Younger people with bowel cancer

A guide for people under 50

Bowel Cancer UK
Beating bowel cancer together

Contents

About this booklet

This booklet is for anyone diagnosed with bowel (colorectal) cancer under the age of 50. It may also be useful for loved ones to help them understand your experiences.

This booklet has information about your diagnosis of bowel cancer, including genetic testing and your treatment options. It also explains 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 and support. At the end of the booklet you will find a list of all the organisations mentioned and their contact details. There is also a list of all the medical words we used and what they mean.

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

Don't forget

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

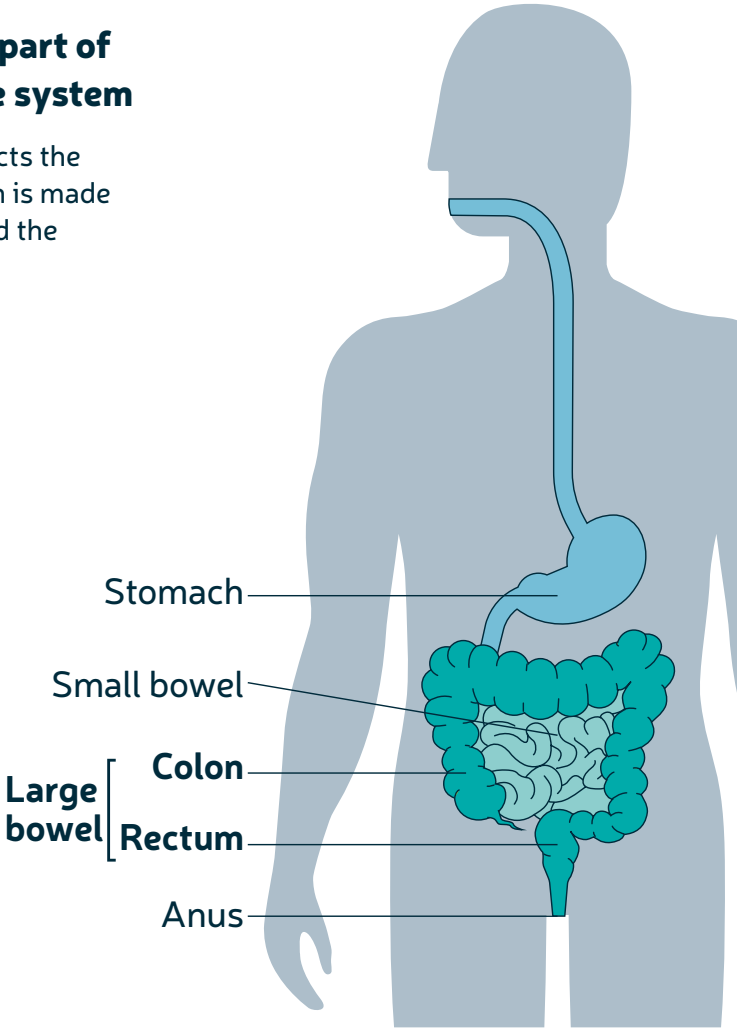
Your diagnosis

What is bowel cancer?

Bowel cancer starts in the large bowel, which is made up of the colon and rectum. You may also hear bowel cancer being called colorectal cancer, colon cancer or rectum cancer, depending on where it is found.

Your bowel is part of your digestive system

Bowel cancer affects the large bowel, which is made up of the colon and the rectum.



If you've been diagnosed with bowel cancer, you'll have more tests to find out the size of the tumour and whether it has spread to other parts of the body. This is called staging.

You will have a CT scan of the middle of your body (chest, abdomen and pelvis). If the cancer is in your rectum, you will also have an MRI scan. This will show whether the cancer can be removed with surgery alone or if you'll need to have another treatment, 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.

Read more about cancer staging and tests for bowel cancer at **bowelcanceruk.org.uk** and our booklet *Your pathway*.

You'll be taking in lots of information about diagnosis and treatment, so it's normal to have problems concentrating or remembering things. You may find it useful to write down what is said at your appointments. There is space for notes at the back of this booklet.

You might want to take someone with you to your appointments. They can take notes and help you remember what was said.

You should be given contact details for your specialist nurse. They are your first point of contact to answer any questions you have.

Get support

If you have any questions, you can use our Ask the Nurse service. You can email them at **nurse@bowelcanceruk.org.uk**

Your feelings

A diagnosis of bowel cancer can come with lots of challenges. You may find that you don't see 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.

When you've been diagnosed you may feel a range of emotions. People have described feeling shocked, numb, sad, scared or angry. Talking to family and friends can help.

Remember your healthcare team is there to support you. They are interested in how your diagnosis and treatment is affecting your emotions and your daily life. Let them know if you need some help.

Your healthcare team can refer you to a counsellor or psychologist, or they may offer you medicines that can help. There may be a long waiting list for counselling services. Charities such as **Macmillan Cancer Support** offer free counselling to people diagnosed with cancer.

