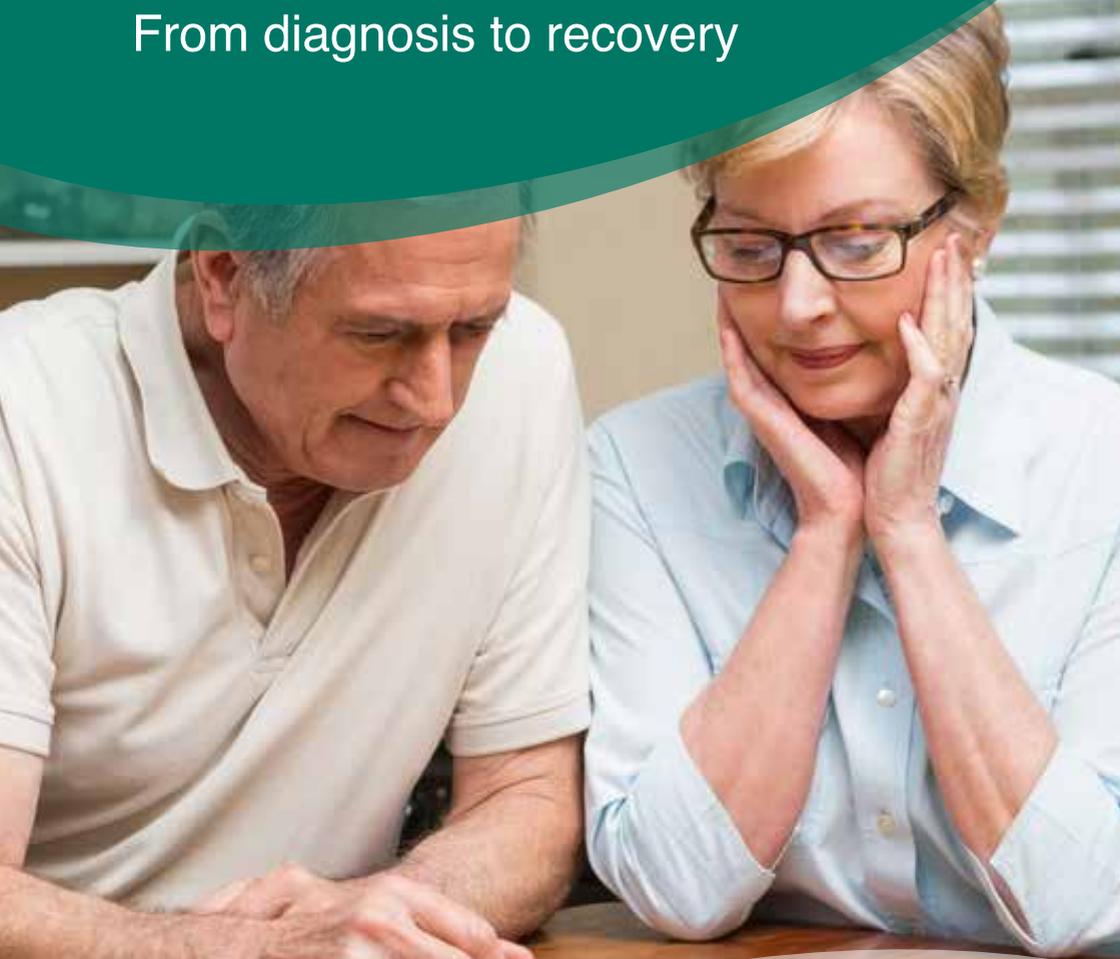


Bowel cancer

From diagnosis to recovery



Marie Keating

FOUNDATION

making cancer less frightening by enlightening

Some of the information in this booklet is taken with permission from the patient information website of Cancer Research UK.
www.cancerresearchuk.org/about-cancer

April 2016

About this booklet

We have developed this booklet because we recognise that bowel cancer is one of the most common cancers in Ireland. About 2,500 men and women are diagnosed here each year.

Being diagnosed with and treated for bowel cancer is a journey full of ups and downs. Some days will be better than others. Your experience will be unique to you, but the challenges you face may be similar to those faced by the thousands of bowel cancer patients and survivors living in Ireland today.

This booklet seeks to answer some of the common questions that people who have been diagnosed with bowel cancer have.

This booklet looks at:

- What is bowel cancer pg 4
- How does it affect you pg 9
- Supportive personnel pg 17
- Feelings and emotions pg 26
- Diet and nutrition pg 30
- Physical affects and sexuality pg 34
- Coping with fatigue pg 39
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- How the Marie Keating Foundation can help you pg 50

There is plenty more information available on our website www.mariekeating.ie.

What is bowel cancer?

The bowel is part of the digestive system. It is divided in two:

- The small bowel; and
- The large bowel.

The food we eat ends up in the large bowel. Here, water and some nutrients are absorbed, leaving waste. Waste passes through the rest of the large bowel before leaving the body.

Bowel cancer includes cancers of the large bowel and back passage (rectum).

The large bowel is also sometimes called:

- The large intestine; or
- The colon.

The small bowel is also sometimes called:

- The small intestine.

Bowel cancer is sometimes called colorectal cancer.

