



Understanding

Cancer of the Colon and Rectum (Bowel)

Caring for people with cancer



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National Cancer Helpline 1800 200 700
 Open Monday to Thursday 9am–7pm; Friday 9am–5pm



Understanding cancer of the colon and rectum

This booklet has been written to help you understand more about cancer of the colon and rectum. This is also known as bowel cancer. The booklet has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information is an agreed view on this cancer, its diagnosis and treatment, and the key aspects of living with it.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections important for you. You can also make a note below of the main contacts and information that you may need.



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Medical oncologist	Tel:
Surgeon	Tel:
Radiation oncologist	Tel:
Radiation therapist	Tel:
Emergency	Tel:
Treatments	Review dates

If you like, you can also add:

Your name _____

Address _____

This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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- *Clinical Practice Guidelines in Oncology: Colon Cancer*, National Comprehensive Cancer Network, 2011.
- *Good Nutrition is Good Medicine: For People with Cancer*, Irish Nutrition and Dietetic Institute/Department of Health and Children, 2002.
- *Cancer Nursing: Principles and Practice*, CH Yarbrow, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.
- *The Chemotherapy Source Book*, M Perry. Lippincott Williams and Wilkins, 1997.

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Introduction

This booklet has been written to help you understand more about cancer of the colon and rectum. This cancer is also known as cancer of the large bowel or colorectal cancer. Cancer of the rectum can also be called rectal cancer. By reading the booklet, you can learn more about its diagnosis, treatment and side-effects. You can also learn about the feelings you may experience at this time.

We hope it answers some questions you may have and encourages you to discuss them with your doctor and nurse too. However, we cannot advise you about which treatment to choose. Only you and your doctors can make this decision when all your test results are ready.

At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



Reading this booklet

Remember you do not need to know everything about bowel cancer straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline on 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm.



What does that word mean?

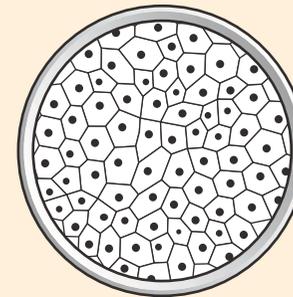
Abdomen	The part of your body that lies between your chest and hips. Sometimes called your belly or tummy.
Adjuvant treatment	Treatment that is given soon after surgery when a diagnosis of cancer is made. For example, chemotherapy or radiotherapy.
Alopecia	Hair loss. No hair where you normally have hair.
Anti-emetic	A tablet, injection or suppository that is given to stop you feeling sick or vomiting.
Benign	Not cancer. A tumour that does not spread.
Biological therapy	Therapies that use your body's immune system to fight infection or disease. Also called targeted therapies. Monoclonal antibodies are an example of biological therapies.
Biopsy	Removing a small amount of cells or tissue from your body to find out if cancer cells are present.
Cells	The building blocks that make up your body. These are tiny and can only be seen under a microscope.
Chemotherapy	Drugs given to cure or control cancer.
Colon	The hollow tube in your intestine where water is absorbed. Also called the large bowel.
Colorectal	This refers to the colon and rectum.
Colostomy	When your large bowel opens onto the surface of your abdomen through a cut in your skin.
Fatigue	Ongoing tiredness often not helped by rest.

Grade	How normal or abnormal the cells look under a microscope. The grade helps doctors to predict how quickly the cancer may grow and behave. A low grade cancer grows slowly, while a high grade cancer grows much faster.
Ileostomy	When your small bowel opens onto the surface of your abdomen through a cut in your skin.
Malignant	Cancer. A tumour that spreads.
Medical oncologist	A doctor who specialises in treating cancer patients with chemotherapy and other drugs.
Metastasis	The spread of cancer from one part of your body to other tissues and organs. Also called secondaries.
Nausea	Feeling sick or wanting to be sick.
Oncology	The study of cancer.
Polyp	A mass of tissue that grows on the inside wall of a hollow organ, like your bowel. It is usually benign.
Radiation oncologist	A doctor who specialises in treating cancer patients with radiotherapy.
Radiotherapy	High-energy X-rays used to cure or control cancer.
Rectum	The large hollow tube that stores waste material in your back passage.
Rectal	This refers to the rectum.
Screening	Testing for cancer before any symptoms of cancer appear.
Staging	A series of tests that measure the size and spread of the cancer.

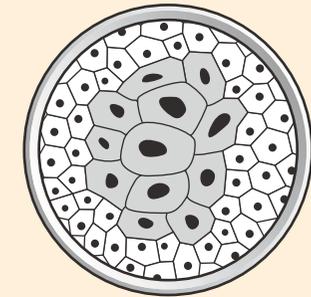
Before diagnosis

>>> What is cancer?

Cancer is a word used to describe a group of diseases. Each one has its own name. For example, skin cancer, lung cancer and breast cancer. Each has their own type of treatment and chance of being cured.



Normal cells



Cancer cells growing

In your body, your organs and tissues are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue, cells are replaced when they get worn out or injured. With cancer, the cells do not behave as normal but keep on growing even when there is no need.

These abnormal cells can form a tumour. Tumours can be either benign or malignant. Benign tumours do not spread to other parts of the body, and so are not called cancer. Malignant tumours are sometimes called primary tumours. They are cancer cells that can spread from where they first grew.

This happens when a cell or group of cells breaks away and travels through your bloodstream or lymph glands to form a new tumour elsewhere in your body. This is called a metastasis or secondary tumour.

Lymph glands or nodes are found in groups throughout your body. These include your neck, armpits and groin. They help your body fight infection and remove unwanted material.



To sum up

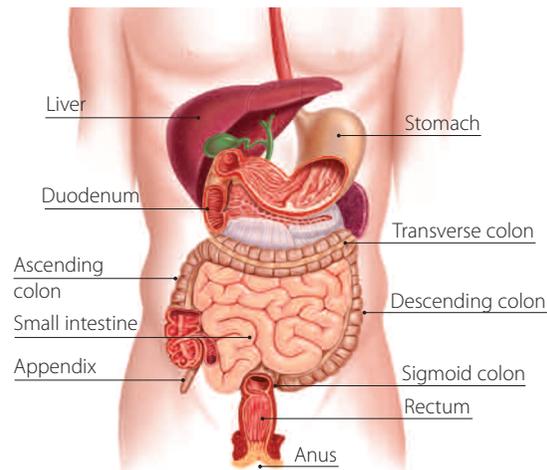
- Cancer is a disease of the cells of your body.
- When cancer occurs, the cells do not develop as normal but keep on growing. These abnormal cells can form a tumour.
- If a tumour is malignant, cells can break away and travel through your bloodstream or lymph glands to form a new tumour somewhere else. This is called a metastasis.

What is the colon and rectum (large bowel)?

The colon and rectum are part of your digestive system. They form a long hollow tube called the large bowel. Your bowel is made up of two parts, the small and the large. The small bowel is narrower and actually longer than the large bowel. The large bowel contains your colon and rectum. Most cancers occur in the large bowel.

After swallowing food, it goes from your gullet (oesophagus) to your stomach and into your small bowel. As it makes its way through your small bowel, it is digested and nutrients are taken into your body. In your large bowel, water is absorbed from digested food.

The waste matter that is left is stored in your rectum (back passage) until ready to pass out of your body through your anus. This waste material is known as faeces or stools.



The digestive system

When cancer occurs

When cancer occurs, cells in your bowel change and start to grow faster than normal. Cancer that begins in the large bowel is called colon cancer. This cancer may cause a blockage in your bowel, which can affect how your bowel works. Cancer of the rectum occurs very low down in your bowel close to your anus. It can be treated differently to cancer of the colon.



To sum up

- The colon is where food is digested and nutrients absorbed into your body.
- The rectum is where waste material is stored until it passes out of your body.
- The normal cells in your bowel may change and grow faster than normal, causing a malignant tumour.
- The tumour can affect how your bowel works normally.

What causes bowel cancer?

The cause of bowel cancer is mostly unknown. But there are certain things that increase your chance of developing it. These are called risk factors and include:

- **Age:** If you are over 60 years.
- **Previous cancer:** If you have had a previous bowel cancer.
- **Family history of bowel cancer:** If a member of your immediate family (mother, father, brother, sister or child) or a number of relatives (uncle, aunt) on the same side of the family has had bowel cancer, or if an immediate family member was diagnosed with bowel cancer at a young age, under 45.
- **Inherited bowel conditions:** If you or someone in your family have or had an inherited bowel conditions such as FAP and HNPCC. FAP stands for familial adenomatous polyposis; HNPCC is hereditary nonpolyposis colorectal cancer (also called Lynch syndrome).

- **Other bowel conditions:** If you have a history of a bowel condition such as benign polyps, ulcerative colitis or Crohn's disease.
- **Obesity:** If you are obese (overweight).
- **Diet:** A diet high in fat and red meat and low in fibre, fruit and vegetables can increase your risk of bowel cancer. Drinking alcohol to excess and smoking may increase the risk for some people.

If you feel you could be at risk...

First talk to your family doctor (GP) about your concerns. He or she may advise you to visit a colorectal specialist. Nowadays there are special screening clinics you can visit if worried about the risk of bowel cancer in your family. Tests can be done to see if you are likely to develop bowel cancer.



Guide to preventing bowel cancer or its recurrence:

- Eat a healthy diet.
- Be physically active.
- Be a healthy weight.
- Quit smoking.
- Reduce the amount of alcohol you take.



What should I eat or drink to help prevent bowel cancer?

What you eat may increase your risk of developing bowel cancer. It is best to:

- Eat foods high in fibre. This means more fruit and vegetables.
- Eat foods low in fat. This means less red meat.
- Avoid salt.
- Reduce the amount of alcohol you take.

What is bowel cancer screening?

Testing for bowel cancer when you have no symptoms is called screening. It can help your doctor to find polyps or early cancer. In the case of polyps, they can be removed to prevent cancer occurring. If early cancer is found, it can be treated and greatly improve your chances of survival.

There are plans to start a national bowel cancer screening programme in Ireland in 2012. Screening will be offered to men and women aged between 55 and 74 years every 2 years. It will be introduced gradually, starting with men and women aged between 60 and 69 years. After that it will include everyone between 55 and 74 years.

The tests involved in screening may include:

- **Faecal immunochemical test (FIT):** This test checks for any hidden blood in your stool sample. It does not check for bowel cancer. If it is positive, you will be asked to have a colonoscopy.
- **Colonoscopy:** This test checks for polyps or tumours inside your colon and rectum using a flexible tube and camera.

If you need a colonoscopy, the Irish Cancer Society believes that you should wait no longer than 6 weeks from first seeing your GP. If you are waiting longer than 6 weeks, contact your GP to see if it can be organised earlier. See page 12 for more about these tests.

What are the symptoms of bowel cancer?

