Colon and Rectal Cancer

JASCAP

JASCAP JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS

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JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

Registered under the Societies Registration Act, 1860 No.1359 / 1996 G.B.B.S.D., Mumbai and under the Bombay Public Trusts Act, 1950 No. 18751 (Mumbai). Donations to JASCAP qualify for deduction u/s 80G (1) of the Income Tax Act, 1961 vide Certificate No. DIT (E) / BC / 80G / 1383 / 96-97 dated 28.02.97 subsequently renewed.

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Publisher: JASCAP, Mumbai 400 055

Printer: Surekha Press, Mumbai 400 019

Edition: March, 2011

Donation suggested ₹ 30.00

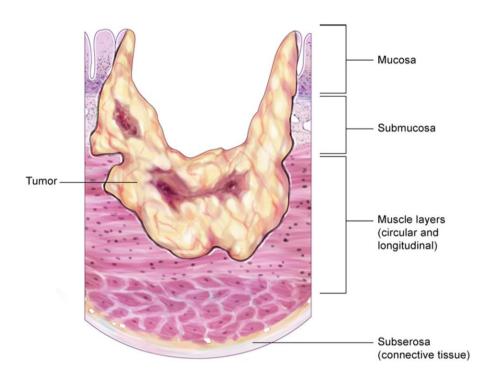
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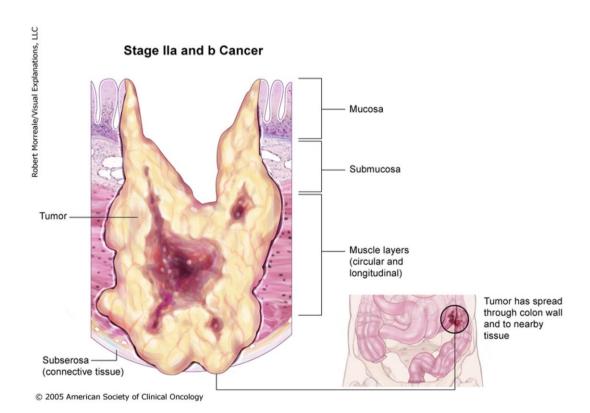
Stage 0 Cancer Tumor Mucosa Submucosa Muscle layers (circular and longitudinal) Subserosa (connective tissue)

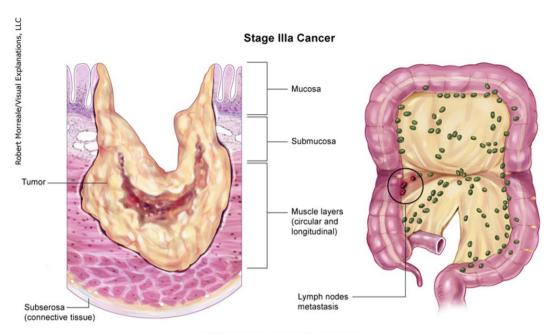
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Stage I Cancer

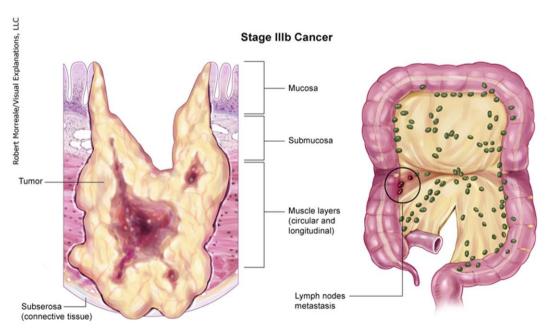


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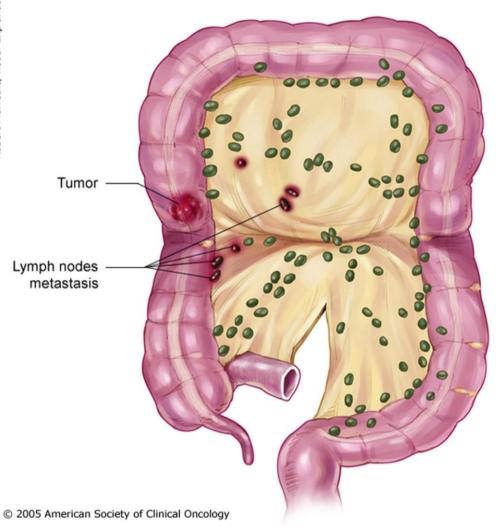


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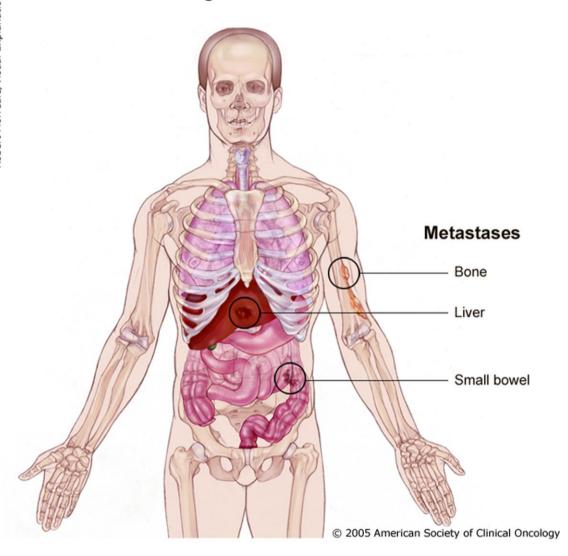


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Stage IIIc Cancer



Stage IV Cancer



Contents

Colon and Rectal Cancer

Introduction
The large bowel– colon and rectum

About cancer

What is cancer?
Types of cancers

Risk factors and causes of colon and rectal cancer

How common are cancers of the colon or rectum? What causes cancer of the colon or rectum?

Screening for colon and rectal cancer

Symptoms & diagnosis of colon and rectal cancer

Treating colon cancer

Surgery for colon cancer
Types of colon cancer surgery
After your operation for colon cancer
Living with a stoma
Chemotherapy for colon cancer
Biological therapies (targeted therapies) for colon cancer
Radiotherapy for colon cancer
Research - clinical trials for colon cancer
Follow-up after treatment for colon cancer

Treating rectal cancer

Surgery for rectal cancer
Types of rectal cancer surgery
After your operation for rectal cancer
Living with a stoma
Chemotherapy for rectal cancer
Radiotherapy for rectal cancer
Chemoradiotherapy for rectal cancer
Biological therapies (targeted therapies) for rectal cancer
Research - clinical trials for rectal cancer
Follow-up after treatment for rectal cancer

Living with colon and rectal cancer

Colon and Rectal Cancer

Introduction

This booklet is for you if you have or someone close to you has Colon or Rectal Cancer.

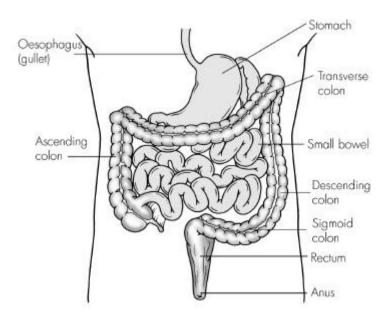
If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are particularly important for you.

The large bowel – colon and rectum

The colon and rectum make up the large bowel, which is part of our digestive system. The colon is where water is absorbed as part of the digestive process and the rectum is where waste matter (stools or faeces) is held until it's ready to be passed.

About two-thirds of cancers that develop in the large bowel occur in the colon and one-third occur in the rectum.

The walls of the colon and rectum are made up of layers of body tissue. Most colon and rectal cancers start in the innermost lining of the bowel and develop from small growths called polyps.



Large bowel - colon and rectum

Once food has been swallowed, it passes down the gullet (oesophagus) to the stomach, where digestion begins. It then passes through the small bowel, where essential nutrients are taken into the body. The digested food then moves into the colon, where water is absorbed. After the colon, the remaining waste matter, known as stools or faeces, is held in the rectum (back passage) until it's ready to be passed from the body through the anus as a bowel motion (stool).

Close to the bowel are lymph nodes, also known as lymph glands, which are about the size of a baked bean. The lymph nodes are part of the lymphatic system.

The colon

The colon is divided into four sections:

- 1. Ascending colon: The first part of the colon starts at the bottom, right-hand side of the abdomen just after the small bowel and the appendix. This part goes up the right side of the abdomen.
- 2. Transverse colon: The second section goes across the abdomen from right to left.
- 3. Descending colon: The third section goes down the left hand side of the abdomen.
- 4. Sigmoid colon: The final part of the colon is a 's' shape bend which joins onto the rectum.

The rectum

The rectum is the last part of the large bowel before it opens to the outside at the anus. It is approximately 15cm long.

To help describe the position of a cancer within the rectum it is sometimes divided into three sections – upper, middle and lower. The upper rectum is the section directly after the sigmoid colon, and the lower rectum is where the large bowel joins the anus.

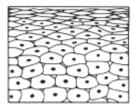
About cancer

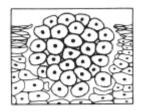
This section provides an overview of what cancer is - for further information, please see specific cancer types or treatments.

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a **tumour**.





Normal cells

Cells forming a tumour

Not all tumors are cancerous. Tumors that aren't cancer are called **benign**. Benign tumors can cause problems -- they can grow very large and press on healthy organs and tissues. But they cannot grow into (invade) other tissues. Because they can't invade, they also can't spread to other parts of the body (metastasize – see below). These tumors are almost never life threatening.

Cancer is the name given to a **malignant** tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a **biopsy**.

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

The lymphatic system is part of the immune system - the body's natural defence against infections and diseases. It is a complex system made up of organs, such as bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

Cancer cells often travel to other parts of the body, where they begin to grow and form new tumors that replace normal tissue. This process is called **secondary cancer** or **metastasis**. It happens when the cancer cells get into the bloodstream or lymph vessels of our body.

No matter where a cancer may spread, it is always named for the place where it started. For example, breast cancer that has spread to the liver is still called breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is metastatic prostate cancer, not bone cancer.

Different types of cancer can behave very differently. For example, lung cancer and breast cancer are very different diseases. They grow at different rates and respond to different treatments. That is why people with cancer need treatment that is aimed at their particular kind of cancer.

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Types of cancer

Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

- squamous cells that line different parts of the body, such as the mouth, qullet (oesophagus), and the airways
- adeno cells form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
- transitional cells are only found in the lining of the bladder and parts of the urinary system
- basal cells that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

- bone sarcomas that are found in the bones
- soft tissue sarcomas that develop in the other supportive tissues of the body.

Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

Risk factors and causes of colon and rectal cancer

How common are cancers of the colon or rectum?

Cancer of the large bowel (colon and rectum) is the third most common type of cancer diagnosed in the UK. In UK, each year, approximately 23,000 people develop colon cancer and approximately 14,000 people develop rectal cancer.

How common are the cancers of the colon and rectum in India?

Colon and rectal cancer is one of the common cancers among men and women from the Indian subcontinent. It ranks sixth or seventh among all other cancers. The incidence (newly diagnosed cases of cancer in a year) of colon and rectal cancers in India is about 4 patients per 1,00,000 population for both sexes together.¹

In India, between the years 2001-2003, across five urban centers - Mumbai, Delhi, Chennai, Bhopal and Bangalore, – and one rural center - Barshi, a total of 1,922 cases of colon cancer (2.17% of all cancers) were registered for men and women combined across all age groups, while a total of 1,915 cases of rectal cancer (2.16% of all cancers) were registered for men and women combined across all age groups.

Considering all men, women and children with all types of cancers together, a grand total of 3,837 cases of colon and rectal cancer (4.33% of all cancers) were registered at the six centers mentioned above, between the year 2001-2003².

The TATA Memorial Hospital (T.M.H.) in Mumbai, India registered a grand-total of 19,127 cases of all types of cancer patients in the year 2006 for men, women and children combined. In that same year at T.M.H., 278 people were diagnosed with Colon Cancer, out of which 193 (70%) were males and 85 (30%) were females and 438 people were diagnosed with Rectal Cancer, out of which 302 (70%) were males and 136 (30%) were females³

Like most types of cancer, colon and rectal cancers are more common in older people – more than 80% of these cancers are diagnosed in people over 60.

What causes cancer of the colon or rectum?

In most people, the cause of colon and rectal cancer is still unknown, but research is going on to try to find the cause. We do know that certain risk factors can increase our chances of developing colon or rectal cancer. These risk factors include eating a lot of processed meats, being overweight, getting very little exercise, and smoking.

¹ Globocan 2008: Cancer incidence and mortality rates worldwide

²Population based cancer registry 2001-2003 Mumbai, Delhi, Chennai, Bhopal, Barshi and Banglore, Indian Cancer Society.

³ TATA Memorial Hospital Registry Data for 2006

Some people have a higher risk of developing bowel cancer as they have inherited a faulty gene.

Colon cancer and rectal cancer are not infectious and can't be passed on to other people.

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Diet

There is evidence that a diet that contains a lot of animal fat and red meat (especially processed meats such as sausages, bacon and pies) can increase the risk of developing bowel cancer.

The greatest increase in risk seems to be for people eating two or more portions of red or processed meat a day. People who eat less than two portions per week seem to have the lowest risk.

No link has been found between eating poultry such as turkey and chicken, and an increased risk of colon or rectal cancer. Eating a diet low in fruit and fresh vegetables may also increase the risk.

Lifestyle

Cancer of the colon or rectum may be more common in people who get very little exercise and who are overweight. It's also more common in people who have smoked cigarettes for a long time, such as 20 years or more.

Bowel diseases

People who've had Ulcerative Colitis or Crohn's disease (diseases of the lining of the bowel) for a long time also have an increased risk of developing bowel cancer.

Inherited faulty genes

A person who has one or more family members with bowel cancer may have a higher risk of developing it. They are usually only at higher risk, if bowel cancer has been diagnosed in a close family member (such as a parent, sister or brother) under the age of 45, or when there is colon or rectal cancer in several close members on the same side of a family.

People who are worried about bowel cancer because of their family history can be referred to specialist clinics. At the clinic their risk will be carefully assessed. Regular screening, usually with a colonoscope, can be arranged for people who have a high risk of developing the disease. Contact your GP or our cancer support specialists for more information.

