow up

You will have regular follow up after you finish treatment. This is to check that the cancer hasn't come back or spread. This could be in the form of appointments with your healthcare team at the hospital.

During these appointments you can tell your doctor or nurse if you are having trouble coping or if you need extra support. Your specialist nurse or GP will be able to help you if you have any worries or questions between your appointments.

Some hospitals are now moving towards offering more tailored follow up for each individual patient known as 'supported self-management'. This approach means patients won't always need to go to the hospital for appointments if they are feeling well.

Follow up appointments

National guidelines suggest you should have your first follow up appointment four to six weeks after you finish treatment. In the first three years after treatment you should have:

- At least two CT scans
- CEA tests at least every six months (CEA stands for 'carcinoembryonic antigen' – this is a blood test that can show if a cancer has started to grow again)
- Colonoscopy (a test to look inside your bowel) one year after treatment

You will have follow up appointments for as long as you and your doctor feel they are useful. This is usually for up to five years. Some hospitals have introduced different types of follow up, which might mean there are less face to face appointments, unless there are any problems.

Useful questions to ask

You might want to think about some questions to ask before your appointment. We've suggested some examples below:

- Where can I get help dealing with side effects?
- Who should I contact if I notice any new symptoms?
- When is my next follow up appointment?
- Where can I get support to make lifestyle changes such as stopping smoking, doing more physical activity or making changes to my diet?
- Who do I contact if I'm feeling upset or low?

You can use the space on this page to make notes.

More support



Online community

Our online community is a welcoming place for everyone affected by bowel cancer to ask questions, read about people's experiences and support each other. Join us at [bowelcanceruk.org.uk/community](https://www.bowelcanceruk.org.uk/community)



Ask the Nurse

If you have any questions about bowel cancer, contact our nurses at [bowelcanceruk.org.uk/nurse](https://www.bowelcanceruk.org.uk/nurse)



Publications

We produce a range of expert information to support anyone affected by bowel cancer. Order or download our free publications at [bowelcanceruk.org.uk/ourpublications](https://www.bowelcanceruk.org.uk/ourpublications)



Website

Visit our website for a range of information about bowel cancer including symptoms, risk factors, screening, diagnosis, treatment and living with and beyond the disease. Visit [bowelcanceruk.org.uk](https://www.bowelcanceruk.org.uk)

You might also find the following organisations helpful

Colostomy UK

W [colostomyuk.org](https://www.colostomyuk.org)

T 0800 328 4257

Provides support, reassurance and practical information to anyone who has or is about to have a stoma.

Cancer Research UK

W [cancerresearchuk.org](https://www.cancerresearchuk.org)

T 0808 800 4040

Information for people affected by cancer. You can speak to an information nurse by calling their helpline.

IA (Ileostomy and Internal Pouch Support Group)

W [iasupport.org](https://www.iasupport.org)

T 0800 018 4724

A support group run by and for people with ileostomies and internal pouches.

Macmillan Cancer Support

W [macmillan.org.uk](https://www.macmillan.org.uk)

T 0808 808 0000

Offers support and information for people with cancer, including information on diet and recipes.

National Institute for Health and Care Excellence (NICE)

W [nice.org.uk](https://www.nice.org.uk)

Produces national guidance and advice to improve health and social care. Their website has information on the diagnosis and management of colorectal cancer.

Pelvic Radiation Disease Association

W [prda.org.uk](https://www.prda.org.uk)

T 01372 744338

Support for people with pelvic radiation disease.

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

We support and fund targeted research, provide expert information and support to patients and their families, educate the public and professionals about bowel cancer and campaign for early diagnosis and access to best treatment and care.

To donate or find out more visit
bowelcanceruk.org.uk

 [/bowelcanceruk](https://www.facebook.com/bowelcanceruk)

 [@bowelcanceruk](https://twitter.com/bowelcanceruk)

Please contact us if you have any comments about the information in this booklet: feedback@bowelcanceruk.org.uk



This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

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