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# **About this booklet**

This booklet is for anyone who may be having surgery to treat bowel cancer, also known as colorectal cancer. We hope it will also be helpful for family and friends.

The booklet describes the different types of bowel cancer surgery. It explains what will happen before, during and after your operation. We also explain what a stoma is and why some people have them.

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

# Get in touch

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

# Your healthcare team

A team of healthcare professionals will look after your treatment and care. This includes surgeons, oncologists, radiologists, specialist nurses and other specialists. This team is called the multidisciplinary team (MDT). In this booklet, we call them your healthcare team.

Your healthcare team will meet to discuss your test results and treatment options. You'll meet a member of the team to decide together which treatment would be the best option for you.

If you've had emergency surgery for a blocked bowel, your healthcare team will talk to you about your ongoing treatment and care.

### Your surgeon

A surgeon who specialises in bowel surgery will usually do the operation. Emergency surgery for a blocked bowel may be done by a general surgeon who specialises in abdominal (stomach area) surgery.

# Your specialist nurse

Your main point of contact at the hospital will usually be a colorectal clinical nurse specialist (CNS). They have specialist training in caring for bowel cancer patients. They'll give you support and information throughout your diagnosis, treatment and follow up.

You can usually contact your specialist nurse on weekdays or leave a message for them to call you back.

If there's a chance that you may need a stoma, you'll see a stoma care specialist nurse. They'll offer you support and advice before and after your operation. You can read more about stomas on page 22.

Some hospitals have an enhanced recovery nurse or an advanced nurse practitioner. These nurses specialise in preparing you for surgery and helping with your recovery.

### Getting a second opinion

Everyone in your healthcare team will work together to give you the best possible treatment and care. But you might feel you want a second opinion about your treatment, for example:

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

Before getting a second opinion, you may want to ask for another appointment with your surgeon to discuss your concerns. Or you can speak to someone else in your healthcare team, such as your specialist nurse.

If you would like a second opinion, you can ask your GP or surgeon to refer you to another specialist. This may be a surgeon at the same hospital or a different hospital.

Getting a second opinion does not necessarily mean that you'll be offered a different treatment or that you'll change to a different team or hospital. It could also delay the start of your treatment.

Don't worry about offending your surgeon if you would like a second opinion. They want you to feel confident about your treatment plan.

# **Bowel cancer surgery**

Surgery is the most common treatment for bowel cancer that is diagnosed at an early stage. Not everyone can have surgery. Your healthcare team will help you decide which is the best treatment for you.

In advanced bowel cancer, surgery can help to control symptoms. For some people, the risks of surgery may be greater than any benefits if the surgeon is not able to remove all the cancer.

Your surgeon will help you decide whether surgery is a good option for you. If you're not able to have surgery, your healthcare team will talk to you about your other treatment options.

The pathway shown below may help you to understand what to expect if surgery is an option for you.

## Treatment before surgery

Before surgery, you may need treatment to shrink the tumour. This gives the surgeon the best chance of completely removing the cancer.

You may have radiotherapy, chemotherapy or both treatments. This is called neoadjuvant treatment. You may be more likely to have neoadjuvant treatment if you have rectal cancer.

# **More information**

Our website has more information about treating cancer that has spread to other parts of the body.
Visit bowelcanceruk.org.uk





### Treatment before surgery

Before surgery, you may need treatment with radiotherapy, chemotherapy, or both, to shrink the tumour.



#### Pre-operative assessment and prehabilitation

You'll have an appointment at a pre-operative assessment clinic to make sure you're fit and ready for surgery.

Your healthcare team will help you improve your physical and emotional health before treatment starts. This can help reduce the risk of complications.



#### Going into hospital

You'll usually go into hospital on the day of your operation or the day before.



Depending on the stage and location of the cancer, you may have:

- a local resection to remove the cancer from the colon
- a colectomy to remove the part of the colon that contains the cancer and the nearby lymph nodes

See page 27



#### Rectal cancer

Depending on the stage and location of the cancer, you may have:

- transanal surgery TEMS or TAMIS
- total mesorectal excision (TME)
- · anterior resection
- abdomino-perineal resection

See page 31



#### Recovery in hospital

Your healthcare team will support you with pain relief, getting out of bed, preventing blood clots and breathing exercises.



### **Going home**

Your healthcare team will tell you when you can expect to go home and make sure you have support at home.



# Planning your surgery

If your operation is planned, you'll have time to talk to your healthcare team about the best type of surgery for you. This will depend on your general fitness, your test results, where the tumour is and any signs that it may have spread.

Your healthcare team will meet to discuss the results of the tests you had to diagnose bowel cancer. You may have had a colonoscopy, CT scan, PET-CT scan, ultrasound or MRI scan. These results will help you and your surgeon decide on your treatment options.