Only about 5% (5 in every 100) of colon and rectal cancers are caused by an inherited faulty gene.

Familial conditions – FAP and HNPCC

There are two very rare conditions that can run in families (familial) called familial adenomatous polyposis (FAP) and hereditary non-polyposis colon cancer (HNPCC). People with either condition have a very high risk of developing colon or rectal cancer.

Familial Adenomatous Polyposis (FAP)

People with FAP have many hundreds of thousands of benign tumours (polyps) in the lining of the colon. They should be regularly screened using colonoscopy or sigmoidoscopy to look for signs of cancer. Usually, people with FAP are recommended to have an operation to remove their colon. Unless the colon is removed, nearly everyone with FAP will develop colon cancer.

FAP causes about 1% (1 in every 100) of bowel cancers.

Hereditary Non-Polyposis Colon Cancer (HNPCC)

People with HNPCC have an increased risk of developing bowel cancers at a young age, sometimes in more than one place in the colon. Unlike FAP, people with HNPCC have very few polyps in the bowel. If you have HNPCC you are likely to be screened every couple of years using colonoscopy. Screening usually starts from the age of 25, or five years before the age at which your youngest relative developed bowel cancer.

HNPCC causes about 3% (3 in every 100) of bowel cancers.

Screening for colon and rectal cancer

Screening means testing to find a cancer at an early stage, before there are any symptoms. The earlier that colon and rectal cancer is diagnosed and treated, the more likely it is that treatment will be successful. In the UK, a national screening programme to detect bowel cancer is being introduced across the country.

All men and women aged between 60 and 69 (50 and 74 in Scotland) will be offered a faecal occult blood (FOB) test every two years. Older people won't routinely be invited to take part, but are encouraged to request a FOB test every two years.

The test doesn't diagnose bowel cancer but can detect tiny amounts of blood, which you can't normally see, in your bowel motions (stools). Occult blood means 'hidden blood'. Bowel cancers and polyps can sometimes bleed, which is why screening looks for blood in your bowel motions. People who have a positive FOB test (have blood in their stools) are invited to have a colonoscopy to have a closer look at the bowel. Most blood in the bowel motions is caused by polyps and not cancer.

Symptoms & diagnosis of colon and rectal cancer

Symptoms of colon and rectal cancer

The symptoms of bowel cancer may include any of the following:

- blood in, or on the stools (bowel motions) the blood may be bright red or dark in colour
- a change in your normal bowel habit (such as diarrhoea or constipation) for no obvious reason, lasting longer than six weeks
- pain in the tummy (abdomen) or back passage
- a feeling of not having emptied your bowel properly after a bowel motion
- unexplained weight loss
- · unexplained tiredness.

The tiredness can happen if the cancer has been bleeding so the number of red blood cells is reduced (anaemia). Anaemia may also make you feel breathless.

Sometimes the cancer can cause a blockage (obstruction) in the bowel. The symptoms of this are:

- being sick (vomiting)
- constipation
- · pain in the abdomen
- a bloated feeling.

When to consult your doctor

Although these symptoms can be caused by conditions other than colon or rectal cancer, it's important that you always have them checked by your doctor. As bowel cancer usually occurs in people over the age of 50, these symptoms in younger people are often thought to be due to other bowel problems, such as haemorrhoids (piles), irritable bowel syndrome (IBS) or ulcerative colitis.

If you have symptoms that don't improve within a few weeks, or if your symptoms are getting worse, it's important that you're referred to a specialist for tests to find out what the problem is.

How colon and rectal cancers are diagnosed

Usually, you begin by seeing your GP (family doctor). He will examine you and may refer you to hospital for tests.

Seeing your GP

Your GP will feel your abdomen and examine your back passage (a rectal examination). To do this, the doctor places a gloved finger into your back passage to feel for any lumps or swellings. This may be slightly uncomfortable but it should not be painful. It will be less uncomfortable if you are able to relax while he is doing this.

You may have a blood test to check for anaemia (a low number of red blood cells), which is common in people with cancer of the colon or rectum. You may also have blood tests to check the health of your liver and kidneys.

If your GP is unsure what the problem is, or thinks that your symptoms could be caused by cancer, he will refer you to a hospital specialist.

How long should I expect to wait for a referral?

The Department of Health has given the following guidelines to GPs to help them know when to arrange an urgent referral.

They should arrange an urgent referral for:

- people aged 40 and over, who have bleeding from the back passage and a change in bowel habit (a change in stool frequency or consistency) that has lasted for six weeks or more
- people aged 60 and over, who have bleeding from the back passage which has lasted six weeks or more and no other bowel symptoms (such as change in bowel habit or anal pain or itching)
- people aged 60 and over, who have looser and/or more frequent stools lasting for six weeks or more, and no bleeding from the back passage
- anyone with a lump or swelling on the right side of the abdomen (tummy) or in the rectum
- all men, and women who no longer have menstrual periods, who have unexplained anaemia.

At the hospital

At the hospital the specialist will ask you about your general health, any previous medical problems, and whether you have any family history of bowel cancer. The specialist will examine you, and will probably repeat the rectal examination (as above).

The following tests may be used to diagnose colon and rectal cancer:

- <u>proctoscopy or sigmoidoscopy</u> to look at the inside lining of the rectum or sigmoid colon
- colonoscopy to look inside the whole length of the large bowel
- <u>barium enema</u> a special x-ray of the colon and rectum
- CT colonography a scan that is sometimes done instead of a barium enema

Waiting for your test results

It will probably take several days for the results of your tests to be ready and this waiting period will obviously be an anxious time for you. It may help if you can talk things over with a relative or close friend.

How the tests are carried out

Proctoscopy/sigmoidoscopy

These tests are done in the hospital outpatient department or on the ward by a doctor or nurse colonoscopist.

You will be asked to lie curled on your left side while a tube is gently passed into your back passage. A small hand-pump is attached to the tube so that air can be pumped into the bowel. This makes you feel that you want to pass a bowel motion, but the feeling will gradually go away once the test is over.

A proctoscope is a short tube that goes just into the rectum.

A sigmoidoscope is a longer tube that can be passed further up into the large bowel. Any abnormal areas can be seen with the help of a tiny light and camera on the end of the tube.

If necessary, a small sample of the cells (a biopsy) can be taken for examination under a microscope. The biopsy is not painful.

A proctoscopy or a sigmoidoscopy can be uncomfortable but shouldn't usually be painful. You should be able to go home as soon as the test is over.

Colonoscopy

If your doctor wants to look inside the whole length of the large bowel, you may have a colonoscopy. This will usually be done in the hospital outpatient department and takes about an hour.

For a colonoscopy the bowel has to be completely empty. This means following a careful diet for a few days before your test. The preparation is similar to that for a barium enema (see below). You will be given instructions by your hospital.

Just before the test, you may be given a sedative tablet to help you feel more relaxed, and you may feel sleepy during the colonoscopy. Once you are lying comfortably on your side, the doctor or nurse will gently pass a flexible tube (a colonoscope) into your back passage. The tube is made up of flexible fibres. It can easily pass around curves, and most of the large bowel can be examined. A tiny light and camera on the end of the tube help to show any abnormal areas or swelling.

During the test, photographs and samples (biopsies) of the cells on the inside of the large bowel can be taken. A colonoscopy can be uncomfortable, but the sedative will help you feel more relaxed.

Most people are ready to go home a couple of hours after their test. It's a good idea to arrange for someone to collect you from the hospital, as you shouldn't drive for several hours after a sedative.

Barium enema

This test will be done in the hospital x-ray department.

It's important that the bowel is empty so that a clear picture can be seen.

Your doctor or nurse will give you an instruction sheet before the test. On the day before the test, you will be asked to drink plenty of fluids and to take medicine (a laxative) to empty your bowel. Usually, on the morning of your enema, you shouldn't have anything to eat or drink. This may vary slightly from hospital to hospital.

Just before the test, to make sure that the bowel is completely clear, you may be given a bowel wash-out. The nurse will ask you to lie on your left side while a tube is gently passed into your back passage. Water is then passed through the tube.

You will be asked to hold the liquid in the bowel for a few minutes before you go to the toilet.

For the barium enema, a mixture of barium (which shows up on x-ray) and air is passed into the back passage in the same way as the bowel wash-out. It's important to keep the mixture in the bowel until all the x-rays have been taken. The doctor can then watch the passage of the barium through the bowel on an x-ray screen. Any abnormal areas can be seen.

The test can be uncomfortable and tiring, so it's a good idea to arrange for someone to travel home with you if possible.

For a couple of days after your enema, you may notice that your stools are white. This is the barium being removed from the body and is nothing to worry about. The barium can also cause constipation, and you may need to take a mild laxative for a couple of days after your test.

CT colonography

This is a newer test that is also called a virtual colonoscopy. It isn't widely available, so if you need one you may have to travel to a specialist centre. Instead of having a colonoscope put into your bowel, a computer uses <u>CT scanning</u> images to examine your bowel. Sometimes a CT colonography is done instead of a barium enema. It is still being researched as a way of diagnosing bowel cancers. Your doctor or nurse can discuss it with you further.

The preparation is the same as if you were having a colonoscopy, so you will be asked to drink fluids and take a laxative. CT colonography is done in the hospital CT scanning department and can usually be done as an outpatient. Just before the CT scans are taken the doctor will pass a tube into your back passage (rectum) and pump in some air and gas (carbon dioxide). This expands the bowel and helps to give a clearer picture. You will have two CT scans – one while lying on your back and one on your front. The computer then matches up the two scans to create a 'virtual' image of the inside of your bowel. You may still have a colonoscopy (see above) if biopsies are needed.

Tests after a diagnosis of colon or rectal cancer

If the initial tests show that there is a cancer in the colon or rectum, further tests will be done to find out the size and position of the cancer, and to see whether it has spread. This process is called staging, and may take some time. The results will help

you and your doctor decide on the best treatment for you. Sometimes these tests may be done again, during and after treatment, to check on your progress.

The following additional tests are used most often:

- Chest x-rays to check the health of your heart and lungs
- Blood tests
- Abdominal ultrasound scan uses sound waves to look at internal organs
- CT (computerised tomography) scan uses x-rays to build up a threedimensional picture of the inside of your body
- PET (positron emission tomography) scan a scan that shows how tissues inside your body are working
- Combined PET and CT scan
- MRI (magnetic resonance imaging) scan uses magnetic fields to build up a series of cross-sectional pictures of your body

Waiting for your test results

It will probably take several days to a couple of weeks for the results of your tests to be ready. The results of the tests will show the <u>grade and the stage</u> of the cancer. This information will be used by a team of doctors and nurses, known as the multidisciplinary team or MDT, to decide on the most appropriate treatment.

Waiting for results can be a difficult time. It may help to talk things over with a friend or relative. You can also contact one of our cancer support specialists or one of the organisations listed in the further resources section.

What the tests involve

Blood tests

You will probably have blood tests to assess your general health, and also to check for a particular protein that is sometimes produced by bowel cancer cells. The protein is called carcinoembryonic antigen (CEA). Proteins produced by cancer cells are sometimes called tumour markers as they may give an indication about how treatment is working or whether a cancer is coming back.

Abdominal ultrasound scan

This uses sound waves to look at internal organs, such as the liver and the inside of the abdomen, to see whether the cancer has spread to other organs. You will usually be asked not to eat or drink for at least six hours before the test.

Once you are lying comfortably on your back, a gel is spread onto your abdomen. A small device that produces sound waves is passed over the area. The sound waves are then converted into a picture by a computer. The test only takes a few minutes.

In some situations you may have a probe (like a tube) inserted into the rectum to produce ultrasound scans. This is known as an endoscopic ultrasound (EUS).

CT (computerised tomography) scan

A CT scan can show the size of the cancer and whether it has spread beyond the bowel. The scan is painless but takes longer than an ordinary x-ray (10–30 minutes).

CT scans use a small amount of radiation, which is unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. If you are allergic to iodine, or have asthma, you could have a more serious reaction to the injection, so it's important to let your doctor know beforehand.



The CT scan is painless but takes 10–30 minutes.

Just before the scan, a similar liquid is also passed into your back passage through a small tube. Although this may be unpleasant at the time, it makes sure that the best possible picture is produced. Once you are in position, the scan will be taken.

You will probably be able to go home when the scan is over.

PET (positron emission tomography) scan

PET scans are a newer type of scan and you may have to travel to a specialist centre to have one. They are not always necessary but you can discuss with your doctor whether one would be useful in your case. PET scans can be used to accurately define the cancer and find out if it has spread to other parts of the body.

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. A very small amount of the glucose is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and show up on the scan.

PET/CT scan

Usually a PET scan is combined with a CT scan. A small amount of a radioactive substance is injected in the same way as a standard PET scan, and then the CT scan takes a series of x-rays. The scanner combines the two different types of information and allows your doctor to measure any changes in the activity of cells and to know exactly where in the body the changes are.

A PET/CT scan can be used to show whether the cancer has spread and to give information that will help the doctors decide on the best treatment. It is not used to replace a CT scan, so you may need to have both types of scans.

MRI (magnetic resonance imaging) scan

If you have a rectal cancer, this test can help to show the stage of the cancer and can give the surgeon information to help them plan an operation or to decide whether radiotherapy should be given before surgery. People with a rectal cancer will often have an MRI scan before surgery.

MRI scans aren't always needed for people with a colon cancer and your doctor can discuss whether you need to have this type of scan.

Before the scan you may be asked to complete and sign a checklist. This is to make sure that it's safe for you to have an MRI scan, because the scanner is a powerful magnet. The checklist asks about any metal implants you may have, for example a pacemaker, surgical clips, bone pins etc. You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body it's likely that you won't be able to have an MRI scan. In this situation another type of scan can be used.

Before having the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and helps the images from the scan show up more clearly. During the test you'll be asked to lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic during the scan. It's also noisy, but you'll be given earplugs or headphones. You'll be able to hear, and speak to, the person operating the scanner.

Staging and grading of colon and rectal cancer

The stage of a cancer describes its size and whether it has spread beyond its original area of the body. Knowing the extent of the cancer helps the doctors decide on the most appropriate treatment.

