Mid Cheshire Hospitals
NHS Foundation Trust

Consultation Record
What happens now?

Important information about colorectal cancer

Contents

How will this booklet help you?

Your doctor or a member of the colorectal team will have told you that you have a cancer in your large bowel or rectum and you may be wondering what exactly this means. Often, when we are given information like this we find that later, we cannot remember what has been said. The written information in this booklet will help with this. At the back of this booklet you will find pages where you can write notes, questions you would like to ask, and appointments that are arranged for you.

What does cancer of the large bowel or rectum mean?

Cancer is a word that is used to describe many different diseases all of which have different causes and are treated in different ways.

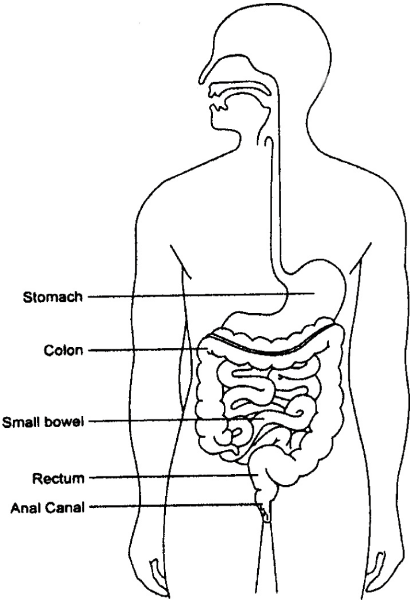
Our bodies are made up of tiny structures called cells, which are not visible to the naked eye. Each group of cells has a very particular function. Cells reproduce themselves by dividing in a very controlled way so that the body can grow and repair itself.

Sometimes, some cells grow in an uncontrolled way which can cause a swelling or tumour. Some tumours stay within a limited area and after treatment, which is often an operation, they usually don’t cause any more problems. These sorts of tumours are called benign. Malignant tumours or cancers are tumours that can spread to other parts of the body.

This can happen when cancer cells travel through the blood stream or lymphatic fluid. This fluid is part of the lymphatic system of the body, which helps it to fight infection. The lymphatic system is made up of a network of vessels (tubes) and nodes (glands) throughout the body.

What do the large bowel and rectum do?

Your bowel is a hollow tube, which lies coiled up in your abdomen. It is made up of two parts, the small bowel and the large bowel. The small bowel absorbs nutrients from the food we eat. Waste products then pass into the large bowel, which is made up of the colon and rectum. Here water is absorbed back into the body making the waste products (stools) more solid. They are then passed out of the body through the rectum (back passage) and anal canal as faeces or stools.



What causes bowel cancer?

Unfortunately we still know very little about the causes of cancer of the large bowel, (also called colorectal cancer) and research is continuing.

Each year there are over 28,000 new cases of bowel cancer in the UK. For a small number of people their cancer is caused by a condition that runs in families (inherited).

Some studies have shown that bowel cancer occurs more frequently in countries where people eat a diet high in fat and low in fibre and also that a high alcohol intake may be linked to bowel cancer.

What are the signs and symptoms?

The commonest symptom of bowel cancer is a change in bowel habit. It may be that there is a difference in the number of times you empty your bowels each day, or you could have diarrhoea (loose stools) or be constipated (hard stools), or you might have alternating diarrhoea and constipation. Sometimes the stool may be streaked with blood or mucous (a jelly-like substance) or you may feel that you haven’t emptied your bowels completely and you have to go back to the toilet.

You may feel a colicky type pain or discomfort in your abdomen. You may feel generally unwell. Maybe very tired or anaemic.

You may have experienced one or more of these symptoms which is why you went to see your doctor in the first place.

Will I need more investigations?

You will already have had some investigations, but you may need more. This will be so the doctors have as much information as possible about the size and exact position of the cancer. This will help them decide on the best treatment for you. If you do need any more investigations they may include more than one or more of the following:

CT (computerised tomography) scan

This is a series of x-rays which give a three dimensional picture of the inside of the body. This can show the size of the tumour and whether it has spread. This test is not painful and takes about 15 minutes.

You maybe given a special liquid dye to drink. This helps certain areas to be seen more clearly. It can also make you feel hot all over for a few minutes.

It is important that you tell us if you know that you are allergic to anything. This is because you could have a serious reaction to the dye which contains iodine.