#### **Understanding your options**

You'll have the chance to speak to your surgeon and specialist nurse at a hospital appointment. They'll explain:

- why you need surgery
- what type of operation they recommend
- what your operation involves
- the success rates for surgery
- your other treatment options
- the benefits and risks of surgery and other treatment options
- the expected recovery time after surgery and other treatment options

• what happens if you do not want any treatment

You may want to have a family member or friend with you during this conversation. If they can't be there in person, they may be able to join in by phone or video call. They could help you ask questions and write down the answers. They can also remind you what was discussed.

It's important that you understand all the information and are confident that this is the right treatment for you.

# **More information**

For more information about tests to diagnose bowel cancer visit bowelcanceruk.org.uk



# Questions to ask at your outpatient appointment

You might find it useful to take a list of questions with you to your hospital appointments. Here are some examples.

What is the aim of the surgery?

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

What type of operation can I have?

What are the benefits and risks?

What are the possible side effects?

Who will treat me? How much experience do they have with this type of surgery?

When and where will I have the operation?

Will I need a stoma? If so, how long for?

When can I start my usual activities after surgery? For example, physical activity, driving a car or going back to work?

Do you offer an enhanced recovery programme? What does this involve? (See page 16)

Is there someone I can speak to if I need support while I'm waiting for surgery?

How will surgery affect my relationships, sex life and intimacy?

What other options are there if I don't want to have surgery?

Notes

# Getting ready for surgery

The hospital will arrange an appointment before your operation. This is called a pre-operative assessment. The appointment may be in person, online or by phone.

A nurse will ask you about your general health to make sure you're fit and ready for surgery. They'll also ask for details of any medicines you're taking.

The nurse may invite you to an appointment at the hospital if they need to do any routine tests. For example, they may need to take your blood pressure, test for infection or check your heart and lungs.

You may also see an anaesthetist to talk about what type of anaesthetic you'll have.

They may refer you for heart and lung tests to make sure you're fit enough for surgery. They work with the surgeon and operating theatre staff to look after you during the operation.

If there's a chance you may need a stoma, you'll meet your stoma care nurse specialist before your operation. This may be at the pre-operative assessment clinic or at a separate stoma clinic. You can read more about stomas on page 22.

# Questions to ask at your pre-operative assessment

You may want to write down a list of questions to help you remember what you'd like to ask your pre-assessment nurse. Here are some suggested questions about how to get ready for your operation.

When should I stop eating and drinking?

Do I need to take off any jewellery or make-up?

Should I stop taking my usual medication?

Do I need to arrange transport home after the operation?

Will I need any medication before surgery, such as medicine to clear the bowel? Will I need someone to stay with me when I get home? If so, how long for?

What should I take to hospital with me?

How long will I be in hospital before and after the operation?

# More information

**Anaesthetic** – a medicine that stops you feeling any pain during your operation



**Anaesthetist** – a doctor who gives anaesthetic before and during the operation and pain relief afterwards

Notes	Notes

### **Prehabilitation**

Prehabilitation is a way of improving your physical and emotional health before surgery. It aims to help your recovery and reduce your risk of complications afterwards.

Your doctor or specialist nurse will help you manage any other health problems you might have, such as high blood pressure or diabetes.

They can also give you information about things you can do yourself, such as:

- eating a balanced diet. You may see a dietitian if you need support with this
- keeping active
- giving up smoking
- cutting down on alcohol. Try to drink less than 14 units of alcohol a week
- looking after your emotional health. For example by keeping to a routine, doing relaxation and mindfulness exercises or making time to do the things you enjoy

# **Enhanced recovery programme**

Many hospitals have an enhanced recovery programme. This is also known as rapid or accelerated recovery.

The enhanced recovery programme aims to help you recover from your operation more quickly. It can reduce the risk of complications and help your bowel to start working sooner after the operation. It can also mean a shorter hospital stay. Your nurse will make sure you have support at home and know who to contact if you're worried about anything.

The programme may involve:

- prehabilitation to improve your physical and emotional health
- having carbohydrate drinks the night before and two to three hours before surgery. A nurse will give you these to take at home and/or in hospital
- eating and drinking within 24 hours after surgery

- removing your catheter as soon as possible after surgery so you can move around. A catheter is a tube that drains pee (urine) from your bladder. If this isn't possible, you may have a leg bag
- getting out of bed and moving around as soon as possible after surgery

Your surgeon and specialist nurse will explain the programme and tell you whether it will be suitable for you.



# Going into hospital

You'll usually go into hospital on the day of your operation or the day before. Your healthcare team will tell you when to arrive and what to take with you.

You'll have the chance to speak to the anaesthetist and someone from the surgical team before your surgery. If you haven't already signed a consent form, your surgeon will ask you to sign to say you agree to have the operation.

### **Before surgery**

Your healthcare team will tell you when you should stop eating and drinking. This is usually a few hours before your operation. They'll also tell you whether you need to avoid any foods or take medicine to clear your bowel before surgery.