Grading refers to the appearance of the cancer cells under the microscope. The grade gives an idea how quickly they may develop.

Staging systems

The exact stage of a colon or rectal cancer can often only be determined after surgery, when the pathologists can examine the cancer and the piece of healthy colon or rectum that has been removed.

Generally, colon and rectal cancers are divided into four stages, ranging from small and localised to cancer that has spread to other parts of the body. If the cancer has spread, this is known as secondary or metastatic cancer. If the cancer comes back after initial treatment it's known as recurrent cancer.

There are two different staging systems used to stage colon and rectal cancer. The first system, called the Dukes staging system, is gradually being replaced by the TNM staging system, which gives more detailed information.

The Dukes staging system:

Dukes A: The cancer is contained within the bowel wall.

Dukes B: The cancer has spread through the muscle of the bowel wall, but the lymph nodes are not affected.

Dukes C: The cancer has spread to one or more of the lymph nodes close to the bowel. Lymph nodes are usually the first place the cancer spreads to.

Dukes D: The cancer has spread to another part of the body such as the liver or the lungs (secondary cancer).

TNM staging system:

TNM stands for T for Tumour, N for Node and M for Metastases.

- T describes the tumour and if it has spread into the bowel wall.
- N describes whether the cancer has spread to the lymph nodes.
- M describes whether the cancer has spread to another part of the body, such as the liver or the lungs (secondary or metastatic cancer).

Tumour

There are four levels used to describe the tumour:

T1 The tumour is only in the inner layer of the colon or rectum.

T2 The tumour has begun to grow into the muscle layer of the colon or rectum, but not all the way through it.

T3 The tumour has grown through the muscle layer or into structures next to the bowel.

T4 The tumour has broken through the outer covering of the bowel, or spread to other parts of the bowel, or other organs or structures close to the bowel.

Nodes

There are three levels describing whether the lymph nodes are affected:

N0 No lymph nodes are affected.

N1 Between one and three lymph nodes close to the colon or rectum (regional nodes) are affected.

N2 The cancer has been found in four or more regional nodes.

Metastases

There are two different levels to describe whether the cancer has spread to other parts of the body (metastases):

M0 The cancer hasn't spread to other parts of the body.

M1 The cancer has spread to other parts of the body.

Number stages

To make it easier to understand the TNM system, doctors often combine the information about the tumour, the lymph nodes and whether the cancer has spread into stage groups:

Stage 0 – The cancer is in the very earliest stage and is only in the inner lining of the colon or rectum. This stage is sometimes called carcinoma in situ.

Stage 1 – The cancer is affecting the inner lining of the colon or rectum, or has begun to grow into the muscle, but no further. No lymph nodes are affected (T1, N0, M0 or T2, N0, M0).

Stage 2A – The cancer has grown through the outer muscle layer of the colon or rectum, but has not spread to nearby structures or to any lymph nodes or other parts of the body (T3, N0, M0).

Stage 2B – The cancer has spread through the outer muscle layer of the colon or rectum and into nearby structures, but it's not affecting any lymph nodes or other parts of the body (T4, N0, M0).

Stage 3A – The cancer is affecting the inner lining of the colon or rectum, or has begun to grow into the muscle, and is affecting between one and three lymph nodes close to the colon. It has not spread to other parts of the body (T1, N1, M0 or T2, N1, M0).

Stage 3B – The cancer has grown through the outer layer of the colon or rectum, or into nearby structures, and is affecting between one and three lymph nodes (T3, N1, M0 or T4, N1, M0).

Stage 3C – The cancer may or may not have grown through the wall of the colon or rectum, but is affecting four or more nearby lymph nodes. It has not spread to other parts of the body (Any T, N2, M0).

Stage 4 – The cancer may or may not have grown through the wall of the colon or rectum, may or may not have spread to nearby lymph nodes, but has spread to other parts of the body, such as the liver or lungs (Any T, Any N, M1).

Grading

There are three grades: grade 1 (low-grade), grade 2 (moderate- or intermediate-grade) and grade 3 (high-grade).

Low-grade means that the cancer cells look very like the normal cells of the bowel (the cells are sometimes described as being well differentiated). They are usually slow-growing and are less likely to spread.

In high-grade cancers the cells look very abnormal (the cells are poorly differentiated). They are likely to grow more quickly and are more likely to spread.

Moderate-grade cancers fall between these two grades and have a level of activity somewhere in between. They are sometimes described as being moderately differentiated.

Treating colon cancer

In most hospitals, a team of specialists will discuss the treatment that is best for you. This multidisciplinary team (MDT) will include a surgeon who specialises in bowel cancers, one or more oncologists (doctors who specialise in cancer treatments such as radiotherapy or chemotherapy) and a number of other health professionals.

How treatment is planned

Together, the MDT will be able to advise you on the best course of action and plan of treatment. They will take into account a number of factors, including your general health, age, the size of the cancer, where it is in the colon, and whether it has begun to spread.

The stage is very important in determining treatment:

- Surgery is the most common treatment. Most stage 1 colon cancers can be treated successfully with surgery alone.
- For stage 2 and stage 3 colon cancers, chemotherapy may be used in addition to surgery. Research is being carried out into additional treatments for stage 3.
- It isn't usually possible to cure stage 4 (advanced) colon cancer but treatment may be able to control it for some time.

Your doctors will have carried out various tests and investigations to help them plan your treatment. Although they will have a good idea about which treatments you need, they may not be able to tell you exactly until after an operation.

You will be asked to give your permission (consent) for the hospital staff to give you the treatment. It's important that you discuss with your doctors the treatments they are recommending and that you understand why a particular type of treatment has been suggested for you.

Treatment according to stage

Stage 1

Often, the cancer can be completely removed with surgery, and for most people it will never come back. People who have stage 1 colon cancer don't usually need to have any further treatment after their surgery.

Stage 2

People with stage 2 colon cancer are also usually treated with surgery. There may be a risk that the cancer could come back in the future, especially if cancer cells are found in the blood vessels or lymph vessels around the cancer. So, treatment with chemotherapy is sometimes given after surgery to help reduce the risks of the cancer coming back.

Stage 3

In people with stage 3 colon cancer, there is a greater risk that the cancer will come back after surgery, so chemotherapy is usually recommended. Research trials are trying to find out whether giving drugs known as monocolonal antibodies, as well as chemotherapy, after surgery can further reduce the chance of the cancer coming back. Other types of treatment that are in the very early stages of research are being tested in clinical trials.

Stage 4

Stage 4 colon cancer means that the cancer has spread from where it started in the bowel. It is also called advanced colon cancer. It can spread into the area around the bowel, such as the abdomen, and this is known as local spread. If the cancer has spread to other parts of the body such as the liver or lungs, this is known as secondary or metastatic cancer.

It's not usually possible to cure stage 4 colon cancer, but treatment may be able to control it for some time. Treatment may also be used to reduce symptoms and give a good quality of life. However, for some people in this situation, treatment will have little effect upon the cancer and they will have the side effects with little benefit.

The treatment that is most appropriate for you will depend on:

- which part of your body the cancer has spread to
- the treatment that you have already had.

Chemotherapy is the most commonly used treatment for stage 4 colon cancer. It may be given into a vein by injection or drip, or may be taken as tablets or capsules.

Surgery may sometimes be used – to remove a cancer that is blocking the bowel, for example, or sometimes to remove secondary bowel cancers from the liver or lungs.

Radiotherapy may be used to shrink a cancer that is causing pain. This is known as palliative radiotherapy.

Monoclonal antibodies such as bevacizumab (Avastin®), cetuximab (Erbitux®) and panitumumab (Vectibix®) may be used to control advanced colon cancer for a time.

The benefits and disadvantages of treatment

Many people are frightened at the thought of having cancer treatments, because of the side effects that may occur. Some people ask what will happen if they don't have any treatment.

Although the treatments can cause side effects, these can often be well controlled with medicines.

Treatment can be given for different reasons and the potential benefits will vary depending upon your particular situation.

Treatment decisions

If you have early-stage colon cancer (stages 1, 2 and 3) and have been offered treatment that is intended to cure it, it may be easy to decide whether to accept the treatment. Your doctor will talk through your treatment and any other options with you.

However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to decide whether to go ahead. Making decisions about treatment in these circumstances is always difficult. You may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to, you can still be given supportive (palliative) care, which often involves medicines to control any symptoms.

You can ask for a second opinion if you feel it would be helpful.

For more on planning your treatment, you may find it helpful to read our information on:

- giving your permission (consent) for treatment to begin
- · making decisions about cancer treatment
- getting a second opinion
- the role of the multidisciplinary team.

Surgery for colon cancer

Surgery is the most common type of treatment for colon cancer and should be carried out by a surgeon who specialises in bowel surgery.

There are different types of colon cancer surgery. Your doctor will discuss with you the most appropriate type of surgery, depending on the stage of your cancer and where it is in your bowel.

Before your operation

Before your surgery the doctor and specialist nurses will explain the operation to you. They will tell you what to expect immediately after the surgery and in the few days

following. This is a good opportunity to ask any questions you may have about the operation.

You'll probably be admitted to the ward the day before your operation, so that the doctors and nurses can do any further tests. To make sure that your bowel is completely empty, you'll be asked to follow a strict diet and take a medicine (laxative) to help your bowels to empty the day before surgery. Your nurse or the doctor will explain this to you.

You'll be given antibiotics as an injection into a vein (intravenously) just before and after surgery to prevent infections.

Types of colon cancer surgery

Removal of all or part of the colon

Removal of the whole colon is called a total colectomy.

If only half of the colon needs to be removed, this is known as a hemi-colectomy . Either the left side or the right side may be removed, depending on the location of cancer.

Some people have a sigmoid-colectomy, (removal of the sigmoid colon), or a transverse colectomy (removal of the transverse colon). The sigmoid colon and transverse colon are shown in the diagram in our section on the large bowel.

During the surgery, the piece of bowel that contains the cancer is removed and the two open ends are then joined together. The join is known as an anastomosis. The lymph nodes near to the colon are also removed, because this is usually the first place the cancer spreads to.

After surgery to remove a cancer in the colon, you will usually have a wound that goes in a straight line from just below your breast bone (sternum) to just above your pelvis.

Laparoscopic colectomy

This operation uses four or five small cuts in the abdomen rather than one bigger incision. A laparoscope (a thin, flexible tube containing a light and camera) is passed into the abdomen through one of the cuts and the cancer is removed. Recovery from this operation is usually quicker. However, this is a new operation that is currently being researched to find out its risks and benefits.

Local resection

Very early-stage colon cancers can sometimes be removed using an operation called local resection. Using an endoscope, similar to the one used to take a biopsy, the surgeon will remove the cancer from the lining of the bowel. A pathologist will examine the cancer that has been removed. If it's found to be high-grade your surgeon may recommend that you have a second operation. This is done to remove more of the colon to make sure that no cancer cells have been left behind.

Colostomy

If the ends of the bowel can't be rejoined, the upper end can be brought out onto the skin of the abdominal wall. This is known as a colostomy, and the opening of the bowel is known as a stoma. A bag is worn over the stoma to collect the stool (bowel motions). Sometimes a colostomy is only temporary and another operation to rejoin the bowel can be done a few months later.

The operation to rejoin the bowel is known as stoma reversal. If it isn't possible to reverse the colostomy, the stoma is permanent. However, only a small number of people with cancer of the colon will need a permanent colostomy.

lleostomy

Some people need to have an operation called an ileostomy. Here, the end of the small bowel (ileum), or a loop of ileum, is brought out onto the right side of the abdominal wall. As with a colostomy, stools are then collected in a bag worn over the stoma.

For people with cancer of the colon, this is generally a temporary operation. If it's likely that at a later date the bowel will be rejoined and the stoma removed (reversed), your specialist nurse will discuss this with you.

Surgery for advanced colon cancer

If the cancer is too large to be removed and is pressing on the bowel causing it to narrow, it may be possible to insert a thin metal tube (a stent) into the bowel to keep it open. The stent is inserted using a colonoscope. You will be given a mild sedative to help you relax and may have a short stay in hospital.

Surgery may sometimes be used to remove the cancer when it has spread to another part of the body, such as the liver or lungs. Sometimes chemotherapy may be given before or after the surgery.

You may find our JASCAP booklets on <u>Secondary Liver Cancer</u> and <u>Secondary Lung</u> <u>Cancer</u> helpful.

After your operation for colon cancer

How quickly you recover from your operation will depend on your age and health, and the type of surgery you've had. Your doctor and specialist nurse can give you an idea about what to expect.

In the hospital

Getting moving

After your operation you'll be encouraged to start moving around as soon as possible. This is an essential part of your recovery. Even if you have to stay in bed, it's important to do regular leg movements and deep-breathing exercises.

A physiotherapist or nurse will explain the exercises to you.

As you won't be moving around as much as usual, you may be at risk of blood clots forming. To prevent this you will be asked to wear special stockings, and may be given an anti-clotting drug called heparin.

Drips and diet

When you go back to the ward, you will have a drip (infusion) which gives you fluids through a thin tube (cannula) inserted into a vein in your hand or arm. This will be taken out once you are able to eat and drink normally again.

You may also have a thin tube that passes down your nose into your stomach (nasogastric or NG tube). This allows any fluids to be removed from your stomach so that you don't feel sick. It's normally taken out within a few days.

As an anaesthetic slows down the movement of the bowel, it's important that you don't start drinking until the bowel is working normally again. You will probably be ready to start taking sips of water within a few days. This will be increased gradually over a couple of days until you are able to eat a light diet.

Drains

Often, a small tube (catheter) is put into your bladder, and your urine is drained through this into a collecting bag. This is usually taken out after a couple of days.

You may also have a drainage tube in your wound, to drain any extra fluid and make sure that the wound heals properly. A drain isn't always needed.

Pain

After your operation, you'll probably have some pain or discomfort for a few days. There are several different types of painkillers that can be given to you at regular intervals or when you need them. You may be given painkillers into a vein in your arm through a pump. The pump can be set to give you a controlled amount of painkiller, or you may be able to control this yourself by pressing a button. This is called patient controlled analgesia (PCA).