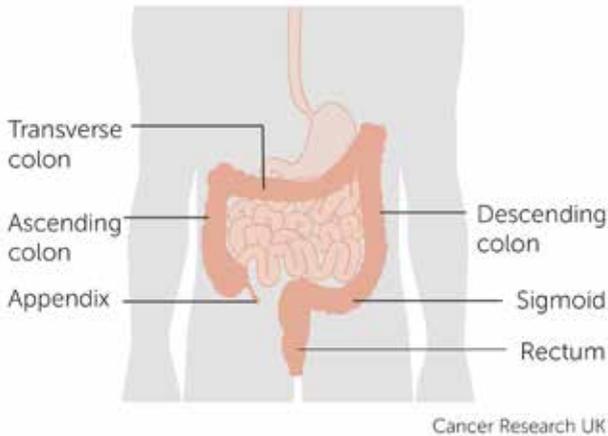


Figure 1: The parts of the colon, also called the large bowel or the large intestine

Image courtesy of Cancer Research UK

Symptoms of bowel cancer

The symptoms of bowel cancer can include:

- Bleeding from the back passage or blood in your poo;
- A change in normal bowel habits;
- A lump that your doctor can feel in your back passage or abdomen (more commonly on the right side);
- A feeling of needing to strain in your back passage (as if you need to pass a bowel motion), even after opening your bowels;
- Losing weight;
- Pain in your abdomen or back passage; or
- A lower than normal level of red blood cells (anaemia).

The 'stages' of bowel cancer

The 'stage' of a cancer means how big it is and whether or not it has spread. This is important because treatment is often based on the stage of a cancer.

Diagnosing the stage of cancer

'Clinical' stage testing

The tests and scans you have when diagnosing your cancer gives information about the 'clinical' stage.

'Pathologic' stage testing

During surgery the doctor finds out more about the cancer. The tissue the surgeon removes, including the lymph nodes, is carefully examined in the laboratory. These results are combined with the clinical stage to give a 'pathological' stage. This is more accurate than the clinical stage.

The pathological stage may be different to the clinical stage. For example, the surgeon may find that the cancer is more advanced than it looked on the scans.

On your staging report, you may see a lower case letter (c or p) written before the stage. This shows that it is the clinical or pathological stage.

TNM staging system

Your doctor will then decide what 'stage' your cancer is at using the 'TNM' staging system. TNM stands for:

- **T**umour
- **N**ode
- **M**etastases.

The TNM staging system describes:

- The size of a primary tumour (T);
- If any lymph nodes contain cancer cells (N); and
- If the cancer has spread to another part of the body (there is metastasis) – (M).

T – Tumour size

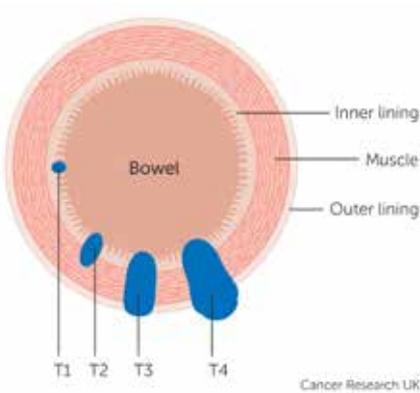


Figure 2: The T stages of bowel cancer

Image courtesy of Cancer Research UK

There are 4 stages of tumour size in bowel cancer:

- T1 means the tumour is only in the inner layer of the bowel;
- T2 means the tumour has grown into the muscle layer of the bowel wall;
- T3 means the tumour has grown into the outer lining of the bowel wall; and
- T4 means the tumour has grown through the outer lining of the bowel wall.

At stage T4, the tumour may have grown into another part of the bowel, or other nearby organs or structures. Or it may have broken through the membrane covering the outside of the bowel (the peritoneum). See Figure 2: the T stages of bowel cancer.

N – Lymph nodes

There are 3 possible stages describing whether or not cancer cells are in the lymph nodes.

- N0 means there are no lymph nodes containing cancer cells;
- N1 means that 1 to 3 lymph nodes close to the bowel contain cancer cells; and
- N2 means there are cancer cells in 4 or more nearby lymph nodes.

M – Cancer spread

There are 2 stages of cancer spread (Metastasis).

- M0 means the cancer has not spread to other organs; and
- M1 means the cancer has spread to other parts of the body.

Your doctor puts the T, N and M results together to give you your stage. For example, you may see a bowel cancer described as T2, N0, M0. This means:

- The tumour has grown into the muscle layer of the bowel wall;
- There is no evidence of cancer cells in the lymph nodes; and
- No evidence of spread to other parts of the body.

Stage 1 bowel cancer

The cancer is in the inner lining of the bowel. There is no cancer in the lymph nodes. In TNM staging, this is the same as:

- T1, N0, M0;

Stage 2 bowel cancer

The cancer has grown into the muscle layer of the bowel wall. In TNM staging, this is the same as:

- T2,N0,M0

Stage 3 bowel cancer

The tumour has grown into the outer lining of the bowel wall. In TNM staging, this is the same as:

- T3,N0,M0

Stage 4 bowel cancer

The cancer has grown through the outer lining of the bowel wall. It may have grown into another part of the bowel or other nearby organs or spread to other parts of the body (such as the liver or lungs) through the lymphatic system or bloodstream: In TNM staging, this is the same as:

- T4, any N, M1.

Grading of bowel cancer

As well as the stage of bowel cancer, doctors also consider what the cancer cells look like under the microscope (the grade) when deciding on treatment. The grade tells you how normal or abnormal the cancer cells are. As a normal cell grows and matures, it becomes more specialised for its role and place in the body. This is called differentiation. A pathologist grades bowel cancer as:

- Grade 1 (low grade) – the cancer cells are well differentiated, which means they look quite similar to normal cells
- Grade 2 (moderate grade) – the cancer cells are moderately differentiated, which means the cells look more abnormal
- Grade 3 (high grade) – the cancer cells are poorly differentiated, which means they look very abnormal

The grade gives doctors an idea of how the cancer is likely to behave. A low grade cancer is likely to be slower growing and less likely to spread than high grade cancers.

How does bowel cancer affect you?

Coping with your diagnosis

It can be very difficult coping with a diagnosis of bowel cancer, both practically and emotionally. At first, you are likely to feel very upset, frightened and confused. You may feel that things are out of your control.

It is very important to get the right information about your type of cancer and how it is best treated. People who are well informed about their illness and treatment are better able to make decisions and cope with what happens.