The symptoms of bowel cancer can vary and include any of the following:

- A lasting change in your bowel habit – going more often, looser motions or constipation
- Blood in your stools or bleeding from your back passage
- Pain or discomfort in your tummy area or back passage
- Trapped wind or fullness in your tummy
- A lump in your tummy area or rectum
- Feeling you have not emptied your bowel fully after a motion
- Unexplained weight loss
- Feeling tired and breathless due to anaemia (fewer red blood cells)

Remember these symptoms can also be due to complaints other than bowel cancer. Make sure to get them checked out by your doctor, especially if they go on for more than 4–6 weeks. Sometimes bowel cancer may cause a blockage. In this case, you will feel bloated or constipated or vomit. You are also likely to have gripping pains in your abdomen. Don't delay contacting your doctor in this case.

How is bowel cancer diagnosed?

If you are worried about any symptom of bowel cancer, visit your family doctor (GP). He or she will do a small number of tests first, such as:

- Rectal exam
- Blood tests
- Stool sample

Rectal exam: During a rectal exam, your doctor puts a gloved finger into your back passage to feel for any lumps or swelling. This quick test may be a little uncomfortable but does not hurt.

Blood tests: Your doctor will take blood to see if you are anaemic. Also, he or she may check how well your liver and kidneys are working.

Stool sample: Your doctor may ask for a sample of your stools (bowel motion) to check for any hidden blood.

Special tests

If your doctor has concerns about you, he or she will refer you to a hospital. There you will see a specialist who may arrange special tests to look inside your colon and rectum. Most of the tests take place in the X-ray department and you may be admitted to hospital for them. You can discuss this with your specialist. These tests include:

- Proctoscopy
- Sigmoidoscopy
- Colonoscopy
- CT colonography

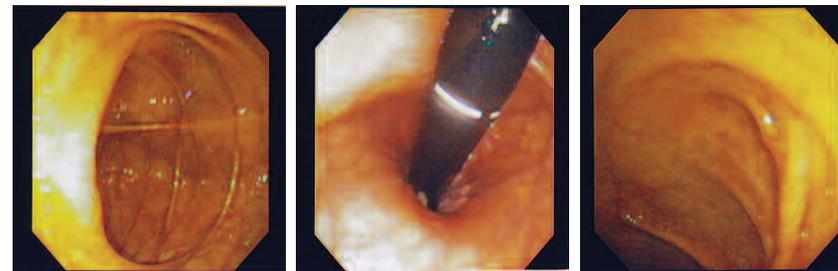
Proctoscopy: During this test, your doctor looks inside your back passage (rectum). First, he or she passes a short thin tube into your back passage while you are lying on your side. Air is then pumped in so the doctor can see the area more clearly.

Sigmoidoscopy: This test looks at the lower part of your large bowel. A longer tube is passed further up into your bowel. A light inside the tube helps your doctor to see any abnormal areas. Your nurse will give you an enema or laxatives beforehand so the inside of your

bowel can be seen clearly. Air or carbon dioxide is pumped into your bowel for this test too. A sample of cells can also be taken during the test. These cells (biopsy) can be checked in the laboratory. The test is painless but can be a little uncomfortable. Once the test is over, you can go home.

Colonoscopy: This test looks at your entire large bowel. You will be given advice on fasting or drinking and how to clear your bowels fully beforehand. The test takes about 1 hour and may be a little uncomfortable. Just before the test, you may be given sedation to help you relax.

When you are lying on your side, your doctor puts a long flexible tube into your back passage. This tube is called a colonoscope. A light inside the tube helps your doctor to see any abnormal areas or swellings. During the test, photos and samples of your bowel can be taken. After the test, you should be ready to go home within a couple of hours. You will be sleepy and not be able to drive for several hours. Do arrange for someone to take you home instead.



Pictures of the bowel taken during a colonoscopy

CT colonography: This test is also known as a virtual colonoscopy. In general, it is only available in specialist cancer centres. It is like a colonoscopy except that a computer uses CT images to examine your bowel. A CT is a special type of scan that builds up a detailed picture of the tissues inside your body.

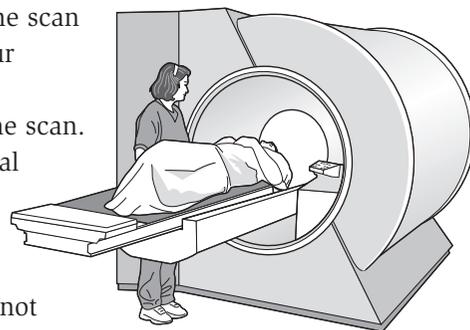
Your bowels will need to be fully cleared beforehand with laxatives and fluids. During the test, your doctor puts a tube into your back passage and pumps in air or carbon dioxide to give a clearer picture. Then two CT scans are taken: one while you are lying on your back

and the other on your front. You may be asked to hold your breath during the scan. The computer then matches up the two scans to make a 3D picture of your bowel. This is a 'virtual' picture. If biopsies need to be taken, you will also have a colonoscopy.

How is bowel cancer staged?

If the tests show you have bowel cancer, your doctor may wish to do more tests. These extra tests will find out the extent of the disease and if it has spread. This is called staging. It will also help your doctor to decide on the best treatment for you. These tests are done in the X-ray department of the hospital. Further tests might include:

MRI scan of pelvis: This is a special scan that uses magnetic energy to build up a picture of the tissues inside your pelvis. The pelvis is the lower part of your abdomen between your hipbones. This type of scan is usually used for rectal cancer. You may have an injection before the scan to show up certain areas of your pelvis. You cannot wear metal jewellery or hair clips during the scan. Also, if you have certain medical devices, like a pacemaker, you are not suitable for the test. Your doctor will advise you about this. The MRI scan does not hurt and most people can go home afterwards.



MRI scan

CT scan of chest, abdomen and pelvis: This is a special type of X-ray that builds up a detailed picture of your chest, abdomen and pelvis. The scan does not hurt. For some CT scans you cannot eat or drink for 4 hours beforehand. For others, you may be given a special drink to help show up certain parts of your body on the scan. Preparation for a CT scan can vary. Your doctor or nurse will tell you what to do. Most people can go home once the test is over.

Ultrasound scan of abdomen or back passage: A picture is built up of the tissues inside your body using sound waves in this test. First you lie on your back and then a gel is spread over the area to be scanned. A small device like a microphone is used to take the scan. A picture is then made by a computer. This test is painless and only takes about 10 minutes.

PET scan: This is a positron emission tomography scan. It may be used if the results of other tests are unclear. PET uses a low dose of radioactive sugar to measure activity in your cells. This sugar is injected into your arm and travels to all the cells in your body. Because cancer cells absorb a lot of sugar, there will be more radioactivity where the cancer cells are found. After an hour, the scan is taken and can show if the cancer has spread to other tissues and organs.

Before the test you may have to fast for a few hours. The scan itself may take up to 1 hour. You will be given advice beforehand on what is involved. PET is safe to use and there are no side-effects. Because it is a fairly new type of scanning, it may not be available in the hospital in your area.

Waiting for results

It may take about a week for all the test results to come back. This can be an anxious time for you. It may help to talk things over with a relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to a specially trained nurse.

Staging systems

Doctors can describe bowel cancer in different ways. You may hear your doctor talk about TNM. TNM refers to the size of the tumour (T), if it has spread to your lymph nodes (N), and if it has spread to other parts of your body as metastases (M). The TNM system is complex but can be roughly described in stages.

- | | |
|----------------|--|
| Stage 1 | The cancer is in the inner wall of your colon or rectum only. |
| Stage 2 | The cancer is in the muscle layer of your colon or rectum and may have spread to nearby tissues. |

Stage 3 The cancer has spread to nearby lymph nodes.

Stage 4 The cancer has spread to other parts of your body, for example your liver or lungs. It is advanced.

Cancer that has come back is known as recurrent cancer.

Grading of cancer

Grading refers to what the cancer cells look like under the microscope. The grade helps your doctors to predict how quickly the cancer may grow or behave. Grading can be low, moderate or high.

- The more normal a cancer cell looks, the lower its grade.
- The more abnormal a cancer cell looks, the higher its grade.



To sum up

Tests to diagnose bowel cancer include:

- Proctoscopy
- Sigmoidoscopy
- Colonoscopy
- CT colonography
- Biopsy of bowel tissue or cells

Tests to stage bowel cancer can include:

- MRI scan of pelvis (for rectal cancer only)
- CT scan of chest, abdomen and pelvis
- Ultrasound scan of abdomen and/or back passage
- PET scan

National Cancer Helpline 1800 200 700

Treatment and side-effects

In Ireland there are eight specialist cancer centres. Colon cancer does not necessarily need to be treated in one of these. Because cancer of the rectum is less common, it needs more specialist care. As a result, it is important that you are referred to the right centre to receive the best treatment. Discuss this with your GP.

How is bowel cancer treated?

Surgery is the main treatment for bowel cancer and currently the only way to cure it. Chemotherapy and radiotherapy can also be given. They may be used before surgery to shrink the tumour, especially with rectal cancer. Biological therapies like monoclonal antibodies are also becoming part of treatment now.



The type of treatment you receive will depend on:

- The type and size of the tumour
- The stage (spread) and grade of the tumour
- Your age
- Your general state of health

Choices and options

It is natural to be anxious about what is going to happen next. Do not be afraid to ask your doctor questions. He or she can discuss your cancer and treatment choices. You also have the option of getting a second opinion, if you wish. Make sure you are fully aware of your cancer and your treatment options. You may want to use the fill-in page at the back of this booklet to write down your questions and the answers you receive. If you prefer not to know any details, let a family member or close friend talk to your doctor instead.

Individual treatment

Do not worry that other patients with bowel cancer are getting different treatment to you. Their cancer may not be the same type or stage as yours. As a result, their treatment needs may be different.

Surgery

The main treatment for bowel cancer is surgery. It is specialised surgery carried out by specialist surgeons after discussion with all the medical teams involved in your care. The type of surgery you have will depend on:

- Where in the bowel the tumour is found
- The type of tumour
- The size of the tumour
- If it has spread to other tissues

Types of surgery

The aim of surgery is to remove the part of the bowel that contains the tumour. There are different types of surgery:

- Open surgery
- Keyhole surgery

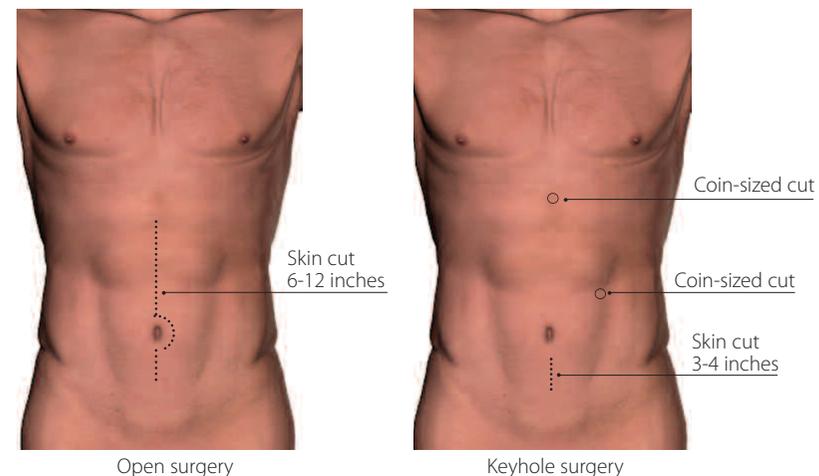
Open surgery: Here a long cut is made in your abdomen. This means your wound will go from below your breastbone down towards your pelvis in a straight line. The length can vary depending on the location of the cancer.