Always let your doctor or nurse know if you have any pain or discomfort. The painkillers or their dose can be changed to suit your needs. Some people may continue to have some pain after they go home. Let your doctor or nurse know if you think you might need painkillers to take home with you.

Going home

Depending on the type of operation you've had, you'll probably be ready to go home between 3–10 days after surgery. If you think that you might have problems when you go home (for example, if you live alone or have several flights of stairs to climb), let your nurse or the social worker know when you are admitted to the ward. They can then arrange help before you leave hospital.

You'll be given an appointment to attend an outpatient clinic for your post-operative check-up. At the appointment your doctor will be able to discuss with you whether you need to have any further treatment, such as chemotherapy.

Some people take longer than others to recover from their operation. If you have any problems, you may find it helpful to talk to someone who is not directly involved with your illness. See our useful organisations section for more information about who can help.

Our cancer support specialists can talk to you, and tell you how to contact a counsellor or local cancer support group.

Enhanced Recovery Programmes (ERP)

Some hospitals follow an Enhanced Recovery Programme that can help to reduce complications following surgery and speed up your recovery. The programme involves careful planning before your operation so that you are properly prepared and any arrangements that are needed for you to go home are already in place. You'll also be encouraged to take high-protein and high-calorie supplements before and after your surgery, and to start moving around as soon as possible, sometimes on the day of the operation. After you have gone home you'll be regularly reviewed to make sure that you are recovering well.

Diet after bowel surgery

After any bowel operation, you may notice that certain foods upset the normal working of your bowel, or your colostomy if you have one. High-fibre foods, such as fruit and vegetables, may give you loose stools and make you pass them more often than normal. Depending on the type of surgery you've had, you may have diarrhoea. Tell your doctor or nurse if this happens, as they can give you medicine to help.

It's important to drink plenty of fluids if you have diarrhoea. This is often a temporary reaction, and after a while you may find that the same foods don't have any effect. There are no set rules about the types of food to avoid and each person needs to experiment for themselves. Some foods that disagree with one person may be fine for another.

You may also find that your bowel produces more wind than before, and this can sometimes build up in the abdomen and cause pain. Drinking peppermint water or taking charcoal tablets can help to reduce this. Your doctor can prescribe these for you, or you can get them from your chemist.

It can sometimes take months for your bowel movements to get back to normal after surgery, and you'll probably need to find out which foods are right for you by trial and error. Some people may find that their bowel is always more active than before their surgery, and that they have to eat carefully to control their bowel movements.

If you continue to have problems, it's important to talk to a dietitian at the hospital, as they can give you specialist advice for your individual situation.

You may find JASCAP booklet on <u>Diet and Cancer</u> helpful.

Sex life after bowel surgery

Once you have recovered from the operation, there is usually no medical reason why you shouldn't have a normal sex life again. However, you may find that you feel self-

conscious about the change in your body's appearance, especially if you now have a colostomy. This may stop you from wanting to make love.

Talking about your feelings may help lessen your anxieties. Try not to feel embarrassed talking to your nurse or doctor about what is troubling you. They can refer you for specialist counselling if you think that would be helpful.

Sometimes the operation can cause damage to the nerves that go to the sexual organs. If this occurs, a man may not be able to have or maintain an erection, and may have problems with orgasm and ejaculation. Women may also find that their sexual function or response is affected. This may improve over time, but sometimes it is permanent. There are treatments available, such as sildenafil (Viagra®) that can help men achieve erections. It's important to discuss this with your doctor as soon as you notice a problem, as treatment can often be more effective if started sooner.

We may find JASCAP booklet on <u>Sexuality and Cancer</u> helpful.

If you have any problems, your doctor or specialist nurse will be able to discuss them with you in more detail.

Living with a stoma

Some people with cancer of the colon will need to have a colostomy or ileostomy. In these operations, the colon is brought to the outside of the body through the abdominal wall. The opening is called a stoma.

This can be daunting at first. Learning to look after a stoma takes time and patience and no-one expects you to be able to cope straight away. Like anything new, it will get easier with time and practice.

Stoma care nurses

In most hospitals there are specially trained nurses called stoma care nurses (or colorectal nurses) who you will usually meet before your operation. They will show you how to look after your stoma and help you cope with any problems.

Before your operation, the nurse or doctor will carefully plan the position of your stoma so that your bag stays in place, whether you are sitting, standing or moving around.

For the first few days after your operation, the nurse will look after your colostomy or ileostomy for you and make sure that the bag is emptied and changed as often as necessary. At first your stoma will be slightly swollen and it can take several weeks before it settles down to its normal size. As soon as you are feeling well enough, the nurse will show you how to clean your stoma and change the bags. There are several different types of bag or appliance available and the nurse will help you choose a suitable one.

Talking to people who have a stoma

You may find it helpful to talk to someone who has a colostomy or ileostomy. Your nurse or doctor can often arrange for a volunteer to visit you and talk to you about the more practical and personal aspects, or you can contact the Colostomy Association

or the Ileostomy and Internal Pouch Support Group. This advice, coming from personal experience, can be invaluable, particularly in the first few months after your operation. The Healthtalkonline website has information about colostomies and ileostomies. It also has video and audio clips of people who have stomas talking about their experiences.

Looking after a stoma

When the nurse is showing you how to look after your stoma, it may help for a close relative or partner to be with you, in case you have any difficulties when you get home.

Before you leave hospital, your nurse will make sure that you have a good supply of stoma bags.

Make sure that you have plenty of bags and cleaning materials to hand before you start to change or empty your bag. It's a good idea to keep everything you need in one place, so that you don't have to start searching for things at the last minute. Make sure that you allow yourself plenty of time and privacy, so that you can work at your own pace without any interruptions.

Some people with a colostomy avoid wearing a bag by flushing out (or irrigating) their colostomy about once a day, although this method doesn't suit everyone. Your stoma nurse will be able to discuss this with you in more detail.

Stoma supplies

There are different ways of getting stoma supplies when you are at home. You can get all your supplies from your chemist. Sometimes it's better to get them direct from a specialised supply company. These may also offer a cutting and delivery service. The Colostomy Association has details of companies. The supplies are free, but you'll need a prescription from your GP. If you are aged between 16 and 60, make sure that your doctor signs the form saying that you're entitled to free prescriptions.

Home support

Once you are at home you can phone the stoma nurse if you have any problems. Your GP may also arrange for a district nurse to visit you for a few days when you first leave hospital. They can make sure that you are coping at home, and sort out any problems you may have with your stoma.

Having a colostomy or ileostomy is a big change in your life. Many people find that they are embarrassed by the stoma, and that it affects the way that they feel about their body. Embarrassment about a stoma can also affect relationships and some people are uncomfortable about their partner seeing it. These feelings are a natural part of coming to terms with the changes that a stoma causes, and usually decrease gradually over time.

You can contact our cancer support specialists if you want to chat about any concerns you have. Details of other helpful organisations can be found in the further resources section.

Chemotherapy for colon cancer

Chemotherapy is the use of special anti-cancer (cytotoxic) drugs to destroy cancer cells. In colon cancer, it's mainly used after surgery. Its aim is to get rid of any remaining cancer cells and reduce the chance of the cancer coming back in the future. This is called adjuvant chemotherapy.

If the cancer is advanced (stage 4), chemotherapy may be used to reduce symptoms.

Chemotherapy for early-stage colon cancer (stages 1, 2 and 3)

Chemotherapy usually isn't needed for stage 1 colon cancers that haven't begun to grow through the muscle wall and aren't affecting the lymph nodes (Dukes A).

In the treatment of stage 2 colon cancer (Dukes B), the risk of the cancer coming back is low, so chemotherapy may not be needed. However, after surgery the cancer will be examined carefully under the microscope, and your doctor may recommend that you have chemotherapy if cancer cells are found in the blood or lymph vessels very close to the cancer. You may also be offered chemotherapy as part of a clinical trial. Your cancer specialist will discuss whether chemotherapy will be of any benefit to you if you have stage 2 colon cancer.

People with stage 3 colon cancer (Dukes C) are usually offered chemotherapy. They may also be offered chemotherapy as part of a clinical trial.

Drugs used to treat early-stage colon cancer

The main drugs used are:

- fluorouracil (5FU), which is often given with the vitamin folinic acid (leucovorin) to make it more effective
- capecitabine (Xeloda) which is a tablet form of 5FU
- oxaliplatin (Eloxatin), which is often used if the cancer has spread to the lymph nodes close to the colon

Your specialist will discuss your particular course of treatment with you.

There are several research trials in the UK looking at different chemotherapy drugs, or combinations of drugs, to treat colon cancer. Some of these may be given as tablets. You may be asked if you'd like to take part in a clinical trial to test one of these treatments.

Pros and cons of chemotherapy for early-stage colon cancer

There are various benefits and risks of having chemotherapy and your doctor can discuss these with you.

Chemotherapy can reduce the chance of the cancer coming back, but doesn't guarantee this. It can also sometimes cause side effects that may be unpleasant. To help decide whether adjuvant chemotherapy may be appropriate in your case, your specialist will take into account the risk of any cancer cells being left behind, the

likelihood that the chemotherapy will get rid of them, and the possible side effects of the treatment.

If the chance of the cancer coming back is low, the chemotherapy may only slightly reduce the chance of the cancer returning. However, if the risk of the cancer coming back is high, the benefit of chemotherapy may be greater. It's important to discuss with your doctor the possible risks and benefits of chemotherapy in your particular situation.

Chemotherapy for advanced (secondary) cancer of the colon

Chemotherapy may also be given when the cancer has spread to another part of the body. Many people have no further problems after their original treatment for colon cancer, but unfortunately, in some people the cancer comes back or spreads to other parts of the body. This is called secondary, advanced or metastatic cancer.

Sometimes, when the cancer is first diagnosed, it may already have spread beyond the bowel. The most common place for it to spread to is the liver. JASCAP has a booklet about <u>Secondary Cancer in the Liver</u>. The next most common place is the lungs.

Although secondary cancer of the colon can't usually be cured, treatment with chemotherapy may be recommended by your doctor. The aim of the chemotherapy is to shrink the cancers and reduce symptoms. This can sometimes help to prolong life. Chemotherapy may also be given to shrink cancers before they are removed from the liver or, more rarely, the lungs. Sometimes drugs called monoclonal antibodies are given in combination with chemotherapy.

Improvements in surgical techniques combined with drug treatment have meant that some people who have had liver secondaries removed, often combined with drug treatment, appear to be cured as a result of their treatment. Your doctor or specialist nurse can discuss this with you further.

JASCAP has booklets about <u>Secondary Cancer in the Liver</u> and <u>Secondary Cancer in the Lungs</u>.

Drugs used to treat advanced colon cancer

The most commonly used chemotherapy drugs for advanced colon cancer are:

- 5-fluorouracil (5FU), which is usually given with the vitamin folinic acid
- Capecitabine (Xeloda®) tablets
- Tegafur with uracil (Uftoral®) tablets, which are usually given with the vitamin folinic acid
- oxaliplatin (Eloxatin®)
- irinotecan (Campto®)
- mitomycin

Several research trials are being carried out to test new drugs for advanced colon cancer, and to help find the best way of using the current drugs. You may be asked if

you'd like to take part in a research trial using new chemotherapy drugs or new types of treatments.

If the cancer starts to grow again, during or after the chemotherapy, you may be given a different type of chemotherapy (this is known as second-line treatment). Sometimes a third course of chemotherapy (third-line treatment) may also be given.

Benefits and disadvantages of chemotherapy for advanced colon cancer

There are various benefits and disadvantages of chemotherapy for advanced colon cancer, and it's important to discuss these with your cancer specialist.

It isn't possible to predict whether chemotherapy will work for a particular person, but if they are fairly fit the treatment is more likely to be effective. It's also less likely to have side effects than in someone who is unwell when they start the treatment.

You don't have to have chemotherapy unless you want to. If you choose not to, you'll still be given treatment to help control any symptoms caused by the cancer. This is known as supportive, or palliative, care. Palliative care can also be given alongside chemotherapy if needed.

Your doctor will consider a number of things before asking you to make a decision about particular treatments. This will include the position of the secondary cancer, your general health and any chemotherapy treatment you've had in the past.

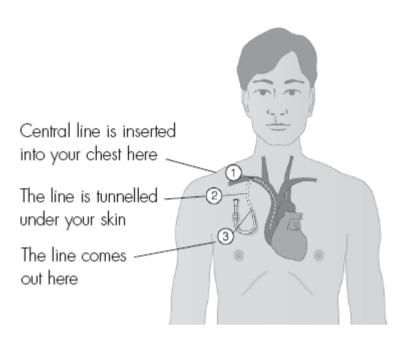
If you have advanced cancer, there are many difficult issues to deal with. You may find it helpful to read our JASCAP booklet on <u>Coping with advanced cancer</u>.

Our JASCAP booklets on <u>Controlling Cancer Pain</u> and <u>Controlling Cancer Symptoms</u> explain ways that pain and symptoms can be treated. They also give information on the support that is available from health professionals and other sources.

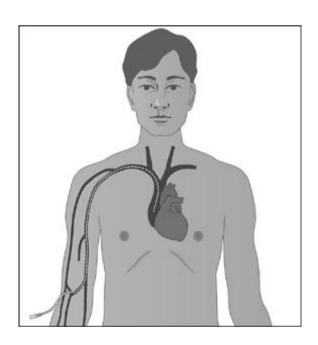
How chemotherapy is given

Many people having chemotherapy for colon cancer are given capsules or tablets, which are swallowed with water.

Some people with colon cancer will have their chemotherapy drugs given by injection into a vein (intravenously). The drugs may be given through a vein in the back of your hand; a plastic line called a central line, in your chest; or a thin tube inserted into a vein in the crook of your arm (a PICC line).



Position of a central line



The PICC line is threaded through the vein until the end is near your heart

Sometimes chemotherapy can be given to you continuously through a small portable pump which is attached to your central or PICC line. A controlled amount of the drug can be given into the bloodstream over a period of time. This means that you can go home with the pump, and spend less time in hospital. Some people whose cancer has spread to the liver may be given chemotherapy into an artery that goes directly into the liver.