Sometimes before the scan some liquid may be passed into your rectum (back passage) through a small tube, which also helps to get a better picture.

MRI (magnetic resonance imaging)

This is similar to a CT scan but it uses magnetic rays to build up better pictures. Sometimes an injection of the dye is given to help get a better picture. This test will give us more information about the tumour itself.

The test takes about 30 minutes and is not painful. You will be asked to lie still on a couch in a long chamber. This can be noisy so you will be given headphones or earplugs to wear.

This test uses a very powerful magnet, so before going into the MRI room you must remove any metal objects. If you have a heart monitor or a pacemaker or certain types of surgical clips you may not be able to have a MRI scan. This is because they maybe affected by the magnets in the machine.

Chest x-ray

A chest x-ray maybe taken to check your heart and lungs. This is not painful and only takes a few minutes.

Abdominal ultrasound scan

This uses sound waves to build up a picture of organs such as the liver. This is not at all painful and takes about 15 minutes. A gel is spread on your skin and a small probe is passed over it. The gel helps to conduct the sound waves, which form a picture on a television screen.

What treatment will I have?

When all your investigations are complete you will start your treatment.

Treatment for the cancer is planned for each individual, so not everyone will have the same. The treatment you will have will depend on the size and type of your cancer, your general health, the results of your tissue sample (biopsy), the results of all your investigations and your wishes. Don't be concerned if you speak to other people who are having different treatments.

The main treatment for bowel (colorectal) cancer is surgery to try and remove the tumour. If your tumour is in the rectum your consultant may suggest a course of radiotherapy (x-ray treatment) or chemotherapy (drug treatment) before your operation to try and shrink the cancer and make it easier to remove during the operation.

Your treatment will be discussed by the Multi-Disciplinary Team (MDT) involved in your care. The options available to you will be discussed with you, and a member of the colorectal team who will help you make an informed choice.

An MDT meeting is held on every Thursday at 8.30am in the Macmillan Cancer Unit. This meeting gives the specialists involved in your care the opportunity to discuss and co-ordinate your treatment on an individual basis. This is to ensure that you are offered the most appropriate treatment for your cancer.

The MDT comprised the following members:

- Consultant Surgeons
- Colorectal Nurse Specialists
- Stoma Care Nurses
- Research Nurse
- Consultant Pathologist
- Consultant Radiologist
- Consultant Oncologist
- Consultant Gastroenterologist

The Colorectal Nurse Specialist will be your Key Worker and they will remain in contact with you throughout your treatment.

If you are worried about your treatment or want more information, please let your Key Worker know. They can also arrange for you to talk about your care with a member of the MDT.

Your Key Worker is..

Telephone number ....

Will I be asked to take part in a research study?

You may be invited to take part in a research study or a clinical trial when you first come into hospital or at some point later on.

Research continues to help find more effective treatments but your Doctor or Colorectal Nurse Specialists will discuss this with you if it is appropriate in your case. If you do not want to be involved, this is entirely your choice and is not a problem.

What operation will I have?

You may have an operation to remove the cancer and part of your bowel on either side of this. The operation you will have will depend on your individual situation and your care will be planned around this. You will be given an information booklet about the operation that you are going to have.

If the tumour is in the lower part of your rectum there may not be enough bowel left to join together. In this case you may have a stoma formed. This is called a colostomy or an ileostomy and is an artificial opening created when the healthy part of your bowel is brought out onto the surface of your abdomen. Faeces comes out of the opening and into a bag which is attached to the surface of the skin on your abdomen.

Sometimes a temporary stoma is formed to rest the bowel for a while after your operation and allow it to heal. It is known before your operation that you will need a stoma, the Stoma Care Nurse will visit you and explain what to expect. They will also show you how to care for your stoma and provide support.

Are there any risks associated with bowel surgery?

There are risks to having any operation but the risks associated with bowel cancer surgery are quite low. This means that most people have no problems. Your Key Worker or Consultant Surgeon will talk to you about the risks for the operation you are going to have.

A leak may develop where the bowel has been joined but this happens in less than 1 in 10 patients. This can lead to complications, such as abscess, or peritonitis (inflamed lining of the abdomen). If the leak is very small it may heal if the bowel is rested (by not eating and drinking for a few days, and having fluids through a drip instead). However, a further operation may be needed to form a temporary stoma to allow the bowel to heal.

