



Younger people with bowel cancer

A guide for the
under 50s



Bowel Cancer UK
Beating bowel cancer together

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About this booklet

This booklet is for anyone diagnosed with bowel (colorectal) cancer under the age of 50. We hope it will also be helpful for your family and friends.

Bowel cancer usually affects older people, so it can be hard to find information and support that meets your needs. This booklet gives an introduction to how bowel cancer can affect your body, emotions, relationships and daily life. We've included some personal experiences of younger people diagnosed with bowel cancer.

At the end of each section, we tell you where you can find more information. Contact details for all the organisations mentioned are listed at the end of this booklet. There's also a list of the medical words used with their meanings.

Don't forget

Please speak to your healthcare team if you have any questions about how the information in this booklet affects you.

Never Too Young

Most people with bowel cancer are diagnosed over the age of 50. But more than 2,500 people under 50 are diagnosed each year in the UK. At Bowel Cancer UK we hear from younger people who have had problems getting a diagnosis and who find it hard to get information and support that's relevant to them.

So, we launched our Never Too Young campaign in 2013, which is leading change for younger bowel cancer patients. The campaign is giving younger patients a voice, and changing clinical practice and policy.

Find out more at

-  bowelcanceruk.org.uk
-  [@bowelcanceruk](https://twitter.com/bowelcanceruk)
-  [#Never2Young](https://www.instagram.com/bowelcanceruk)
-  [/bowelcanceruk](https://www.facebook.com/bowelcanceruk)

Know your healthcare team

You'll be looked after by healthcare professionals who specialise in different areas of your care. They form a team, called a multidisciplinary team (MDT). In this booklet, we call them your healthcare team.

It's important to know the names of the healthcare professionals looking after you so you can contact them if you need to. It can also help to avoid delays if you can tell other members of the team the names of the professionals you've seen. You can keep a record of your healthcare professionals here. We've listed some of the professionals you're likely to see but you may not have contact with all of them. There's also space for you to add other healthcare professionals and an emergency contact.

Colorectal clinical nurse specialist

A nurse with specialist knowledge of bowel cancer. They are your main point of contact with your healthcare team. They offer information and support.

Name
Tel
Email

Colorectal surgeon

A doctor who treats bowel cancer with surgery.

Name
Tel
Email

Clinical or medical oncologist

A doctor who specialises in radiotherapy, chemotherapy and other drug treatments.

Name
Tel
Email

Stoma care nurse specialist

A nurse who specialises in stoma care.

Name
Tel
Email

Other healthcare professionals

You may also come into contact with physiotherapists, social workers, district nurses, dietitians and other professionals. If you have chemotherapy, you will have a key worker who will give you a phone number you can call at any time during the day or night.

Name
Tel
Email

Name
Tel
Email

Emergency contact

Ask your medical team who you can contact outside office hours for urgent help.

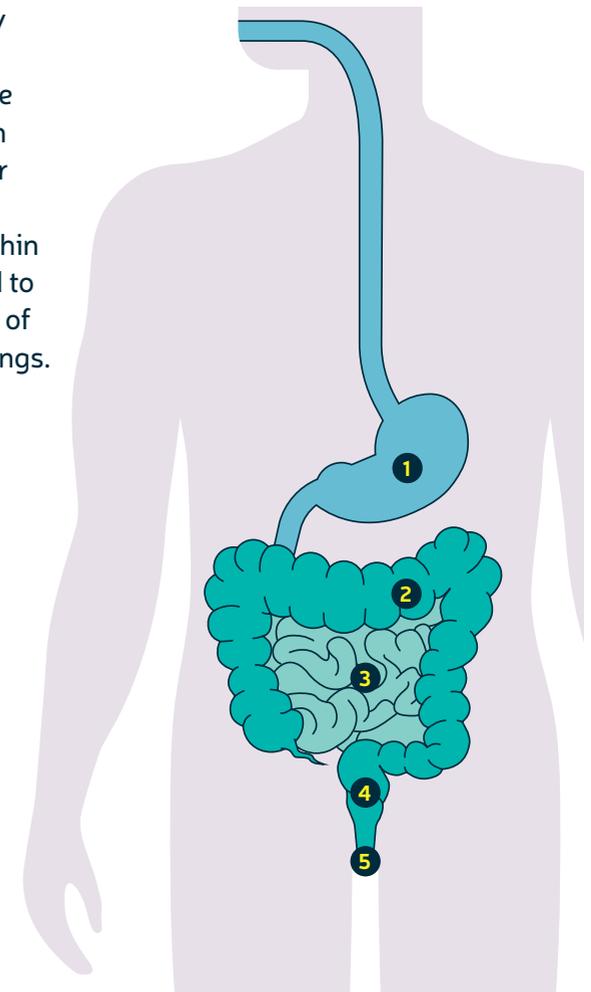
Name
Tel
Email

Your diagnosis

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. Bowel cancer starts in the colon or rectum. The cancer cells might stay within the bowel or they might spread to the lymph nodes or other parts of the body, such as the liver or lungs.



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

Your diagnosis

Diagnosis

You may have been diagnosed with bowel cancer after being referred by your GP for tests at a hospital. Some people are diagnosed after going to hospital as an emergency with pain in the stomach area (abdomen) and sickness (vomiting).

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I was misdiagnosed with irritable bowel syndrome and ended up being rushed to hospital with an obstruction. I didn't know I had bowel cancer until I was told ten days after the operation.

Lindy, diagnosed at age 43

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You may have had a camera test, which looks at the left side of the colon and rectum (flexible sigmoidoscopy) or the whole of the colon and rectum (colonoscopy). During the camera test, the doctor can take samples of tissue (biopsies) to be looked at later under a microscope. The doctor also checks the health of the rest of the colon and rectum.

If the biopsies show cancer, you will need more tests to find out the size of the cancer, where it is and whether it has spread. This is called staging the cancer. You will have a CT scan of your chest and stomach area (abdomen and pelvis). If the cancer is in your rectum, you will also have an MRI scan. This will show whether all of the cancer can be removed with surgery or whether you need to have other treatment first, such as radiotherapy or chemotherapy.

If the CT scan shows that the cancer may have spread outside the colon or rectum, you may need other tests, like an MRI scan or a PET scan. The results will help you and your healthcare team decide on the best treatment.

Find out more

Read more about cancer staging systems and tests for bowel cancer at bowelcanceruk.org.uk

You may want to take someone with you to your hospital appointments to help you remember what has been said. You could also take a list of questions that you want to ask and a pen to write down the answers. This can help you remember the information once you get home. We've suggested some questions throughout this booklet. Your healthcare team may use words that you haven't heard before. Don't be afraid to ask for information to be repeated or explained until you feel comfortable that you understand what is being said. We've explained the medical words used in this booklet on [page 56](#).

You should be put in touch with a specialist nurse who you can contact with any questions you have about your cancer or your care. Ask if your hospital has an information centre where you can pick up booklets and find out about local support. You can also contact our nurse advisor by emailing nurse@bowelcanceruk.org.uk



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I went to see my GP after noticing blood in my stool. I was sent for a blood test but I didn't chase up the results until my symptoms flared up again. My GP referred me for a colonoscopy, which showed I had bowel cancer. I remember thinking at the time that my GP didn't think much of my symptoms because I was young and generally healthy.