Many people survive bowel cancer, but treatment can be hard and it takes time to fully recover. You may have side effects that generally improve over the weeks and months after treatment, but for some these may be long lasting.

Coping practically with bowel cancer

As well as coping with the fear and anxiety that a diagnosis of bowel cancer brings, you may also have to work out how to manage practically. There may be money matters to sort out. You may need information about financial support, such as:

- Benefits;
- Sick pay; and
- Grants.

See the later section in this booklet:

- 'Coping with financial implications'.

Ask for help

Just try to remember that you don't have to sort everything out at once. It may take some time to deal with each issue. Do ask for help if you need it. Your doctor or specialist nurse will know who you can contact for help. They can put you in touch with people specially trained in supporting those with cancer. These people are there to help so do use them if you feel you need to.

Staff can support you

You may need access to support staff, such as a stoma nurse or dietitian. Social workers can help you with information about your entitlement to sick pay and benefits. If you live alone, a social worker may be able to help by organising convalescence when you first come out of hospital.

What to expect

How bowel cancer can affect you physically

Bowel cancer and its treatment may cause physical changes in your body. These changes can be very difficult to cope with and may affect the way you feel about yourself.

Surgery for bowel cancer may cause scarring. It can be especially difficult if you need to have a colostomy or ileostomy. You will then need support to help you learn how to deal with it. These body changes can affect your self esteem and the way you relate to other people, especially close family and friends.

After bowel surgery or radiotherapy you may have loose stools or diarrhoea for some time. Diarrhoea is more likely if you have had a large part of your bowel removed. You may also have diarrhoea alternating with constipation. Your doctor or specialist nurse can advise you on managing any changes in your bowel habits. If you are in a sexual relationship, one or all of these changes may affect your sex life.

In the section 'Physical effects and sexuality' there is information about:

- Coping with a stoma;
- Diarrhoea; and
- How bowel cancer can affect your sex life.

You may find that you need to change your diet to help your bowel work as normally as possible.

- See 'Diet and nutrition after bowel cancer', later in this booklet.

Another problem you may have to cope with is feeling very tired and lacking in energy a lot of the time, especially for a while after treatment or if your cancer is advanced.

- The 'Fatigue' section later in this booklet has more information

Treatment options

‘Surgical oncology’

Treating cancer with surgery is known as ‘surgical oncology’. Some types of cancer can be treated with surgery. This involves cutting away malignant tissue. Your doctor may recommend surgery for a number of reasons:

- Confirming a diagnosis;
- Removing a tumour;
- Staging (judging the size and extent of the cancer);
- Reconstructing a part of the body; and
- Palliative surgery to relieve symptoms.

You may have surgery before or after other cancer treatments such as:

- Chemotherapy; or
- Radiotherapy.

Different cancers may respond to different types of treatment and your treatment plan will be designed specifically for you. Your case will be discussed at a multidisciplinary meeting where all specialists in bowel cancer come together.

Eight cancer centres

There are eight ‘designated cancer centres’ in Ireland that provide surgery and multidisciplinary care for cancers. These centres should give you quick access to high quality diagnosis and treatment. In general, you will be referred for care to the designated cancer centre closest to your home. There is a list of these centres and contact details in the section: ‘Supportive personnel’.

Some of your cancer care will be provided in a wider number of acute hospitals, for example:

- X-rays;
- CT scans;
- Blood tests;
- Chemotherapy; and
- Palliative care.

Radiotherapy

If you have bowel cancer you may receive radiotherapy:

- To destroy a tumour;
- To control symptoms, like pain;
- Before surgery to shrink your tumour so it is easier to remove; or
- After surgery, to destroy any small amounts of tumour that may be left.

In recent years there have been significant developments in clinical research and improvements in radiotherapy equipment which allow for more accurate treatment and less damage to non-cancerous cells. These new technologies enable patients to receive more accurate and precise treatment, frequently over a shorter time period.

These developments include:

- Intensity-modulated radiotherapy (IMRT);
- Image guided radiotherapy (IGRT); and
- Stereotactic radiotherapy.

Brachytherapy is a specific type of internal radiotherapy in which the radioactive material is placed directly into or near a tumour using a special needle, wire or catheter.

All radiotherapy centres in Ireland offer external beam radiotherapy. Brachytherapy, intensity modulated and image guided radiotherapy is available for specific tumour types in all centres.

Biological therapy

Many patients who are diagnosed with bowel cancer will need some treatment with cancer drugs. Treatment with cancer drugs is usually led by a doctor known as a medical oncologist.

There are four main types of treatment with cancer drugs which together are often known as 'systemic therapy'.

Chemotherapy

Chemotherapy drugs slow the process of cancer cells growing or multiplying. They are also sometimes called 'cytotoxic drugs'. You may receive chemotherapy as a tablet that you swallow, or by injection.

The chemotherapy drugs doctors commonly use to treat bowel cancer include:

- Fluorouracil (also called 5FU) – often given with a vitamin called folinic acid;
- Capecitabine (Xeloda);
- Oxaliplatin (Eloxatin); and
- Irinotecan (Camppto).

You may have chemotherapy before surgery for cancer of the back passage (rectal cancer). The chemotherapy aims to shrink the cancer and make it easier to remove during surgery. Chemotherapy before surgery is called neo-adjuvant chemotherapy (pronounced nee-oh-ad-joo-vant). You are likely to have this alongside radiotherapy (chemo-radiation).

You may have chemotherapy after surgery for bowel cancer. This is to reduce the chance of the cancer coming back and is called adjuvant chemotherapy.

You may also have chemotherapy as a treatment for bowel cancer that has spread (advanced bowel cancer).

Daily life with chemotherapy

Some people find that they can lead an almost normal life during chemotherapy but others find everyday life more difficult.

You may feel unwell during and shortly after each treatment, but recover quickly between treatments. You may find you can get back to your usual activities as you begin to feel better.