If the tumour is low in the pelvis there is a risk that the surgery may damage the nerves responsible for sexual function.

What will happen before my operation?

Pre-op admission clinic

You will be sent an appointment to come to the pre-admission clinic to check your general health. You will be seen in the clinic a couple of weeks before your operation and you will have further tests which may include a blood test, ECG (electrocardiograph: a trace of your heart) and a blood pressure check. You will be asked questions about your general health and given any further information about your operation that you need.

Consent

Before your operation, we will need your written consent to say that you agree to have the operation. Please ensure that you have asked all of the questions that you want to and have received all of the information you require.

What will happen when I come into hospital?

You will be admitted to the Surgical Admissions Lounge (SAL) the day of your surgery and be transferred to the ward following your operation. You may also be asked to take a strong laxative to empty your bowel before surgery.

What will happen after my operation?

Your bowel will take some time to start working normally again after your operation so you will only be able to have sips of water at first. Until you are able to eat and drink again you will be given fluids through an infusion (drip) into a vein, usually in your arm - this maybe for a few days.

A thin tube (catheter) will be put in your bladder - this is to drain away any urine and stop you feeling uncomfortable. This will be taken out as soon as possible.

You may have a thin tube (wound drain) coming out of your wound - this is to drain away blood and fluid that collects after your operation.

You will have stitches or clips in your wound and your nurse will tell you when they will be removed. Some stitches dissolve by themselves and do not need taking out.

You maybe offered a patient controlled analgesia (PCA) pump following your operation. This allows you to control the amount of pain relief you give yourself. It is very safe as it is controlled so that you cannot give yourself too much by mistake.

If you have pain or feel sick tell the nurse straight away as they can give you something to stop this.

You will probably be in hospital for between 5 - 14 days.

When will I be told about the results of my operation?

The piece of bowel that is removed during your operation contains the cancer. This is sent to the pathology laboratory to be looked at see what the extent of the cancer is and decide whether further treatment is necessary. It can take up to 14 days to get this result back. Your doctor or Colorectal Nurse Specialists will talk to you about the results and what they mean. We will try to get the results back to you before your discharge from hospital. Sometimes this is not possible. If this is the case an appointment will be made for you to see the consultant in the out-patient department as soon as possible once the results are available.

Will I need further treatment?

If you are likely to need chemotherapy or radiotherapy we will discuss this with you. You will be given written information when you come to have the treatment.

What happens when I go home?

You will probably feel very tired physically and will need to take things slowly at first. If you live alone or think you may have problems coping, please tell your nurse or ask the ward staff to contact a social worker for you when you come into hospital so that help can be arranged.

You may feel anxious or even angry as you come to terms with what you have just been through. Everyone is different but you may find that you have “good” days and “bad” days as you adjust.

Try to rest and take a little gentle exercise such as short walks and slowly build this up.

Try to eat a well balanced diet. There are no restrictions on what you can eat although you may find that certain foods upset you and are best avoided.

Do not lift anything heavy for about 6 weeks. Your abdomen will feel sore and tender after surgery and you will be advised when you can start driving again (this is usually about 6 weeks after the operation).

Accept offers of help and talk to your partner, family and friends about how you feel and the support you need. You may be concerned about your scar or having a stoma - talk to your partner about this or people close to you. Many people find this helps them realise that they are still the same person as before and just as valuable. You may find it easier to talk to someone who is not affected by your situation. You will find useful contact numbers of support organisation at the back of the book.

As soon as you feel well enough you will be able to resume your normal activities although you may wish to work part-time or cut down your social activities for a while.

Will my operation/treatment affect my sex life?

Once you have recovered from your operation there is no reason why you cannot resume your sex life again. Some people find their sex drive (libido) decreases - don't worry this happens. This isn't unusual and it often goes back to normal when you have fully recovered.

In some cases, an operation or treatment to the area around the rectum can cause damage to the pelvic nerves that lead to the sexual organs. Men may have problems with erection or ejaculation. Women may experience vaginal dryness or painful intercourse or find that their response is affected. Sometimes these problems resolve by themselves, in other cases drug treatment may be necessary.

If you are having any problems do speak to your doctor or nurse practitioner/specialist nurse who will be able to offer advice or support. They will also be able to recommend or prescribe medication where appropriate e.g. Viagra.