Jaimin, diagnosed at age 31

”

Your diagnosis

Your feelings

Many younger people experience delays in getting a diagnosis or are given the wrong diagnosis at first. Your GP might not expect someone so young to get bowel cancer.

In the early days following diagnosis, you may feel all sorts of emotions. People have described feeling shocked, numb, sad, scared, angry or a sense of disbelief. Sometimes people lose interest in things they used to enjoy or have trouble sleeping or eating. Most of these feelings will ease off in time. Talking to family and friends can help.

If you have any difficult feelings that don't go away or are hard to cope with, speak to your healthcare team or GP. They can refer you to a counsellor or psychologist, or they may offer you medicines that can help.

For some people there can be a sense of relief that they finally know what's wrong with them. Some people deal with their diagnosis in a practical way and focus all their energy on getting better.

Your mind will be busy processing all the new information about diagnosis and treatment, so it's normal to have problems concentrating or remembering things.

Waiting for treatment and test results can be stressful and worrying. Finding something to keep you busy can help. This doesn't need to be anything too tiring but could be something like visiting family if you feel up to it, or a hobby that you can do for short periods of time. Finding out what to expect from the treatment can help you feel more in control.

If you'll be spending time in hospital, you could take something to help you pass the time, like magazines, a phone, tablet, or audio relaxation exercises. Earplugs and an eye mask may help you to sleep better.

People who have been through treatment often say that once treatment starts it's a bit like being on a rollercoaster. There can be ups and downs, but they know that their healthcare team is there to support them. Your team is interested in how your diagnosis and treatment is affecting your emotions and your daily life so let them know if you think you need some help.



It took a few years to get the right diagnosis. I was very ill and couldn't go to work. For a long time I didn't know what was causing my symptoms. It didn't just affect me but also my family and partner.

Nicola, diagnosed at age 25



More information

The organisations listed at the end of this booklet offer support and information.

Your diagnosis

Telling people

Talking about your cancer can sometimes help you feel closer to the people who are important to you and can help you cope with your diagnosis. But people aren't always used to talking about cancer and there can be many strong emotions or difficult situations that make it harder.

Choose who you want or need to tell. If possible, start with telling those who are likely to react in a supportive way – people you think might help you. Sometimes people are upset, shocked and may struggle to think of what to say. If you're feeling uncomfortable with any silence you could let the person know that you don't expect them to know what to say and return to the conversation later. Or you could ask them to help you with a particular task.

Friends and family can be a great support, even if you've had a difficult relationship before your diagnosis. Don't be afraid to take up their offers or to ask for help. If you're used to managing by yourself, this can take a bit of getting used to. But by accepting help, you can save your energy for the things that are most important to you.

If you have a lot of people to tell, friends or family may help you. Or you might want to send a group email or text. Some people write blogs or set up WhatsApp groups so they can update everyone on their progress at the same time.

There may be some people you don't want to talk to about your cancer. You might want to practise a few things to say, so you can use them if you need to. One example might be, "I'm not bad thanks, how are you getting on?" to turn the attention away from you and on to the other person.

You and your partner

Your relationship with your partner may change when you're diagnosed with bowel cancer. You may feel a closer bond between you as you deal with your diagnosis together. Or one or both of you might be finding it difficult to cope. Your usual roles at home may have changed, for example if you stop working or if you're not able to do things around the house that you used to. You might find it difficult to get used to these changes.

Try to keep talking and listening to each other. Suggest ways your partner can help you, for example, by answering phone calls from friends and family. You may want to ask your partner to go to your hospital appointments with you. This gives you both the chance to be involved in discussions about test results and treatments. Your healthcare professional may also find it helpful to talk to you both together and to get to know your partner.

Your partner might need support themselves. Our online forum at [bowelcanceruk.org.uk/forum](https://www.bowelcanceruk.org.uk/forum) is a good way for partners to share experiences with others.

Coping on your own

If you live alone, there may be times when you feel you don't have the support you need. Joining a support group can help you meet others who are going through similar experiences to you. The Macmillan Cancer Support website lists support groups in your area.

Talk to others

Our online forum allows you to chat to others at any time of the day or night. You can also get support and information from our nurse advisor by emailing nurse@bowelcanceruk.org.uk

Your diagnosis

Talking to children

Whether you have children of your own or young children in your family, talking to them about cancer can be difficult and upsetting for you both. Some people are unsure what the 'right' things to say or do are and may try to protect the child from upset by not telling them what's happening. But even very young children will sense when something is wrong in the family and they can get more worried when they're not told what is going on. They may even fear that something worse is happening. Talking to children stops them getting wrong information from other places like the television or internet.

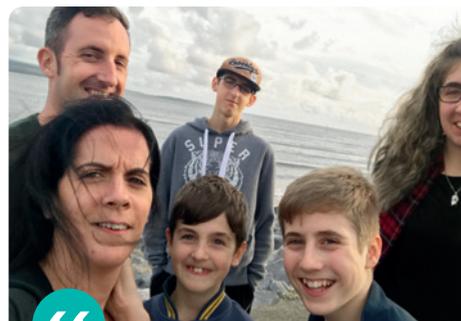
You don't need to tell the child everything at once. Tell them in a language that they will understand and be prepared to answer their questions. You can check that they've understood by asking them to tell you what's happening, in their own words. If you don't have an answer, it's okay to say you don't know.

Ask how they're feeling and try to find out what they're worried about. Generally, children need to be reassured that they will still be loved and cared for. Young children may want to know who will make dinner or take them to school if the person who normally does this is unwell.

You may want to tell your child's school or any clubs they go to. This will help the staff to support your child and understand any changes in their mood or behaviour.

More support

If you feel you need some support with telling children about your cancer, speak to your specialist nurse.



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When I was diagnosed, we kept our four children informed of everything. Throughout this whole situation, the aim was to limit the impact to my family and more so to the kids. This meant liaising with the children's schools to ensure that adequate support was available.

Roger, diagnosed at age 38

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Telling a parent

Your parent may already know that you've been having tests for a medical problem. They may have no idea that you've been worried about your health or they may have noticed that something was wrong. Whatever the situation, telling a parent or older family member that you have cancer can be difficult. You may worry about upsetting them or you may need to think about their health. For example, if they have dementia, they may find it difficult to understand.

You may decide that you don't want to tell your parent. Be aware that someone else may tell them or your parent may notice that something is different. You know your own family best. You may want to talk to another member of the family or friend about what to do.

Your diagnosis

You can't make difficult or bad news good, but these things may make it a bit easier for you and your parent.

- Think about whether you want to tell your parent straight away or wait until there's a treatment plan to talk about. This can give you something positive to focus on.
- Is there a good time of day to tell your parent? If you tell them earlier in the day they may have more time to take the news on board or contact someone else for support. If you tell them nearer the end of the day, both of you may find it difficult to sleep.
- Think about taking a booklet that explains your cancer.
- Sometimes parents can feel helpless because they haven't been able to protect their child from cancer. You can let them know how they can help. For example, by asking them to look after grandchildren, help with housework or just be there for a cup of tea and a chat.
- If your parent is in a care home or hospital you may want to tell the staff so that they can support your parent.