Once the tumour is removed, the two healthy ends of your bowel are joined together. This is known as a resection. Lymph nodes may also be removed to prevent the cancer spreading. Sometimes it is not possible to join up your bowel again. Instead, your bowel is brought out onto the skin of your abdomen. This is called a colostomy. See page 22 for more details.



Open surgery

Keyhole surgery: This is also known as laparoscopic surgery. It is where a small cut is made in your abdomen and the tumour removed with special instruments. Keyhole surgery can be used for some types of bowel cancer. Your surgeon will discuss it with you but remember not everyone is suitable for this type of surgery.



Your surgeon will put a tube with a tiny telescope and light inside your body through a very small cut. Special instruments can then be used to remove the tumour. Keyhole surgery is very skilled and needs to be done by highly trained specialists. As a result, not all hospitals can offer this kind of surgery. Discuss this with your GP. With keyhole surgery, you usually recover quicker and need to spend less time in hospital than for open surgery. The scar is very small and you can start eating sooner.

More treatment

The part of your bowel removed will be examined fully in the laboratory. It may take up to 10 days to get the results back. Your doctor will then discuss the results and decide if you need more treatment or not.

Consent for surgery

Before any surgery, discuss it fully with your doctor. You will be asked to sign a form giving permission for the surgeon to do the surgery. No surgery will be done without your consent. All the possible risks and benefits of the surgery will be discussed.

➤➤➤ Your surgeon will discuss all the risks and benefits of the surgery.

Surgery for cancer that has spread or recurred

Sometimes the cancer may have spread beyond your bowel. For example to your liver. In this case, you may still be suitable for surgery. Your doctor will discuss your options with you.

How do I prepare for surgery?

Before surgery: To make sure you are fit for surgery, some extra tests may be done. These could include a chest X-ray, heart test (ECG), blood pressure and some more blood tests. Your nurse will also give you advice on how to clear your bowels fully. You may be allowed one light meal and fluids only for 1 or 2 days beforehand.

Your physiotherapist will show you how to do deep breathing exercises. These will help prevent you getting a chest infection after your surgery. Your nurse may also arrange for you to have a pair of elastic stockings. These are to prevent you getting clots in your legs after surgery.

If your surgery will involve making a stoma (artificial opening into your bowel), your stoma care nurse will also visit you before surgery. She or he will talk to you about where the stoma will be placed and ask for your opinion. See page 22 for more about stoma and surgery.

Night before surgery: You will not be allowed to eat anything from 12 midnight. You may get an injection of an anti-clotting drug like heparin to prevent any clots in your legs later.

Morning of surgery: You will continue to fast at this time. Before you go to theatre, your doctor may give you a tablet to make you feel sleepy and more relaxed.

What happens after surgery?

When you wake up you may notice some tubes attached to your body. They may look alarming but are normal after an operation like this.

- **Drip:** A drip will be put into a vein in your arm. This will give you fluids until you can drink again.
- **Catheter:** A small thin tube called a catheter may be put into your bladder. This helps to drain your urine into a bag.
- **Wound drains:** Small tubes will drain any extra fluid from your wound and so help it to heal.

- **Epidural:** There may be a thin epidural tube in your back to help relieve any pain.

Painkillers: You are likely to have some pain for the first few days. You may also feel or get sick. Your nurses can give you painkillers and medication to prevent you feeling sick if needed. Always ask for help before the pain or sickness gets too bad. If the injections do not work, let your nurse know as they can be changed.

Eating and drinking: The surgery can slow down your bowels, making the motions loose afterwards. As a result, it will take a few days before you can return to normal eating and drinking. At first, you will be able to take sips of water. Gradually the amount of fluids will be increased. You may be able to manage a light meal after 2 or 3 days. As soon as you can drink again the drip will be removed.

Exercising: You will be asked to move your legs in bed and do deep breathing exercises at least once an hour. On the day after surgery, your nurses will help you out of bed and take you for a short walk. As you get better, these walks will become longer and you can go on your own. Sitting down may not be easy at first but it should get better as your wound begins to heal.

Going home: More than likely you will be ready to go home 5–10 days after surgery. If you live alone or have problems getting around the house, talk to the medical social worker on your ward. Do this as soon as you are admitted to the hospital. That way, he or she can organise the community services that you may need after you leave hospital. On the day you go home, you will be given a date to come back for a check-up.



To sum up

- Surgery is currently the only treatment to cure cancer of the large bowel.
- The aim of surgery is to remove the part of your bowel with the tumour.
- After surgery you may have some drips, drains and tubes in for a short while.
- Most people are ready to go home 5–10 days after surgery.

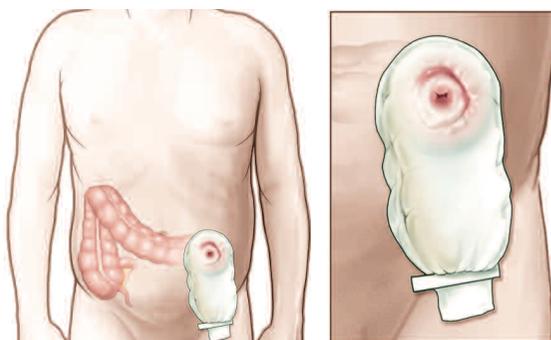
What if I need a colostomy or ileostomy?

You may need to have a colostomy or ileostomy. This is where part of your small or large bowel is brought out onto the skin of your abdomen. It may be temporary or permanent after surgery. It will all depend on where the tumour is found and your general health. It may be done if you have low rectal cancer or if your bowel cannot be rejoined.

If your large bowel is brought out, it is known as a colostomy and if it is your small bowel, it is an ileostomy. If it is done in the short term, your bowel can be rejoined inside some months later. The opening onto your skin is known as a stoma. Bowel motions will no longer pass out through your back passage but into a small bag or pouch over the stoma instead.

How do I manage a colostomy?

Most hospitals have colorectal nurse specialists. These are also known as stoma care nurses. Part of their job is to help you learn more about caring for your colostomy. They will help you with dressings, changing bags, and dealing with leakages and sore skin.



Colostomy bag

Location of stoma: Before surgery, you and your doctor or stoma care nurse will discuss the best place for your stoma. Having a stoma is something you will need to adjust to in your life. The stoma will need to feel comfortable whether you are sitting, standing or moving about. You will also need to think about the type of clothes you normally wear, such as trousers, skirts and swimwear.

Dressings: For the first few weeks, your stoma will be red and swollen. At first your nurse will change your dressings and empty and change your bag as needed. When you are feeling better, you will be shown how to do this on your own.

Looking after the stoma: It takes a while to get into the routine of looking after the stoma yourself. It can help to keep all dressings and bags together in one box. It is natural to be slow at first, so allow yourself plenty of time and privacy to work at your own pace. When your nurse is showing you how to care for the stoma, bring along a close friend or relative to watch. This is in case you have problems later when you get home.

Support groups: You may find it helpful to talk to someone who has had the same surgery. They can give you first-hand advice and tips on how to care for your stoma. See page 70 for details of the Bowel Cancer Support Group.

What happens when I go home?

Getting supplies: On leaving hospital, you will be given some dressings and colostomy bags to last a few days. You will also get a prescription for more supplies from your pharmacy. Go to the pharmacy to get these as soon as possible. Most pharmacies do not keep them in stock and it may take a few days for supplies to arrive. Some pharmacies have a direct delivery service where you can telephone in your order and they will send out your supplies by post. Ask your stoma care nurse if this service is available in your area.

Support: You can contact the hospital or stoma care nurse if you have any problems at home. Your local public health nurse and/or community stoma care nurse may also come out to see you. This visit can be set up before you go home.

Being comfortable: There are many accessories to help make life comfortable for you. These include girdles, support belts, deodorisers, wipes, skin protective wipes, lotions and creams, adhesive removers, stoma paste, rings and disposal bags. There are also snug clothes like underwear and swimwear you can wear.

Will I have to change the foods I eat?

At first you may find that some foods affect your bowels or colostomy. It may be a few weeks or months before things settle down. It also takes some time to find out which foods agree with you and those that do not.

Change in bowel habits: Some people find their bowels are more active after surgery. As a result, you may have to control what you eat for a while. If you have a colostomy, your bowels may move at certain times of the day. You may notice that your colostomy is more active after a meal or that it works a little bit all day.

Special diet: You do not need to follow a special diet unless your doctor or dietitian advises it. It is a good idea to eat a variety of items from all the food groups. For example, fruit and vegetables, bread and other cereals, potatoes, meat, fish, fatty and sugary foods, milk and dairy products. This will give your body all the nutrients it needs. But be careful not to eat too much fibre as it may cause loose stools or make your bowels more active. You may have to try out certain foods and see what agrees with you. If you need help choosing the right foods to eat, ask your dietitian or nurse for help.

Meals: Start with light meals and eat them slowly. Avoid big platefuls of food as it can be off-putting. Eating nutritious snacks often can help you to build up to larger portions.

Fibre and fat: Too much fibre in bran, fruit and vegetables may cause wind or loose motions. Also, if you are trying to regain weight, it may be better to use full-fat milk and cheese rather than low-fat or skimmed ones.

>>> If you need help choosing the right foods to eat, ask your dietitian or doctor and nurse.

Wind (flatulence): Sometimes wind can be a problem. It can build up and give you pain and discomfort. Talk to your nurse about taking peppermint water. Your doctor can prescribe medication to relieve it as well.

Diarrhoea: Depending on your surgery, you may have diarrhoea for a short while. Drink plenty of clear fluids and let your doctor and nurse know. They can give you medication to control it.

If you would like more information on food and cancer, call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Diet and Cancer*.

Chemotherapy

Chemotherapy is the most common treatment if the cancer has spread outside your bowel. It is a treatment using drugs that cure or control cancer. It can also reduce the risk of cancer returning. The drugs can be used on their own or with each other (in combination). They can be given into a vein (by drip or pump) or else in tablet form. A central line that gives drugs into a large vein in your chest may be used. Or a PICC line can give drugs into your arm.



PICC line

Chemotherapy is carried in your bloodstream to almost every part of your body. It is often given in cycles. For example, it can be given every 3–4 weeks with a rest period between treatments.

When is chemotherapy given?

Your doctor may tell you that you need more treatment. The doctor who specialises in chemotherapy is called a medical oncologist. Further treatment after surgery for bowel cancer is known as adjuvant therapy. Adjuvant therapy is given after the tumour has been removed to kill any tiny cancer cells left behind. It can also help to prevent the cancer coming back. If chemotherapy is needed before surgery, it is called neo-adjuvant. It may be given to shrink a tumour and make it easier to remove.