You can connect with other younger people with bowel cancer on our forum and Facebook groups at **bowelcanceruk.org.uk/online-communities**

More information

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

Get support

You can find your local bowel cancer support group at **bowelcanceruk.org.uk/local-support-groups**

Telling people

Talking about your cancer can help you feel closer to the people who are important to you. It can also help you cope with your diagnosis.

Here are some tips for telling people about your cancer:

Start with people you feel closest to
You'll be more comfortable around your close friends and family and they'll know how to support you best.

Accept offers of help. Or ask for help
Helping with things like shopping or cleaning can be great ways for your loved ones to support you. It can also help you to save energy for things most important to you.

Choose a suitable time
Telling people about your diagnosis might be upsetting for you and who you're telling. Pick a time when neither of you are busy or distracted.

Be kind to yourself afterwards
Think about what may help you after you've told someone. Perhaps having quiet time on your own, or having someone supportive to talk to.

Ask someone you trust to let others know
Explaining your diagnosis to lots of people can be exhausting and upsetting. You could send a group text or email to let everyone know at the same time. Some people set up a WhatsApp group or blog to keep people updates on their progress.

Being diagnosed with cancer is a personal experience. You don't have to tell everyone, and you can choose which things keep private.

If you have a partner

If you have a partner, your relationship with them may change when you're diagnosed with bowel cancer.

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 may feel closer to each other as you deal with your diagnosis together. 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.

Remember

Your partner might need support themselves. Our family, friends and carers hub at **bowelcanceruk.org.uk/family-and-friends** has lots of information and support for your loved ones. They can also read about other peoples' experiences.

Talk to others

Our online forum allows you to chat to others at any time of the day or night.

Get support

You can also get support and information from our team of nurses by emailing **nurse@bowelcanceruk.org.uk**

Talking to children

Talking to children about cancer can be difficult and upsetting for you and them.

Some people aren't sure what to say or do. They may try to protect the child from getting upset by not telling them what's happening. But even young children can sense when something is wrong in the family. They might be more worried if they're not told what's going on.

Here are some tips for talking to children about your cancer:

- Being honest with children stops them getting wrong information from other places like the television or internet
- You don't need to tell them everything at once. Information is often better given in stages
- Tell them what is happening in a way they will understand and encourage them to ask 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
- Tell them how this will affect their normal routine. For example, 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

“We wanted our children to hear about my diagnosis from us, so they knew it was ok to talk to us about it. Their schools supported them and us beyond belief. The children could be vulnerable there when they didn’t feel they wanted to be in front of us. Never underestimate the support you can get from the school community.”

Lee

More support

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

There are organisations that can help support your children through your cancer diagnosis and treatment:

- **Fruitfly Collective** provides support, workshops and coaching for parenting with cancer. They also produce age-appropriate resources for children of different ages to help explain your cancer
- **Riprap** provides support to teenagers who have a parent with cancer
- **Hope Support Services** provides support to young people aged 5 to 25 who have a parent with cancer or other serious illness
- **Cancer Research UK** and **Macmillan Cancer Support** also have resources to help you talk to children

Get support

You can also get support and information from our team of nurses by emailing **nurse@bowelcanceruk.org.uk**

If you're under 25

If you're 16-24 years old, you can get more support from a Teenage and Young Adult (TYA) Cancer Team.

The TYA team is usually made up of specialist nurses, youth workers, social workers and psychologists. They're experts in looking after young people going through cancer treatment.

The TYA team can give advice and support with educational problems, work and employer related issues, relationships, fertility, sexual health and much more. They can also direct you to other support, including peer support from other young people with cancer.

Sometimes it might seem like you are the only young person with cancer. Some young people find it helpful to talk to someone of a similar age that has cancer. The TYA team can help you meet other young people with cancer. They also run events to help with this.

TYA teams are not in every hospital, but they can provide support wherever you're being treated. If you're under 25, you can choose to be treated at a hospital that has a TYA team. If you haven't heard from your TYA team, ask your specialist nurse to introduce them to you.

More support

TrekStock provide support for people in their 20s and 30s who have cancer. They also run online and in-person events that provide opportunities to meet other young people with cancer. Find out more at **trekstock.com**

Genetic risk

Some bowel cancers are caused by a change in one or more genes.

A gene change may also be called a mutation, variant, gene fault or gene error. These gene changes can be passed down through a family. If you have one of these gene changes, you may have a higher risk of getting bowel cancer at some point in your life.

Around 1 in 5 (20%) bowel cancers in people diagnosed under 50 years are caused by a change in a known gene. If you are under 40, you should be offered testing to see if you have a genetic condition related to your bowel cancer.

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 getting bowel cancer and they're more likely to be diagnosed at a younger age.

Lynch syndrome

Lynch syndrome is a genetic condition that can be passed down in families. It increases a person's risk of getting bowel cancer and other types of cancer.

Lynch syndrome is linked to around 1 in 30 (3%) cases of bowel cancer. Both men and women with Lynch syndrome have a higher risk of developing bowel cancer. Around 8 in 10 (80%) people with Lynch syndrome will get bowel cancer during their lifetime.