- If your parent has personality or behavioural changes caused by an illness, such as dementia, they may react by saying something that seems insensitive or irrelevant. These reactions can be difficult to cope with but they can be easier to deal with if you prepare yourself for them. You might want to ask someone else to repeat the information to your parent later on.
- Think about what may help you after you've told your parent. Perhaps having quiet time on your own, or having someone supportive to turn to.

More information

Macmillan Cancer Support has information to help you, your family and friends talk about cancer.

Cancer Research UK, Maggie's and **Marie Curie Cancer Care** have information to help with talking to children about cancer.

Winston's Wish have information to help children with a seriously ill parent.

Getting support

A diagnosis of bowel cancer can bring with it all sorts of challenges. You may find that you don't come across many other people your age when you go to your hospital appointments. You might even feel as though you're the only younger person with bowel cancer.

There are ways you can get in touch with other people your age to share experiences and support. Many of these sources of support are online but you could ask your healthcare team if there is any local support for people your age.

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A bowel cancer diagnosis can make you feel so alone, especially when you're under 50. The online cancer community has been a constant source of encouragement and comfort to me, both during treatment and after.

Catherine, diagnosed at age 37

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Connect with others

Follow us on Twitter
@bowelcanceruk #Never2Young

Join our online forum at
bowelcanceruk.org.uk/forum

Your specialist nurse will be your main point of contact with your healthcare team. They will tell you how you can get in touch with them if you have any questions or worries. You can keep a note of their contact details at the front of this booklet so they're easy to find when you need them.

Your GP or practice nurse can also give you information and support. They may offer a 'cancer care review', which looks at what support you need and gives you the chance to ask any questions about your diagnosis and treatment. You should be offered this review within six months of your diagnosis. Ask your GP surgery if they offer this.

Genetic risk

Some bowel cancers are caused by a change or fault in one or more genes. The changed gene can be passed down through a family. If you have the changed gene, you have a higher risk of getting bowel cancer at some point in your life. Around one in every 20 bowel cancers (five per cent) is caused by a change in a known gene.

The genetic conditions we know about include Lynch syndrome, familial adenomatous polyposis (FAP) and MUTYH associated polyposis (MAP). People with these conditions have a much higher chance of developing bowel cancer and they're more likely to be diagnosed at a younger age.

Lynch syndrome

Lynch syndrome used to be called hereditary non-polyposis colorectal cancer (HNPCC). It causes up to one in 30 bowel cancers (3.3 per cent). Both men and women with Lynch syndrome have a higher risk of bowel cancer. Lynch syndrome also increases the risks of other cancers, such as cancer of the womb, ovary, stomach, small bowel, urinary tract, brain, pancreas and a type of skin tumour.

The National Institute for Health and Care Excellence (NICE) recommends that everyone diagnosed with bowel cancer is tested for Lynch syndrome. But this doesn't always happen. That's why we're campaigning to improve the diagnosis and care of people with Lynch syndrome. You can find out more on our website.

If you have Lynch syndrome, your family members may be able to have genetic testing. There's a one in two (50 per cent) chance of your children, brothers and sisters having Lynch syndrome.

If any of your family members have Lynch syndrome, they'll be offered regular colonoscopies from the age of 25. This allows any growths (polyps) to be removed and cancer to be picked up early. Doctors don't usually start screening family members under this age because the risks of the colonoscopy are greater than the chance of picking up a cancer. They might be offered other preventative measures, such as taking aspirin, making lifestyle changes or having surgery to remove part of the colon (colectomy). Ask your healthcare team for more information on what screening is available.

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When I was told I might have Lynch syndrome, I was overwhelmed. I found it easy to be strong and positive when dealing with my own health but to think my children may one day have to suffer the same was heartbreaking. Then I spoke to my colorectal nurse who explained what Lynch syndrome was and how not everyone with it develops cancer. Once I was armed with the facts I was able to think much more rationally. If I had Lynch syndrome then I was going to get educated on it and ensure I was ready to help my children in the future.

Hannah, diagnosed at age 27

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Your diagnosis

FAP

Less than one in every 100 bowel cancers (one per cent) is caused by FAP (familial adenomatous polyposis). People with FAP have a large number of growths (polyps) in the lining of the bowel. If these are left untreated, there's a high chance of bowel cancer developing. Most people with FAP have surgery to remove the colon, and sometimes the rectum, to reduce their risk of developing bowel cancer. FAP isn't always inherited from a parent. About a quarter (25 per cent) of cases are caused by a new change in the FAP gene.

MAP

MAP (MUTYH associated polyposis) is similar to FAP but is passed down through a family in a different way. To develop MAP, you must inherit two copies of the changed gene – one from each of your parents. Your parents may not have MAP themselves but may carry one copy of the changed gene.

Genetic testing

If genetic testing shows you have an inherited bowel cancer syndrome, your family members may also be offered testing to see if they carry the gene variant. If they do carry the gene variant, they will be offered regular bowel screening. If your relatives don't want to have a genetic test, they can still have regular screening if they have a one in two (50 per cent) chance of carrying the gene variant.

In most cases, people diagnosed with bowel cancer don't have any known gene faults and so their family members don't need genetic testing. But current guidelines recommend that your first-degree relatives should have a colonoscopy at the age of 55, or earlier if other members of your family have bowel cancer.

All family members should tell their GP if they have:

- one first-degree relative (parent, brother, sister or child) diagnosed with bowel cancer before the age of 50, or
- two or more first-degree relatives diagnosed with bowel cancer at any age, or
- one or more relatives with a known genetic (inherited) condition linked to bowel cancer

More information

You can watch a series of videos about genetic conditions linked to bowel cancer at bowelcanceruk.org.uk

Macmillan Cancer Support produces information about genetic risk. They also have an online forum for people with Lynch syndrome.

The **West Middlesex University Hospital** has information on its website – the family history of bowel cancer clinic.

You can also find information on the **Lynch Syndrome UK** website and Facebook group.

St Mark's Hospital Polyposis Registry supports people who have a polyposis condition, such as FAP or MAP.

The **Genetic Alliance** is a charity working to improve the lives of patients and families affected by genetic conditions.

Fertility

Some treatments for bowel cancer carry a risk of infertility for men and women. Your healthcare team should discuss this risk with you when you're diagnosed. Even if you're not ready to have a child now, you may want the option to begin or grow your family in the future. Coping with a cancer diagnosis as well as possible infertility can be hard. You might feel that things are moving very quickly with little time to make important decisions. Your healthcare team will give you support and can refer you to a counsellor and a fertility specialist. You may also want to get in touch with other people in the same situation on our online forum.

Both men and women should use contraception during radiotherapy and chemotherapy and for about a year after treatment ends. These treatments can damage sperm and eggs or harm a developing baby.

When you're ready to start a family, you may need fertility treatment to have a baby.

Fertility in women

There isn't enough evidence to show how surgery for bowel cancer may affect fertility. Your healthcare team can give you information about how your treatment may affect your fertility.

Radiotherapy to the pelvis (area between the hips) can often cause infertility and early menopause. Radiotherapy can affect the uterus and may affect your chances of having a successful pregnancy after fertility treatment. Your healthcare team will explain your options, which may include surrogacy.