Before your operation, your nurse may give you:

- a carbohydrate drink the night before and on the morning of your operation to help your bowel to start working more quickly after the operation
- a laxative, an enema, or both, to clean out the bowel
- antibiotics to help prevent infection

#### Anaesthetic

You'll have a general anaesthetic for your operation, which means you'll be asleep and unable to feel anything. Before your general anaesthetic, you may also have anaesthetic medicine through a thin tube into your spine. This is called an epidural or spinal anaesthetic.

You may keep an epidural in place for a few days after your operation for ongoing pain relief. Your anaesthetist will tell you what type of anaesthetic you'll have and will explain the benefits and risks.

# Talk to others

You can speak to people who've gone through similar experiences on our online forum.



bowelcanceruk.org.uk/forum



# **Stomas**

If you have bowel surgery you may need to have a stoma. This is an opening on your stomach area (abdomen) where a section of bowel is brought out. Poo (waste) is collected in a bag attached to the skin around your stoma.

A stoma can be reversible or permanent. A reversible stoma is formed to allow the bowel to heal after surgery. This is sometimes called a temporary stoma. A permanent stoma is formed if there's not enough bowel left to join the healthy bowel to the anus or if the two ends of bowel cannot be joined together.

Your surgeon will tell you how likely you are to need a stoma. But they may not know for certain whether you'll need a stoma until they have started your operation.

Your surgeon or specialist nurse will explain:

- · why you may need a stoma
- what type of stoma you might have
- · how long you might need it for

You'll meet your stoma care specialist nurse before the operation. They'll show you the stoma equipment and talk to you about living with a stoma. They may put an ink mark on your stomach area (abdomen) where the stoma will be. They'll also support you after surgery while you learn how to look after your stoma.

There are two main types of stoma. A colostomy is formed from the large bowel and an ileostomy is formed from the small bowel.

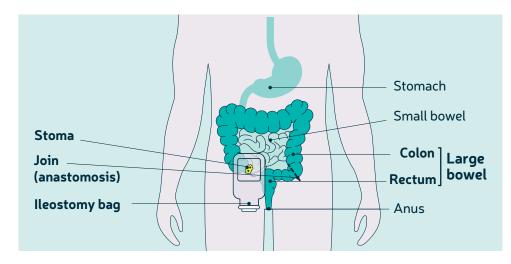
### Colostomy

A colostomy is a stoma formed by bringing part of the large bowel (colon) out on to the surface of your abdomen. This is usually on the left side of your body. If you have a colostomy, the poo will usually be more solid than liquid. This is because the body absorbs water from the waste as it passes through the large bowel. The poo passes out of the colostomy into a sealed bag outside the body (colostomy bag). You'll need to change your colostomy bag once or twice a day, depending on your bowel habits.

#### **lleostomy**

An ileostomy is a stoma formed by bringing the end or a loop of the small bowel (ileum) out on to the surface of your abdomen. This is usually on the right side of your body, as shown in the picture below.

Waste (output) passes out of the ileostomy into a bag outside the body (ileostomy bag). The poo produced is usually liquid rather than solid. You'll need to empty your ileostomy bag four to six times a day and fit a new bag every one to three days. You may have an ileostomy to let the newly-formed join in the bowel (anastomosis) rest and heal after surgery.





I'd never heard the term 'stoma' before waking up after emergency surgery to be told I had one. Early on, I had a few embarrassing leaks, but soon got the hang of secure bag changes. My fear of it coming off is now a distant memory. With support from other ostomates, my stoma nurses, and confidence in products that work for me, living with a stoma has become easier.

Phil

## Stoma supplies

Your stoma care nurse will give you a two-week supply of stoma supplies to take home. They'll offer you a follow up appointment to see how you're coping with your stoma. This may be in an outpatient clinic or online. If this is not possible, they may visit you at home.

Once your stoma has settled, your stoma care specialist nurse will give your GP the details of your stoma supplies. You can then get a monthly prescription from your GP. You can use this to get more supplies from a pharmacy or stoma supply company.

If you live in England and usually pay for your prescriptions, your GP or specialist nurse can help you apply for free prescriptions. All GP prescriptions are free if you live in Scotland, Wales or Northern Ireland.

#### Stoma reversal

If you have a reversible stoma, you'll usually have another operation to reverse it after you finish treatment. Your healthcare team will tell you when this is likely to happen. Some people have their stomas reversed after a few months, while others have their stomas for several years before they have a reversal. Sometimes, it's not possible to reverse a stoma.

It can take a while for your bowel function to settle after your stoma is reversed. Your specialist nurse will offer you advice on diet and medication to help with this.

# More information

You can find more information about stoma reversals on our website at bowelcanceruk.org.uk



# Types of surgery

Surgery aims to remove the cancer along with some of the surrounding tissue, blood vessels and lymph nodes. This is called a margin. This is to make sure no cancer cells are left behind.