For some people, the cancer does come back after their first treatment for bowel cancer. For others the cancer may have already spread by the time the diagnosis is made. Even so, it can still be treated. In deciding treatment, your doctor will consider your general health and where the cancer has spread. He or she will also take into account the treatment you have had in the past.

»»» Cancer that has spread beyond the bowel or recurs can still be treated.

What drugs are used?

A number of drugs are commonly used to treat bowel cancer. They can be given on their own or in groups (combinations). Your doctor will decide on the best combination of drugs for you, depending on the stage of your cancer.

Adjuvant chemotherapy: Two of the most common combinations are 5-fluorouracil (5-FU) and oxaliplatin. A drug called folinic acid (Leucovorin®) might be given with 5-FU or not. There are different ways of giving these treatments. Your doctor will discuss your treatment programme with you and any side-effects to expect.

Advanced cancer or secondary cancer: 5-FU and oxaliplatin can be given for advanced bowel cancer as well. Some newer drugs include irinotecan, capecitabine and tegafur-uracil. Biological therapies can also be given. See page 31 for more details.

For more information on chemotherapy drugs and their side-effects, visit the Irish Cancer Society website: www.cancer.ie

Where do I go for treatment?

Where your chemotherapy is given can vary. It can be given as a day patient or sometimes as an inpatient, depending on the drugs being used. Your nurse will give you more information about your own treatment. This includes where and how often you will receive it and any possible side-effects. Do ask as many questions as you like so that you know what to expect.

Side-effects of chemotherapy

Some people who have chemotherapy have little or no side-effects. These unwanted effects happen because chemotherapy works not only on cancer cells but also normal cells. These cells are those that divide quickly like in your mouth, hair and bone marrow. But the effect on normal cells lasts for a short while. In most cases, the side-effects go away once the treatment ends or soon after.

Before you start your treatment, ask your doctor about any possible side-effects that may occur. Do tell him or her about the way you are feeling during your treatment, as most side-effects can be eased with medication.

»»» Side-effects usually go away when the treatment ends or soon after.

Side-effects may include:

- Diarrhoea
- Sore mouth
- Feeling sick or wanting to be sick (nausea)
- Infection
- Loss of appetite
- Feeling very tired (fatigue)
- Thinning of your hair or hair loss (alopecia)
- Peripheral neuropathy
- Hand-foot syndrome

Diarrhoea

Passing more than three watery bowel motions a day is known as diarrhoea. You may also have cramping and/or abdominal pain. If this happens, drink lots of clear fluids to replace the fluid you are losing. You must tell your doctor or nurse if you get diarrhoea. There is medication that can stop this side-effect of treatment.

Sore mouth

Some drugs used to treat bowel cancer can cause a sore mouth. They can also cause little ulcers on your tongue, gums and inside your cheeks. Try to keep your teeth, gums and mouth very clean. If you have dentures, remove them if your gums are sore. There are also special mouthwashes that you can use. Your nurse will tell you which ones are safe and how to use them properly.

Feeling sick or wanting to be sick (nausea)

Not everyone feels sick after chemotherapy. But if you do, it can happen before, during or after treatment. It may last for several hours. Ask your doctor to give you medication to stop you feeling sick. Take it as advised by your doctor. Special build-up drinks can help to give you more calories, if you are not eating. Talk to your dietitian for advice.

>>> Tips & Hints – nausea, vomiting, diarrhoea

- Find out when is best for you to eat and drink before treatment. Some people need a light snack, while others need an empty stomach.
- Have about 5 or 6 small meals or snacks each day.
- Drink plenty of clear fluids, more if you have diarrhoea (1½ to 2 litres a day).
- Eat bland, easy-to-digest foods and drinks, like cream crackers, toast or plain biscuits.
- Do not fill your stomach with fluids before eating.
- Avoid food and drinks with a strong smell, like garlic, onions, fried foods, etc.
- Eat warm or cool foods if you cannot tolerate the smell of hot food.
- Avoid milk, alcohol, very hot or cold drinks, spicy or fried foods, if you have diarrhoea.
- Eat less raw fruit, cereals and vegetables, if you have diarrhoea.
- Some complementary therapies, like acupuncture, may help nausea and vomiting.

**Infection**

Chemotherapy can increase your risk of infection. Most chemotherapy drugs affect your bone marrow, so it becomes harder to make white blood cells. These white cells normally fight infection. If you do not have enough white cells, even minor infections like a cold or sore throat could make you quite ill. During treatment cycles, you will have blood tests to make sure you have enough white blood cells.

Signs of infection: Your doctor will ask you to watch out for signs of infection at all times, especially if your white cells are low. These signs could include feeling shivery and unwell or running a high temperature of 38°C or higher. If this happens, tell your hospital doctor straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly. Check this out with your doctor or nurse before you start treatment. If you have a high temperature, you will need a blood test and maybe antibiotics to treat the infection.

>>> If you feel shivery and unwell or have a high temperature of 38°C or higher, contact your hospital doctor straight away.

Avoiding infection: Avoid close contact with people who have colds or flu or other infections such as chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections. Wash your hands often during the day, especially before you eat and after going to the bathroom. Try to avoid crowds. Talk to your doctor or nurse who can give you more advice.

Loss of appetite

It is best to eat well while on chemotherapy to keep your strength up. However, this may be hard in practice. You may find that you have little or no appetite. Eating very small amounts of food often can help. Taking special build-up drinks can give you extra proteins and calories. Talk to your nurse or dietitian if you would like some advice. If you would like more information on loss of appetite, call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Diet and Cancer*.

Feeling very tired (fatigue)

You may notice that you feel very tired during chemotherapy. This is common. If you feel tired, do balance rest periods with exercise. The tiredness can last for some weeks or months after treatment has ended. Ask your family or friends to help you at home, especially with shopping, childcare or housework. At work, your colleagues may also be able to help. Call 1800 200 700 for a free copy of the booklet, *Coping with Fatigue*. See page 38 for more about fatigue.

Hair loss (alopecia)

Hair loss does not happen very often with the drugs used to treat bowel cancer. However, you may notice that your hair thins out a little. If you do lose your hair, it will fall out quite quickly but will grow again when treatment stops.

You may feel upset at the thought of losing your hair. This is normal. Talk to your nurse about your feelings. He or she will help you find ways of coping with hair loss. You can wear a wig when it happens or you may prefer to wear a hat or scarf. In some hospitals, your medical social worker or nurse will arrange this for you. If your hospital does not provide this service, ask if they know the name of a wig fitter you could go to see. Your local hairdresser may also be able to help. For more information, call the National Cancer Helpline 1800 200 700 for a copy of the factsheet, *Hair Loss and Cancer Treatment*.

Peripheral neuropathy

With peripheral neuropathy, you may experience tingling or numbness in your fingers and toes. It is best to protect your hands and feet from extremes of temperature. Keep them well wrapped up in cold weather. If you also have diabetes, keep your feet clean and avoid any tight-fitting shoes, socks or tights. For a free copy of the factsheet, *Peripheral Neuropathy*, call the National Cancer Helpline on 1800 200 700.

Hand-foot syndrome

This is pain, swelling and redness of your hands and/or your feet. It is due to small amounts of chemotherapy leaking out of the tiny blood vessels in the palms of your hands and soles of your feet. It can look like sunburn, where your skin begins to peel as well. It is temporary and will improve once treatment stops. It can help to avoid friction and heat, so do not rub your skin or put pressure on it. Ice packs may help.

Do tell your nurse or doctor if you notice this side-effect. It might not always be seen if it just happens on your feet. The drug dosage may need to be reduced or stopped. Your doctor can also prescribe medication to relieve any pain. They can also advise you on what creams to use, e.g. lanolin or Eucerin.

Other side-effects

If you have any other side-effect or symptom that concerns you, tell

your doctor or nurse straight away. He or she will give you advice. If you would like more information on chemotherapy, call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Understanding Chemotherapy*.

**To sum up**

- Chemotherapy is a treatment using drugs that cure or control cancer.
- Chemotherapy can be given in tablet form, directly into a vein as an injection, or by intravenous infusion (drip).
- Your nurse and doctor will give you information about any possible side-effects.
- Side-effects can be controlled by medication.

Biological therapies

New drugs and different ways of treating bowel cancer are being developed all the time. One new form of drug treatment is called monoclonal antibodies. This is not chemotherapy but a biological treatment. These drugs affect the blood supply to the tumour and so prevent the growth of cancer cells. As a targeted therapy, it affects only cancer cells and not healthy cells. This means there are no chemotherapy side-effects. Monoclonal antibodies can make chemotherapy drugs work better as well. Bevacizumab (Avastin®), cetuximab (Erbix®) and panitumumab (Vectibix®) are examples of this type of treatment.

There are some side-effects of monoclonal antibodies, such as rashes, blood clotting, high blood pressure, etc. These side-effects are usually short term and improve over time. Your doctor can prescribe medication if they become a problem for you.

See page 44 for more information on research and clinical trials of new drugs.

>>> Biological therapies affect only cancer cells and not healthy cells.

Radiotherapy

Radiotherapy is a treatment using high-energy rays to kill cancer cells. Radiotherapy is also called radiation oncology and the doctor who specialises in this treatment is called a radiation oncologist. The person giving you your treatment is called a radiation therapist.

The X-rays come from a machine called a linear accelerator. This is known as external beam radiotherapy. The rays are accurately aimed at the cancer cells and a small area of normal tissue around the tumour. This is just in case any cancer cells have spread.

Radiotherapy destroys the cancer cells but can also affect normal cells nearby.



External radiotherapy

When is radiotherapy given?

Neo-adjuvant radiotherapy: Radiotherapy can now be given before surgery for rectal cancer. It can help to shrink the tumour and make it easier for your surgeon to remove. Radiotherapy before surgery also means that there are less side-effects to surgery. Your radiation oncologist will tell you how many sessions you need.

Adjuvant radiotherapy: Radiotherapy can be given after surgery for rectal cancer in case some cancer cells may have been left behind. These remaining cells are so tiny they cannot be found by tests. Adjuvant radiotherapy is given to kill these cells and prevent the cancer coming back.

Radiotherapy for secondary cancer: Radiotherapy may be used to relieve symptoms caused by a rectal tumour where surgery is not possible. It works by shrinking the tumour, which can ease pain and pressure. In some cases you might need more radiotherapy if the

tumour has come back, even if you had this treatment before. Your doctor or nurse might call this palliative treatment.

Chemoradiotherapy: Both chemotherapy and radiotherapy can be given in the same time period, especially for rectal cancer. It may be given before or after surgery. Chemotherapy drugs like 5-FU can make the radiotherapy work better. Your surgeon and doctors will decide if this treatment is best for you.

How is treatment planned?

Before radiotherapy, your doctors and other specialists plan your treatment. Planning is a very important step. Your first visit to the radiotherapy unit will be to plan your treatment only. Radiotherapy is carefully planned so that a high dose is given to the tumour and as little as possible to the nearby normal cells.

Simulation: Simulation is the first stage of planning. You may be asked to lie under a machine called a simulator. This machine will pinpoint the exact area to be treated. It is called the treatment area. You may need a few planning visits before your treatment can go ahead.