Chemotherapy can cause temporary or permanent infertility, depending on the drugs and doses used. Your periods may continue during your treatment, or they may become irregular or stop. The younger you are, the more likely you are to carry on having monthly periods. But having periods doesn't always mean that you'll be able to become pregnant. If your periods stop, they may return six months to a year later. Or they may stop permanently and you will go through the menopause.

The newer biological therapies may affect your fertility, depending on which drug you're having. Your healthcare team can tell you how your treatment may affect your fertility.

Your fertility options will depend on how much time you have before your cancer treatment starts and how well you are. The chances of having a baby after fertility treatment vary from person to person. Your fertility specialist can give you an idea of how successful the different fertility treatment options are likely to be.

If you have a partner, you may be able to have your eggs fertilised using in vitro fertilisation (IVF). This will take two to four weeks once you have been referred to a fertility specialist. The embryos can then be frozen and used once you're ready to start a family. You will need your partner's agreement before you can use the embryos.

If you don't have a partner, you may be able to store unfertilised eggs, which you can use in the future in fertility treatment. This procedure is less likely to result in a pregnancy

than using frozen embryos. Some women use donated sperm so they can freeze embryos, rather than eggs. This isn't funded by the NHS and may cause too much of a delay to your cancer treatment. Speak to your healthcare team if you'd like to find out more about this.

NHS fertility clinics will usually freeze and store embryos and eggs for ten years. But in some parts of the UK, you may have to pay.

If there isn't time to freeze embryos or eggs before your treatment starts, you may be able to freeze tissue from one of your ovaries. This procedure is still being tested and only a few babies have been born this way. It's not available on the NHS and only a few clinics offer it.

Fertility in men

Surgery can cause erection and ejaculation problems, so may affect your fertility. Radiotherapy to the pelvis (area between the hips) often causes infertility, depending on where the cancer is in your rectum.

Chemotherapy can cause your body to slow down or stop the production of sperm. This can be temporary or permanent, depending on the drug and the dose. If it's temporary, sperm production can take several years to fully recover. If you're having more than one chemotherapy drug, you are more likely to have a low sperm count or stop producing sperm completely.

You'll be offered the chance to store sperm before you start treatment. The NHS may pay for sperm to be stored for ten years and sometimes for longer. Funding may depend on where you live. Your healthcare team can tell you more about this.

More information

Macmillan Cancer Support has information about protecting your fertility.

Fertility Network UK has information on NHS funding for storing sperm, eggs and embryos and the costs of fertility treatment.

The Human Fertilisation & Embryology Authority website has information on costs and funding of fertility treatment, and how to choose a fertility clinic.

Questions to ask after your diagnosis

What happens next?
Who do I need to see and when?

When will my healthcare team discuss my treatment at their meeting (MDT meeting) and how will I know the outcome?

Should I be referred for genetic testing?

Will my treatment cause early menopause or affect my fertility?

Can you refer me to a fertility clinic?

What emotional support is available?

Can you put me in touch with other people my age who have been diagnosed with bowel cancer?

What support or information is there for my family or children?

Who can I speak to about getting help with childcare during my treatment and recovery?

Where can I get information and advice about work and money?

How do I get free prescriptions (in England – see page 54)?

Your treatment

Your treatment

Your treatment options

The healthcare professionals looking after you meet regularly as a team, called a multidisciplinary team (MDT). They will talk about your test results and your options and wishes for treatment. You will have an appointment with a member of the team to talk about your test results and the benefits and risks of the treatment options.

You may want to take a list of questions with you, as well as a pen and paper to write down the answers. We've suggested some questions on [page 37](#).

Possible treatments include surgery, chemotherapy, radiotherapy and biological therapies. You may be offered more than one of these. The treatments you can have will depend on where your cancer is and whether it has spread.

Find out more

You can read more about these treatments on our website.

Surgery

The most common treatment for bowel cancer is surgery. This may be keyhole (laparoscopic) or open surgery. Ask your surgeon to explain the benefits and risks of each type of surgery.

If you were diagnosed with bowel cancer after being taken to hospital with a blockage (obstruction) in your bowel, you may have had emergency surgery to remove the cancer. Sometimes, surgeons put in a flexible tube (stent) to open the blocked section of bowel instead. If you have a stent, you may need another operation to remove the cancer later on.

Usually surgery involves removing the segment of bowel containing the cancer and joining the bowel back together. You may have a temporary stoma for a few months to rest the bowel while the join heals. If the bowel can't be re-joined, you will have a permanent stoma.

Your treatment

If you have FAP or MAP, your surgeon may advise removing the whole of the colon, and sometimes the rectum as well. This is to prevent you getting other bowel cancers. It may be possible to join the remaining bowel together, in which case you won't need a permanent stoma.

If you have Lynch syndrome, you will have yearly colonoscopies to monitor the remaining colon. Women with Lynch syndrome who have bowel cancer surgery around or after the menopause may also be offered a hysterectomy at the same time. This is to avoid the risk of womb and ovarian cancer.

Stomas

Your surgeon should tell you if you're likely to need a stoma, which is where a section of bowel is brought out through an opening on your stomach area (abdomen). Your bowel motions (poo) are collected in a pouch or bag attached to the skin around your stoma.

There are two types of stoma – a colostomy is formed from the large bowel and an ileostomy is formed

from the small bowel. Both types can be temporary or permanent. Your surgeon or specialist nurse will explain why you need a stoma, what type of stoma you might have and how long you might need it for. A stoma care nurse specialist will show you how to look after your stoma and will offer you practical and emotional support.



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Stomas are a life-changer, a lifesaver. After months of having a stoma I now know it doesn't stop you from living your life. You can still go out, still exercise, still work, still be you, but now with your very own designer bag.

Andrea, diagnosed at age 37

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Staging and grading

Your healthcare team will have got an idea of the size and spread (stage) of your cancer from the tests you've had. After surgery, your team will have more information about the stage of the cancer, whether it has spread to the lymph nodes and whether you need more treatment.

A doctor called a pathologist will look at the cancer cells under a microscope to see how normal or abnormal they look. This is called grading the cancer and it can help to show whether the cancer is likely to spread and how quickly.

Radiotherapy

External radiotherapy uses high-energy X-ray beams to kill cancer cells. Radiotherapy is a treatment option for rectal cancer but it's not usually used to treat colon cancer.

Your healthcare team may offer you radiotherapy before surgery to shrink the tumour and make it easier to remove. Or, you may have radiotherapy after surgery if there's a chance the cancer could come back in the same place.

A course of external radiotherapy can last a few days or several weeks. You may have radiotherapy together with chemotherapy (chemoradiotherapy).

Your healthcare team may offer you internal radiotherapy (brachytherapy), depending on the size of the cancer and where it is in the rectum.

Chemotherapy

Chemotherapy uses drugs to kill cancer cells. You may have chemotherapy after surgery if the cancer has spread to the lymph nodes or if there's a high risk of it coming back. This is called adjuvant chemotherapy. If your cancer has spread, you may have chemotherapy to keep the cancer under control or ease symptoms.

Some chemotherapy drugs are given as an injection or drip into a vein. Others are tablets that you take by mouth.

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The treatment was very up and down. To start with, the chemotherapy made me sick and I lost a lot of weight. Then I got a PICC line, which meant I could have the chemotherapy through a tube in my arm. This reduced my sickness and meant I would have one week recovering in bed after the treatment and then the following week I felt stronger.