The type of surgery you have will depend on where your cancer is, what size it is and whether it has spread to other parts of the body.

- Appendix
- Caecum

- **5** Descending colon
- 6 Sigmoid colon
- Rectum

# Surgery for colon cancer

#### Local resection

If you have a very small, early-stage cancer, the surgeon may remove it from the lining of the bowel without needing to make a cut in your stomach area (abdomen). Instead, they use a flexible tube with a light at the end, called a colonoscope or sigmoidoscope. They pass the tube into your bottom (anus) and up into your bowel. They then pass instruments through the tube to remove the cancer from the colon.

### Common types of surgery for colon cancer

The surgeon will remove the part of the colon that contains the cancer and the nearby lymph nodes. This is called a colectomy. The surgeon joins the remaining ends of colon together using stitches or staples. The join is called an anastomosis.

The pictures on these pages show which parts of the bowel (shaded yellow) are removed in each type of surgery.



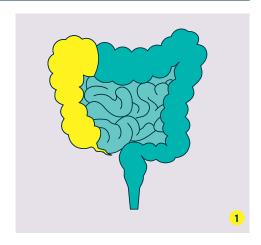


3 Ascending colon

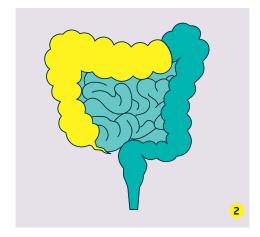
4 Transverse colon



1 A **right hemicolectomy** removes the right half of the bowel. If the cancer is in the middle section of the colon, your surgeon may also remove the middle section of colon.



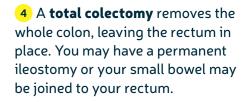
2 This is called an **extended right** hemicolectomy.

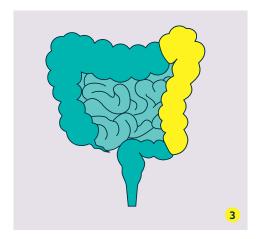


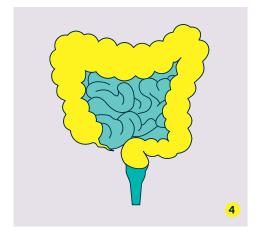
3 If the cancer is in the left side of the colon, you will have a **left hemi-colectomy**.

# Other types of surgery

You may have one of these operations if you have more than one cancer in your bowel or if you have a genetic condition, such as Familial Adenomatous Polyposis (FAP) or Lynch syndrome.





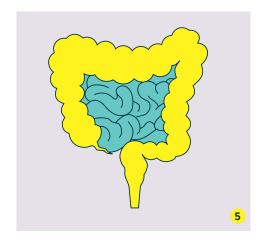


5 A panproctocolectomy removes the colon, rectum and anus. You'll have a wound where the anus has been closed. Avoid putting pressure on this wound while it heals. You'll need to lie on your side in bed and sit on a pressure-relieving cushion.

A **proctocolectomy** removes the colon and rectum.

Some people may have more operations to make a pouch from the end of the small intestine. This stores bowel movements before you go to the toilet. This is called an ileoanal pouch.

If you can't have an ileoanal pouch, you'll have a permanent stoma (ileostomy).



# **Surgery for rectal cancer**

### **Transanal surgery**

If you have a small, early rectal cancer or if you can't have major surgery, your surgeon may offer you a local resection. This is called transanal endoscopic microsurgery (TEMS) or transanal minimally invasive surgery (TAMIS).

The surgeon passes surgical instruments through your bottom (anus) so you won't have any cuts in your stomach area (abdomen). The surgeon uses the instruments to remove the cancer and the surrounding healthy tissue.

If the surgeon can't remove the cancer this way, they may need to switch to keyhole or open surgery. If there's a chance of this happening, your surgeon will tell you before your operation. You can read more about keyhole and open surgery on pages 35 and 38.

Transanal surgery is not available in every hospital. You can ask your healthcare team to refer you to another centre if they think it would be suitable for you.

# Total mesorectal excision (TME)

Surgeons use TME to treat cancers in the middle or lower rectum. You'll have a TME as part of a low anterior resection or an abdomino-perineal resection.

For this surgery, the surgeon removes:

- the part of the rectum where the cancer is
- the surrounding fatty tissue
- the envelope of tissue that contains lymph nodes and blood vessels (mesorectum)

This lowers the risk of the cancer coming back after treatment.

30 Your operation Your operation Your operation

# **Anterior resection**

This operation removes all or part of the rectum or sigmoid colon.

Depending on where the cancer is, you may have a high anterior resection or a low anterior resection.

You may need to have a reversible stoma for a few weeks or months to allow the join in the rectum to heal. For information about stomas see page 22.

For cancers in the lower part of the rectum, the surgeon will remove most of the rectum. They will join the end of the colon to the anus. This join is called a coloanal anastomosis. Not everyone can have a coloanal anastomosis. Speak to your surgeon about the benefits to you and how it may affect your bowel function.