A simulator

Skin markings: The skin on the treatment area may also be marked.

This is so that the rays can be aimed at the same area each day. These marks should not be washed off until your course of treatment is finished. Before starting radiotherapy, your radiation therapist will tell you how to look after your skin during and after treatment.

How is treatment given?

Having radiotherapy is quite straightforward. You will be asked to come for treatment every day during the week with a rest at weekends. Your course of treatment can last from 4 to 6 weeks. Each treatment session only takes a few minutes. It will not cause you any pain but you will be

asked to lie still while it is being given. How much treatment you get will depend on the type and size of the tumour. Your doctor will discuss this with you.

Radiotherapy room: Each time you come for treatment you will go into a radiotherapy room. The radiation therapist will ask you to lie or sit in a certain position under a machine called a linear accelerator. Once you are ready, he or she will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you at all times through a closed-circuit camera. You can talk to the staff through an intercom if you wish.

Radiation: External radiotherapy does not make you radioactive. It is safe for you to mix freely with family and friends.

>>> External radiotherapy does not make you radioactive.

Radiotherapy side-effects

Radiotherapy is given directly to the site of the cancer. This means that any side-effects that happen only affect the part of your body being treated. The side-effects can vary from person to person and depend on the amount of radiotherapy received.

Some people get only mild effects. Others get side-effects that may last longer and develop into long-term problems. But before your treatment, your doctor and nurse will explain how these effects can be managed. The side-effects should go away when treatment ends or soon after. But do let your doctor know if they continue.

When your bowel is being treated with radiotherapy, the most common side-effects are:

- Diarrhoea
- Bladder irritation
- Irritation to your back passage (rectal discomfort)
- Skin changes
- Tiredness and fatigue
- Feeling sick (nausea)
- Sexual problems and infertility

Diarrhoea

Passing more than three watery bowel motions a day is known as diarrhoea. This is a fairly common side-effect. You may also have stomach cramps and wind. If this happens, drink lots of clear fluids to replace the fluid you are losing. It is also best to eat a low fibre diet and cut down on fruit and vegetables, brown bread, porridge and beans. There is also medication that can help to stop diarrhoea. Do talk to your radiation therapist and nurse for advice.

Bladder irritation

Your bladder may become irritated during radiotherapy for rectal cancer. This can make you pass urine more often with a stinging or burning feeling. There may be a trace of blood in your urine too. If you get these side-effects, discuss them with your nurse or radiation therapist.

Irritation to your back passage (rectum)

Radiotherapy can cause irritation to your back passage and anus. It can cause a feeling of fullness and pressure there. You may have the urge to empty your bowel but without success when you go to the toilet. It may be itchy around your anus as well as sore. You may also notice a slimy mucous discharge. Piles too may get irritated from the treatment. There are creams and suppositories that you can take to relieve these problems. So do tell your radiation therapist or nurse about them.

Skin changes

During radiotherapy your skin in the treated area may become red, sore and itchy. This can be helped by special creams. Your radiation therapist or nurse can give you advice on suitable creams to buy. You can take baths and showers while on treatment, but avoid perfumed soaps or powders to the treated area. Do not rub the area and when drying your skin, pat it gently with a soft towel.

Tiredness and fatigue

While having radiotherapy and for some time afterwards, you may feel very tired (fatigued). It can often come on in the later weeks of treatment. It is best to allow yourself plenty of time to rest. But try to stay as active as possible without getting overtired. In general the tiredness will ease off gradually once the treatment has ended. For some people the tiredness may last for several months. See page 38 for more details on fatigue.

Feeling sick (nausea)

You may feel sick while having radiotherapy. Eating small meals often should help. Your doctor can also give you medication to prevent you feeling or being sick. Do talk to your doctor or nurse if you feel sick.

Sexual problems and infertility

Both men and women can have sexual problems due to radiotherapy treatment. In some cases, it can cause infertility. See page 40 for more details.

Other problems

If you would like more information on radiotherapy or other side-effects, call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Understanding Radiotherapy*.

**To sum up**

- Radiotherapy is a treatment using high-energy rays to cure or control cancer.
- It is used more often in the treatment of rectal cancer.
- Radiotherapy is painless and each treatment session only takes a few minutes.
- Your treatment may go on for 4–6 weeks.

What follow-up do I need?

Once your treatment is over, you will need regular check-ups. Your doctor or nurse may refer to this as follow-up. Your first visit might be 4–6 weeks after surgery. At first these check-ups will be quite often but gradually become less frequent. The check-ups usually involve seeing your doctor and having tests such as a physical exam, X-rays, scans, a colonoscopy and blood tests.

If you are between check-ups and have a symptom or problem that worries you, let your doctor know or your specialist nurse, if available. Make an appointment to see him or her as soon as possible.

The follow-up will continue for at least 5 years. In general, if the cancer has not returned after 5 years, you are considered cured. Because of the genetic link in bowel cancer, talk to your doctor about getting other family members screened.

Even if the cancer does come back, it can still be treated. This could include more surgery, chemotherapy and radiotherapy.

**Should I quit smoking?**

It is never too late to quit smoking. If you quit, it reduces your chances of developing other cancers and illnesses. These include emphysema, heart disease, stroke and osteoporosis. Smoking can also affect the treatment of cancer. For example, it can reduce how well chemotherapy or radiotherapy works. It can also make their side-effects worse. Sometimes it may cause rarer side-effects such as breathing and heart problems. This is because radiotherapy can make body organs like the lungs more sensitive to tobacco smoke.

How can I quit?

Like many others, you may find giving up smoking hard. But with the right information and support you can do it. If you would like advice or support on quitting, call the National Smokers' Quitline on CallSave 1850 201 203. It is open Monday to Saturday from 8am to 10pm.

If you would like further personal support locally, the helpline can put you in touch with the smoking cessation officer in your area. For more information on giving up smoking, see www.giveupsmoking.ie

Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.

How can I cope with fatigue?

Fatigue is a fairly common symptom of cancer and often described as an overwhelming tiredness. The reasons for fatigue can be many and varied. Often it can be due to treatment, in particular chemotherapy and radiotherapy. If your red blood cells are low, this can cause fatigue as well. The anxiety of a cancer diagnosis can also lead to fatigue over time.

Lifestyle changes

The effect of fatigue on your lifestyle can be huge. It may affect your appetite or prevent you from doing your favourite pastimes and activities. You may also find it hard to concentrate or make decisions. You may have to stop working for a time. Discuss with your doctor about a suitable time to return to work. Do not drive until you are well enough to concentrate and feel confident to make a quick movement, like an emergency stop. Check with your insurance company if they will cover you directly after surgery.

How is fatigue helped?

Cancer treatment: For many patients, treatment can relieve symptoms such as pain and nausea. This can also help fatigue and get you back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

Sleep and rest: Get as much rest as possible. If you are feeling very worried and find it hard to sleep at night, ask your doctor or nurse for advice.

Counselling: If anxiety is a problem, talk to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

Exercise: If you are able to do physical exercise, do some regularly. Ask your doctor or nurse for advice on what type will suit you. For example, a half-hour walk 3 days a week might be a realistic goal and will boost your morale when you achieve it.

Housework/childcare: Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping.

Enjoyment: Save your energy for doing the things you most enjoy. If you are going somewhere special, have a rest before you go out.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



Tips & Hints – fatigue

- Get out of bed each morning at the same time and get dressed.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs such as ironing, etc.
- Build rest periods into your day.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Ask for help with housework or childcare or at work.
- Do some gentle exercise each day like walking to the shop or yoga.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.
- Go to bed each night at the same time.
- Make sure your bedroom is quiet and not too hot or cold.
- Use relaxation techniques to get to sleep: relaxation tapes, yoga, meditation, etc.



Will treatment affect my sex life and fertility?

Sex and sexuality

For some people sex is an important part of their relationships, while it is less so for others. During treatment you may lose the desire for sex. This is normal and there can be many reasons for it.

Physical problems: Some aspects of treatment, such as losing your hair or having a colostomy, may make you feel less sexually attractive. You may also just feel too tired or perhaps not strong enough for the level of physical activity you are used to during sex. If your treatment is making you feel sick, then you may want to delay having sex for a while.

Anxiety: Anxiety or stress may play a part in losing your desire for sex. Often this anxiety is not about sex but other things. You may be worried about your chances of surviving your cancer, how your family is coping with your illness, or about your job and finances. Your emotions may be turned upside down and you may find it hard to relax. These are all normal feelings at this time.

Resuming sex: There is no set time for you to be ready to have sex again. It varies from person to person and may take a while. Often it depends on how long it takes you to adjust to your illness and treatment. Most changes are usually short term.

Support: If you have a supportive partner, talking about your feelings may help ease your anxiety. Your partner may have anxieties too and could be waiting for a sign that you are ready to discuss them. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

Talking: Discuss your worries before your treatment starts. Don't feel guilty or embarrassed about talking to your doctor or nurse. They are there to help you. They may suggest useful ways or medications to help you. If the problem is affecting you deeply, you can be referred for specialist counselling if you wish. Call the National Cancer Helpline 1800 200 700 for advice in confidence.

After surgery

Most people have no problem resuming their sex life after bowel surgery. You should do so when it is comfortable for you and your partner. This may be a number of weeks after your surgery. For others, resuming sex may cause problems, especially if their rectum has been removed (proctectomy). In this case, do talk to your doctor and specialist nurse for advice. They may advise you to see a sex therapist, if you think it would be helpful.

Colostomy and sex

If you have a colostomy it may change the way you feel about your body. You may also have concerns about how your partner will react. Try to talk to your partner about the way you are feeling. Talking can help to ease your anxiety. If you need more advice, talk to your doctor. He or she can refer you for special counselling if you feel it would help.

Food and drink: It is best to limit your food intake before sex. Also, watch the types of food you eat. You could plan times for sex when a bowel movement is less likely. Although the ostomy pouch is usually changed when about one-third full, you should empty the pouch before sexual intimacy.

Intimacy: You may be afraid that the bag will interfere with sex, become dislodged or cause damage to the stoma. These are all normal fears. But an empty and flat bag will not become loose from the stoma. It can be rolled up or taped down so it will not get in the way.

Decorative covers: It is possible to wear decorative covers as well. There are also a variety of pouches to suit your needs. Smells can also be controlled. Your stoma care nurse can give you advice on any of these matters.

Sexual problems

Men: Sometimes surgery to the rectum can affect the nerves and blood supply to the sexual organs. For men, this may result in problems having an erection and ejaculation. But this usually clears up over time. In some cases, it may last much longer.

Women: For women who have surgery to the rectum, sex may be painful. This happens because the vagina narrows and shortens after surgery. In some cases, this can also bring a loss of sensation or less vaginal secretions. Usually simple solutions, such as lubricants, can help these problems.

Your doctor can advise you about any medical treatment that could help. Before surgery, he or she will also discuss the possible risks of such problems developing.

During and after chemotherapy or radiotherapy

Chemotherapy: There is no reason why you cannot have an active sex life while on chemotherapy. Not unless you have problems due to surgery. The side-effects of chemotherapy depend on the drugs used and vary from one person to another. You may notice that feeling tired reduces your desire for sex.