If you are taking chemotherapy tablets at home, you may notice very little change to your everyday life. You may be able to work and carry on your usual social life. Some people manage by working part time or only between treatments. You may find that working helps you to cope with your cancer and distracts you or you may prefer to stop working while you are having your treatment.

Some treatments are harder going than others, and everyone is different. So it is best to do whatever you feel is right for you.

As well as feeling unwell physically, it is not unusual for people to have ups and downs emotionally. It can be difficult coping with a diagnosis of cancer and having treatment.

So you may find you have good and bad days. Remember that there isn't a right and a wrong way to be.

Side effects of chemotherapy can include:

- Fatigue;
- Nausea and vomiting;
- Hair loss;
- Being vulnerable to infection;
- Anaemia;
- Bruising and bleeding;
- Pain and inflammation on the inside of your mouth;
- Loss of appetite;
- Skin becomes dry and sore;
- Short-term memory loss;
- Reduced libido;
- Loss of fertility, temporary or permanent;
- Hand and foot syndrome
- Peripheral neuropathy
- Diarrhoea and constipation; and
- Depression.

Living with and adapting to the side effects of chemotherapy can be challenging, but it is important to realise that most, if not all, side effects will disappear once treatment is complete.

Immunotherapy

Immunotherapy drugs specifically target cancer cells by inducing, enhancing or suppressing the body's natural immune response. Some of these drugs may also be known as 'monoclonal antibodies'.

Hormonal

Hormonal treatments interfere with the role of hormones in helping some cancers to grow.

Biological

Biological drugs help the immune system to fight cancer.

How is cancer drug treatment provided?

You may receive your cancer drugs as a:

- Tablet;
- Capsule;
- Liquid that you swallow; or
- By an injection.

Drugs provided as tablets may often be taken by you in your own home or sometimes in the hospital. It is important that you follow the instructions given to you on how to take the tablets and how often.

If you need to receive cancer drugs by injection, you will need to attend a hospital for your treatment but usually won't need to stay overnight.

Treatment is usually provided in a special area of the hospital and you can usually sit in an armchair or a couch when receiving it. The amount of time needed to get your drug depends on the type of drug. It could last from under an hour to several hours. Specially-trained oncology nurses are on duty while you are in the hospital receiving your treatment.

Drugs which are provided by injection into a vein are known as 'intravenous' or 'IV'. These drugs are usually administered through a 'drip' or through an IV syringe or 'IV push'.

In some cases, you may have a 'port' inserted that will stay in place for some time to allow for easy access to a vein.

As well as injections into a vein, your cancer drugs may be injected in other ways, including:

- Under the skin (sub-cutaneous);
- Into a muscle (intra-muscular); or
- Into an artery (intra-arterial).

You may also receive other types of medication to help ease the side effects of the cancer drugs you receive. These may include medicine to help with:

- Nausea;
- Diarrhoea; and
- Chills.

Supportive personnel

Specialist surgeons

Surgical oncologists are surgeons who devote most of their time to the study and treatment of malignant tumours. They have the necessary knowledge, skills, and clinical experience to perform standard and extraordinary surgical procedures needed for people with cancer.

Surgical oncologists can also diagnose tumours accurately and tell the difference between benign and cancerous tumours. They understand radiation oncology, medical oncology, and haematology.

Clinical Nurse Specialists

In ideal circumstances, Clinical Nurse Specialists (CNS):

- Give you information about the disease and side effects;
- Give you emotional support;
- Help you make decisions;
- Assess your fitness for starting and maintaining treatment;
- Are part of the multidisciplinary team looking after you;
- Introduce you to the oncology liaison nurse
- Organise transport, accommodation and funding of these if you need it; and
- Are always available to you and your family.

Oncology liaison nurses

The role of the oncology liaison nurse is to meet the needs of people with cancer including:

- Psychological;
- Emotional; and
- Information.

They work with you in the:

- Inpatient oncology unit;
- Oncology day unit; and
- Throughout the hospital with people who are referred to the oncology service through a consultant.

Oncology liaison nurses also provide support to the family and significant others, through listening, problem solving, and education. They provide outreach support to patients at home and help patients who need referral to specialist services.

Stoma nurses

The stoma nurse is responsible for helping you adjust to living with either a permanent or temporary stoma:

- A colostomy;
- Ileostomy; or
- Urostomy.

Your stoma nurse will show you how to care for your stoma and the skin around it. A number of different protective pastes, membranes and powders are available. Your stoma nurse will show you how to use these, and what to do if your skin becomes damaged or sore.

The role of the stoma nurse includes:

- Pre-operative counselling;
- Immediate post-operative care and education; and
- Follow-up assessment and counselling after you are discharged from hospital.

Public Health/Community Nurse

A Public Health nurse may come to your home to help you with wound care and other aspects of your treatment. A Public Health Nurse is sometimes called a community nurse.

Psycho-oncologists

The psycho-oncology service is usually part of the psychological medicine service which aims to provide expert, compassionate care to patients with cancer who are attending the hospital. It aims to:

- Recognise psychological distress early;
- Deliver best practice in terms of interventions; and
- Promote psychological well-being.

This service is available in some of the larger hospitals:

- During your diagnosis; and
- Through treatment and recovery.

This service includes interventions and expertise ranging from psycho-education and self-directed learning to specific interventions. These interventions may be provided by:

- Senior Clinical Nurse Specialists;
- Principal Clinical Psychologists; and sometimes
- Consultant Psychiatrists.

Where to go for complementary therapy

When you are treated in hospital for cancer you receive what we call 'standard medical treatment'. Complementary treatments can be given along with standard treatment, but it is extremely important to make sure you have discussed the possibility with your oncologist or nurse before you plan this kind of therapy.