Lynch syndrome also increases the risk of womb (endometrial) cancer. It also slightly increases the risk of other cancers, such as ovarian cancer.

For people who have been diagnosed with bowel cancer, testing for Lynch syndrome usually involves three steps:

Step one: Screening tests

All patients diagnosed with bowel cancer should be offered screening tests on their tumour. These tests check how well your DNA repairs itself to prevent cancer. There are two different types of screening test.

Mismatch repair (MMR) protein testing – this test looks for levels of proteins (called MMR proteins) in the tumour

MSI genetic testing – this test looks for genetic changes in short sections of DNA called microsatellites

It's useful to write down your screening test results (sometimes called status), as you may be asked about them in the future. There's space to write notes at the end of this booklet.

Step two: Genetic counselling

If the screening test results suggest you might have Lynch syndrome, you'll be referred to clinical genetics services. They'll explain genetic testing, what it involves, and how the results could affect you and your family. You can then decide whether to go ahead with genetic testing.

Step three: Genetic testing

If you decide to have a genetic test, it involves a simple blood or saliva test to check for Lynch syndrome.

People a with Lynch syndrome are offered a colonoscopy every two years to catch cancer early when it's most treatable and curable. Colonoscopies can start at the age of 25 or 35 until you're 75 years of age. The age they start depends on what type of Lynch syndrome gene change you have. You can find more information about Lynch syndrome on our website.

Lynch syndrome is caused by a change in one of the mismatch repair (MMR) genes or the EPCAM gene.

Only one copy of the changed gene needs to be passed on (inherited) for a person to have Lynch syndrome. This is called **autosomal dominant inheritance** (see diagram on page 19). If you have Lynch syndrome, there's a 1 in 2 (50%) chance of your children, full siblings and parents having it too. You can find information about genetic testing on page 22.

More information

Read more about Lynch syndrome on our website, **bowelcanceruk.org.uk**

More support

Lynch Syndrome UK provide information through on website and Facebook group

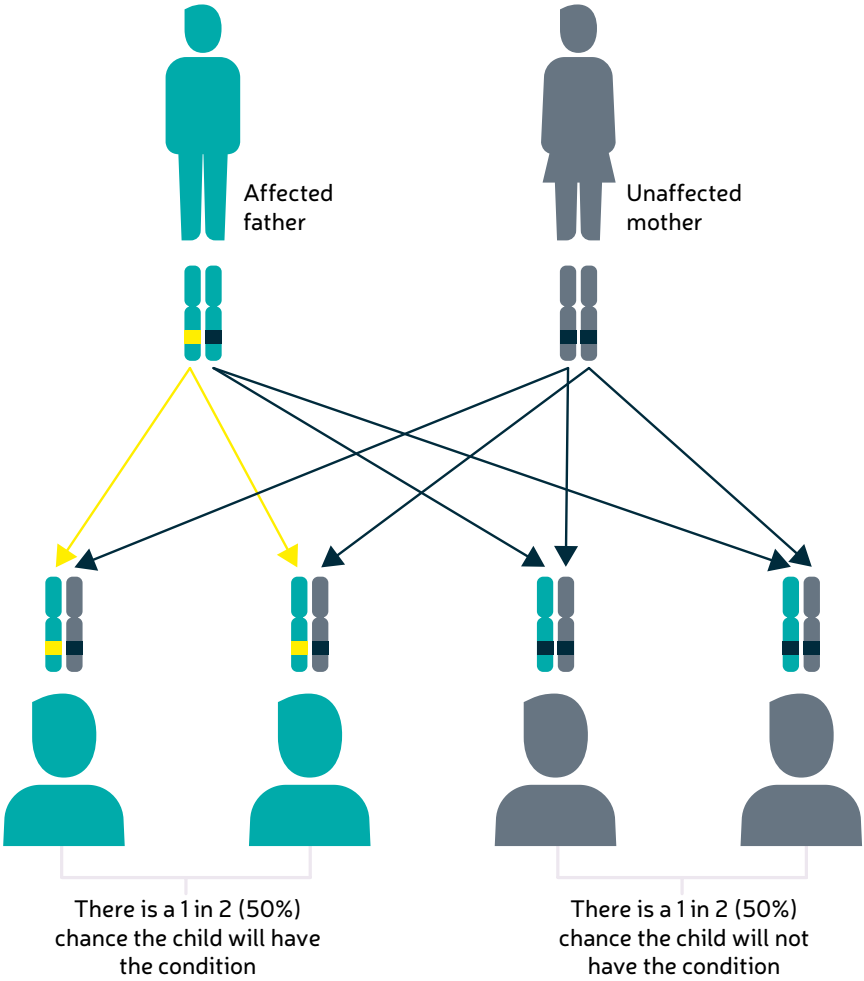
FAP

Familial adenomatous polyposis (FAP) is a rare genetic condition. People with FAP have a large number of growths (polyps) in the lining of the bowel, called adenomas. If the polyps are not treated, there's a very high risk of getting bowel cancer. Less than 1 in 100 (1%) bowel cancer cases are caused by FAP.