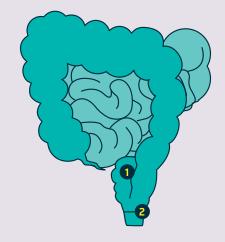
Sometimes the surgeon uses the end of the colon to make a pouch, called a coloanal pouch. This acts like the rectum to store bowel movements before you go to the toilet.

### **Abdomino-perineal resection**

If the cancer is very low down in the rectum, your surgeon will need to remove the rectum and anus. This operation is called abdomino-perineal resection or excision of the rectum (APER).

After surgery, you'll have a permanent stoma (colostomy). You'll also have a wound where the anus has been closed. Avoid putting pressure on this wound while it heals. You'll need to lie on your side in bed and sit on a pressure-relieving cushion.

# Coloanal pouch surgery

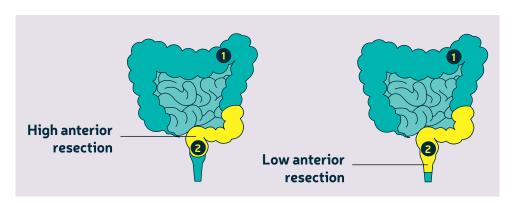


- 1 Coloanal pouch made from the end of the colon acts as a new rectum
- Rectum removed and colon joined to the anus

# Key







# Surgery for locally advanced cancer

Locally advanced bowel cancer is when cancer has spread into tissues next to the bowel, such as the bladder or nearby lymph nodes.

In women, trans men and other people assigned female at birth, cancer may spread to the uterus and vagina. In men, trans women and other people assigned male at birth, it may affect the prostate.

If you have locally advanced bowel cancer, your healthcare team will explain your treatment options to you.

They may offer you surgery to remove the cancer from the bowel and any other affected organs. This is called pelvic exenteration. The team will explain the benefits and risks of surgery.

If you decide to have surgery, you'll have your operation at a centre that specialises in this type of operation.

A team of doctors will carry out the operation. This may include a colorectal surgeon, urologist, gynaecologist and plastic surgeon.

### More information

Our pelvic exenteration support Facebook group is for people who have had pelvic exenteration due to bowel cancer, or are considering it as a treatment option. It's a place to ask questions, get support and share your experiences. bowelcanceruk.org.uk/online-communities

# **Keyhole surgery**

If your operation is planned, your surgeon is likely to offer you keyhole surgery. This is sometimes called laparoscopic surgery or minimally invasive surgery.

Keyhole surgery involves making several small openings in the stomach area (abdominal wall). The surgeon removes the tumour using surgical instruments, guided by a camera.

#### Advantages

Compared with open surgery, the advantages of keyhole surgery include:

- less pain after surgery
- lower chance of complications after surgery, such as infection
- lower chance of needing a blood transfusion
- a shorter hospital stay
- faster recovery

### **Disadvantages**

Compared with open surgery, the disadvantages of keyhole surgery include:

- not being suitable for all rectal cancers
- a longer operation than open surgery
- not being suitable if you are very overweight, if you have had abdominal surgery before or if the tumour is large
- the surgeon may need to switch to open surgery during the operation



I know surgery can be scary, especially surrounding cancer, and I was very nervous. But at the same time I just wanted to live, so couldn't wait to get in there and wake up knowing I was a huge step closer to getting back to normal. Everything went perfectly and I honestly woke up feeling brand new. After my keyhole surgery peppermint tea helped with pain from trapped wind and Jelly Babies were an absolute god send. With a few home comforts, an amazing hospital team and support from my loved ones, the whole process was definitely made a lot easier.

Lucy

# **Robotic-assisted surgery**

Robotic-assisted surgery (RAS) is a new type of minimally invasive surgery. The surgeon makes a few small openings in the stomach area and uses a surgical robotic system to help remove the tumour.

The robotic system has four arms that hold a camera and the surgical tools. It allows the surgeon to see the operation in 3D. A surgeon controls the robotic system from the surgeon console, which is in the operating theatre. Their team helps with the operation.

Robotic-assisted surgery is not available in all hospitals in the UK yet but it's becoming more common.

Not everyone can have robotic-assisted surgery. Your healthcare team will talk to you about which surgery is best for you.

Some evidence shows that it has similar benefits and risks to keyhole surgery. This could mean a shorter stay in hospital and a faster recovery time compared to open surgery, but doctors are still studying the long-term outcomes.

It may be an option for some people who can't have keyhole surgery, such as people who are very overweight.

Speak to your healthcare team if you have any questions about your surgery.

Visit our website for more information about robotic-assisted surgery. **bowelcanceruk.org.uk** 

# **Important**

The robotic system itself does not perform your surgery. Your surgeon will carry out the operation alongside their team and will be in control of your operation the whole time.