Intravenous chemotherapy (see above) is usually given as a session of treatment. A session may last from a few hours to several days. If you have treatment for a few hours, this may be repeated each week for several months. This chemotherapy is usually given as an outpatient.

If your treatment lasts a few days you'll usually have a rest period of a few weeks before the next session. This allows your body to recover from the side effects of the treatment. The chemotherapy session and the rest period make up a cycle of treatment. You may need to stay in hospital for your treatment, but it can also often be given to you as an outpatient. Your specialist will discuss this with you.

The number of cycles you have will depend on the stage of the cancer and how well it's responding to the drugs.

Contraception during chemotherapy

It is not advisable to become pregnant or father a child while taking any of the chemotherapy drugs used to treat colon cancer, as they may harm the developing baby. It's important to use effective contraception during your treatment and for a year afterwards. You can discuss this with your doctor or specialist nurse.

Condoms should be used during sex within the first 48 hours after chemotherapy to protect your partner from any of the drug that may be present in semen or vaginal fluid.

Our JASCAP Chemotherapy booklet describes the treatment in more detail.

Side effects of chemotherapy for colon cancer

Chemotherapy can sometimes cause unpleasant side effects. These will vary depending on which chemotherapy drugs you are given. Your doctor or nurse will tell you what problems to expect from your treatment. Common side effects include:

- lowered resistance to infection
- bruising or bleeding
- anaemia (low number of red blood cells)
- tiredness
- feeling sick
- diarrhea
- sore mouth
- hair loss
- soreness of hands and feet
- numbness or tingling.

Although side effects may be hard to bear at the time, they will gradually disappear once your treatment is over. For some people this can take some months.

Most people have some side effects from chemotherapy. But if your cancer is causing symptoms it can also make you feel better by relieving them.

There are many things that can be done to help reduce and control side effects so let the staff looking after you know if you are having problems.

Lowered resistance to infection (neutropenia)

While the drugs are acting on the cancer cells in your body, they may also temporarily reduce the number of normal white blood cells. This is called neutropenia. When these cells are reduced you are more likely to get an <u>infection</u>. While your level of white blood cells is low, it's important to avoid crowded places, where you may come into contact with infection, and to avoid anyone who already has an infection, such as a cold or flu.

Contact your doctor or the hospital straight away if you have any signs of infection, such as a high temperature (above 38°C or 100.5°F), or if you suddenly feel unwell (even with a normal temperature). During chemotherapy your blood will be tested regularly and, if necessary, you will be given antibiotics to treat any infection.

Bruising or bleeding

Chemotherapy can reduce the production of platelets (which help the blood to clot). Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, or bleeding gums.

Anaemia (low number of red blood cells)

While having treatment with chemotherapy you may become anaemic. This may make you feel tired and breathless.

Tiredness

You're likely to find that you become very tired and have to take things much more slowly. Just do as much as you feel like and try not to overdo it. We have a section on coping with fatigue, which you may find helpful.

Feeling sick

Some of the drugs may make you feel sick (nauseated) and possibly be sick (vomit). There are anti-sickness drugs (anti-emetics) to prevent or reduce nausea and vomiting. Your doctor will prescribe these for you. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take. Our section on controlling nausea and vomiting has further information about this.

Diarrhoea

Some of the chemotherapy drugs used to treat bowel cancer can cause diarrhoea. This often starts several days after the treatment. If you're taking chemotherapy tablets or capsules at home, it's important that you let your doctor or nurse know if you have diarrhoea. Your treatment may need to be stopped.

If you have diarrhoea your doctor can give you medicine to reduce this and slow down the bowel. You may also be able to help control it by eating a low-fibre diet. Our section on diet and cancer has useful advice on this.

If you've had a colostomy or ileostomy, it may be more difficult to cope with diarrhoea caused by the chemotherapy. Your stoma nurse or cancer specialist can give you advice and support. Some people find that they need to make sure they are close to a toilet during the course of their treatment and for a while afterwards. This can be frustrating, but usually improves gradually a few weeks after the treatment has ended. If the diarrhoea continues after this time it's important to talk to your cancer specialist or stoma nurse, so that they can help you find ways of overcoming the diarrhoea.

Sore mouth

You may find that you get a sore mouth and mouth ulcers while having chemotherapy. Keeping your mouth clean with regular mouthwashes is important. Your nurse will show you how to use these properly. If a sore mouth makes eating difficult, you can try replacing meals with nutritious drinks — our section on mouth care during chemotherapy has some useful tips on coping with a sore mouth.

Hair loss

Ask your doctor if the drugs you are taking are likely to make your hair fall out. Most drugs used to treat colon cancer do not, but some may make your hair thin. If your hair does fall out, it will start to grow back again once your treatment is over.

JASCAP has a booklet about Coping with Hair Loss.

Soreness of hands and feet

If 5FU or capecitabine are given over a long period of time or are given continuously through a pump, soreness and redness of your palms and the soles of your feet can occur. This is known as hand/foot syndrome or palmar-plantar syndrome. Vitamin B6 may be prescribed to help reduce this side effect and non-perfumed moisturising creams can often help to relieve the symptoms. If the symptoms are severe your doctor may reduce the dose of the chemotherapy or give you a short break from it.

Numbness or tingling

Oxaliplatin can affect the nerve endings and cause numbness, burning or tingling in the hands, feet, neck or throat (known as peripheral neuropathy). You may also find it hard to do up buttons etc. The numbness or tingling may not happen with the first treatment. If it occurs, it should gradually disappear once the treatment has finished.

Sometimes in the first few days after oxaliplatin is given, these side effects can be triggered by anything cold, such as cold drinks or washing water, but often they only last a few minutes.

Our <u>Chemotherapy</u> booklet discusses the treatment in more detail and has tips for coping with the side effects.

Biological therapies (targeted therapies) for colon cancer

Biological therapies use substances that occur naturally in the body to destroy cancer cells. There are several different types of biological therapies. The main ones used to treat colon cancer are monoclonal antibodies and include bevacizumab (Avastin®), cetuximab (Erbitux®) and panitumumab (Vectibix®).

They can be used to treat some cases of colon cancer that have spread outside the bowel (stage 4, advanced or metastatic cancer).

Research trials are trying to find out whether, for stage 3 colon cancer, giving monoclonal antibodies, as well as chemotherapy, after surgery can further reduce the chance of the cancer coming back.

How monoclonal antibodies work

Monoclonal antibodies are drugs that recognise and lock onto specific proteins (receptors) that are present in particular cancer cells. Because of this they are often called targeted therapies, because they 'target' the cancer cells.

Some cancer cells have proteins known as epidermal growth factor receptors (EGFRs). When other proteins in the body, known as growth factors, attach to these receptors, the cancer cell is stimulated to grow and divide. The monoclonal antibodies cetuximab (Erbitux®) and panitumumab (Vectibix®) lock onto the EGFR, stopping growth factors from attaching, and so may prevent the cancer cell from growing and dividing.

Not all colon cancers respond to cetuximab or panitumumab. Before having either drug your doctors will test the cancer cells for a gene called KRAS. Knowing if the KRAS gene is normal or changed (mutated) can help the doctors to decide whether cetuximab or panitumumab will be appropriate for you.

Bevacizumab (Avastin®) works by preventing the cancer from developing a new blood supply, and so starves the cancer of oxygen and nutrients. Drugs that interfere with blood vessel growth in this way are called angiogenesis inhibitors or antiangiogenics.

How the drugs are given

Cetuximab is usually given in combination with chemotherapy, although it can be used on its own. It's given as a drip (infusion) into a vein. Panitumumab is usually given on its own as an infusion into a vein.

Bevacizumab is given as an infusion through a small tube (cannula) inserted into a vein. It may be given in combination with chemotherapy drugs.

The National Institute for Health and Clinical Excellence (NICE), which advises doctors about treatment, have recommended the use of cetuximab in combination with chemotherapy for some people who have advanced (metastatic) colon cancer that has spread to the liver. Treatment with the combination of cetuximab and chemotherapy may make it possible to remove the secondary cancers in the liver using surgery. The NICE guidance doesn't recommend cetuximab for everyone in

this situation. Your cancer specialist can discuss with you whether cetuximab is recommended for you. Currently, panitumumab is not recommended by NICE.

Bevacizumab can also be used to treat advanced cancers of the colon that have not been controlled by other chemotherapy combinations. Bevacizumab is currently not recommended by NICE and as a result it may not be possible to get it on the NHS.

Side effects

Some people can have an allergic reaction to monoclonal antibodies. This can make you have a flu-like reaction, a drop in blood pressure or feel sick.

Other possible side effects include skin rashes and tiredness. With some monoclonal antibodies, the first dose is given slowly, over a number of hours. You may be given some other drugs first to make a reaction less likely.

Radiotherapy for colon cancer

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy is rarely used to treat colon cancer except occasionally to shrink the cancer and relieve symptoms such as pain. This is called palliative radiotherapy.

Radiotherapy doesn't make you radioactive and it's perfectly safe for you to be with other people, including children, throughout your treatment.

How radiotherapy is given

Radiotherapy is usually given at a hospital outpatient clinic as a series of short daily treatments. The treatments are usually given each weekday with a rest at the weekend. How the treatment is given can vary, depending on what is considered to be most effective for your cancer and best for you. The course may last for just one week or a few weeks. Your doctor will discuss your treatment with you beforehand, including how it will be given and how long it will last.

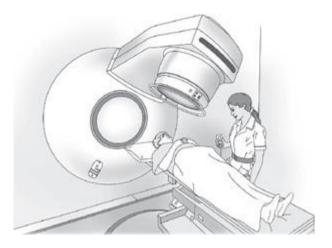
Planning your treatment

To make sure that your radiotherapy is as effective as possible, it has to be carefully planned. Planning ensures the radiotherapy rays are aimed precisely at the cancer and cause the least possible damage to the surrounding healthy tissues. The treatment is planned by a specialist doctor known as a clinical oncologist. Planning is important and may take a few visits.

Marks may be drawn on your skin to help the radiographer, who gives you your treatment, to position you accurately and to show where the rays are to be directed. These marks must stay visible throughout your treatment, but they can be washed off once your course is over. At the beginning of your radiotherapy you will be told how to look after the skin in the area to be treated.

What happens in the treatment sessions

Before each session of radiotherapy, you'll be carefully positioned on the couch, either sitting or lying. The radiographer will make sure that you are comfortable. During your treatment, which only takes a few minutes, you'll be left alone in the room, but you are able to talk to the radiographer who will be watching you carefully. Radiotherapy is not painful, but you do have to be still for a few minutes during your treatment.



Positioning the radiotherapy machine

Side effects of radiotherapy for colon cancer

Radiotherapy to the bowel area can cause side effects such as diarrhea, feeling sick (nausea) and tiredness. It can also cause more specific side effects, such as inflammation of the bowel or bladder lining. These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of your treatment. Some radiotherapy side effects can be permanent. Your clinical oncologist will tell you what to expect, and you can ask your radiographer for advice if side effects are becoming a problem for you.

Our Radiotherapy booklet discusses the treatment and its side effects in more detail.

Research - clinical trials for colon cancer

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials.

Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, to make them more effective or to reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

There can be many benefits from taking part in a trial. Trials help improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study. Usually, several hospitals around the country take part in trials. It's important to bear in mind that some treatments that look promising at first are often later found to be not as good as existing treatments, or to have side effects that outweigh the benefits.

If you decide not to take part in a trial your decision will be respected and you do not have to give a reason. If you do decide to take part, you are allowed to withdraw from the trial at any time. In either case, there will be no change in the way that you are treated by the hospital staff and you will be offered the standard treatment for your situation.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you are taking part in a trial you may also be asked to give other samples which can be frozen and stored for future use, when new research techniques become available. These samples will have your name removed from them so you can't be identified.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, and it may be many years before the results are known. The samples will be used to increase knowledge about the causes of cancer and its treatment. This research will hopefully improve the outlook for future patients.

Our booklet on <u>Clinical Trials</u> describes the process in more detail. It includes details of databases you can search to look at trials for colon cancer.

Follow-up after treatment for colon cancer

After your treatment has finished, you will have regular check-ups and blood tests, and possibly scans (CT, MRI or ultrasound), x-rays and sometimes colonoscopies. These may continue for several years, but will become less and less frequent.

If you have any problems or notice any new symptoms between your appointments, let your doctor know as soon as possible.

At the present time a lot of research is being carried out to find the best way of following up people who have had colon cancer. The pattern of timing of hospital visits and tests and the amount of follow-up done by GPs varies considerably.

Many people find that they get anxious for a while before their appointments. This is natural and it may help to get support from family, friends or one of the organisations listed during this time.

For people whose treatment is over apart from regular check-ups, JASCAP booklet on <u>Recovery and Life after Cancer</u> treatment gives useful advice on how to keep healthy and adjust to life after cancer.

Treating rectal cancer

In most hospitals, a team of specialists will discuss the treatment that is best for you. This multidisciplinary team (MDT) will include a surgeon who specialises in bowel cancers, one or more oncologists (doctors who specialise in cancer treatments such as radiotherapy or chemotherapy) and a number of other health professionals.

How treatment is planned

Together, the MDT will be able to advise you on the best course of action and plan of treatment. They will take into account a number of factors, including your general health, age, the size of the cancer, where it is in the rectum, and whether it has begun to spread.

The stage is very important in determining treatment.

- Surgery is the most common treatment. Most stage 1 rectal cancers can be treated successfully with surgery alone.
- For stage 2 and stage 3 rectal cancers, radiotherapy or chemoradiotherapy (a combination of chemotherapy and radiotherapy) may be used in addition to surgery.
- It's not often possible to cure stage 4 (advanced) rectal cancer but treatment can be given to control it.

Your doctors will have carried out various tests to help them plan your treatment. Although they will have a good idea about which treatments you need, they may not be able to tell you exactly until after an operation.

You will be asked to give your permission (consent) for the hospital staff to give you the treatment. It's important that you discuss with your doctor the treatments they recommend, and that you understand why a particular treatment has been suggested for you.