Jaimin, diagnosed at age 31

”

“

When my cancer metastasised to my liver, I went into a depression. Thankfully I was offered counselling, which really helped. It was great to be able to confide in someone who would not be personally affected by me discussing my fears.

Jaz, diagnosed at age 46

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If your cancer has spread

Bowel cancer most commonly spreads to the liver or lungs but it can spread to other parts of the body.

If your cancer has spread to your liver, your healthcare team may offer you surgery to remove the cancer from your liver, biological therapies or chemotherapy. If you're thinking of having surgery, your doctor will refer you to the liver (hepatobiliary) surgeons who will tell you whether surgery is suitable for you and, if so, will plan your treatment. Or you may be able to have other treatments such as radiofrequency ablation, microwave ablation or stereotactic radiotherapy.

If your cancer has spread to your lungs, your healthcare team may refer you to the lung (thoracic) team. You may be offered chemotherapy, biological therapies, surgery, radiofrequency ablation, microwave ablation or stereotactic radiotherapy, depending on where else the cancer is in your body.

Biological therapies

Biological (targeted) therapies can be used with chemotherapy to treat bowel cancer that has spread to other parts of the body. They are drugs that help your body control the way cancer cells grow. They can be given as a drip into a vein or you may take them as tablets, depending on which drugs you're having. This is called personalised medicine, because your treatment is being tailored to the genetic make-up of your cancer.

Your healthcare team should offer you a biomarker test to find out which biological therapies would work best and which ones are unlikely to work for you. The test looks for changes (mutations) in groups of genes, such as the RAS genes.

Not everyone is offered the biomarker test, so we're campaigning for this to change. If your cancer has spread, ask your healthcare team if you can be tested.

Biological therapies are not always available on the NHS. If you and your healthcare team think you would benefit from these drugs, your team can apply for funding. Or you may be able to have them as part of a clinical trial.

Clinical trials

Medical research trials that involve patients are called clinical trials. The aim is to compare different treatments to see if they're safe, if they work and how they work best. There are different types of clinical trials, looking at prevention, diagnosis, treatment and quality of life.

If you'd like to take part in a clinical trial, ask your healthcare team if you are suitable for any trials in your area.

Your treatment

The benefits of taking part in a clinical trial include possibly having a treatment that isn't normally available and having extra check-ups and support. Some people feel it's a good way of taking control over their cancer. You might also like the idea of helping to improve treatment and care for people in the future.

Possible disadvantages include not being able to choose which treatment you have or not knowing which treatment you're getting. Some people find the extra check-ups tiring or difficult to fit into their daily life. There might also be a risk of side effects that the researchers don't know about yet.

The research team will give you detailed information about the trial before you agree to take part and they will answer any questions you might have. You can leave a trial at any time without giving a reason.

If you're thinking about taking part in a clinical trial, ask your healthcare team for information on:

- what the trial is testing – for example, a new treatment or combination of treatments
- how long the trial will last
- whether you will get the new treatment
- the benefits and risks
- what support you will get during the trial
- what expenses will be paid
- whether you can continue having the new treatment if the trial is successful
- whether you'll see your usual healthcare team during the trial
- whether you can have a copy of the trial results

Coping with side effects

Many people don't feel fully prepared for the side effects of their treatment. Your healthcare team should give you written information about the possible side effects. But they won't be able to tell you in advance which side effects you'll get or how long they'll last.

At your hospital appointments, your healthcare team will ask you about the side effects you're getting. You may want to keep a diary to help you remember the details.

Most side effects get better a few weeks after you finish treatment. But some people may have side effects that last longer or they may get new side effects later on. You can read more about this on [page 41](#).



Chemotherapy was tough. Sickness, fatigue, diarrhoea, mouth ulcers, loss of taste, weight loss, a lack of focus; my life changed almost overnight. Thanks to having a supportive family and a network of expertise I somehow managed to keep going.

Mo, diagnosed at age 31



Your treatment

Complementary therapies

Some people use complementary therapies alongside their medical treatment to help them cope with side effects and to relax. Some hospitals and charities, like Penny Brohn UK and Maggie's, offer treatments like massage or reflexology for people with cancer.

Complementary therapies can't cure cancer and there's not much evidence to show that they improve symptoms or quality of life in people with bowel cancer. But some people find that therapies like acupuncture, meditation, yoga and aromatherapy help them cope with their cancer.

Speak to your healthcare team before starting any complementary therapies to make sure they won't affect your medical treatment.

“

I had reflexology, which really helped with the nerve damage caused by my chemotherapy.

Hina, diagnosed at age 44

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More information

Macmillan Cancer Support has information on treatment and side effects.

Colostomy UK and IA (Ileostomy and internal pouch support group) have information on stomas.

Cancer Research UK and the **UK Clinical Trials Gateway** websites have lists of clinical trials.

Questions to ask about your treatment options

What stage is the cancer?

If surgery is an option, will I need a stoma? How long for?

What are my treatment options?

Can you tell me about the outcomes and success rates of surgery in this unit?

What are the benefits and risks of each treatment?

Who will treat me? How much experience do they have of this treatment?

What other options do I have if I don't want to have the recommended treatment?

After treatment finishes, what appointments will I have and what will they be for? Who with and when?

What is the aim of the treatment?

What does treatment involve?

Will you send details of my treatment (called a treatment summary) to my GP? Can I have a copy?

How long does the treatment take? How many times will I visit the hospital for treatment?

What are the side effects?

What support is available at the end of treatment?

After treatment

Worries about the future

When you finish treatment it can feel like coming off a rollercoaster. The biggest part is over but you are still feeling 'wobbly'. You may have been putting all your effort into coping with treatment and now you have the chance to look back at what you've been through. At the same time, your hospital appointments may become less frequent and you may feel less supported.

Recovery from treatment often takes longer than people expect. Try not to push yourself too hard. Setting yourself small achievable goals can help.

You may worry about your cancer coming back or spreading and you may have lost confidence in your body. You may feel differently about yourself, in both positive and negative ways. If your cancer can't be cured, you may be finding it hard to cope with the uncertainty of the future.

Some hospitals offer Health and Wellbeing events where you can get information on coping with daily life after treatment. It's also a chance

to meet other people in a similar position to you. Ask your healthcare team if there are any events in your area.

Some hospitals also offer 'holistic needs assessments' to find out what practical or physical help you may need. Your healthcare team can refer you to other local services, if you need them. Your specialist nurse can tell you if these assessments are available at your hospital.

Most people feel stronger over time and get back to enjoying normal life again. But this isn't possible for everyone. If you feel you can't cope, your GP or specialist nurse may refer you to a counsellor or clinical psychologist. Some of these services are free on the NHS but you may need to pay for long-term counselling.

Friends, family and other people with cancer can be a great support. You could use our online forum or join a local support group. You can keep in touch with other younger people with bowel cancer by following us on twitter [@bowelcanceruk](#) using the hashtag [#Never2Young](#).



“

While cancer doesn't grant many magical moments, reaching milestones – even unplanned ones – and celebrating each and every step, can shine a little light into the darkness.

Deborah, diagnosed at age 35

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Follow-up

Your healthcare team will offer you regular follow-up appointments after you finish treatment. This is to find out how you are coping physically and emotionally. If you had treatment to cure the cancer, your team will check the cancer hasn't come back or spread. If the cancer does come back, regular checks will increase the chance of it being picked up early.