# Open surgery

# In open surgery, the surgeon will make one long opening in the stomach area (abdomen).

Your surgeon may recommend open surgery if:

- the tumour is large or difficult to access
- you have had abdominal surgery before
- you're very overweight

#### **Advantages**

Compared with keyhole surgery, the advantages of open surgery include:

- the surgeon directly seeing and feeling what they're doing, which may make the operation more straightforward
- a shorter operation time

#### **Disadvantages**

Compared with keyhole surgery, the disadvantages of open surgery include:

- a larger wound that takes longer to heal
- a higher chance of a wound infection and part of the bowel pushing through the wound (hernia)
- a longer hospital stay
- a longer recovery time

# Emergency surgery for a blocked bowel

Sometimes cancer can block the bowel, stopping poo from passing through. This is called bowel obstruction. It can cause pain, bloating and being sick (vomiting). If this happens you'll need treatment as soon as possible and you may need an operation.

If you need surgery, the surgeon may:

- create a stoma
- remove the affected part of bowel
- put in a hollow, expandable tube called a stent

# Creating a stoma

The surgeon may create a stoma above the blockage, to divert bowel movements out of the body. This gives you time to have tests and any other treatment before surgery to remove the cancer.

### Removing the blockage

If the surgeon removes the blocked part of the bowel, you may need a reversible or permanent stoma afterwards. If re-joining the bowel is too risky and the blockage or damage is in the left side of the bowel, your surgeon may remove the sigmoid colon and the top part of the rectum. This is called Hartmann's procedure. You'll have a stoma, which is usually permanent but may be reversible in some cases. Your rectum and anus will still be in place.

### Putting in a stent

Stents are sometimes used to treat blockages in the large bowel (colon). The stent relieves symptoms of the blockage by holding the bowel open so that poo can pass through. The stent stays inside your bowel. You may have another operation later to remove the cancer.

Find out more about colonic stenting on our website **bowelcanceruk.org.uk** 

# After surgery

After your operation, you'll spend a few hours in a recovery room before you move to the ward. You may spend a day or two in a high dependency unit or critical care unit if you need more care after your operation. For example, if you had a larger operation, such as an anterior resection.

When you wake up from surgery, you'll have some tubes in your body. These help you recover from the operation. They may include:

- a drip into a vein in your hand or arm to give you fluids until you're eating and drinking again
- a thin tube in the skin near your wound to drain any fluid
- a catheter to drain pee (urine) from your bladder

A nurse will usually remove these after a few days.

You may also have oxygen for a few hours, through a mask or a tube in your nose. Your nurses will regularly check for possible problems, such as infection, bleeding or blood clots. If you do not have a stoma, they will also look for any signs that the new join in the colon (anastomosis) is leaking. If this happens, you may need another operation and possibly a stoma.

If you have any problems after surgery, your healthcare team will explain what is happening and offer you further tests or treatment.

#### Pain relief

Your nurse or doctor will give you medicines to relieve pain. You may have a PCA (patient controlled analgesia) pump for the first few days after your surgery. You can control this yourself by pressing a button when you need extra pain relief.

You may have medicine through a tube in your back (epidural) to control pain.

Tell your nurse if you're in pain as soon as possible so that they can change the type or dose of pain relief.

### **Eating and drinking**

The nurses will tell you when you can start to eat and drink. If you're not able to eat or drink for more than a few days, you may have nutrients through a thin tube into a vein.

If you're on an enhanced recovery programme, you'll be encouraged to eat and drink soon after you return to the ward, as long as you're not feeling or being sick. See page 16 for information about the enhanced recovery programme.

Most people find that small meals and bland, low fibre foods are easier to digest to start with.

You may have loose poo (diarrhoea) for a few months after your operation. Or you may find it difficult to empty your bowel (constipation). Your healthcare team can give you diet advice and medicines to help.

If you have wind, your nurse may recommend oats, linseed or peppermint. Avoid foods that cause wind, such as beans and pulses. If wind is causing you pain, your nurse can give you medicines to help.

Learn more about eating well after bowel cancer treatment on our website bowelcanceruk.org.uk

#### **Stoma**

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

See page 22 for more information about stomas.

### Getting out of bed

Your healthcare team will encourage you to sit up and get out of bed soon after your operation. When you feel ready, ask them when you can start walking around the ward. Doing this several times a day may help your recovery and reduce the risk of complications.

# Preventing blood clots

To help prevent blood clots, you'll wear compression stockings (known as TEDS) after your operation. You'll also have daily injections of blood-thinning medicine for 28 days. The nurse will give you medicine to take home and will explain how to give yourself these injections. If you or someone you live with is unable to give the injections, you may be able to get help from a district nurse.

A nurse or physiotherapist will show you leg exercises to do while you're sitting in a chair or lying in bed. For example, moving your feet in circles and up and down.