Treatment according to stage

Stage 1

Often, the cancer can be completely removed with surgery, and for most people it will never come back. People with stage 1 rectal cancer don't usually need to have any further treatment after their surgery, although very occasionally <u>chemotherapy</u> or radiotherapy may be given.

Stage 2

People with stage 2 rectal cancers are also usually treated with surgery. Radiotherapy, or a combination of radiotherapy and chemotherapy (chemoradiotherapy) may be given before surgery to shrink the cancer and make it easier to remove. Giving treatment before surgery is called neo-adjuvant therapy.

Chemoradiotherapy or chemotherapy on its own can be given after the operation if there is a risk that the cancer may come back in the future and treatment wasn't given before surgery.

Stage 3

People with stage 3 rectal cancers may be given radiotherapy or chemoradiotherapy before surgery to shrink the cancer and make it easier to remove. There is a greater risk that the cancer will come back after surgery, and chemotherapy is usually recommended unless neo-adjuvant treatment has been given.

Stage 4

Stage 4 (advanced) rectal cancer means that the cancer has spread from where it started in the bowel. It can spread into the area around the bowel, such as the abdomen, and this is known as local spread. If the cancer has spread to other parts of the body such as the liver or lungs, this is known as secondary, or metastatic, cancer.

It isn't usually possible to cure stage 4 rectal cancer, but treatment may be able to control it for some time. Treatment may also be used to reduce symptoms and give a good quality of life.

However, for some people in this situation, treatment will have little effect upon the cancer and they will have the side effects without many of the benefits.

The treatment that is most appropriate for you will depend on:

- · which part of your body the cancer has spread to
- the treatment that you've already had.

Chemotherapy is the most commonly used treatment for stage 4 rectal cancer. It may be given into a vein by injection or drip, or taken as tablets or capsules.

Surgery may sometimes be used, for example to remove a cancer that is blocking the bowel, or sometimes to remove secondary bowel cancers from the liver or lungs.

Radiotherapy may be used to shrink a cancer that is causing pain. This is known as palliative radiotherapy.

Monoclonal antibodies such as bevacizumab (Avastin®), cetuximab (Erbitux®) and panitumumab (Vectibix®) are sometimes used to control advanced rectal cancer for a time.

The benefits and disadvantages of treatment

Many people are frightened at the thought of having cancer treatments because of the side effects that may occur. Some people ask what will happen if they don't have any treatment.

Although the treatments can cause side effects, these can often be well controlled with medicines.

Treatment can be given for different reasons and the potential benefits will vary depending upon your particular situation.

Treatment decisions

If you have early-stage rectal cancer (stages 1, 2 and 3) and have been offered treatment that is intended to cure it, it may be easy to decide whether to accept the treatment. Your doctor will talk through your treatment and any other options with you.

However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to decide whether to go ahead. Making decisions about treatment in these circumstances is always difficult.

You may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to, you can still be given supportive (palliative) care, which often involves medicines to control any symptoms.

You can ask for a second opinion if you feel it would be helpful.

Surgery for rectal cancer

Surgery is the most common type of treatment for rectal cancer and should be carried out by a surgeon who specialises in bowel surgery.

There are different types of rectal cancer surgery. Your doctor will discuss with you the most appropriate type of surgery, depending on the stage of your cancer and where it is in the rectum. You may be given radiotherapy or chemoradiotherapy before surgery to shrink the cancer and make it easier to remove.

Before your operation

Before your surgery the doctor and specialist nurses will explain the operation to you. They will tell you what to expect immediately after the surgery and in the few days following. This is a good opportunity to ask any questions about the operation.

You will probably be admitted to the ward the day before your operation, so that the doctors and nurses can do any further tests. To make sure that your bowel is completely empty, you'll be asked to follow a strict diet and take a medicine (laxative) to help empty your bowels the day before surgery. Your nurse or the doctor will explain this to you. You will be given antibiotics as an injection into a vein (intravenously) just before and after surgery to prevent infections.

Types of rectal cancer surgery

Local resection, transanal resection or transanal endoscopic microsurgery

Very early-stage rectal cancers can sometimes be removed using an operation known as a local resection or a transanal resection. Using an endoscope, similar to the one used to take a biopsy, the surgeon removes only the cancer from the wall of the rectum. This operation is sometimes called transanal endoscopic microsurgery (TEM). If the cancer is close to the anus, the surgeon may be able to operate without the need for an endoscope. A pathologist will examine the cells of the cancer and if

it's then found to be high-grade your surgeon may recommend that you have a second operation. This is done to remove more of the rectum to make sure that no cancer cells have been left behind.

Total mesorectal excision

Total mesorectal excision (TME) is an operation commonly used to remove a rectal cancer. It involves careful removal of the whole of the rectum as well as the fatty tissue that surrounds it, which contains the lymph nodes. This operation takes from 3–5 hours. Research has shown that a TME is better than other types of surgery at reducing the risk of the cancer coming back.

Depending upon the position of the cancer in the rectum, its size, and how far it is from the anus, your surgeon will do the TME operation by using either an anterior resection or an abdomino-perineal resection.

Anterior resection

An anterior resection is usually used for cancers in the upper and middle parts of the rectum (close to the colon). During the surgery, the piece of bowel that contains the cancer is removed and the two ends are then joined together. The join is known as an anastomosis.

The lymph nodes near the bowel are also removed, because this is usually the first place the cancer spreads to. After this operation you'll have a wound that goes in a straight line from just below your breast bone (sternum) to just above your pelvis.

If for some reason the bowel can't be rejoined, the upper end can be brought out onto the skin of the abdominal wall. This is known as a colostomy and the opening of the bowel is known as a stoma. A bag is worn over the stoma to collect the stool (bowel motions).

Sometimes a colostomy is only temporary and another operation to rejoin the bowel can be done a few months later. The operation to rejoin the bowel is known as stoma reversal. We can send you information about this.

If it isn't possible to reverse the colostomy, the stoma is permanent. Having radiotherapy or chemoradiation before surgery can help to reduce the chance of needing a permanent colostomy.

Abdomino-perineal resection

An abdomino-perineal resection is usually used for cancers in the lower end of the rectum. This operation will result in a permanent colostomy because the whole rectum and anus are removed. After the surgery there will be two wounds – an abdominal wound and a second wound where the anus has been surgically closed.

Surgery for advanced rectal cancer

If the cancer is too large to be removed and is pressing on the bowel causing it to narrow, it may be possible to insert a thin metal tube (a stent) into the bowel to keep it open. The stent is inserted using a colonoscope. You'll be given a mild sedative to help you relax and you may have a short stay in hospital.

Surgery may sometimes be used to remove the cancer when it has spread to another part of the body, such as the liver or lungs. Sometimes chemotherapy may be given before or after the surgery.

You may find JASCAP booklets on <u>Secondary Cancer in the Liver</u> and <u>Secondary Cancer in the Lungs</u> helpful.

After your operation for rectal cancer

How quickly you recover from your operation will depend on your age and health, and the type of surgery you've had. Your doctor and specialist nurse can give you an idea about what to expect.

In the hospital

Getting moving

After your operation you'll be encouraged to start moving around as soon as possible. This is an essential part of your recovery. Even if you have to stay in bed, it's important to do regular leg movements and deep-breathing exercises. A physiotherapist or nurse will explain the exercises to you.

As you won't be moving around as much as usual, you may be at risk of blood clots forming. To prevent this you will be asked to wear special stockings, and may be given an anti-clotting drug called heparin.

Drips and diet

When you go back to the ward, you will have a drip (infusion) which gives you fluids through a thin tube (cannula) inserted into a vein in your hand or arm. This will be taken out once you are able to eat and drink normally again.

You may also have a thin tube that passes down your nose into your stomach (nasogastric or NG tube). This allows any fluids to be removed from your stomach so that you don't feel sick. It's normally taken out within a few days.

As an anaesthetic slows down the movement of the bowel, it's important that you don't start drinking until the bowel is working normally again. You will probably be ready to start taking sips of water within a few days. This will be increased gradually over a couple of days until you are able to eat a light diet.

Drains

Often, a small tube (catheter) is put into your bladder, and your urine is drained through this into a collecting bag. This is usually taken out after a couple of days.

You may also have a drainage tube in your wound, to drain any extra fluid and make sure that the wound heals properly. A drain isn't always needed.

Pain

After your operation, you'll probably have some pain or discomfort for a few days. There are several different types of painkillers that can be given to you at regular

intervals or when you need them. You may be given painkillers into a vein in your arm through a pump. The pump can be set to give you a controlled amount of painkiller, or you may be able to control this yourself by pressing a button. This is called patient controlled analgesia (PCA).

Always let your doctor or nurse know if you have any pain or discomfort. The painkillers or their dose can be changed to suit your needs. Some people may continue to have some pain after they go home. Let your doctor or nurse know if you think you might need painkillers to take home with you.

Going home

Depending on the type of operation you've had, you'll probably be ready to go home between 3–10 days after surgery. If you think that you might have problems when you go home (for example, if you live alone or have several flights of stairs to climb), let your nurse or the social worker know when you are admitted to the ward. They can then arrange help before you leave hospital.

You'll be given an appointment to attend an outpatient clinic for your post-operative check-up. At the appointment your doctor will be able to discuss with you whether you need to have any further treatment, such as chemotherapy.

Some people take longer than others to recover from their operation. If you have any problems, you may find it helpful to talk to someone who is not directly involved with your illness. See our useful organisations section for more information about who can help.

Our cancer support specialists can talk to you, and tell you how to contact a counselor or local cancer support group.

Enhanced Recovery Programmes (ERP)

Some hospitals follow an Enhanced Recovery Programme that can help to reduce complications following surgery and speed up your recovery. The programme involves careful planning before your operation so that you are properly prepared and any arrangements that are needed for you to go home are already in place.

You'll also be encouraged to take high-protein and high-calorie supplements before and after your surgery, and to start moving around as soon as possible, sometimes on the day of the operation. After you have gone home you'll be regularly reviewed to make sure that you are recovering well.

Diet after bowel surgery

After any bowel operation, you may notice that certain foods upset the normal working of your bowel, or your colostomy if you have one. High-fibre foods, such as fruit and vegetables, may give you loose stools and make you pass them more often than normal. Depending on the type of surgery you've had, you may have diarrhoea. Tell your doctor or nurse if this happens, as they can give you medicine to help.

It's important to drink plenty of fluids if you have diarrhoea. This is often a temporary reaction, and after a while you may find that the same foods don't have any effect. There are no set rules about the types of food to avoid and each person needs to

experiment for themselves. Some foods that disagree with one person may be fine for another.

You may also find that your bowel produces more wind than before, and this can sometimes build up in the abdomen and cause pain. Drinking peppermint water or taking charcoal tablets can help to reduce this. Your doctor can prescribe these for you, or you can get them from your chemist.

It can sometimes take months for your bowel movements to get back to normal after surgery, and you'll probably need to find out which foods are right for you by trial and error. Some people may find that their bowel is always more active than before their surgery, and that they have to eat carefully to control their bowel movements.

If you continue to have problems, it's important to talk to a dietitian at the hospital, as they can give you specialist advice for your individual situation.

You may find JASCAP booklet on Diet and Cancer helpful.

Sex life after bowel surgery

Once you have recovered from the operation, there is usually no medical reason why you shouldn't have a normal sex life again. However, you may find that you feel self-conscious about the change in your body's appearance, especially if you now have a colostomy. This may stop you from wanting to make love.

Talking about your feelings may help lessen your anxieties. Try not to feel embarrassed talking to your nurse or doctor about what is troubling you. They can refer you for specialist counselling if you think that would be helpful.

Sometimes the operation can cause damage to the nerves that go to the sexual organs. If this occurs, a man may not be able to have or maintain an erection, and may have problems with orgasm and ejaculation. Women may also find that their sexual function or response is affected. This may improve over time, but sometimes it is permanent. There are treatments available, such as sildenafil (Viagra®) that can help men achieve erections. It's important to discuss this with your doctor as soon as you notice a problem, as treatment can often be more effective if started sooner.

We may find JASCAP booklet on Sexuality and Cancer helpful.

If you have any problems, your doctor or specialist nurse will be able to discuss them with you in more detail.

Living with a stoma

Some people with cancer of the rectum will need to have a colostomy. In this operation, the bowel is brought to the outside of the body through the abdominal wall. The opening is called a stoma.

This can be daunting at first. Learning to look after a stoma takes time and patience and no-one expects you to be able to cope straight away. Like anything new, it will get easier with time and practice.

Stoma care nurse

In most hospitals there are specially trained nurses called stoma care nurses (or colorectal nurses) who you will usually meet before your operation. They will show you how to look after your stoma and help you cope with any problems.

Before your operation, the nurse or doctor will carefully plan the position of your stoma so that your bag stays in place, whether you are sitting, standing or moving around.

For the first few days after your operation, the nurse will look after your colostomy for you and make sure that the bag is emptied and changed as often as necessary. At first your stoma will be slightly swollen and it can take several weeks before it settles down to its normal size.

As soon as you are feeling well enough, the nurse will show you how to clean your stoma and change the bags. There are several different types of bag or appliance available and the nurse will help you choose a suitable one.

Talking to people who have a stoma

You may find it helpful to talk to someone who has already learned to live with a stoma. Your nurse or doctor can often arrange for a volunteer to visit you and talk to you about the more practical and personal aspects, or you can contact the Colostomy Association.

This advice, coming from personal experience, can be invaluable, particularly in the first few months after your operation..

Looking after a stoma

When the nurse is showing you how to look after your stoma, it may help for a close relative or partner to be with you, in case you have any difficulties when you get home.

Before you leave hospital, your nurse will make sure that you have a good supply of stoma bags. Make sure that you have plenty of bags and cleaning materials to hand before you start to change or empty your bag. It's a good idea to keep everything you need in one place, so that you don't have to start searching for things at the last minute. Make sure that you allow yourself plenty of time and privacy, so that you can work at your own pace without any interruptions.

Some people with a colostomy avoid wearing a bag by flushing out (or irrigating) their colostomy about once a day, although this method doesn't suit everyone. Your stoma nurse will be able to discuss this with you in more detail.