You may have a blood test to check the levels of a protein called CEA (carcinoembryonic antigen). It's not a perfect test and other things, like smoking and non-cancerous bowel conditions, can increase your CEA level. But, for some bowel cancers, it can give a good idea of whether your treatment is working.

You may have two or more CT scans in the three years after you finish treatment. You may also have a colonoscopy a year after treatment ends and then every few years to check for growths (polyps) and any new cancers developing in the colon or rectum. Ask your doctor when you will have these checks and how often.

Your follow-up appointments may be with a doctor or specialist nurse at the hospital or over the phone. Your doctor or nurse should ask you about your bowel function, weight, appetite and your stoma, if you have one. The doctor or nurse will give you your test results and explain how they affect your future care and the risk of the cancer coming back or spreading. If they don't give you this information, you should ask for it. You can use these appointments to tell the doctor or nurse if you're having trouble coping or if you need extra support.

When you have your appointment, you might want to take:

- a list of questions you'd like answers to – we've suggested some on [page 51](#)
- your latest medicines prescription
- spare stoma appliances, in case your doctor needs to examine your stoma
- a friend or family member for support

You will have follow-up appointments for as long as you and your doctor feel they're useful and the risks of the tests aren't greater than the risk of the cancer coming back.

If you have been diagnosed with advanced cancer, are having ongoing treatment with intensive monitoring, or lots of problems with side effects, you will find that you have more follow-up appointments with doctors, nurses and other healthcare professionals.

Side effects

The side effects of treatment usually get better over time. But some people may have side effects that carry on for more than six months (long-term effects) or that start months or years after they've finished treatment (late effects).

Speak to your healthcare team if any side effects aren't getting better or if you're having any new problems. The team can offer treatment and support.

After treatment

People cope with side effects in different ways. Things that people with cancer say have helped them include:

- changing their work-life balance
- focusing on the positive things in their lives
- improving their diet
- taking more exercise
- using complementary therapies

“

I spent the first couple of days after each cycle of chemotherapy just sleeping, as I felt extreme tiredness. This wore off as the week progressed. The second week wasn't too bad and I felt relatively normal during week three just in time for the next session.

Hina, diagnosed at age 44

”

Tiredness

Extreme tiredness (fatigue) is one of the most common effects of cancer and its treatment. It can feel completely draining and can affect all areas of your life. Fatigue can get worse if you're feeling stressed or low in mood. If you think this is the case, ask your healthcare team for help.

The following things can help you cope with fatigue.

- Making a plan of what you want to do each day
- Doing the most important things first
- Pacing yourself by taking regular rest breaks, even when you're having a good day. This can help you feel better in the long term
- Trying to keep physically active, even if you don't feel like it – see [page 49](#)

Hernia

After surgery to your stomach area (abdomen), your muscles will not be as strong as before and you may be at risk of getting a hernia.

This is caused by part of your insides pushing through a weak part of the muscle or tissue wall.

After surgery for colon or rectal cancer, part of your bowel can push through the wound. Some people develop a hernia around their stoma (para-stomal hernia). Others may get a hernia after having their stoma reversed. You may not have any symptoms but you might notice a slight lump or bulge, especially when you cough or strain the muscle. Some people have some pain in the area.

To help prevent a hernia, avoid lifting anything heavy for up to three months after surgery. Once you have recovered from surgery, ask your healthcare team about abdominal exercises to build up your core (abdominal) muscles. They may also advise you to wear a support belt or garment.

If you have a hernia, you may not need any treatment or your healthcare team may offer you surgery to repair it.

Nerve damage

The chemotherapy drug oxaliplatin can damage the nerve endings in the hands, feet and lower legs. This is called neuropathy. In some people, neuropathy can last for months or years after treatment. You may get pins and needles, weakness or numbness. This can make it hard to do everyday things like writing, picking up small items and walking. Some people become sensitive to the cold and need to wear gloves when they use the fridge or freezer. Your symptoms may get worse before they get better.

“

Chemotherapy affected my life but I adapted to it and did what I could to help myself. The main things that helped were heat packs for vein pain, sheepskin boots for nerve damage in my feet and cotton gloves to make it easier to touch cold items.

Nicola, diagnosed at age 25

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After treatment

Bowel function

Your bowel habits will have changed after your cancer treatment and you may have:

- more frequent bowel motions
- looser poo
- wind
- constipation
- a feeling that you haven't completely emptied your bowel

These problems may be worse in the year after treatment but can carry on long-term.

If you have had surgery for rectal cancer that avoids a permanent stoma, you may have several bowel symptoms. This is due to a condition called low anterior resection syndrome (LARS). These symptoms often get better over six to 12 months but you may find them bothersome and they can affect your daily life. Having radiotherapy increases your risk of getting this syndrome.

If you have a temporary stoma, you will usually have it reversed after you finish treatment. Some people find it can take several months for their bowel habit to return to normal.

Tell your healthcare team about any bowel problems you're having or if your symptoms aren't getting better. Your specialist nurse can give you information on ways to improve bowel frequency and control. They can also help you find out which foods might cause you problems.

Your GP or specialist nurse may refer you to a specialist if:

- you wake at night to empty your bowels
- you need to rush to the toilet to empty your bowels
- you ever have any leaks, soil yourself or lose control of your bowels
- your bowel symptoms stop you living a full life

If you have any of these problems, you may be referred to a continence specialist, a team who specialise in retraining the bowel and the muscles involved in emptying the bowel (biofeedback team) or a doctor who specialises in problems with the digestive system (gastroenterologist).

Find out more

We have more information on diet, including coping with bowel problems, eating and drinking with a stoma and losing and gaining weight on our website.

Bladder function

Surgery for rectal cancer can affect the nerves to the bladder. You may not be able to fully empty your bladder and you might leak urine. Radiotherapy can irritate your bladder so you may need to pass urine more often or with little warning. Your healthcare team can give you information on how to manage bladder problems or they can refer you to a continence service.

After treatment

Sexual function

Cancer treatment affects your emotions and your relationships. This can lead to problems with intimacy and sex. If you have a stoma, this can add to any anxiety and change the way you see yourself as a sexual person.

If you have a partner, working together and being open about the effect of treatment on your sex life can help you both. Being physically and emotionally close with your partner may help you feel better able to cope with cancer. This doesn't need to lead to sex, but if you want to be sexually active or want to start a new relationship, there are professionals who can help. Whether or not you have a partner, a psychosexual therapist can also help you to understand and come to terms with any sexual problems.

Many people find it embarrassing to talk about their sex lives but your healthcare team are used to answering questions and talking openly about sexual matters and want to help.

Surgery and radiotherapy for rectal cancer can cause long-term problems getting an erection and problems with ejaculation in some men. These problems may get worse a few years after radiotherapy finishes. Possible treatments include tablets that increase blood supply to the penis, injections to help you get an erection, pellets that you insert into the end of the penis, vacuum pumps and penile implants. The success of the treatment will depend on whether the nerves or blood supply to the penis have been affected by the cancer treatment.