Many people find some of these therapies very helpful during their illness. They may help you to cope better with some of the physical side-effects of cancer and the distressing emotions that cancer can raise. Some therapies like these can also focus on spiritual healing.

These are examples of different types of complementary therapies:

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

If you are interested in any of these complementary therapies, do speak to your oncologist first. Many of these therapies will be on offer in your local cancer support centres.

Alternatively, you can speak to your GP who can provide a contact for you.

You will very likely need a supporting letter from your oncologist to receive this treatment. You will also receive a full assessment from a health professional at the support centre to make sure you are getting the right type of therapy for you. See a list of cancer support centres at the end of this section.

Counselling organisations

Coping with a diagnosis of cancer can be very difficult and very stressful on you and your family. A cancer diagnosis will change how you think about things and life itself will change.

Sometimes it is hard to come to terms with your diagnosis and you and your family will experience some reactions which are very common and normal. These emotions may include:

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

It may be difficult for you to come to terms with these feelings and emotions. You may even find it difficult to talk to close friends or relatives. It is therefore important for you to recognise this and ask for help. Counselling can provide you with the emotional support you need in a professional and confidential place.

If you feel that counselling is something you or a member of your family may need, do speak to your oncologist first. There are many qualified counsellors available in your local cancer support centres. Alternatively you can speak to your GP who can provide a contact for you.

You or any member of your family will receive a full assessment from a health professional or counsellor at the support centre to make sure you are getting the right type of support for you and your family.

Designated Cancer Centres and cancer support centres

Cancer treatment works best when the treatment team deals with large numbers of cases. This is why cancer care is mainly delivered in eight hospitals around Ireland. These hospitals can provide very specialised care for your type of cancer.

On the next pages you will see contact details for these Designated Cancer Centres; and for cancer support centres around the country.

Ireland's eight Designated Cancer Centres			
Area	Cancer Centre	Phone	HSE Region
Dublin North East	Beaumont University Hospital; www.beaumont.ie/oncology	Main switch: 01-809 3000	HSE Dublin – North East
Dublin East	Mater University Hospital; www.mater.ie	Oncology: 01-803 4447	HSE Dublin – North East
	St Vincent's University Hospital; www.stvincents.ie	Main switch: 01-221 4000	HSE Dublin – Mid Leinster
Dublin Midlands	St James's University Hospital; www.stjames.ie	Main switch: 01-410 3000 Stoma care: 01-410 3899	HSE Dublin – Mid Leinster
South/Southwest	Cork University Hospital; www.cuh.hse.ie	Main switch: 021-492 2000	HSE South
	Waterford Regional Hospital; www.hse.ie/waterfordregional/	Main switch: 051-848 000	HSE South
West/Northwest	Galway University Hospital http://www.saolta.ie/	Main switch: 091-524 222	HSE West
	Satellite: Letterkenny General Hospital; www.hse.ie/go/LGH/	Main switch: 074-912 5888	HSE West
Midwest	University Hospital Limerick; www.hse.ie/eng/services/list/3/hospitals/ulh/uhl/	Main switch: 061-301 111	HSE West

Cancer support centres - Ireland

Go to www.mariekeating.ie for a more comprehensive list

Name	Address	Phone	Email
Leinster			
ARC House	65 Eccles Street, Dublin 7	01-830 7333	info@arccancersupport.ie
Arklow Cancer Support Centre	25 Kings Hill, Arklow, Co Wicklow	085-110 0066	arklowcancersupport@gmail.com
Cancer Support Sanctuary LARCC	Coole Road, Multyfarnam, Mullingar, Co Westmeath	1850 719719/ 044-937 1971	info@cancersupport.ie
Cois Nore – Kilkenny Cancer Support Centre	Walkin Street, Kilkenny, Co Kilkenny	056-775 2222	coisnorekilkenny@gmail.com
Dochas Offaly Cancer Support	Teach Dóchas, Offaly Street, Tullamore, Co Offaly	057-932 8268	info@dochasoffaly.ie
Gary Kelly Cancer Support Centre	George’s Street, Drogheda, Co Louth	041 9805100	phil@gkccancersupport.com
Greystones Cancer Support	La Touche Place, Greystones, Co Wicklow	01-287 1601	info@GreystonesCancerSupport.com

Cancer support centres - Ireland

Go to www.mariekeating.ie for a more comprehensive list

Name	Address	Phone	Email
Hope Cancer Support Centre	22 Upper Weafer Street, Enniscorthy, Co Wexford	053-923 8555	info@hopesupportcentre.ie
Midland Area Cancer Support Centre	Cancer Support Sanctuary LARCC, Coole Road, Multyfarnham, Mullingar, Co Westmeath	044-937 1971	info@cancersupport.ie
Purple House Cancer Support Bray	Aubrey Court, Parnell Road, Bray, Co Wicklow	01-286 6966	info@purplehouse.ie
The Cuisle Centre	Cancer Support Service, Block Road, Portlaoise, Co Laois	057-868 1492	cuislecentre@eircom.net
Connaught			
Mayo Cancer Support Association	Rock Rose House, 32 St Patrick's Avenue, Castlebar, Co Mayo	094-903 8407	info@mayocancer.ie
Sligo Cancer Support Centre	44 Wine Street, Sligo, Co Sligo	071-917 0399	scsc@eircom.net
East Galway and Midlands Cancer Support Centre	Le Cheile, Brackernagh, Ballinasloe, Co Galway	090-964 2088	info@egmcancersupport.com