Will my fertility be affected?

Radiotherapy and chemotherapy may affect your fertility. Sperm and eggs may not be formed or even formed at all. This should be discussed with you before treatment.

Will I be followed up after my operation?

After your treatment is finished you will have regular check-ups which may consist of:

- Blood tests
- X-rays
- Flexible sigmoidoscopies
- Scans
- Colonoscopies

These may continue for several years but will gradually become less frequent. If you have any problems between visits, let your doctor or nurse practitioner know as soon as possible.

Information discussed

Questions

Write any questions here that you may wish to ask when you see your doctor or nurse.

Appointments arranged

With the surgeon

With the Colorectal Nurse Specialists

With the radiologist (X-ray doctor)

With the oncologist (chemotherapy / radiotherapy doctor)

Follow-up schedule

Where can I get help?

If you have any queries, please contact your Key Worker

Useful organisations

Beating Bowel Cancer
Harlequin House
7 High Street, Teddington
TW11 8EE
Nurse helpline: 020 8973 0011
www.beatingbowelcancer.org

Beating Bowel Cancer is a leading UK charity for bowel cancer patients, working to raise awareness of symptoms, promote early diagnosis and encourage open access to treatment choice for those affected by bowel cancer.

Bowel Cancer UK
Willcox House
140 - 148 Borough High Street
London
SE1 1LB
Tel: 020 7940 1760
www.bowelcanceruk.org.uk

Colostomy UK
Enterprise House
95 London Street
Reading
Berkshire
RG1 4QA
Helpline: Freephone 0800 328 4257
www.colostomyuk.org/

Ileostomy and Internal Pouch Support Group
Danehurst Court
35-37 West Street
Rochford
Essex
Freephone: 0800 018 4724
www.iasupport.org

IA is a UK registered charity whose primary aim is to help people who have to undergo surgery which involves the removal of their colon (known as a colectomy) and the creation of either an ileostomy or an ileo-anal pouch.

Macmillan Cancer Support
89 Albert Embankment
London
SE1 7UQ
Telephone: 0808 808 0000
Website: www.macmillan.org.uk

Macmillan's goal is to make a real difference to the lives of people living with cancer. They work in partnership with people affected by cancer, and with other organisations such as other charities and the NHS, to deliver services (including the provision of patient information).

Your hospital may have a local support group. Ask your Key Worker about this.

The Customer Care Team
Telephone: 01270 612410 Monday - Friday 9am - 5pm (excluding Bank Holidays) (24 hour answer machine)
Email: customercareteam@mcht.nhs.uk.

Questions? Make a note here

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Translation and interpretation service

Do you have difficulty speaking or understanding English ?

আপনি কি ইংরেজীতে বুঝতে কিংবা বুঝাতে পেরেছেন ? (BENGALI)

क्या आपको अंग्रेजी बोलने या समझने में कठिनाई है ? (HINDI)

તમે ભાષા કારણે વાતચીત કરવામાં મુશ્કેલી આવે છે ? (GUJARATI)

ਕਿ ਤੁਹਾਨੂੰ ਅੰਗ੍ਰੇਜ਼ੀ ਬੋਲਣ ਜਾਂ ਸਮਝਣ ਵਿਚ ਦਿੱਕਤ ਹੈ ? (PUNJABI)

Miyey ku adagtahay inaad ku hadasho Ingriisida aad sahamto (SOMALI)

هل لديك مشاكل في فهم اوالتكلم باللغة الأنجليزية ؟ (ARABIC)

你有困難講英語或明白英語嗎？ (CANTONESE)

کیا آپکو انگریزی سمجھنے اور سمجھانے میں دقت پیش آتی ہے ؟ (URDU)

Czy masz trudności z mówieniem i zrozumienia Angielski? (POLISH)

The Association of Coloproctology of Great Britain and Ireland

The Association's website has information for patients about a variety of bowel conditions at www.acpgbi.org.uk

Coloproctology Unit
Colorectal Nurse Specialists
Leighton Hospital
Middlewich Road
Crewe, Cheshire
CW1 4QJ
Direct Line: 01270 612047

This leaflet is available in audio, Braille, large print, and other languages. To request a copy, please contact the Colorectal Nurse Specialists.

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