### **Breathing exercises**

The nurse or physiotherapist will show you how to do deep breathing exercises until you're out of bed. These exercises help clear secretions from your lungs to reduce the risk of a chest infection. Some people worry about coughing, but this is a good way of clearing your chest. Gently support your abdomen with a rolled-up towel or pillow to make it more comfortable.

Tell your nurse or physiotherapist if you find these exercises painful. You may need to have your pain relief changed to help you continue with the exercises.

### **Going home**

Your doctor or nurse will tell you when you can expect to go home. This is usually when:

- · you're eating and drinking
- you can walk around the ward and you're able to go up and down stairs without help (if you need to do this at home)
- your wound is healing well and there's no sign of infection
- your bowels are working
- you're able to look after your stoma if you have one

You may have some strong feelings or concerns about leaving hospital after your operation. Your healthcare team will give you information about your recovery and make sure you have support at home. They'll also tell you when your first follow up appointment will be.

You can contact your specialist nurse or stoma care specialist nurse at any time if you have any questions.



I felt amazing leaving hospital as I was just so elated at having got through my emergency surgery. My top tip is to take every opportunity to get mobile when you're in hospital. In the early days particularly, when there are various wires and tubes connected to you, walking up and down the ward might seem more hassle than it's worth. But even short walks help massively in settling the abdominal area and help you feel better mentally, which makes heading home easier.

**Jamie** 

# Recovering at home

The first few days at home can be tiring and you may need to rest and sleep more often than usual. You may feel tired from the anaesthetic, lack of sleep in hospital, side effects of medicines or discomfort from the surgery.

It can take several weeks or months for your energy levels and appetite to come back. It'll also take time for your bowel control to return. You can contact your specialist nurse or GP if you have any questions about your recovery.

#### **Your emotions**

After your surgery, you're likely to have more time to think about what you've been through. You may be feeling a range of emotions and you may feel better on some days than others. There may be times when you feel worried or depressed, or you may feel differently about your body or identity. Other times, you may feel positive and strong. There's no right or wrong way to feel.

Talking to people you're close to about how you're feeling can help you when you're feeling low. If you feel you need more support, speak to your specialist nurse. They can tell you about local services, such as health and wellbeing events.

You may want to join a support group, where you can talk to people who have had similar experiences. Ask your healthcare team for details of groups in your area or check the map on our website.

# More support

Find out about the support available at bowelcanceruk.org.uk/how-we-can-help



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# Side effects of surgery

## **Keeping active**

You may not feel like exercising when you're recovering from treatment. But physical activity can improve your mood and wellbeing and reduce tiredness.

Your healthcare team will give you information on how to increase your activity levels safely. The hospital physiotherapist will also give you exercises to do at home.

Start off with gentle activities, like walking around the house or to the local shops. Try to be active every day and limit the amount of time you spend sitting down.

Gradually build up to at least 150 minutes a week of moderate activity, such as fast (brisk) walking. This is about the same as 75 minutes of more energetic activity, like running, cycling or swimming.

# **Eating and drinking**

Start with several small meals through the day and chew your food well. Drink plenty of fluids but avoid fizzy drinks, which can irritate the bowel and cause wind. Nutritious snacks will help you eat enough calories, giving your body the energy it needs to heal.



You can find out more about eating after surgery in our booklet Eating well, available from bowelcanceruk.org.uk/our-publications

All treatments carry a risk of side effects. Your healthcare team should give you written information about the possible side effects of your treatment. They won't be able to tell you in advance which side effects you may get or how long they'll last.

Surgery can change how your bowel works. You may need to empty your bowels urgently, have loose poo (diarrhoea) or find it difficult to have a poo (constipation).

At your hospital appointments, your healthcare team will ask you about the side effects you're getting. They'll offer you treatment or advice to help. You might want to keep a diary to help you remember the details.

You can read more about managing bowel problems after surgery on our website **bowelcanceruk.org.uk** 

#### Please note

Contact your specialist nurse or GP straight away if:

 you have severe pain in your stomach area (abdomen) that lasts for a few hours and does not respond to pain relief medication

- your wound opens, leaks fluid or becomes red, more painful or swollen
- you have any bleeding from the wound or your bottom (anus)
- it stings or burns when you pee (urinate)
- you have a high temperature and feel generally unwell
- you're being sick (vomiting)
- you haven't emptied your bowels for more than two days
- you have loose and runny poo for more than two days
- your stoma is not working and you feel bloated and uncomfortable
- you need to empty your stoma bag more often than usual or the output is loose and watery

# Your pathology report

Most side effects get better a few weeks after surgery. But some people may have side effects that last longer (long-term effects) or they may get new side effects later on (late effects).

Possible long-term and late side effects of surgery include:

- tiredness
- hernia, where body tissue pushes through the operation wound or stoma site
- · bowel problems
- sexual problems
- bladder problems
- low mood

Speak to your surgeon or specialist nurse if you have ongoing side effects. They may give you medicine to help or refer you for specialist advice.