Stoma supplies

There are different ways of getting stoma supplies when you are at home. You can get all your supplies from your chemist. Sometimes it's better to get them direct from a specialised supply company. These may also offer a cutting and delivery service. The Colostomy Association has details of companies. The supplies are free, but

you'll need a prescription from your GP. If you are aged between 16 and 60, make sure that your doctor signs the form saying that you're entitled to free prescriptions.

Home support

Once you are at home you can phone the stoma nurse if you have any problems. Your GP may also arrange for a district nurse to visit you for a few days when you first leave hospital. They can make sure that you are coping at home, and sort out any problems you may have with your stoma.

Having a colostomy is a big change in your life. Many people find that they are embarrassed by the stoma, and that it affects the way that they feel about their body. Embarrassment about a stoma can also affect relationships and some people are uncomfortable about their partner seeing it. These feelings are a natural part of coming to terms with the changes that a stoma causes, and usually decrease gradually over time.

Chemotherapy for rectal cancer

Chemotherapy is the use of special anti-cancer (cytotoxic) drugs to destroy cancer cells.

Chemotherapy may be given after surgery. Its aim is to get rid of any remaining cancer cells and reduce the chance of the cancer coming back in the future. This is called adjuvant chemotherapy.

Chemotherapy is sometimes given before an operation. This is known as neoadjuvant chemotherapy. The aim of the treatment is to reduce the size of the cancer, to make it easier to remove during surgery. This may make it possible to avoid having a permanent colostomy.

Sometimes the chemotherapy is given in combination with radiotherapy – this is known as chemoradiotherapy.

If the cancer is advanced (stage 4), chemotherapy may be used to reduce symptoms.

Chemotherapy for early-stage rectal cancer (stages 1, 2 and 3)

Chemotherapy usually isn't needed for stage 1 rectal cancers that haven't begun to grow through the muscle wall and aren't affecting the lymph nodes (Dukes A).

In the treatment of stage 2 rectal cancer (Dukes B), the risk of the cancer coming back is low so chemotherapy may not be needed. However, after surgery the cancer will be examined carefully under the microscope, and your doctor may recommend that you have chemotherapy if cancer cells are found in the blood or lymph vessels very close to the cancer.

You may also be offered chemotherapy as part of a clinical trial. Your cancer specialist will discuss whether chemotherapy will be of any benefit to you if you have stage 2 rectal cancer.

People with stage 3 rectal cancer (Dukes C) are usually offered chemotherapy. The chemotherapy can be used in combination with radiotherapy or on its own. You may be offered chemotherapy as part of a clinical trial.

Drugs used to treat early-stage rectal cancer

The main drugs used to treat early-stage rectal cancer are:

- 5-fluorouracil (5FU), which is often given with the vitamin folinic acid (leucovorin) to make it more effective
- Capecitabine (Xeloda®), which is a tablet form of 5FU
- Oxaliplatin (Eloxatin®), which may also be used if the cancer has spread to the lymph nodes close to the rectum (stage 3 or Dukes C).

Your specialist will discuss your particular course of treatment.

Pros and cons of chemotherapy for early-stage rectal cancer

There are various benefits and risks of having chemotherapy and your doctor can discuss these with you.

Chemotherapy can reduce the chance of the cancer coming back and increase your chance of being cured, but it doesn't guarantee this. It can also sometimes cause side effects that may be unpleasant. To help decide whether adjuvant chemotherapy may be appropriate in your case, your specialist will take into account the risk of any cancer cells being left behind, the likelihood that the chemotherapy will get rid of them, and the possible side effects of the treatment.

If the risk of the cancer coming back is low, the chemotherapy may only slightly reduce the chance of the cancer returning. However, if the risk of the cancer coming back is high, the benefit of chemotherapy may be greater. It's important to discuss with your doctor the possible risks and benefits of chemotherapy in your particular situation.

Chemotherapy for advanced rectal cancer (stage 4)

Chemotherapy may also be given when the cancer has spread to another part of the body. Many people have no further problems after their original treatment for cancer of the rectum, but unfortunately in some people the cancer comes back or spreads to other parts of the body. This is called secondary, advanced or metastatic cancer.

Sometimes, when the cancer is first diagnosed, it may already have spread beyond the rectum. The most common place for it to spread to is the liver. The next most common place is the lungs.

Although secondary cancer of the rectum can't usually be cured, treatment with chemotherapy may be recommended by your doctor. The aim of the chemotherapy is to shrink the cancer and reduce symptoms. This can sometimes help to prolong life.

Chemotherapy may be given to shrink cancers before they are removed from the liver or, more rarely, the lungs. Sometimes drugs called monoclonal antibodies are given in combination with chemotherapy.

In recent years, improvements in surgical techniques and drug treatment have meant that an increasing number of people with liver secondaries are able to have surgery to remove their cancers – this can sometimes lead to a permanent cure.

Your doctor or specialist nurse can discuss this with you further.

Our organization, JASCAP has further information about <u>Secondary cancer in the liver</u> and <u>Secondary Cancer in the Lungs</u>.

Drugs used to treat advanced colon cancer

The most commonly used chemotherapy drugs for advanced rectal cancer are:

- 5-fluorouracil (5FU), which is usually given with the vitamin folinic acid
- Capecitabine (Xeloda®) tablets
- Tegafur with uracil (Uftoral®) tablets, which are usually given with the vitamin folinic acid
- Oxaliplatin (Eloxatin®)
- Irinotecan (Campto®)
- Mitomycin

Several research trials are being carried out to test new drugs for advanced rectal cancer, and to help find the best way of using the current drugs (those mentioned above). You may be asked if you'd like to take part in a research trial using new chemotherapy drugs or new types of treatments.

If the cancer starts to grow again during or after the chemotherapy, you may be given a different type of chemotherapy (known as second-line treatment). Sometimes a third course of chemotherapy (third-line treatment) is also given.

Benefits and disadvantages of chemotherapy for advanced rectal cancer

There are various benefits and disadvantages of chemotherapy for advanced rectal cancer, and it's important to discuss these with your cancer specialist.

It isn't possible to predict whether the chemotherapy will work for a particular person, but if they are fairly fit the treatment is more likely to be effective. It's also less likely to have side effects than in someone who is unwell when they start treatment.

You don't have to have chemotherapy treatment unless you want it. If you choose not to, you'll still be given treatment to help control any symptoms that the cancer causes. This is known as supportive or palliative care. Palliative care can also be given alongside chemotherapy if needed.

Your doctor will consider a number of things before asking you to make a decision about particular treatments. This will include where the secondary cancer is, your general health, and any chemotherapy treatment you've had in the past.

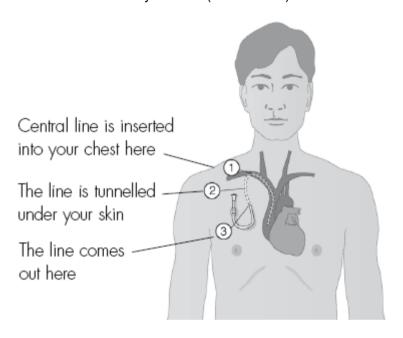
If you have advanced cancer, there are many difficult issues to deal with and you may find it helpful to read JASCAP booklet on <u>Coping with advanced cancer</u>.

JASCAP booklets on <u>Controlling cancer pain</u> and <u>Controlling the symptoms of cancer</u> explain ways that pain and symptoms can be relieved. They also give information on the support that is available from health professionals and other sources.

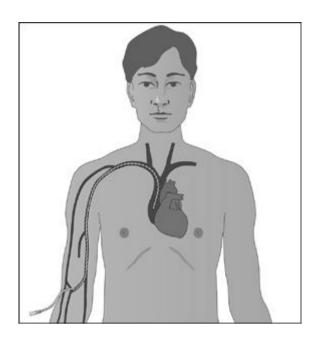
How chemotherapy is given

Many people having chemotherapy for rectal cancer will be given capsules or tablets. These are swallowed with water. Some people are given their chemotherapy drugs by injection into a vein (intravenously).

The drugs may be given through a fine tube in the back of your hand or arm (cannula), a plastic line, called a central line in your chest; or through a thin tube inserted into a vein in the crook of your arm (a PICC line).



Positition of a central line



The PICC line is threaded through the vein until the end is near your heart

Sometimes chemotherapy can be given continuously through a small portable pump, which is attached to your central or PICC line. A controlled amount of the drug can be given into the bloodstream over a period of time. This means that you can go home with the pump, and spend less time in hospital. Some people whose cancer has spread to the liver may be given chemotherapy into an artery that goes directly into the liver.

Intravenous chemotherapy is usually given as a session of treatment. A session may last from a few hours to several days. If you have treatment for a few hours, this may be repeated each week for several months. This chemotherapy is usually given as an outpatient.

If your treatment lasts a few days you'll usually have a rest period of a few weeks before the next session. This allows your body to recover from the side effects of the treatment.

The chemotherapy session and the rest period make up a cycle of treatment. You may need to stay in hospital for your treatment, but it can also often be given to you as an outpatient. Your specialist will discuss this with you.

The number of cycles you have depends on the stage of the cancer and how well it's responding to the drugs.

Contraception during chemotherapy

It is not advisable to become pregnant or father a child while taking any of the chemotherapy drugs used to treat rectal cancer, as they may harm the developing baby. It's important to use effective contraception during your treatment and for a year afterwards. You can discuss this with your doctor or specialist nurse. Condoms should be used during sex within the first 48 hours after chemotherapy to protect your partner from any of the drug that may be present in semen or vaginal fluid.

Our Chemotherapy booklet discusses the treatment in more detail.

Side effects of chemotherapy for rectal cancer

Chemotherapy can sometimes cause unpleasant side effects. These will vary depending on which chemotherapy drugs you are given. Your doctor or nurse will tell you what problems to expect from your treatment. Common side effects include:

- lowered resistance to infection
- bruising or bleeding
- anaemia (low number of red blood cells)
- tiredness
- feeling sick
- diarrhea
- sore mouth
- hair loss
- soreness of hands and feet
- numbness or tingling.

Although side effects may be hard to bear at the time, they will gradually disappear once your treatment is over. For some people this can take some months.

Most people have some side effects from chemotherapy. But if your cancer is causing symptoms it can also make you feel better by relieving them.

There are many things that can be done to help reduce and control side effects so let the staff looking after you know if you are having problems.

Lowered resistance to infection (neutropenia)

While the drugs are acting on the cancer cells in your body, they may also temporarily reduce the number of normal white blood cells. This is called neutropenia. When these cells are reduced you are more likely to get an <u>infection</u>. While your level of white blood cells is low, it's important to avoid crowded places, where you may come into contact with infection, and to avoid anyone who already has an infection, such as a cold or flu.

Contact your doctor or the hospital straight away if you have any signs of infection, such as a high temperature (above 38°C or 100.5°F), or if you suddenly feel unwell (even with a normal temperature). During chemotherapy your blood will be tested regularly and, if necessary, you will be given antibiotics to treat any infection.

Bruising or bleeding

Chemotherapy can reduce the production of platelets (which help the blood to clot). Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, or bleeding gums.

Anaemia (low number of red blood cells)

While having treatment with chemotherapy you may become anaemic. This may make you feel tired and breathless.

Tiredness

You're likely to find that you become very tired and have to take things much more slowly. Just do as much as you feel like and try not to overdo it. JASCAP has a booklet on <u>Coping with fatigue</u>, which you may find helpful.

Feeling sick

Some of the drugs may make you feel sick (nauseated) and possibly be sick (vomit). There are anti-sickness drugs (anti-emetics) to prevent or reduce nausea and vomiting. Your doctor will prescribe these for you. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

Diarrhoea

Some of the chemotherapy drugs used to treat bowel cancer can cause diarrhoea. This often starts several days after the treatment. If you're taking chemotherapy tablets or capsules at home, it's important that you let your doctor or nurse know if you have diarrhoea. Your treatment may need to be stopped.

If you have diarrhoea your doctor can give you medicine to reduce this and slow down the bowel. You may also be able to help control it by eating a low-fibre diet. Our booklet on Diet and Cancer has useful advice on this.

If you've had a colostomy, it may be more difficult to cope with diarrhoea caused by the chemotherapy. Your stoma nurse or cancer specialist can give you advice and support. Some people find that they need to make sure they are close to a toilet during the course of their treatment and for a while afterwards. This can be frustrating, but usually improves gradually a few weeks after the treatment has ended. If the diarrhoea continues after this time it's important to talk to your cancer specialist or stoma nurse, so that they can help you find ways of overcoming the diarrhoea.

Sore mouth

You may find that you get a sore mouth and mouth ulcers while having chemotherapy. Keeping your mouth clean with regular mouthwashes is important. Your nurse will show you how to use these properly. If a sore mouth makes eating difficult, you can try replacing meals with nutritious drinks — our fact-sheet on Mouth Care during Chemotherapy has some useful tips on coping with a sore mouth.

Hair loss

Ask your doctor if the drugs you are taking are likely to make your hair fall out. Most drugs used to treat colon cancer do not, but some may make your hair thin. If your hair does fall out, it will start to grow back again once your treatment is over. We have more information about <u>coping with hair loss</u>.

Soreness of hands and feet

If 5FU or capecitabine are given over a long period of time or are given continuously through a pump, soreness and redness of your palms and the soles of your feet can

occur. This is known as hand/foot syndrome or palmar-plantar syndrome. Vitamin B6 may be prescribed to help reduce this side effect and non-perfumed moisturising creams can often help to relieve the symptoms. If the symptoms are severe your doctor may reduce the dose of the chemotherapy or give you a short break from it.

Numbness or tingling

Oxaliplatin can affect the nerve endings and cause numbness, burning or tingling in the hands, feet, neck or throat (known as peripheral neuropathy). You may also find it hard to do up buttons etc. The numbness or tingling may not happen with the first treatment. If it occurs, it should gradually disappear once the treatment has finished. Sometimes in the first few days after oxaliplatin is given, these side effects can be triggered by anything cold, such as cold drinks or washing water, but often they only last a few minutes.

Our <u>Chemotherapy</u> booklet discusses the treatment in more detail and has tips for coping with the side effects.