Cancer support centres - Ireland

Go to www.mariekeating.ie for a more comprehensive list

Name	Address	Phone	Email
Clare Cancer Support Centre	Kilnamona, Ennis, Co Clare	1850 211 630	admin@clarecancersupport.com
Munster			
Cancer Information and Support Centre	Mid-Western Cancer Foundation, Dooradoyle, Limerick	061 210979	maria.keane@hse.ie
Cork ARC Cancer Support House	Cliffdale, 5 O'Donovan Rossa Road, Cork	021 4276688	ellen@corkcancersupport.ie
South Eastern Cancer Foundation/The Solas Centre	The Solas Centre, Williamstown, Waterford	051-304 604	info@solascentre.ie
Suir Haven Cancer Support Centre	Clongour Road, Clongour, Thurles, Co Tipperary	050 – 421197	suirhaven@gmail.com
Ulster			
Donegal Action for Cancer Centre	Moneygreggan, Newtowncunningham, Lifford, Co Donegal	074-912 8400	holmes.betty@gmail.com

Feelings and emotions

There's no right or wrong

You may find that you have different feelings from other people with cancer. This doesn't mean that you aren't coping with your illness. When you are trying to come to terms with an illness there is no right or wrong way to feel. Everyone is different and you will deal with things in your own way. So you can take what you need to help you from this section. Ignore anything that doesn't seem to apply to you or to help.

How you may feel when you are diagnosed

Being diagnosed with cancer is likely to bring up many emotions. Most people feel shocked when they are told they have cancer, and don't know what to think. You may be confused, upset and worried.

Your feelings may not all be negative.

“When I was told I had cancer after my operation, I was relieved. I had been under the weather for 18 months without being diagnosed. Knowing was better than not knowing.”

Shock

Shock is often the first reaction when a doctor tells someone they have cancer. You may:

- Feel numb;
- Not believe what is happening;
- Be unable to express any emotion;
- Find that you can only take in small amounts of information; and
- Need to have the same information repeated to you.

Needing to have information repeated is a common reaction to shock. You just can't take anything in at first.

Your disbelief may be so strong that you find it difficult to talk about your illness with your family and friends. Or you may find that you need to talk about it over and over again to help the news to sink in.

At times, it may feel like an emotional roller coaster. One day you might be quite positive and able to cope. But the next day you could feel so sad and anxious that coping might not seem so easy. All these feelings are completely natural.

Denial

Some people choose to cope with their situation by pretending it's not happening. It's not that this is necessarily a conscious decision. It can be a gut reaction. You may just feel overwhelmed and that you can't think about it whenever anyone brings the subject up. You may find that you:

- Don't want to know anything about your cancer or treatment; or
- Prefer to talk about it as little as possible or not at all.

This is another completely natural reaction. If you feel this way, you can tell the people around you quite firmly that, for the time being, you don't want to talk about your illness.

But in extreme cases, denial can be unhelpful. Some people deny their cancer so firmly that they convince themselves that either they aren't ill at all, or that their illness isn't cancer. If this reaction starts to get in the way of your treatment or makes your overall situation even worse, you may need professional help from a psychologist or counsellor.

Other people being in denial

Sometimes you may find denial happens the other way round. You may need to talk about your cancer, but your family and friends may be the ones in denial.

They may:

- Try to dismiss the fact that you are ill;
- Seem to ignore the fact that you have cancer;
- Play down your anxieties and symptoms; or
- Deliberately change the subject.

People can react in this way because they are frightened of cancer themselves. They may be embarrassed by talking about it. Or they may be terrified that someone they love has a life threatening condition. If they don't talk about it, they can try to pretend it isn't happening.

If you want their support, and to share how you feel with them, this behaviour may hurt or upset you. If you feel like this, try to:

- Tell them how you feel;
- Reassure them that you know what is happening; and
- Explain that talking to them about your illness will help you.

If you are a friend or relative

Relatives and friends can help by:

- Listening carefully to everything the person with cancer says; and
- Not rushing into talking about the illness.

Sometimes it is enough just to listen, letting the person with cancer talk when they are ready. Take your cues from the person. If they get upset, that is okay. It can be a relief for them to be able to cry and say if they are finding things difficult.

Your emotions during and after treatment

People diagnosed with cancer and going through treatment often feel negative. At times, you may think you will never feel well again. Many questions may arise, such as:

- Will I ever feel happy again?
- Am I going to die?
- Why has this happened to me?
- Will I be able to get myself together and enjoy the things that I used to – even my partner or children can't seem to make me feel happy any more?
- People say I must be positive – am I harming myself when I feel so low?

All these thoughts, feelings and questions are very natural and completely understandable.

Your family and friends may expect you to feel back to normal once your treatment finishes. But many people with cancer find that this is the time when the emotional impact of their diagnosis hits them and they need more support. You may miss the support from the doctors and nurses at the hospital.

Some people say they feel a bit abandoned as they no longer belong to their hospital team in the way that they did when they were having the cancer treatment.

Your feelings when you have advanced cancer

If your cancer is very advanced and you are facing the possibility of dying, all these feelings are likely to be more intense. They will take on a different meaning.

Understanding your feelings

Having negative feelings can be very draining for you and the people around you. You might find that family and friends don't understand. Or they may try to tell you how you should feel. This can put a big strain on your close relationships.

Asking for help

Talking about your situation really can help. If you would like to share your feelings with someone, but don't feel you're able to talk to your friends and family, it may help to talk to a counsellor.

Don't feel you are being weak by asking for help or letting someone know how awful you feel. It is not a weakness.

Talking about how you feel is more likely to help you and the people around you than staying silent.

Doctors and nurses in cancer care are very aware of the range of reactions people can have to cancer. There may also be counsellors or psychologists in the cancer team at your centre. They can help you through difficult, emotional times immediately after your diagnosis, during treatment and afterwards. They will be ready to listen to you, give you support, and suggest ways to help you feel more positive about things.

It is also worth finding out what support is available at your local hospice. Many hospices offer all sorts of help to people with advanced cancer. This includes:

- Complementary therapies;
- Counselling; and
- Short stays to give you and your family a break (respite care).

Support outside the family

In the section 'Supportive personnel', there is information about psycho-oncology and complimentary therapists at cancer support centres in Ireland. If you would like to talk to someone outside your own friends and family, look at this section.