Radiotherapy: Many people continue to enjoy an active sex life when they are getting radiotherapy. The side-effects depend on the area being treated and vary from one person to another. Your skin may become red and sore where you are getting treatment. Other side-effects such as diarrhoea and tiredness may also affect your desire for sex. Talk to your radiation therapist or nurse for advice.

Contraception and fertility

Contraception: If you are having sex and are fertile, you must use a reliable method of contraception. There is a risk of miscarriage or birth defect in children conceived during or just after treatment. It is best not to get pregnant for at least 2 years after the end of your chemotherapy or radiotherapy. This is so you can give your body the time to recover.

Fertility: Sometimes your fertility can be affected by chemotherapy and radiotherapy. This side-effect may be temporary or permanent. It depends on the amount of chemotherapy or radiotherapy you receive. If you need further information talk to your doctor or nurse, who will answer your questions in more detail. It is possible to store sperm or eggs for future assisted reproduction. This takes place at the HARI Unit at the Rotunda Hospital in Dublin. See page 72 for contact details.

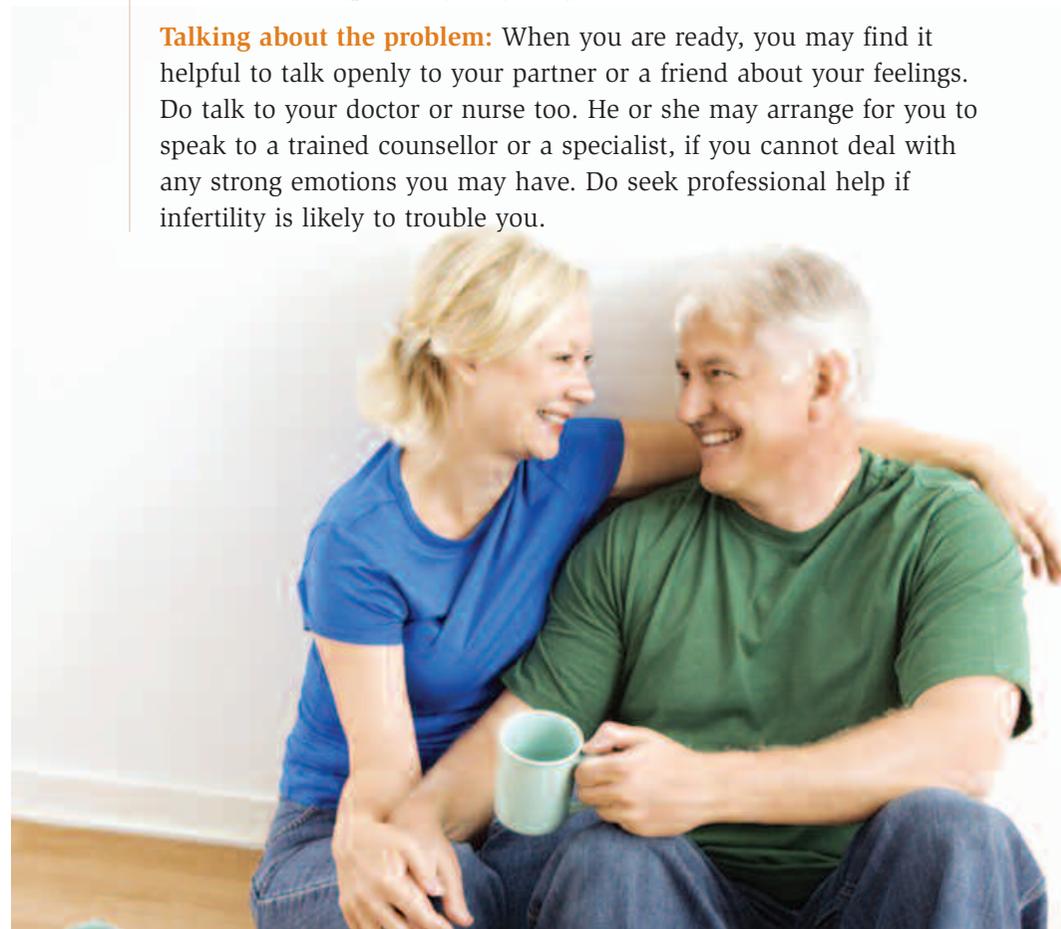
>>> Research continues on reducing the effects of chemotherapy on fertility.

Coping with infertility

Feelings and emotions: It is not easy to come to terms with infertility. You may feel devastated if told you can no longer have children. The sense of loss can be painful regardless of your age or gender. It can take a while to sort out your emotions and be able to talk about them.

Sometimes it can feel as though you have lost a part of yourself. You may also feel less of a man or a woman because you cannot have children. This is a normal reaction. Indeed people's reactions to infertility can vary. You may shrug it off or accept it calmly when first told. The full impact may only hit you when treatment is over.

Talking about the problem: When you are ready, you may find it helpful to talk openly to your partner or a friend about your feelings. Do talk to your doctor or nurse too. He or she may arrange for you to speak to a trained counsellor or a specialist, if you cannot deal with any strong emotions you may have. Do seek professional help if infertility is likely to trouble you.





Research – what is a clinical trial?

Research into new ways of treating bowel cancer goes on all the time. Many patients with cancer take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.



Phases of research

There are many stages or phases when research is being done. If a drug or treatment looks as if it might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur, and see which cancers can be treated.

If early studies suggest that a treatment may be both safe and effective, further trials are done. These aim to:

- Find out if the treatment is better than existing ones.
- Find out if extra benefits result when the new treatment is given along with existing ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits in doing this. You will be helping to improve knowledge about bowel cancer. You will also be carefully monitored during and after the study, so you will be quite safe.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, and you understand what it is about. This is called **informed consent**. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. You are also free to withdraw from a trial at any time if you change your mind.

As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your blood or cancer cells. For a free factsheet on clinical trials, call the National Cancer Helpline 1800 200 700 or visit our website www.cancer.ie.

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Lots of people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country you live in. In Ireland cancer treatments are based on scientific research. This allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments which doctors mainly use to treat people with cancer. These standard treatments include surgery, radiotherapy, chemotherapy and biological treatments. They use tried and trusted methods where the experience with patients is over a long period of time. Many of these treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- | | |
|------------------|--------------------------------|
| ■ Meditation | ■ Acupuncture |
| ■ Relaxation | ■ Music, art and dance therapy |
| ■ Visualisation | ■ Nutrition therapy |
| ■ Gentle massage | ■ Shiatsu |
| ■ Aromatherapy | ■ Yoga |
| ■ Reflexology | ■ Hypnotherapy |

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that cancer can often bring. Some complementary therapies also focus on the spiritual dimension of a person. This can aid healing and promote a sense of well-being. Nowadays complementary therapies are often provided in hospitals, cancer treatment centres and support centres and can be given safely.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism.

Because these therapies are not based on scientific evidence it is very hard to prove if they work for most people or not. The diet therapy can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition.

Alternative treatments can interfere with standard treatment and may not be managed properly. Most doctors do not believe that such treatments can cure or control cancer.

Special diets

Many people who have been treated for bowel cancer worry about what they eat and may decide to try an alternative diet. In practice, these may be harmful for you. It is best to eat a well-balanced diet and one that you enjoy. If you are underweight or losing weight, your dietitian will give you advice on what to eat. If you are overweight, talk to your dietitian about safe ways to lose weight at a suitable time.



If you decide to have complementary or alternative treatments...

Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects.

For that reason, it is important to talk openly with your GP or oncologist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to suggest therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present, this area is not fully regulated in Ireland. Ensure that the practitioners you plan to visit are qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, make sure the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700.

Coping and emotions

Reactions to a cancer diagnosis

There are many possible reactions when told you have bowel cancer. Reactions can often differ from person to person. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis. Others might appear or reappear later during your treatment. Or it may not be until you recover from your illness that your emotions hit hard.



Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. It may take a long time to come to terms with your emotions. Not only do you have to cope with the knowledge you have cancer but also the physical effects of treatment. If you would like more information or to talk in confidence, call the National Cancer Helpline 1800 200 700. You can also ask for copies of the booklets, *Understanding the Emotional Effects of Cancer* and *Who Can ever Understand? Talking about your Cancer*.



Shock and disbelief

*'I can't believe it.'
'It can't be true.'*

Shock is often the first reaction to a diagnosis of cancer. Most people think 'It will never happen to me'. Usually it takes a while for the news to sink in. At this time you may be getting a lot of information about your illness. You may be asking the same questions over and over again or seem to accept the news calmly. These are all common reactions. Because you don't quite believe what is happening, you may not want to talk about your illness, especially to your family and close friends.

Fear and uncertainty

*'Am I going to die?'
'Will I be in pain?'*

For most people when told they have cancer the first question is 'Am I going to die?' Cancer is a very scary word and people think the worst. But nowadays many cancers can be cured. When a cure is not possible, the cancer can often be controlled for many years using modern treatments. And new treatments are being developed all the time.

Another common fear is that cancer is always painful. This is not true. Some cancers cause no physical pain at all. If you do get pain, there are many drugs that can control it. Other ways to relieve pain are radiotherapy and nerve blocks.

Being concerned about your future is a normal way to feel. It can often be hard for your doctor to predict the outcome of your treatment. Not knowing can make you feel anxious. But the more you find out about your illness and treatment, the less anxious you will become.

Sometimes you may have fears about cancer and worry unnecessarily. Talk to your doctor and nurse about your worries. He or she can advise you. Discuss it with your family and friends as they are probably worried too.

Loss of control

*'I can't cope with this.'
'I'll never get through it.'*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident making any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

Sorrow and sadness

*'I used to be so healthy.'
'I had so many plans.'
'I've let my family down.'*

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

Denial

*'There is nothing really wrong with me.'
'I haven't got cancer.'*

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious.

Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

Anger

'Why me of all people?' 'And why right now?'

Anger can hide other feelings such as fear or sadness. As a result, you may vent your anger on those closest to you. You may also feel angry towards the doctors and nurses caring for you. If you have a religious belief you may feel angry with God.

It is easy to see why you may be deeply upset by many aspects of your illness. But don't feel guilty about your angry thoughts or irritable mood. They are all natural reactions. Relatives and friends may not know that your anger is really about your illness and not at them. It may help to tell them this when you are not feeling so angry. Or if you find that too hard, perhaps you could show them this page of the booklet.

If you are finding it hard to talk to your family, tell your nurse or doctor who can give you advice.

Blame and guilt

'If I hadn't ... this would never have happened.'

Sometimes people blame themselves or others for their illness. Or they may wonder why it should happen to them. This may be because we often feel better if we know why something has happened. As doctors rarely know exactly what has caused cancer, there is no reason for you to blame yourself.

Resentment

'It's all right for you, you haven't got to put up with this.'

You may feel resentful and miserable because you have cancer while others are well. This is normal. Similar feelings of resentment may crop up from time to time during your illness and treatment for various reasons.