In women, surgery and radiotherapy can cause tightening and shortening of the vagina. This can make sex difficult and painful. Radiotherapy can also cause dryness of the vagina but lubricants can help with this. Regular intercourse or using a dilator after you've completed radiotherapy may help reduce the risk of vaginal shortening.

More information

If you feel you need help with any sexual problems, ask your GP or healthcare team to refer you to a sexual health specialist or psychosexual therapist.

After treatment

Body image

Cancer and its treatment can change how you think and feel about your body. You may feel sad, angry or worried about any changes to your body. You may have scarring, weight loss, physical discomfort, numbness or other side effects of treatment that can make you feel self-conscious or affect your confidence. Talking about how you feel can help you cope. You could talk to someone close to you or you could ask your specialist nurse for help.

If you have a stoma, you may have strong feelings about the sudden and significant change to your body. Over time, and with support from your stoma care nurse specialist, you will learn to adapt to your new body. Getting through the first few weeks can be tough and you may feel like you have a mountain to climb, but remember family, friends and healthcare professionals are there to help you. Talking about how you feel can help you cope.

Until you get used to looking after your stoma, you might worry about smells or leakage. You may worry that other people can see the pouch through your clothes and you may wonder how other people will respond to your new stoma. Your stoma care nurse specialist can help you with any worries you may have. Having a stoma should not stop you doing the things you enjoy. There are companies that sell underwear, swimwear and other products that can help you feel more comfortable.

Find out more

Ask your stoma care nurse specialist for more information.

Physical activity

You may not feel like exercising when you're having treatment but regular physical activity can help you stay at a healthy body weight and help you keep fit. It can also give you a sense of purpose. More evidence is needed about how helpful exercise may be for reducing side effects or improving survival in people recovering from bowel cancer treatment. But some studies have shown that it can improve fitness, mental wellbeing and quality of life. There's also some evidence of improved survival in people who are more physically active after curative bowel cancer treatment.

Start off gently and, when you're ready, try to build up the amount of activity you do each day. You might start off with a walk around the house and then move on to a short walk outside. As you get your strength and energy back, you'll be able to do more. Try to build up to 30 minutes or more of moderate exercise, such as fast (brisk) walking, at least five days a week. A pedometer can be helpful for setting daily step count targets, which you can gradually increase as your fitness improves.

Be careful not to lift anything heavy while you're recovering from treatment. Speak to a physiotherapist if your job involves manual work. They can also give you advice on when you can start exercising and what exercises would be best for you. You might like to try gentle forms of pilates, yoga or tai chi, which can help build strength in your stomach area (abdomen).

More information

Macmillan Cancer Support has information on coping with side effects.

Colostomy UK and IA (Ileostomy and Internal Pouch Support Group) have information on stoma reversal, hernias, products and clothing for people with a stoma and the National Key Scheme (RADAR) that gives access to toilets for disabled people across the UK.

Bladder and Bowel Community gives information and sells products for people with bowel and bladder problems. They have a free 'just can't wait' card or mobile app, to help you explain you need to use a toilet quickly.

Pelvic Radiation Disease Association has information on the late effects of radiotherapy.

The **Sexual Advice Association** gives practical tips on sex and intimacy for cancer patients.

The **Chartered Society of Physiotherapy** website has a list of physiotherapists.

Questions to ask at your follow-up appointments

What are the chances of the cancer coming back or spreading?

What long-term or late side effects might I get?

How and when will you check to see if the cancer has come back or spread?

Where can I get help with dealing with side effects?

What symptoms should I look out for that might show the cancer has come back or spread?

Are there any Health and Wellbeing events that I can go to?

Who should I contact if I notice any new symptoms?

Do you offer a holistic needs assessment?

Daily life

Work and legal rights

As soon as you're diagnosed with cancer, you are protected as a disabled person by the Equality Act 2010. In Northern Ireland, you're protected by the Disability Discrimination Act 1995. This means your employer must make any reasonable adjustments needed to allow you to continue working. For example, they could let you change your working hours or use your sick leave allowance for hospital appointments. If you've had time off work and are thinking of going back, you may want to ask if you can start off with just a few hours, gradually building up your hours when you feel able to.

If you think you've been treated unfairly at work, you should speak to your employer first. If there's still a problem, you can contact ACAS (the Advisory, Conciliation and Arbitration Service), Citizens Advice or your union, if you have one.



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Nearly two years on, my pace of life is slower and I have relinquished many aspects of my career which I loved, but the pace of which I cannot maintain right now. Life is different and I have surprised myself with what I have endured and the strength I have been capable of.

Sima, diagnosed at age 34

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Money and insurance

You may be worried about money, for example, if you're unable to work or you have extra costs, like childcare or travel to hospital. You can get help with some costs and you might be able to get some benefits or grants.

NHS prescriptions are free in Scotland, Wales and Northern Ireland. If you live in England, you can get free prescriptions if you're having treatment for cancer or the effects of cancer. You will need to fill in a form that you can get from your GP or specialist nurse. You will then get a certificate that allows you to get free prescriptions for five years. You'll be able to renew your certificate if you're still having treatment. You may be able to get free prescriptions even if you're having private treatment. If you have a permanent stoma you will have free prescriptions for life. Ask your GP or hospital doctor for more information.

If you have a low family income, you may be able to get help with travel costs for hospital appointments. You can find out more about the NHS Low Income Scheme in England, Scotland and Wales on the NHS Business Services Authority website. If you're in Northern Ireland, you can find out about getting help with health costs on the nidirect website.

If you have an insurance policy, such as critical illness cover, income protection or mortgage payment protection, you may be able to make a claim when you are diagnosed with cancer.

Childcare

There may be times during your treatment when you need extra help with childcare. Family and friends may be able to help or you may need extra childcare from a nursery or childminder. A social worker will be able to tell you what help is available locally.

Travel

Speak to your healthcare team if you're planning to travel during your treatment. They can tell you how your treatment might affect your plans. They can also give you a letter to take with you, listing the medicines you're taking and what they're for. This can be helpful if you're travelling abroad. If you have a stoma, your stoma care nurse specialist can give you a card that explains, in several languages, what your stoma supplies are for. They can also offer helpful tips for travelling with a stoma. Always carry some supplies in your hand luggage in case of baggage delays.

If you're travelling to Europe, you can get a European Health Insurance Card (EHIC), which gives you free or cheaper health care. You can get more information and a free card from the NHS Choices website. Make sure you also have travel insurance. Some high street companies offer insurance to people with cancer but there may be some limits to what they'll cover you for. There are specialist companies that insure

people with illnesses such as cancer. Some of these can be more expensive so you might need to shop around.

More information

Macmillan Cancer Support has information about work, money and childcare.

Colostomy UK and IA (Ileostomy and Internal Pouch Support Group) have information on travelling with a stoma.