FAP is caused by a change in a gene called APC. Only one copy of the changed gene needs to be inherited for a person to have FAP. This is called **autosomal dominant inheritance** (see diagram on **page 19**).

Most people who have FAP inherit the changed gene from one of their parents. However, FAP isn't always passed on from a parent. About 1 in 4 (25%) of cases are caused by a new change in the APC gene. If you have FAP, there's a 1 in 2 (50%) chance of your children, brothers and sisters having it too.

Autosomal dominant inheritance



Key

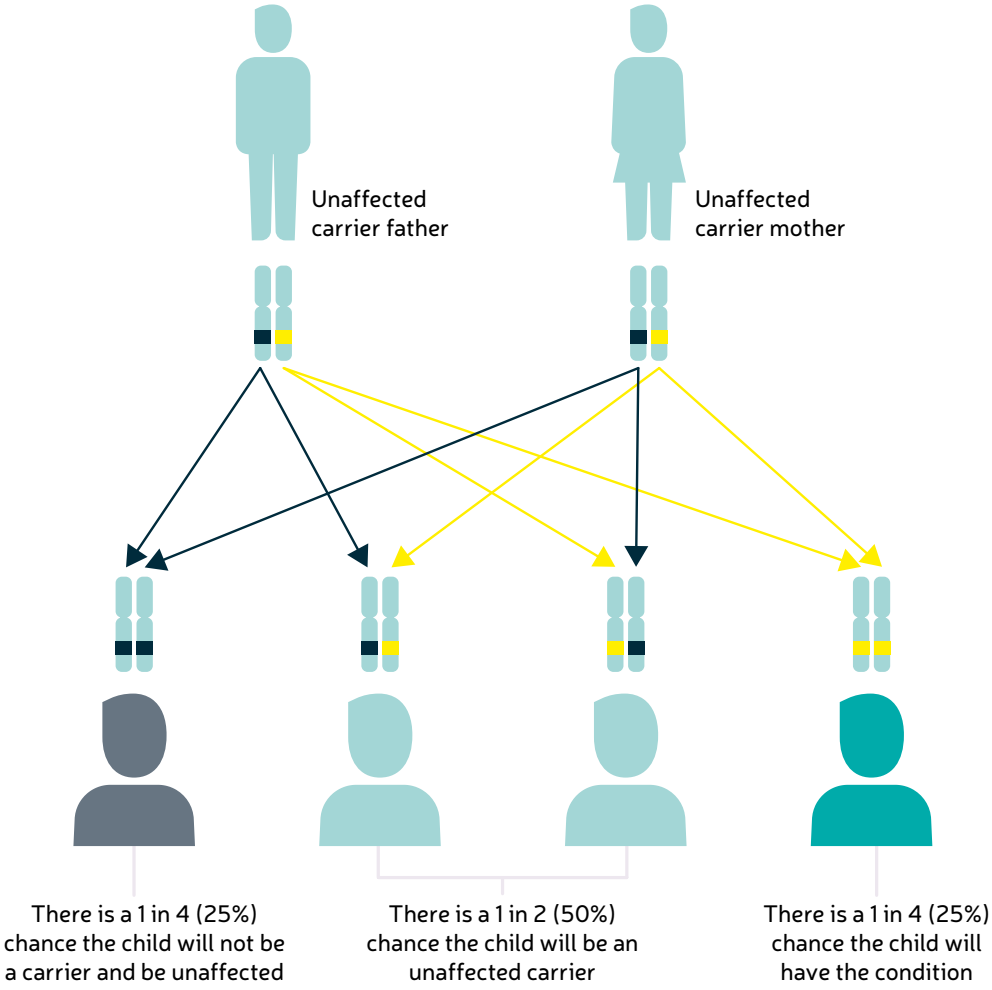
Gene change | Gene | Unaffected | Affected

MAP

MUTYH associated polyposis (MAP) is similar to FAP, but patients usually have fewer polyps in the bowel. MAP is caused by a change in a gene called MUTYH and is passed down through a family in a different way to FAP. To have MAP, you must inherit two copies of the changed gene – one from each of your parents. This is called **autosomal recessive inheritance** (see diagram on **page 21**). Your parents may not have MAP themselves but may carry one copy of the changed gene.

If you have FAP or MAP, your surgeon may advise removing all of the colon, and sometimes the rectum as well. This is to prevent you getting bowel cancer.

Autosomal recessive inheritance



Genetic testing

Genetic testing looks for changes in different genes. If you are offered genetic testing, you will be given information about the test and how to results might affect you and your family. You can then decide if you want to have genetic testing or not.

If genetic testing shows you have an inherited condition linked to bowel cancer, your family members may also be offered testing to see if they carry the same gene change. If they do carry the gene change, they'll 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 1 in 2 (50%) chance of carrying the gene change.