Relatives too can sometimes resent the changes that your illness makes to their lives. It is usually helpful to bring these feelings out into the open. That way, they can be aired and discussed. Bottling up resentment can make everyone feel angry and guilty.

Withdrawal and isolation

'Please leave me alone.' 'I just need to be on my own.'

At times during your illness you may want to be left alone and withdraw from people. It is normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

How can I cope with my feelings?

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem, confidence and well-being. As a result, it may be easier to deal with cancer.

- 1 Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- 2 Live one day at a time:** Take some time off for your treatment as well as time afterwards to recover. Don't think about the future too much. Take one step at a time. Concentrate on getting through each

day of tests or treatment. That way, you may find it easier to cope with your illness.

- 3 **Live well:** Eat as well as you can. Eat little and often, including lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.
- 4 **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while to adjust to your new routine. Change can also bring new opportunities and blessings.
- 5 **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low, but don't feel guilty about it as it will pass.
- 6 **Seek information:** Information can help overcome your fears. Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects to expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones. Call 1800 200 700 for a free copy of *Journey Journal* to help you keep track of your cancer treatment.
- 7 **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.

- 8 **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.
- 9 **Seek professional help:** If you have low moods or strong emotions talk to your close friends and family – or someone who is a good listener. If they are still getting the better of you, discuss them with your nurse and doctor. They may advise you to see a trained counsellor or other specialist.
- 10 **Spiritual care:** When faced with cancer, you may start thinking about the meaning of life and the afterlife. Sometimes spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation can help you focus on what has value and meaning in your life. Even if you don't consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary medicines have a spiritual dimension and may help you focus on being positive and hopeful.
- 11 **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling, they can give more support too. *Who Can Ever Understand? Talking about Your Cancer* is a booklet written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



How can my family and friends help?

Families and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give advice if needed. Others may gather up-to-date information on cancer to know what you can expect and what you are going through. Others again may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friends best.



How can I talk to someone with cancer



When someone close to you has bowel cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with your own feelings too.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may think you are not doing much by just listening. In fact, it is one of the best ways to help.

Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of those with cancer. Call the National Cancer Helpline on 1800 200 700 for a free copy.

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to changes in their lives.

Every family deals with cancer in a different way. You may feel that you do not want your illness to upset family life. Or you may feel guilty that you cannot do activities with your children or that you're letting them down. These are all natural feelings to have at this time.

Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news.

>>> **Being honest with your children really helps.**

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more. Talk to children in language they will understand. But avoid going into the details of your illness.

It is best to prepare children for what to expect from the side-effects of treatments. For example, if you are going to lose your hair, tell them before it happens. Answer their questions simply and honestly.

It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

Coping with children's emotions

During your illness, your children may experience many emotions. They can range from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief. Your family may also find new depths of love and inner strength that will boost your life together.

If you need extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a copy, call the National Cancer Helpline 1800 200 700.



Support resources

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Family doctor (GP)
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society helpline nurses

Medical social worker: The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on benefits, entitlements and services available when you go home.

Cancer nurse specialists: Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. These nurses along with other members of your medical team work together to meet your needs.

Psycho-oncology services: In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

GP (family doctor): You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

Community health services: When you go home, there are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as transport costs, financial worries, etc. All these people in community health services can provide advice and support. More information on the services is available either from the social worker in the hospital before you go home or at your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. For example, the Bowel Cancer Support Group. They can give you practical advice about living with bowel cancer and support you and your family at time of diagnosis, throughout treatment and afterwards. Cancer support centres are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet.

Irish Cancer Society: The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information or practical advice about your financial matters. For example, getting life insurance. Call 1800 200 700 for information about any of the services outlined above or for support services in your area.

>>> Remember that there are many people ready to help you.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances



At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge of 50c per item up to a limit of €10 per family per month.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical

appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €120 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Quinn Healthcare, AVIVA Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI scan, PET scan. Sometimes it might take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



For a free copy of *Social Welfare Support: A Guide for Cancer Patients*, contact the National Cancer Helpline 1800 200 700.

Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare

benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social Protection.

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Benefit

If you are employed but wish to care for a sick relative full time, you might qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Leave

By law you may be entitled to unpaid temporary leave from your employment. Carer's leave allows you to leave your employment for

up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection. For more information, contact the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Appliances

For patients who have medical cards most appliances are free of charge. For example, colostomy bags. Also, if you receive chemotherapy and suffer from hair loss, you are entitled to 1–2 free or subsidised wigs or hairpieces every year.

Travel to hospital

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

See page 71 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you.

Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending

For social welfare queries, contact:

Dept of Social Protection – Information Service	Tel: 1850 662 244
Oisín House	Leaflet line: 1890 202 325
212–213 Pearse Street	Email: info@welfare.ie
Dublin 2	Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

HSE infoline: 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

HSE East Coast Area
[Co Wicklow, South East Dublin]
Southern Cross House
Southern Cross Business Park
Boghall Road
Bray
Co Wicklow
Tel: 01 201 4200

Co Kildare
Tel: 045 880 400

HSE Northern Area
[North Dublin]
Swords Business Campus
Balheary Road
Swords
Co Dublin
Tel: 01 813 1800

HSE Midland Area
[Counties Laois, Offaly, Longford, Westmeath]
Head Office
Arden Road
Tullamore
Co Offaly
Tel: 057 932 1868

HSE South Western Area
[Co Kildare, West Wicklow, South Dublin]
Oak House
Millennium Park
Naas

HSE Mid-Western Area
[Counties Clare, Limerick, Tipperary North]
Head Office
31/33 Catherine Street
Limerick
Tel: 061 483 286

HSE North Eastern Area
[Counties Cavan, Monaghan, Louth and Meath]
Head Office
Navan Road
Kells
Co Meath
Tel: 046 928 0500

Lacken
Dublin Road
Kilkenny
Tel: 056 778 4100

HSE North Western Area
[Counties Donegal, Sligo, Leitrim and West Cavan]
Head Office
Manorhamilton
Co Leitrim
Tel: 071 982 0400 / 1850 636 313

HSE Southern Area
[Counties Cork and Kerry]
Head Office
Wilton Road
Cork
Tel: 021 454 5011

HSE South Eastern Area
[Counties Carlow, Kilkenny, Wexford, Waterford, South Tipperary]
Head Office

HSE Western Area
[Counties Galway, Mayo and Roscommon]
Head Office
Merlin Park Regional Hospital
Galway
Tel: 091 751 131

Information is also available from your local Citizens Advice Centre. A list of these centres is available from:

Citizens Information Board (formerly Comhairle)

Ground Floor, George's Quay House, 43 Townsend Street, Dublin 2
Tel: 01 605 9000; Locall 1800 777 121
Email: info@ciboard.ie; Website: www.citizensinformation.ie

There are also some booklets available that may help you. These include:

- *Information Guide to Health Services* (published by the Dept of Health and Children). Copies are available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers.
- *Guide to Social Welfare Services* (published by the Dept of Social Protection). Copies are available from the Dept of Social Protection. Tel: 01 874 8444. Email: info@welfare.ie. Website: www.welfare.ie
- *Entitlements for People with Disabilities* (published by Comhairle). Copies are available from the Citizens Information Board. Tel: 01 605 9000 / 1890 777 121. Email: info@ciboard.ie Website: www.citizensinformation.ie



If you have financial worries...

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from cancer if you are worried about providing for your family and keeping a roof over your head.



There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 71 for more details. You can also call the National Cancer Helpline 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 1890 283 438. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 72 for contact details.

Irish Cancer Society services

The Irish Cancer Society funds a range of cancer support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres providing cancer information
- Cancer support groups
- Peer-to-peer support
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The freefone helpline 1800 200 700 is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- **Message Board** is a discussion space on our website (www.irishcancer.ie) to share your stories, ideas and advice with others.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

Daffodil Centres providing cancer information

Daffodil Centres are located in a number of Irish hospitals. They were set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give enquirers a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 73 for more details.

Peer-to-peer support

Many patients find it helpful to talk to someone who has had a diagnosis of cancer and who has recovered. For example, the Bowel Cancer Support Group. The Irish Cancer Society can put you in touch with someone who has been trained to give you emotional and practical support. All volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. If you would like to make contact with a volunteer, please call the National Cancer Helpline 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the helpline 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses

The Society funds oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.

Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid.

The Travel2Care scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

Travel2Care: If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society.

Financial Aid: For this kind of help, contact the social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society.

See our website for more information: www.cancer.ie

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected and trained. You, the patient, are collected from your home, driven to your appointment and brought back home again.



If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.



Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline: 1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Bowel Cancer Support Group

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Cancer Research Ireland

Website:
www.cancer.ie/research/why.php

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2933
Email: info@carersireland.com
Website: www.carersireland.com

Dept of Social Protection – Information Service

Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1850 662 244
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted Reproduction Ireland)

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion HSE

Website: www.healthpromotion.ie

All-Ireland Cooperative Oncology Research Group

Website: www.icorg.ie

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Freefone 1890 283 438
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers

AVIVA Health

(formerly VIVAS Health)
PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.vivahealth.ie

Quinn Healthcare (formerly BUPA)

Mill Island
Fermoy
Co Cork
Locall: 1890 700 890
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
Tel: 01 872 4499
CallSave 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

ARC Cancer Support Centres

Dublin and Cork (see pages 74 and 76).

Bowel Cancer Support Group

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

CanTeen Ireland

Young Peoples' Cancer Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Freefone: 1800 200 700
Email: canteen@oceanfree.net
Website: www.canteen.net

I've Got What?!