Diet and nutrition after bowel cancer treatment

You will find that your digestion takes time to settle down after bowel cancer treatment. Some foods can upset the way your bowel works. After treatment, high fibre foods, such as fruit and vegetables, may give you loose stools. You may need to go to the toilet much more often than normal. If you have had a colostomy you may find that it takes a few months for your bowel to work normally again. If you have had a combination of treatments, you may have permanent changes to your bowel. You may need to avoid certain foods.

Some foods can cause wind, which will go into your stoma bag if you have a colostomy or ileostomy. You may need to experiment a bit to find out which foods upset your system. The foods most likely to cause problems are:

- Very high fibre fruits and vegetables;
- Onions, brussel sprouts and cabbage;
- Pulses such as baked beans or lentils;
- Fizzy drinks, beer and lager; and
- Very rich or fatty foods.

Diet after surgery

When you are well enough to go home after your operation, you will be eating fairly normally. You may be on a low fibre diet for about 6 weeks. You can then gradually increase the amount of fibre in your diet.

Diarrhoea

The large bowel (colon) normally absorbs water as the stool passes through it. So if you have had part of your large bowel removed, your stool may become less solid. If you have had a large part of it removed, you may have diarrhoea. Let your doctor or nurse know if this happens, as they can give you medicine to help control it. It is important to drink plenty of fluids if you have diarrhoea. If you are drinking a lot and still feel thirsty you may need to have a drink that replaces fluid and body salts (an electrolyte replacement drink). Your doctor can advise you about this.

Some foods may upset your bowel

You may find that your bowel starts to work more normally after a few weeks, but particular foods may upset things. You may need to experiment with your diet to find out which foods cause a problem for you. As the bowel settles down you may find that you can start to eat these foods again later on. Everyone is different and there are no set rules about what you should eat. If you have problems you can ask to see a dietitian at the hospital. They can give you tips and help you to work out which foods upset you.

It can help to keep a food diary before you go to see the dietitian. The diary is a record of:

- What you eat
- When you eat
- Any digestive problems and when you have them.

Looking back over a weekly diary you may be able to spot which foods are causing you problems and then cut them out. You may be able to try the food again in a few weeks to see if it causes the same problem.

Tips for diet after bowel surgery

Eat foods high in calories and protein to help with healing and fighting infection. High protein foods include meat, fish and eggs.

Eat small, more frequent meals to begin with rather than 3 large meals a day. Try to avoid long gaps between meals.

It may help to eat a low fibre diet at first. Examples of low fibre foods are:

- White pasta and bread;
- Cream crackers;
- Rich tea biscuits;
- Cornflakes; and
- Vegetables and fruit that are well cooked and peeled.

Drink plenty of fluids – at least 3 to 4 pints or 1.5 to 2 litres a day.

Reduce the amount of caffeine you have in a day. Caffeine can stimulate the bowel and make diarrhoea worse.

Take small mouthfuls and chew your food slowly.

Drinking peppermint water may help relieve trapped wind and so ease discomfort.

Diet after radiotherapy

Radiotherapy to the bowel often causes diarrhoea. This can take a few weeks to settle down after the treatment ends. Your doctor can give you tablets to help control the diarrhoea. If it doesn't improve within 4 to 6 weeks of finishing your treatment, let your doctor know.

While you are getting over your treatment it is best to keep taking the diarrhoea medicines. You can gradually reduce the amount you take. Your doctor or nurse will advise you about how to manage this.

Diet and chemotherapy

Chemotherapy for bowel cancer can give you diarrhoea and may make you feel sick. You may also have a sore mouth. These side effects will disappear after your treatment is over. You can gradually get back to a normal diet.

Diet with a stoma

It normally takes about 6 to 8 weeks for the bowel to settle down after surgery. After this, most people can go back to eating the foods they used to eat before their operation. Your stoma nurse will give you advice about what you can eat and drink shortly after your operation and in the long term.

Diet with a colostomy

Generally you can eat what you like. But some people may find that particular foods cause problems such as wind, a bad smell or looser stool (poo). It's often down to trial and error to find out if a particular food disagrees with you. You can try the food again after a few weeks to see if it is still causing a problem. Once your bowel settles down after your operation, you can gradually increase the amount of fibre in your diet. This will help your stool to be more formed.

Diet with an ileostomy

After surgery, most people are advised to follow a low-fibre diet. If your doctor tells you that you are ready to follow a normal diet or introduce new foods, try to introduce them slowly, with one type of food at each meal. This will allow you to judge the effects of the food on your digestive system. You may find it useful to keep a food diary so you can keep a record of the food you have eaten and how you feel afterwards. For example, you may experience diarrhoea after eating spicy foods, or after drinking alcohol or caffeinated drinks. Keeping a diary will highlight which foods might be causing the issue so that you can avoid them in future.

Physical effects and sexuality

It takes time to come to terms with being diagnosed with cancer and having treatment. It can also be difficult to cope with the physical effects of treatment. If you have had a colostomy or ileostomy operation as part of your treatment, the end of the bowel is brought out into an opening on the abdomen.

What is a colostomy?

A colostomy is a surgical operation in which the colon (main part of the large intestine) is shortened to remove a damaged part and the cut end diverted to an opening in the abdominal wall.

What is an ileostomy?

An ileostomy is a surgical operation in which a damaged part is removed from the ileum (part of the small intestine) and the cut end diverted to an artificial opening in the abdominal wall.

What is a stoma?

In both a colostomy and an ileostomy, the opening is called a stoma.

Some people have a temporary colostomy made during their treatment for bowel cancer.

The colostomy is closed a few months later when the bowel has fully healed. But some people have a permanent colostomy or ileostomy.