In most cases, bowel cancer is not caused by an inherited condition, so genetic testing of family members isn't needed.

All family members should tell their GP if they have:

- a close relative (parent, sibling or child) diagnosed with bowel cancer before the age of 50
- two or more close relatives diagnosed with bowel cancer at any age (for example your parent, and their sibling or parent)
- a relative with a known genetic (inherited) condition linked to bowel cancer, such as Lynch syndrome or familial polyposis

If you're planning to have children, you may have questions about the risk to your children. Your genetics team will be able to answer these. They will also be able to discuss other fertility options with you. The **Human Fertilisation and Embryology** Authority have more information about options available to you.

More information

You can find out more 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

Lynch Syndrome UK provide information through on website and Facebook group

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

The St Marks Polyposis Registry provides support to people with polyposis conditions and their families

PolyposisPatient is a support group for people with Polyposis syndromes

Fruitfly Collective has information about talking to family members about inherited conditions linked to bowel cancer

"There's a 50% chance my children might inherit Lynch syndrome. But I know diagnosis, research, treatment options and survival rates are continually improving, so I don't consume myself with worrying about this. I'll discuss it with them when they're older and encourage them to learn about the risks and ways to reduce them. I honestly feel knowledge is power."

Helen

Questions to ask your healthcare team:

- Can I have genetic testing?
- What is my MMR / MSI status?
- Have I had genetic testing?
- Do my family members need to be tested?
- What type of genetic testing have I had?
- Who do I need to tell in my family?

If you have Lynch syndrome, you may want to ask:

- Which gene change do I have?
- Should I take aspirin?
- When is my next screening appointment?

Fertility

Fertility is your ability to have children. Some treatments for bowel cancer affect fertility for men and women. Your healthcare team should discuss this risk with you when you're diagnosed.

Even if you don't want to have a child now, you may want the option to have children 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.

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

If you decide you want to start a family, you may need fertility treatment to have a baby.

Female fertility

This section discusses fertility for women, trans men and other people assigned female at birth.

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 area between the hips (pelvis) will often cause infertility and early menopause. Radiotherapy will affect the uterus and stop you 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. 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'll go through the menopause.

Macmillan Cancer Support have more information and support about menopausal symptoms and cancer treatment.

Biological therapies may also affect your fertility, depending on which drug you're having.

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've been referred to a fertility specialist. The embryos can then be frozen and used once you're ready to start a family. You'll 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 delay 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 not widely available in the UK. Your healthcare team can tell you more about your options.

Male fertility

This section discusses fertility for men, trans women and other people assigned male at birth.

Surgery can cause erection and ejaculation problems, so may affect your fertility.

Radiotherapy to the area between the hips (pelvis) often causes infertility, depending on where the cancer is in your rectum.

Chemotherapy can 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.

Before starting treatment, anyone considering having a family in the future should be given a chance to discuss their options. If you're transgender, you may have specific questions about fertility options available to you. Your clinical team should be able to answer these.

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.

You can speak to people who've gone through similar experiences on our online forum. **bowelcanceruk.org.uk/forum**

Questions to ask your healthcare team:

Will my cancer treatment affect my fertility?

Will the effects be temporary or permanent?

How will my fertility be affected?

Who can I discuss my fertility options with?

When do I need to make decisions about my fertility?

Notes

Treatment

Your treatment options

Possible treatments include surgery, chemotherapy, radiotherapy, biological therapies and immunotherapy. 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.

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.

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.

You can read more about surgery options for people with Lynch syndrome, FAP or MAP on our website.

Stomas

Your surgeon should tell you if you're likely to need a stoma. This is where a section of bowel is brought out through an opening on your stomach area (abdomen). Your poo (bowel movements) 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.

Radiotherapy

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 make the tumour smaller easier to remove. You may have radiotherapy after surgery if there's a chance the cancer could come back in the same place.

You may have radiotherapy together with chemotherapy. This is called chemoradiation.

Chemotherapy

Chemotherapy uses drugs to kill cancer cells. Some chemotherapy drugs are given as an injection or drip into a vein. Others are tablets that you take by mouth.

You may have chemotherapy before surgery to make the tumour smaller and easier to remove. This is called neoadjuvant chemotherapy.

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.

Biological therapies

Biological therapies, also known as 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 to slow or stop the growth of cancer cells. They can be given as a drip into a vein or you may take them as tablets.

This is sometimes called personalised medicine, because your treatment is being tailored to the genetic makeup 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 gene changes in groups of genes, such as the RAS and BRAF genes.

Immunotherapy

Immunotherapy is a type of targeted treatment that helps your own immune system to destroy the cancer. The immune system is made up of the lymph glands, spleen and white blood cells. It works to protect our bodies from infection and diseases.

Immunotherapies for bowel cancer are currently only available for patients with advanced bowel cancer who have low levels of MMR proteins (dMMR), or as part of clinical trials. For more information on MMR proteins, see **page 16**.

Find out more

You can read more about these surgeries and treatments on our website and in our booklets.