[Support for young adults affected by cancer]
c/o Cross Cause Charity Shop
Blackrock
Co Louth
Tel: 086 339 5690

Connaught support groups & centres

Athenry Cancer Care

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080

Ballinasloe Cancer Support Centre

Society Street
Ballinasloe
Co Galway
Tel: 090 964 5574 / 087 945 2300
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590
Email: caraiorrais@gmail.com

CD's Helping Hands

Lakeview Point
Corporate Park
Claregalway
Co Galway
Tel: 091 799 749
Email: info@cdshelpinghands.ie
Website: www.cdshelpinghands.ie

Gort Cancer Support Group

The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220

Inis Aoibhinn – Cancer Care West

Costello Road
University College Hospitals Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: mayocancersupport@eircom.net
Website: www.mayocancer.ie

Roscommon Cancer Support Group

Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: vitahouse@eircom.net

Sligo Cancer Support Centre

44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website:
www.sligocancersupportcentre.ie

Tuam Cancer Care Centre

Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support groups & centres**ARC Cancer Support Centre**

ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group

25 Kingshill
Arklow
Co Wicklow
Tel: 085 110 0066
Email: arklowcancersupport@gmail.com

Balbriggan Cancer Support Group

74 Castleland
Parkview
Balbriggan
Co Dublin
Tel: 086 164 2234

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net
Website: www.cuisle.com

Dóchas – Offaly Cancer Support

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: dochasoffaly@eircom.net
Website: www.dochasoffaly.ie

Dundalk Cancer Support Group

Philipstown
Hackballs Cross
Dundalk
Co Louth
Tel: 086 107 4257

Éist – Carlow Cancer Support Group

5 Mount Clare Court
Carlow
Tel: 085 144 0510

Gary Kelly Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100 086 195 9864
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport
Website:
www.greystonescancersupport.com

HOPE

Enniscorthy Cancer Support &
Information Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie

Lakelands Area Retreat & Cancer Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Little Way Cancer Support Centre

4 Woods Way
College Road
Clane
Co Kildare
Tel: 045 902 996
Email: littlewayclane@eircom.net
Website:
www.littlewaycancersupport.com

Little Way Cancer Support Centre

8 Stanhope Street
Athy
Co Kildare
Tel: 059 863 3725

Manorhamilton Cancer Support Group

(Leitrim)
Tel: Maura Farry 071 985 6220

Rathdrum Cancer Support Centre

34 Main Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Stillorgan Cancer Support

c/o Marsham Court
Stillorgan
Co Dublin
Tel: 01 288 5725

Tallaght Cancer Support Group

Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486

Wicklow Cancer Support Centre

1 Morton's Lane
Wicklow
Tel: 087 691 4657 / 0404 32696

Munster support groups & centres

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE – Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: cancersupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Kerry Cancer Support Group

Acorn Centre
47 Liosdara
Oakpark
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@live.ie
Website: www.kerrycancersupport.com

Listowel Cancer Support Group

Bedford
Listowel
Co Kerry
Tel: 068 21741 / 087 237 0766

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhaven.com

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South East Cancer Foundation

7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net
Website: www.secf.ie

Suimhneas Cancer Support Centre

2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Youghal Cancer Support Group

161 North Main Street
Youghal
Co Cork
Tel: 024 92353

West Cork Cancer Support

Community Work Department
HSE Skibbereen
Co Cork
Tel: 027 53485 / 086 862 5417

Ulster support groups & centres

Cootehill Community Centre Support Group

Cootehill
Co Cavan
Tel: 087 622 0000

Éist – East Inishowen Cancer Support Group

c/o Serenity House
2 Montgomery Terrace
Moville
Co Donegal
Tel: 074 938 2874

Gary Kelly Support Centre

Monaghan
Tel: 086 195 9864 / 041 980 5100

Living Beyond Cancer

Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674)

Solace – Donegal Cancer Support Centre

St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

For other support groups or centres in your area, call 1800 200 700.

Useful contacts outside Republic of Ireland

Action Cancer

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society

Website: www.cancer.org

Beating Bowel Cancer (UK)

Harlequin House
7 High Street
Teddington TW11 8EE
London
Tel: 0044 8450 719300
Website: www.beatingbowelcancer.org

Bowel Cancer UK

4 Rickett Street
London SW6 1RU
Tel: 0044 20 7381 9711
Email: admin@bowelcanceruk.org.uk
Website: www.bowelcanceruk.org.uk

The Colostomy Association (UK)

2 London Court
East Street
Reading RG1 4QL
Tel: 0044 118 939 1537
Email: cass@colostomyassociation.org.uk
Website: www.colostomyassociation.org.uk

Cancer Network Buddies

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerresearchuk.org
Website: www.cancerhelp.org.uk

Healthtalkonline

Website: www.healthtalkonline.org

Lynn's Bowel Cancer Campaign (UK)

39 Crown Road
Twickenham TW1 1EJ
Tel: 0044 20 8892 2409
Email: info@bowelcancer.tv
Website: www.bowelcancer.tv

Macmillan Cancer Support (UK)

89 Albert Embankment
London SE1 7UQ
Tel: 0044 207 840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust

77–81 Lisburn Road

Belfast BT9 7AB

Tel: 028 9069 9202

Email: cancerinfo@belfasttrust.hscni.netWebsite: www.cancerni.net**Memorial Sloan-Kettering Cancer Center (US)**Website: www.mskcc.org**National Cancer Institute (US)**Website: www.nci.nih.gov**Royal Marsden Hospital Foundation NHS Trust**

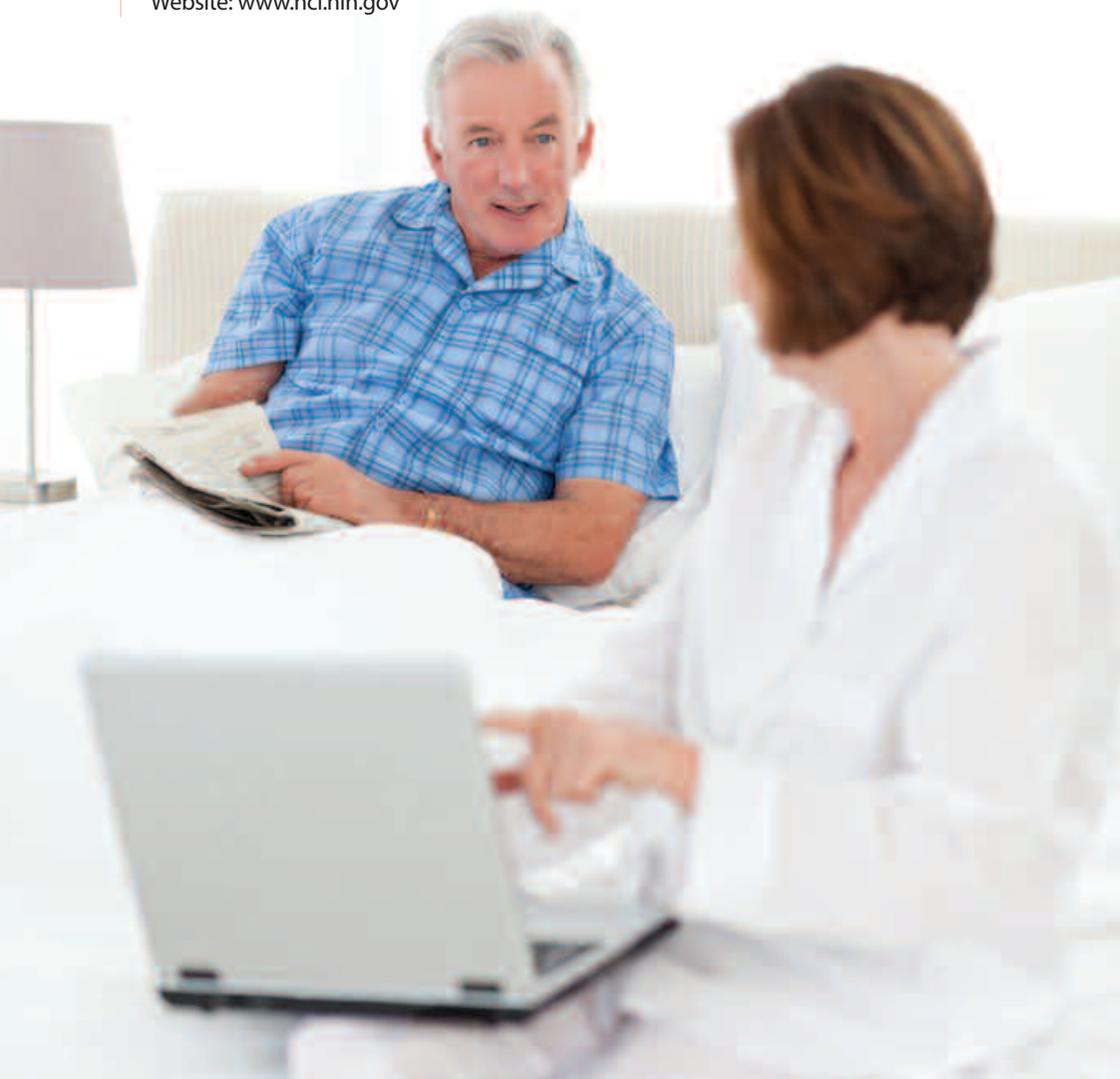
Trust

Website: www.royalmarsden.org**Ulster Cancer Foundation**

40/42 Eglantine Avenue

Belfast 9BT9 6DX

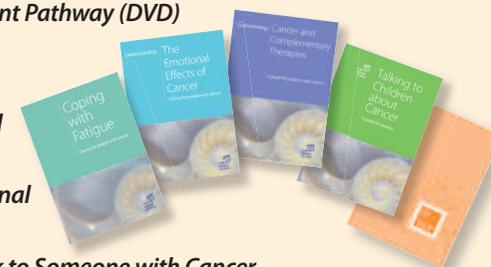
Tel: 048 906 63281

Website: www.ulstercancer.co.uk

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Radiation Therapy: A Patient Pathway (DVD)*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding Cancer and Complementary Therapies*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking about Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Social Welfare Support: A Guide for Cancer Patients*
- *Journey Journal: Keeping Track of Your Cancer Treatment*

***Living with Bowel Cancer: Eating Well***

Beating Bowel Cancer, 2011

[Download from

www.beatingbowelcancer.org]***Bowel Cancer Surgery: Your Operation***

Beating Bowel Cancer, 2011

[Download from

www.beatingbowelcancer.org]***Cancer at Your Fingertips*** (2nd edn)

Val Speechley & Maxine Rosenfeld

Class Publishing, 2001

ISBN 1859590365

Taking Control of Cancer

Beverley van der Molen

Class Publishing, 2003

ISBN 1859590918

Treating Bowel Cancer: Your Pathway

Beating Bowel Cancer, 2010

[Download from

www.beatingbowelcancer.org]***44½ Choices You Can Make If You Have Cancer***

Sheila Dainow, Jo Wright & Vicki Golding

Newleaf, 2001

ISBN 0717132226

101+ Square Meals

[Budget and nutrition]

Norah Bourke et al

MABS/HSE West/Paul

Partnership/Limerick VEC/Safefood, 1998

ISBN 187407514X

[For more details see www.mabs.ie]

Questions to ask your doctor

Here is a list of questions people often ask. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

- What type of bowel cancer do I have? Where exactly is it?
- What tests do I need?
- What is the stage of my cancer?
- What type of treatment do I need?
- Why is this treatment better for me?
- How successful is this treatment for my cancer?
- Are there other treatment options?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- Are there any clinical trials available to me?
- What side-effects will I get?
- How will my bowels be affected during treatment?
- Should I eat special foods or change my diet?
- Do I need to use contraception during my treatment? What will happen if I, or my partner, get pregnant?
- Is there anything I can do to help myself during treatment?
- Who can I contact in an emergency?
- What kind of follow-up do I need when my treatment is over?
- Do my family have a higher risk of bowel cancer?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer



Notes



Notes



Acknowledgements

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Elizabeth Tobin, Cancer Information Service Nurse

Claire Gildea, Clinical Nurse Specialist (Radiation Oncology)

Mary Casey, Medical Social Worker

Dorothy Dunne, Colostomy Care Group

Grace McEvoy, Stoma Nurse Specialist

Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline 1800 200 700.

Would you like to be a patient reviewer?

If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers. Please fill in the postcard in the pocket inside the back cover, and post it back to us for free.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at reviewers@irishcancer.ie

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes patient education booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email fundraising@irishcancer.ie

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The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life, with three programme areas to achieve them: advocacy, cancer services and research.