Radiotherapy for rectal cancer

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells. Radiotherapy is often given in combination with chemotherapy, which is called chemoradiotherapy. The chemotherapy makes the cancer cells more sensitive to radiotherapy.

Radiotherapy doesn't make you radioactive and it's perfectly safe for you to be with other people, including children, throughout your treatment.

Radiotherapy for early-stage rectal cancer

Radiotherapy may be given before surgery to shrink a cancer and make it easier to remove. It also reduces the chance of the cancer coming back.

A short course of radiotherapy consisting of five treatments may be given over a week, just before the surgery.

If the cancer is large, a long course of radiotherapy may be given, lasting for up to six weeks. This is usually given with chemotherapy (chemoradiotherapy), which can help make the radiotherapy more effective. Following the course of radiotherapy you'll have to wait up to six weeks for the side effects to settle down before you can have the operation.

If radiotherapy was not given before surgery, you may have it afterwards if:

- the cancer was difficult to remove
- some cancer cells may be left behind
- the cancer had spread through the bowel wall or into nearby lymph nodes.

This type of radiotherapy may be given as treatment every weekday for 4–5 weeks.

Radiotherapy for secondary rectal cancer

If a rectal cancer has spread or come back after initial treatment (particularly in the pelvic area), radiotherapy may be used to shrink the cancer. It also relieves symptoms such as pain.

How radiotherapy is given

Radiotherapy for rectal cancer is usually given as an outpatient in the radiotherapy department as a series of short daily treatments. The radiotherapy is given using equipment similar to a large x-ray machine and is known as external radiotherapy. The treatments are usually given each weekday with a rest at the weekend. How the treatment is given varies, depending on what is considered to be most effective for your situation. The course may last for just one week or a few weeks.

Your doctor will discuss your treatment with you beforehand, including how it will be given and how long it will last.

Planning your treatment

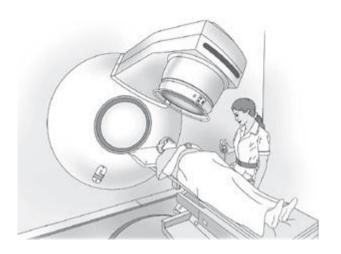
To make sure that your radiotherapy is as effective as possible, it has to be carefully planned. Planning ensures the radiotherapy rays are aimed precisely at the cancer and cause the least possible damage to the surrounding healthy tissues. The treatment is planned by a specialist doctor known as a clinical oncologist. Planning is very important and may take a few visits.

Marks may be drawn on your skin to help the radiographer, who gives you your treatment, to position you accurately and to show where the rays are to be directed. These marks must stay visible throughout your treatment, but they can be washed off once it's over. At the start of your radiotherapy you'll be told how to look after the skin in the area to be treated.

What happens in your treatment sessions

Before each session of radiotherapy, you'll be carefully positioned on the couch, either sitting or lying. The radiographer will make sure that you are comfortable.

During your treatment, which only takes a few minutes, you'll be left alone in the room, but you can talk to the radiographer who will watch you from another room. Radiotherapy isn't painful but you do have to be still for a few minutes during treatment.



Positioning the radiotherapy machine

Side effects of radiotherapy for rectal cancer

Radiotherapy to the bowel area can cause side effects such as diarrhoea, feeling sick (nausea) and tiredness. It can also cause more specific side effects, such as inflammation of the bowel or bladder lining. These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of your treatment, but they tend to get worse as the treatment goes on.

The side effects will usually continue until a week or so after the treatment has finished, and then will gradually start to get better. Your clinical oncologist will tell you what to expect, and you can ask your radiographer for advice if side effects are becoming a problem for you.

Feeling sick

Some people may feel sick (<u>nauseated</u>) but this is usually mild, and anti-sickness drugs (anti-emetics) can usually control this effectively. If you don't feel like eating, you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and can also be prescribed by your GP.

Diarrhoea

Radiotherapy may irritate the bowel and cause <u>diarrhoea</u>. Your doctor can prescribe drugs to reduce this. Our section on <u>diet</u> gives helpful hints on coping with problems such as nausea and diarrhoea.

Tiredness

As radiotherapy can make you feel <u>tired</u>, try to get as much rest as you can, especially if you have to travel a long way for treatment.

Skin reaction

The skin in the area that is treated may become red and sore. Many people find this is mild, but for others, the skin can become very sore and painful. The nurses and radiographers can advise you on how to look after your skin during treatment. If your skin gets very sore, soothing creams can be prescribed.

Inflammation of the bladder lining (cystitis)

Radiotherapy to the rectum may cause inflammation of the lining of the bladder. This can make you feel as though you want to pass urine often. You may also feel a burning sensation when you pass urine. It helps to drink plenty of water and other fluids to make your urine less concentrated. Your doctor can prescribe medicine to make passing urine more comfortable.

These side effects generally continue for several weeks and then disappear gradually once the course of treatment is over. It's important to let your doctor know if they continue.

Possible long-term side effects of radiotherpy

In some people, the bowel or bladder may be permanently affected by the radiotherapy. If this happens, the increased bowel motions and diarrhoea may continue, or you may need to pass urine more often than before. The blood vessels in the bowel and bladder can become more fragile after radiotherapy treatment and this can make blood appear in the urine or in bowel movements.

It can take months or years before these side effects develop. If you notice any bleeding, it's important to let your doctor know so that you can have tests and appropriate treatment.

Infertility and impotence

Radiotherapy to the pelvic area is very likely to cause infertility in men and women. Men may find that they become impotent due to the effect of the radiotherapy on the nerves in the pelvic area. Women may find that sensations during sex are different.

These effects can be distressing and it's important to discuss them with your doctor or specialist nurse, who can help you to find ways of dealing with them.

Our booklet on Sexuality and Cancer has advice on coping with impotence.

Our Radiotherapy booklet discusses the treatment and its side effects in more detail.

Chemoradiotherapy for rectal cancer

Chemoradiotherapy is a combination of chemotherapy and radiotherapy. It's sometimes known as chemoradiation and may be given in the treatment of rectal cancer before surgery to help shrink the cancer, or after surgery to reduce the risk of the cancer coming back.

The chemotherapy drugs can make the cancer cells more sensitive to radiotherapy, so a combination of treatment may be more effective than having either chemotherapy or radiotherapy alone.

The chemotherapy drug that is most commonly used is fluorouracil (5FU), which may be given as a series of injections before the radiotherapy or as a drip (infusion). The chemotherapy can also be given as tablets called capecitabine.

Giving chemotherapy and radiotherapy together can make the side effects of the treatment worse. Your doctor or specialist nurse can give you more information about chemoradiotherapy and the possible side effects.

Biological therapies (targeted therapies) for rectal cancer

Biological therapies use substances that occur naturally in the body to destroy cancer cells. There are several different types of biological therapies. The main ones used to treat rectal cancer are <u>monoclonal antibodies</u> called cetuximab (Erbitux®) and panitumumab (Vectibix®).

These drugs can be used to treat some cases of rectal cancer that have spread outside of the bowel (stage 4, advanced or metastatic cancer).

How monoclonal antibodies work

Monoclonal antibodies are drugs that recognise and lock onto specific proteins (receptors) that are present in particular cancer cells. Because of this they are often called targeted therapies, because they 'target' the cancer cells.

Some cancer cells have proteins known as epidermal growth factor receptors (EGFRs). When other proteins in the body known as growth factors attach to these receptors, the cancer cell is stimulated to grow and divide.

The monoclonal antibodies cetuximab (Erbitux®) and panitumumab (Vectibix®) lock onto the EGFR, stopping growth factors from attaching, and so may prevent the cancer cell from growing and dividing.

How the drugs are given

Cetuximab is usually given in combination with the chemotherapy drug irinotecan, although it can be used on its own. It's given as a drip (infusion) into a vein. Panitumumab is also given as an infusion into a vein and usually in combination with chemotherapy.

When monoclonal antibodies are used

Not all rectal cancers respond to cetuximab or panitumumab. Before having either drug your doctors will test the cancer cells for a gene called KRAS. Knowing if the KRAS gene is normal or mutated can help the doctors decide whether cetuximab or panitumumab will be appropriate for you.

The National Institute for Health and Clinical Excellence (NICE), which advises doctors about treatment, has recommended the use of cetuximab in combination with chemotherapy for some people who have advanced (metastatic) rectal cancer that has spread to the liver. Treatment with the combination of cetuximab and chemotherapy may make it possible to remove the secondary cancers in the liver using surgery.

The NICE guidance doesn't recommend cetuximab for everyone in this situation and your cancer specialist can discuss with you whether cetuximab is recommended for you. Currently, NICE doesn't recommend panitumumab.

Another monoclonal antibody called bevacizumab (Avastin®), which works in a slightly different way, can also be used to treat advanced cancers of the rectum that have not been controlled by other chemotherapy combinations. Bevacizumab works by preventing the cancer from developing a new blood supply, and so starves the cancer of oxygen and nutrients.

Drugs that interfere with blood vessel growth in this way are called angiogenesis inhibitors or anti-angiogenics. NICE doesn't currently recommend bevacizumab and as a result it may not be possible to get it on the NHS.

Side effects of monoclonal antibodies

Some people can have an allergic reaction to monoclonal antibodies. This can make you have a flu-like reaction, a drop in blood pressure or feel sick. Other possible side effects include skin rashes and tiredness. With some monoclonal antibodies, the first dose is given slowly, over a number of hours. You may be given some other drugs first to make a reaction less likely.

Research - clinical trials for rectal cancer

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials.

Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will also be carefully monitored during and after the study. Usually, several hospitals around the country take part in these trials.

It's important to bear in mind that some treatments which look promising at first are often later found not to be as good as existing treatments, or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you do not have to give a reason. If you do decide to take part, you are allowed to withdraw from the trial at any time.

In either case, there will be no change in the way that you are treated by the hospital staff and you will be offered the standard treatment for your situation.

Blood and tumour samples

Many blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you're taking part in a trial you may also be asked to give other samples which can be frozen and stored for future use, when new research techniques become available. These samples will have your name removed so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and it may be many years before the results are known.

The samples will be used to increase knowledge about the causes of cancer and its treatment. This research will hopefully improve the outlook for future patients.

Our booklet on Clinical Trials describes the process in more detail.

Follow-up after treatment for rectal cancer

After your treatment has finished, you'll have regular check-ups and blood tests, and possibly scans (CT, MRI or ultrasound), x-rays and sometimes colonoscopies. These may continue for several years, but will become less and less frequent.

If you have any problems or notice any new symptoms between your appointments, let your doctor know as soon as possible.

At the present time a lot of research is being carried out to find the best way of following up people who have had rectal cancer. The pattern of timing of hospital visits and tests and the amount of follow-up done by GPs varies considerably.

Many people find that they get very anxious before their appointments. This is natural and it may help to get support from family, friends or one of the organisations listed during this time.

For people whose treatment is over apart from regular check-ups, JASCAP booklets on <u>Recovery</u> and <u>Life after Cancer Treatment</u> give useful advice on how to keep healthy and adjust to life after cancer.

Living with colon and rectal cancer

Beginning to recover from colon and rectal cancer

Many people survive colon and rectal cancer. However, the treatment can be very hard on the body and it may be some time before you are feeling fit and well again.

Some people want to make changes to their lifestyle after cancer. Living a healthy lifestyle can help your body recover more quickly and return to normal, and may help

to prevent the cancer from returning. It will also help to reduce the risk of other illnesses, such as heart disease and strokes.

You might choose to make just a few changes or completely change the way you live. If you are considering making some major changes to your lifestyle, it can be a good idea to discuss your plans with your doctor or specialist nurse.

Being involved in your healthcare means taking your medications when directed, always going for follow-up appointments and being aware of symptoms of a possible recurrence of the cancer.

Lifestyle – positive choices, helping yourself

Some people experience treatment side effects that gradually improve over time, while others may have ongoing side effects.

You may have a range of other effects such as trouble sleeping, or feeling weaker and more tired than usual, rather than specific treatment side effects. You may have lost or gained some weight or have stiff muscles or joints.

Living a healthy lifestyle can help you recover but may sometimes appear to be a lot of hard work. However, adopting a healthy lifestyle is about making small, achievable changes to the way you live that will improve your health and well-being. Your healthy lifestyle will be individual to you, and what is right for you may not be right for someone else.

A healthy lifestyle can include having a well-balanced diet, getting some exercise, reducing stress, and being involved in your healthcare. You will need to take any side effects of treatment into consideration when planning changes to your diet and exercise. Don't try to do too much too soon.

Diet

A well-balanced diet should include:

- plenty of fresh fruit and vegetables (at least five portions a day)
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic fluids.

You should also try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

Before making major changes to your diet it's a good idea to discuss your plans with your specialist or with a dietitian at the hospital.

Stop smoking

Stopping smoking has many health benefits and reduces your risk of other diseases such as heart disease and stroke.

Exercise

Exercise doesn't have to be particularly strenuous. You can start gently and build up the amount of physical activity you do. Whatever your age or physical health there will be some kind of exercise you could try, such as walking, hiking, cycling or swimming. Activities like gardening, dancing and playing sport are also good to try.

Managing stress

There are lots of ways to reduce the stress in your life. You could make time to do things that you enjoy, or that make you laugh. Some people find it relaxing to meditate or pray, or to start a new pastime or an evening class. You may find it helpful to write a journal or online blog.

Living with and after colon and rectal cancer

Cancer can affect many areas of your life such as your finances, work, your emotions and relationships. Find information and advice about what the effects might be, how to deal with them and how we can help.

Financial support

Find practical advice on the possible financial impact of a cancer diagnosis, including what benefits you might be entitled to.

Practical issues

Information on dealing with day-to-day problems, including work, travel, and travel insurance.

Emotional effects

Information on the emotions you might experience as a result of your cancer diagnosis, ways that you might manage them and other sources of support.

Relationships and communication

Advice on how to talk to other people, talking to children, relationships and sexuality.

How we can help

Find out about the ways in which JASCAP can offer you information and support.

Questions you might like to ask your doctor

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1.	
2.	
Answer	
3.	
Answer	
4.	
Answer	
5.	
Answer	

JASCAP: We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of "JASCAP".

Note for Reader

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

JASCAP

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