# Low anterior resection syndrome (LARS)

If you had surgery for rectal cancer that avoids a permanent stoma, you may develop long-term bowel problems. This is called low anterior resection syndrome (LARS). If you have a reversible stoma, symptoms may start after the stoma is reversed. Symptoms can include:

- needing to empty your bowels urgently (urgency)
- feeling that you have not fully emptied your bowel
- having small, more frequent bowel movements (clustering or fragmentation)
- difficulty knowing whether you need to pass wind or a bowel movement
- not being able to control when you have a bowel movement (faecal incontinence)

Contact your GP or specialist nurse if you have any of these symptoms. They can give you medicine or refer you for further investigation and treatment. You can find out more about LARS on our website bowelcanceruk.org.uk

After surgery, your healthcare team will know more about:

- whether they were able to remove all the cancer
- how far the cancer has spread
- whether you need more treatment
- whether the cancer is linked to an inherited condition

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.

Your doctor will also stage the cancer. This involves describing the size of the cancer, where it is and whether it has spread.

# More information

You can find out more about tumour grading and staging on our website bowelcanceruk.org.uk

# **Number staging**

Your healthcare team will use information from your diagnostic tests and your pathology report to give the cancer a number stage between 1 and 4.

- **Stage 1** The cancer has not spread outside the bowel wall
- Stage 2 The cancer has grown into or through the outer layer of the bowel wall
- **Stage 3** The cancer has spread to nearby lymph nodes
- Stage 4 The cancer has spread to other parts of the body

Your healthcare team will get your pathology report two to three weeks after the operation. At your follow up appointment, they'll talk to you about the results and whether you need further treatment.

# **Further treatment**

For some cancers, treatment after surgery lowers the chance of the cancer coming back. This is called adjuvant treatment. Your healthcare team will tell you whether you need any further treatment.

#### Early-stage bowel cancer

You won't need any more treatment after surgery if you have stage 1 bowel cancer.

You may not need further treatment if you have stage 2 bowel cancer and there's no evidence that the cancer has spread to the pelvis or lymph nodes. If the cancer is large or deep in the bowel wall, you may have chemotherapy to help make sure there aren't any cancer cells left behind.

### If the cancer has spread

You're likely to need further treatment with chemotherapy if your cancer is stage 3 or 4.

If the cancer has spread to other parts of the body (advanced bowel cancer or stage 4), you'll be under the care of the bowel cancer multidisciplinary team (MDT) and experts who specialise in the parts of the body that your bowel cancer has spread to. This could include specialists in treating the liver, lungs or the tissue that lines the inside of the abdomen (peritoneum).

Your healthcare team may offer you further surgery at a specialist treatment centre to remove the cancer that has spread.

# Inherited (genetic) conditions

Pathologists test all bowel cancers to see if they are linked to an inherited condition called Lynch syndrome. Most bowel cancers are not inherited.

If the test results show there's a chance you may have Lynch syndrome, you'll be offered a genetic test. If you do have Lynch syndrome you may be offered treatment and screening to lower your chance of getting cancer in the future. Your close relatives will also be offered testing.

# More information

Our website has more information about treating advanced bowel cancer and Lynch syndrome bowelcanceruk.org.uk

# Follow up

You'll have regular follow up appointments with your surgeon or specialist nurse. These may be over the phone or at the hospital.

You can use these appointments to talk about how you're recovering from treatment and to ask for any support you need.

For the first three years after treatment ends, your doctor or nurse will offer you tests to check for any signs of the cancer coming back. These tests may include:

- blood tests to check for a protein called CEA (carcinoembryonic antigen)
- CT scans

# More information

You can download a list of questions to ask at your follow up appointments from our website at bowelcanceruk.org.uk/our-publications

# Other useful organisations

#### **Bladder and Bowel Community**

w bladderandbowel.org

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

#### Cancer Research UK

- w cancerresearchuk.org
- T 0808 800 4040

Information and advice for people affected by cancer.

### **Chartered Society of Physiotherapy**

w csp.org.uk

Provides information on information on physiotherapy and cancer.

# **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.

### **Disability Rights UK**

w disabilityrightsuk.org

Sells Radar Keys to open public toilets that are part of the National Key Scheme.

#### 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.

# IA (Ileostomy and Internal Pouch Support Group)

- w iasupport.org
- T 0800 018 4724

A support group run by and for people with an ileostomy or ileo-anal (internal) pouch.

# More support

### Lynch Syndrome UK

w lynch-syndrome-uk.org

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.

#### **NHS**



Provides health and lifestyle information, including general information about diet, physical activity, sleep problems, fatigue and emotional support.



### **Online communities**

Our online communities are welcoming places for everyone affected by bowel cancer to ask questions, read about people's experiences and support each other. Join us at **bowelcanceruk.org.uk/online-communities** 



#### 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** 



## **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/our-publications



# **Ask the Nurse**

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

**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







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

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