Clinical trials

Medical research trials that involve patients are called clinical trials.

The aim of clinical trials 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. Whether or not you can join a clinical trial will depend on the type and stage of cancer, what treatments you've had, and whether you have other medical conditions. Your healthcare team will be able to help you understand the criteria.

The benefits of taking part in a clinical trial include the chance to have a treatment that isn't normally available and having extra check-ups and support. You might also like the idea of helping to improve treatment and care for people in the future.

Possible disadvantages include not knowing which treatment you're getting. Some people find the extra check-ups and tests 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

Find out more

Cancer Research UK has information about current clinical trials that you can search by location, cancer type and treatment type. They also provide information on how to join a clinical trial. Find out more at **cancerresearchuk.org**

Questions to ask your healthcare team:

What is the aim of the treatment?

Who can I ask if I have questions about my treatment?

What does treatment involve and how long will it take?

Who can I talk to about side effects while I'm having treatment?

What are the side effects?

What other options are available to me if I don't want this treatment?

Will you send details of my treatment to my GP? Can I have a copy?

Notes

Getting a second opinion

Your treatment and care will have been discussed by a team of specialists who have expert knowledge and experience of treating people with bowel cancer.

Some patients may want to ask for a second opinion about their treatment. This might be:

- to confirm their diagnosis
- to check all treatment options have been explored
- because they're not happy with the recommended treatment
- because they don't feel that they can talk to their current doctor about their treatment

If you want a second opinion you can ask your consultant to refer you to another specialist. This may be another doctor in the same hospital or in a different hospital. If you don't feel comfortable speaking to your consultant, you can ask to speak to someone else in their team, or your GP.

If you have any concerns about your treatment or care, you can get help and advice from the following organisations:

- In England you can contact the **Patient Advice and Liaison Service (PALS)**
- In Scotland you can contact the Patient Advice and Support **Service (PASS)**
- In Wales you can contact the **Patient Advisory Liaison Service (PALS)**
- In Northern Ireland you can contact the **Patient and Client Council (PCC)**

Find out more

Macmillan Cancer Support and **Cancer Research UK** offer further information to help you if you're looking for a second opinion.

Living with bowel cancer

Body image

Cancer and its treatment can affect your body image. You may feel sad, angry or worried about any changes to your body.

You may have side effects of treatment that make you feel self-conscious or affect your confidence. It can be difficult to stop thinking and worrying about how you look or what other people think. People of any age or gender can feel differently about their body with or after cancer.

Here are some things that might help:

- Talking about how you feel can help you cope. You could talk to someone close to you or you could speak to your specialist nurse
- Spending time around people who make you feel good about yourself can boost your confidence
- You may find it useful to look in the mirror and focus on the parts of your body you do like
- You could also write down reasons you like your body or reasons you are grateful for it

If you have a stoma, you may have strong feelings about the sudden and significant change to your body. Your stoma care nurse specialist can help you to adapt to your new body. Remember that family, friends and healthcare professionals are there to help you.

It can take time to get used to managing your 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. Lots of shops and companies sell underwear, swimwear and other products for people with stomas that can help you feel more comfortable.

Lots of people post on social media about living with a stoma. Some people find comfort by following their journeys.

Our stoma support Facebook group is a supportive place for those who either have a stoma or are considering one as treatment for bowel cancer. The group is a safe space to ask questions, share experiences and give and receive support.

Dating

Being diagnosed with cancer may change how you look at relationships and dating.

You might not know when you're ready to start dating. You may also worry about when or how to tell someone new about your cancer. You may be looking for a more serious relationship, or you might want to experiment and try something new.

Dating might feel daunting, but it can help to build back confidence after surgery or treatment. It can help you to rediscover yourself and have new experiences.

More support

Shine Cancer Support have more information about dating with cancer. Find out more at **shinecancersupport.org**

Here are some tips for dating with bowel cancer:

- **Only share what you want to**
  Your cancer is personal to you and you can choose when and what to share with someone
- **Give yourself time**
  There is no perfect time to start dating, but you should take time to recover and prioritise your health
- **Put yourself first**
  You have been through a very difficult time. Be kind to yourself and take breaks from dating when you need to
- **Have a support network**
  It can help to talk about dating with people who know you well. You can also connect with other people with bowel cancer on our online communities

“I wanted to be honest about having cancer when I started dating. I was pleasantly surprised by the positive reaction I got. It gave me confidence to know I was still me and not my diagnosis. I just owned it and didn’t let it stop me.”

Natalie

Sexual functioning

Cancer treatment can affect your emotions and your relationships. This can lead to issues with intimacy and sex. If you want to be sexually active or want to start a new relationship, there are professionals who can help.

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.

Whether or not you have a partner, a psychosexual therapist can offer practical advice and help you to understand and come to terms with any sexual problems.

Surgery and radiotherapy for rectal cancer can cause long-term problems getting an erection and problems with ejaculation. 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.