Medical words used in this booklet

Abdomen	The part of the body underneath the ribs and above the hips.
Adjuvant	Treatment used together with, or after, the main treatment to improve the chance of controlling the cancer.
Biological therapies	Drugs that change the way cancer cells work to stop them growing. Also called targeted therapies.
Biopsy	A sample of tissue taken to check for cancer.
Brachytherapy	Internal radiotherapy that uses a source of radiation inside the body for a short period of time.
Chemotherapy	Treatment that uses drugs to kill cancer cells.
Colon	The longest part of the large bowel, which ends just above the rectum.
Colonoscopy	A test that uses a long thin tube with a camera on the end to look inside the colon and rectum.
Colostomy	Where a section of the large bowel is brought out onto an opening on your abdomen, allowing bowel motions (poo) to pass into a pouch or bag.
CT scan	Computerised tomography scan. A scan that uses X-rays to take a series of pictures of the body.
FAP	Familial adenomatous polyposis. A rare inherited bowel cancer syndrome that greatly increases the risk of getting bowel cancer. Causes a large number of growths (polyps) in the lining of the bowel.
Genes	A set of instructions that control how the cells in your body grow and work. Genes are inherited from your parents. They control things like eye colour.

Ileostomy	Where a section of small bowel is brought out onto an opening on your abdomen, allowing bowel motions (poo) to pass into a pouch or bag.
Lymph nodes	Small glands that make up part of the lymphatic system, which defends the body against infection. They are a common place for colon or rectal cancer to spread to.
Lynch syndrome	A rare inherited bowel cancer syndrome that increases the risk of bowel cancer and some other cancers.
MAP	MUTYH associated polyposis. A rare inherited bowel cancer syndrome that causes growths (polyps) in the lining of the bowel and increases the risk of bowel cancer.
MRI	Magnetic resonance imaging. A scan that uses magnets to produce pictures of the body.
Microwave ablation	Treatment for bowel cancer that has spread to the liver. It uses heat from microwave energy to kill cancer cells.
Neo-adjuvant	Treatment used before the main treatment to improve the chance of controlling the cancer.
Pathologist	A doctor who looks at cells under a microscope to see how normal or abnormal they look.
Pelvis	The area of the body between the hips.
Polyp	A non-cancerous growth. Polyps can grow in the lining of the body's organs, including the bowel. Some polyps may develop into cancer over time.
PET scan	Positron emission tomography. A scan that uses a low dose of radiation to take pictures of the whole body.

Radiofrequency ablation	Treatment for bowel cancer that has spread to the liver. It uses radio waves to heat cancer cells to a high temperature.
Radiotherapy	Treatment that uses high-energy radiation to kill cancer cells.
Rectum	Part of the large bowel that sits between the colon and the anus. Bowel motions (poo) are stored here before passing out of the anus.
Selective internal radiotherapy (SIRT)	Treatment for bowel cancer that has spread to the liver. It involves injecting millions of tiny radioactive beads into the liver.
Sigmoidoscopy	A test that uses a long thin tube with a camera on the end to look inside the rectum and sigmoid colon.
Stereotactic radiotherapy	Treatment for bowel cancer that has spread to other parts of the body, such as the liver or lungs. It uses thin beams of radiation to give a high dose to the tumour, while limiting the dose to the surrounding healthy tissue.
Stoma	An opening on the abdomen, where a section of bowel is brought out so bowel motions (poo) can be passed into a pouch or bag.
Ultrasound scan	A scan that uses sound waves to build up a picture of the body.

Other useful organisations

ACAS

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

T helpline 0300 123 1100

Provides free information and advice on problems in the workplace and employment law.

Bladder and Bowel Community

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

T helpline 0800 031 5412

An organisation providing support and products for people with bladder and bowel control problems.

Cancer Research UK

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

T freephone 0808 800 4040

Information for people affected by cancer.

Carer's Trust

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

Provides services and support to unpaid carers across the UK.

Citizens Advice

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

Provides free, confidential advice on money, work and housing. You can find details of your local Citizens Advice on their website or in your phone directory.

Colostomy UK

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

T 24-hour helpline 0800 328 4257

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

Daisy Network

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

Provides support and information for women who have experienced premature menopause.

FAP Gene Support Group

W [fapgene.com](https://www.fapgene.com)

Provides information for people affected by FAP.

Fertility Network UK

W fertilitynetworkuk.org

Provides support, information and advice on fertility and NHS funding.

Genetic Alliance

W geneticalliance.org.uk

T 020 7831 0883

An alliance of over 200 patient organisations working to improve the lives of patients and families affected by all types of genetic conditions.

Healthtalk.org

W healthtalk.org

Watch videos of people sharing their stories about health issues including colorectal cancer.

Topics include diagnosis, treatment, talking to children and daily living.

Human Fertilisation & Embryology Authority

W hfea.gov.uk

Provides information on what happens at a fertility clinic and gives details of fertility clinics in the UK.

IA (Ileostomy and Internal Pouch Support Group)

W iasupport.org

T freephone 0800 018 4724

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

Lynch Syndrome UK

W lynch-syndrome-uk.org

A volunteer-run organisation that raises awareness of Lynch syndrome and provides information and support.

Macmillan Cancer Support

W macmillan.org.uk

T freephone 0808 808 0000

Provides support and information on cancer, money, benefits and work.

Maggie's

W maggiescentres.org

Provides free practical, emotional and social support to people with cancer and their family and friends. Maggie's has centres at some NHS hospitals as well as an online centre.

National Institute for Health and Care Excellence (NICE)

W 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.

NHS Business Services Authority

W nhsbsa.nhs.uk

For information on help with health costs in England, Scotland and Wales.

NHS Choices

W nhs.uk

The UK's biggest health website.

nidirect

W nidirect.gov.uk

Government website for Northern Ireland citizens. Includes information on help with health costs.

Pelvic Radiation Disease Association

W prda.org.uk

T 01372 744 338

Provides support and information for people who have had pelvic radiotherapy.

Penny Brohn UK

W pennybrohn.org.uk

T helpline 0303 3000 118

Helps people live well with cancer by offering a range of services, including wellbeing courses and complementary therapies.

Sexual Advice Association

[W sexualadviceassociation.co.uk](http://sexualadviceassociation.co.uk)

Provides information on sex and intimacy, including information for people with cancer.

Shine Cancer Support

[W shinecancersupport.co.uk](http://shinecancersupport.co.uk)

A network for anyone living with cancer in their 20s, 30s and 40s.

St Mark's Hospital Polyposis Registry

[W polyposisregistry.org.uk](http://polyposisregistry.org.uk)

Supports people who have a polyposis condition, such as FAP or MAP.

Teenage Cancer Trust

[W teenagecancertrust.org](http://teenagecancertrust.org)

Provides services and support for young people with cancer between the ages of 13 and 24.

The Family History of Bowel Cancer Clinic

[W familyhistorybowelcancer.wordpress.com](http://familyhistorybowelcancer.wordpress.com)

A blog from West Middlesex University Hospital that includes information for the public.

UK Clinical Trials Gateway

[W ukctg.nihr.ac.uk](http://ukctg.nihr.ac.uk)

Provides easy to understand information about clinical research trials running in the UK.

Winston's Wish

[W winstonswish.org](http://winstonswish.org)

Provides childhood bereavement support services.

Further support

Our online patient forum is a place for anyone affected by bowel cancer to talk about their experiences, share their knowledge and support each other. Visit bowelcanceruk.org.uk/forum

You can also email our nurses at nurse@bowelcanceruk.org.uk

Order or download our range of health information publications at bowelcanceruk.org.uk/order-publication

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



Certified member

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

Registered Charity Number 1071038 (England and Wales) and SC040914 (Scotland).
Version 2.0. Information correct at time of publication: August 2018.
To be reviewed: August 2021.