Surgery and radiotherapy can cause narrowing 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 sex or using a dilator after you've completed radiotherapy may help reduce the risk of vaginal narrowing.

Some chemotherapies and radiotherapies affect how the ovaries work. This can reduce the amount of hormones the ovaries produce and lead to early menopause.

Symptoms of the menopause can affect your sex life and how you feel about sex. Symptoms might include:

- Loss of interest in sex (low libido)
- Vaginal dryness
- Hot flushes and sweats
- Mood swings
- Trouble sleeping

Find out more

Menopause and Cancer give support and advice to people going through the menopause brought about through cancer treatment.

Relate.org give advice for couples about talking about their relationship. They can provide counselling and psychosexual therapy.

OUTpatients provide information about all aspects of sex for anyone with cancer.

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.

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 keep fit.

Evidence shows that exercising can improve survival after bowel cancer surgery. Studies have also shown that it can also improve fitness, mental wellbeing and quality of life. It can also give you a sense of purpose.

The side effects of your cancer or treatment may affect how much exercise you can do. If you were very active before you were diagnosed with cancer, you may have to build your fitness back up slowly.

You may feel very tired (fatigued) during or after having treatment. This is very common. If you're feeling very tired, don't push yourself to exercise. It's also important to rest and let your body recover.

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 walking, at least five days a week.

A fitness monitor or phone app that counts your steps 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 surgery.

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).

A mix of exercise types is important. This can include cardiovascular (which makes your heart beat faster), strength-building (which builds muscle), flexibility and balance activities. Many physiotherapists and physical activity trainers have done training to specialise in working with people affected by cancer and can help you build a programme which works for you.

If you have advanced cancer, it is still safe for you to do light exercise such as a short walk. It's important to listen to your body. You can speak to your healthcare team if you have any questions.

More support

Move Against Cancer provide advice and support for keeping active with cancer.

“Exercise is not as easy as it used to be but it really helps with my mental health and helps with my recovery from surgery. The main thing I’ve learnt during this is that you have to keep going it’s just about taking one step after another and living in the moment.”

Rachel

Daily life

Work and legal rights

As soon as you're diagnosed with cancer, you are protected from discrimination at work by the Equality Act 2010. In Northern Ireland, you're protected by the Disability Discrimination Act 1995.

Your employer must make any reasonable adjustments needed to allow you to continue working. Examples of reasonable adjustments are:

- Working different hours or working part-time
- Allowing time off for doctors appointments
- Changing your role to remove difficult tasks

If you've had time off work and are thinking of going back, you may want to ask if you can start off with a few hours and gradually build them up when you feel able to.

Your employer can also make practical adjustments to help you feel more comfortable at work.

These might include:

- Moving your desk nearer to the toilets
- Having a parking space near your work
- Allowing extra breaks if you feel tired
- Flexible hours to avoid a stressful commute
- Having a quiet space where you can rest

Your employer can also refer you to an occupational health advisor or the HR team to discuss other ways they can support you. They will keep your information confidential if you ask them to.

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 apply for a medical exemption certificate. This means you can get free NHS prescriptions if you're receiving treatment for cancer, its side effects or the side effects of treatment. To get your certificate, you'll need to fill in a form called an FP92A form that you can get from your GP or specialist nurse.

A medical exemption certificate allows you to get free NHS prescriptions for five years. This also includes medicines that aren't related to your cancer. 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'll have free prescriptions for life. You'll need to apply for a medical exemption certificate. Ask your GP, hospital doctor or specialist nurse 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**. **Macmillan Cancer Support** also offer useful advice and information. 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.

If you're receiving palliative care or caring for someone who is, you might be able to receive financial support to cover your energy bills. **Marie Curie** can give you expert information on things like supplier-specific support, grants, and energy efficiency updates. To find out more, call the Marie Curie helpline on **0800 090 2309** and ask to speak to an Energy Support Officer.

If you have family, friends or carers that help look after you, they may also be able to get financial support. You can find more information on our website: **bowelcanceruk.org.uk/friends-and-family**

Being a parent

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.

More support

Parenting with Cancer offers helpful advice and resources.

Travel

Speak to your healthcare team if you're planning to travel during your treatment. You may need to plan ahead to make sure your trip runs smoothly.

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 travel certificate that explains, in several languages, what your stoma supplies are for. You can also download and print a travel certificate from **Colostomy UK**.

Your stoma care nurse specialist can also offer helpful tips for travelling with a stoma. Always carry some supplies in your hand luggage in case of baggage delays.

In some countries you can use a Global Health Insurance card (GHIC). This may reduce the cost of some emergency or pre-arranged treatment, so that you pay the same as a local resident in that country. You can get more information and a free card from the **NHS website**.

It can sometimes be more expensive and difficult to get travel insurance after a diagnosis but a letter from your hospital team can help. 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.

Your Cancer Support Worker or Cancer Care Coordinator may be able to give advice on travel insurance.

Macmillan Cancer Support has more information about finding travel insurance when you have cancer. They also have a travel insurance blog and forum where you can find out about recommended travel insurers for people with cancer.

Thinking about the future

Being diagnosed with cancer can change your outlook on lots of things.

Some people choose to see their diagnosis as a fresh start. This could be a change in priorities or trying new things.

Some people want to change career or find new hobbies. You may want to focus on yourself by doing more things you enjoy. You might try to see more of your loved ones or choose to reconnect with old friends.

Your experience is personal to you. You may want to talk things through with a professional. **Macmillan Cancer Support** offer short courses of counselling to people diagnosed with cancer. You may also be able to access counselling through your workplace or local charities.

You can self-refer for talking therapies with the NHS in your local area.

Words used in this booklet

Abdomen	The part of the body underneath the ribs and above the hips.
Adenomas	A type of growth (polyp) in the bowel which can turn into cancer.
Adjuvant	Treatment used together with, or after, the main treatment to improve the chance of controlling the cancer.
Autosomal dominant inheritance	Only one copy of a gene change needs to passed down to children for them to have the genetic condition.
Autosomal recessive inheritance	Two copies of a gene change need to be passed down to children for them to have the genetic condition. One copy is passed down from each parent.
Biological therapies	Drugs that change the way cancer cells work to stop them growing. Also called targeted therapies.
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 condition that greatly increases the risk of getting bowel cancer. It 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.
Hysterectomy	Surgery to remove the uterus.
Ileostomy	Where a section of small bowel is brought out onto an opening on your abdomen, allowing poo (bowel movements) to pass into a pouch or bag.

Immunotherapy	A type of targeted treatment that helps your own immune system to destroy the cancer.
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 condition that increases the risk of bowel cancer and some other cancers.
MAP	MUTYH associated polyposis. A rare (mostly) inherited condition that causes growths (polyps) in the lining of the bowel and increases the risk of bowel cancer.
Mismatch repair protein testing	A test that looks for levels of proteins called MMR proteins, in the cancer. It can tell doctors whether you're likely to have Lynch syndrome.
MRI	Magnetic resonance imaging. A scan that uses magnets to produce pictures of the body.
MSI genetic testing	A test that looks for genetic changes in short sections of DNA called microsatellites. It can tell doctors whether you're likely to have Lynch syndrome.

Neo-adjuvant	Treatment used before the main treatment to improve the chance of controlling the cancer.
Oophorectomy	Surgery to remove the ovaries.
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.
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. Poo (bowel movements) are stored here before passing out of the anus.
Stoma	An opening on the abdomen, where a section of bowel is brought out so poo (bowel movements) can be passed into a pouch or bag.

Other useful organisations

Cancer Research UK
W cancerresearchuk.org
T 0808 800 4040

Information and advice for people affected by cancer.

Citizens Advice
W 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
T 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

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

Fertility Network UK
W fertilitynetworkuk.org

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

Fruitfly Collective
W fruitflycollective.com

Provides resources for children who have a parent with cancer and support for parents living with cancer.

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.

Hope Support Services
W hopesupport.org.uk
T 01989 566317

Provides support to young people, aged 5-25, who have a family member living with illness such as cancer.

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.

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 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.

Menopause and Cancer
W menopauseandcancer.org

Provides support and information for people affected by menopause and cancer.

Move Against Cancer
W moveagainstcancer.org

Provides information and advice for keeping physically active while living with cancer.

NHS Business Services Authority
W nhsbsa.nhs.uk

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

nidirect
W nidirect.gov.uk

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

OUTpatients
W outpatients.org.uk

Provides support and advice for LGBTIQ+ people living with cancer.

Patient Advice and Liaison Service (PALS) England
W Search online for 'NHS England PALS'

Offers advice, support and information on NHS treatment in England.

Patient Advice and Liaison Service (PALS) Wales
W Search online for 'NHS Wales PALS'

Offers advice, support and information on NHS treatment in Wales.

Patient Advice and Support Service (PASS) Scotland
W pass-scotland.org.uk

Offers advice, support and information on NHS treatment in Scotland.

Patient and Client Council (PCC) Northern Ireland
W pcc-ni.net

Offers advice, support and information on health and social care in Northern Ireland.

Polyposis Patient
W polyposispatient.support

Support group for people with polyposis syndromes.

Relate.org
W relate.org.uk

Provides a range of counselling services.

Riprap
W riprap.org.uk

Provides information for teenagers who have a parent with cancer.

Shine Cancer Support
W shinecancersupport.org

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

St Mark's Hospital Polyposis Registry

W polyposisregistry.org.uk

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

Teenage Cancer Trust

W teenagecancertrust.org

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

TrekStock

W trekstock.com

Provides support and information for people diagnosed with cancer in their 20s and 30s.

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**

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**

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**

Ask the Nurse

If you have any questions about bowel cancer, contact our nurses at **bowelcanceruk.org.uk/nurse**

Notes

Bowel Cancer UK
Beating bowel cancer together

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

@bowelcanceruk

Trusted Information Creator

Patient Information Forum

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

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