It can take a while to get used to dealing with a stoma. You will have help both practically and emotionally. Your stoma nurse can give a lot of advice and support.

Altered body image

It is normal to feel worried about how you will look. You may also worry about how other people react. While you are in hospital the stoma nurse will teach you how to manage the stoma. It might be helpful for a close family member to be there too. Then you can both get used to your colostomy or ileostomy and can ask the nurse questions.

Once you get home, help is still available if you need it. You might have problems or questions about looking after and dealing with your stoma. Or you may feel low or depressed. Do talk to your GP or stoma nurse. They will either be able to help you, or put you in touch with someone who can.

Coping with your stoma

As you learn to look after your stoma, it should affect your daily life less and less. With time, things like going to work, going out socially and taking part in sports and hobbies will feel easier.

Your relationships and sex life

You may worry about how the stoma will affect your relationships with a partner or with friends. You may have practical worries about the stoma bag being noticeable, leaking or smelling. Or you may have emotional worries about your friends or partner rejecting you.

Stoma bags are very well designed. They can't be seen through your clothes and should not smell or leak.

Many people find that if they talk openly to close family and friends their fears of rejection disappear. Most people want to understand what is happening so they can help you. It may help to read our section about sex, sexuality and cancer.

If the stoma bag smells

If the stoma bag smells it could be due to the bag not fitting properly or it could be due to diet. There are anti odour products that can help. You can ask your stoma nurse about these.

Types of colostomy bag

Stomas are different shapes and sizes. If the bag doesn't fit properly you are likely to have problems with smell and possibly leakage. You could get in touch with a stoma nurse at your hospital. They can get different types of bags for you to try. If you don't have a stoma nurse, ask your GP or surgeon to refer you. You might have to try a few before you find the one that suits you best.

Some bags have charcoal filters built into them. Charcoal is good for absorbing smells and the filter lets gas escape from the bag so that it doesn't get too full and uncomfortable. If the bag fits properly you should only be aware of the smell when you are changing or emptying the bag.

Anti-odour products

Some products can help to mask the smell from a colostomy. They are often liquids, and you use a few drops each time you change your bag. These are a last resort, because you shouldn't have this problem if at all possible. But some people have difficulty finding the perfect fit for their colostomy bag and these products can then help.

Rectal discharge

After having a stoma, some people may have discharge from the back passage. The discharge is mucus from the lining of the bowel. The mucus may leak out of the anus, or you may feel the urge to go to the toilet. The mucus is normally clear or white, and looks a bit like egg white or glue. Sometimes the mucus dries up into a ball inside the rectum and can cause pain.

Depending on the type of stoma you have, a small amount of faeces may pass into the bottom part of the bowel, resulting in a brown discharge.

How often and how much rectal discharge there is varies in different people. It may be once every few weeks or months, or a couple of times a day. If the mucus looks green, smells or has blood in it, you should let your stoma nurse or doctor know as you may have an infection.

Sitting on the toilet every day and gently bearing down (without straining) may help you to pass the mucus out of your rectum naturally. Some people may need a suppository to help loosen the mucus. If you are worried about leaking discharge unexpectedly, you may want to wear a small absorbent pad to protect your clothes.

If mucus does leak out, it can make your skin sore. So you may want to use a barrier cream to help protect your skin. If you are having radiotherapy, you should check with the team looking after you before using any creams. After a shower, remember to pat your skin dry with a towel rather than rub it.

Although having rectal discharge may feel embarrassing, the team looking after you will be very used to supporting people with this. Your stoma nurse can give you advice on what to expect and how to deal with any discharge.

Coping with diarrhoea

When going back to your normal diet, it's a good idea to introduce one food a day at first. You can keep a food diary and make a note if a particular food causes cramps or diarrhoea. If so, you can try it again in a few weeks to see if it has the same effect. The small bowel is narrower than the large bowel, and so some foods such as celery, tough fruit skins, nuts and mushrooms, may cause a blockage. This is usually only temporary but can cause pain and cramps. When you start to eat these types of foods again, try eating them in small portions and chew them really well. It is important to drink plenty.

Side effects of radiotherapy

Radiotherapy destroys cancer cells in the area of the body it is aimed at. The treatment also affects some of the normal cells nearby. Radiotherapy affects people in different ways, so it's difficult to predict exactly how you will react. Some people have only mild side effects but for others the side effects are more severe.

Before you start your treatment, talk about any likely side effects with the staff in your radiotherapy team. Knowing about the side effects may help you to prepare and to manage any problems.

Side effects during treatment

The main side effects of radiotherapy treatment include:

- Tiredness and weakness;
- Sore skin; and
- Loss of hair in the treatment area.

Most people feel tired while they are having radiotherapy, particularly if they are having treatment over several weeks. This is because the body is repairing the damage to healthy cells, or tiredness can be due to low levels of red blood cells (anaemia).

Some people get sore skin in the area being treated. The skin may look reddened or darker than usual. It may also get dry and itchy. The skin may break or small blisters can start to form in the area. The staff in the radiotherapy department can advise you on the best way of coping with this. Radiotherapy makes the hair fall out in the treatment area. Hair in other parts of the body is not affected. The hair should begin to grow back again a few weeks after the treatment ends.

Long-term side effects of radiotherapy

It is important to ask your doctor, specialist nurse or radiotherapist about the possibility of long-term side effects. Depending on the position of the cancer the possible long-term effects may include:

- A change in skin colour in the treatment area;
- Loss of ability to become pregnant or father a child (infertility);
- Low sex drive;
- Erection problems (impotence);
- Long term soreness and pain;
- Bowel changes; and
- Bladder inflammation.

Coping with fatigue

We all feel fatigue at times – maybe when we are working too hard, worrying about something or just doing too much partying! Fatigue for people with cancer can be very different. The cancer or its treatment may make you feel very tired. It can go on for weeks, months or even years after you finish treatment. This is called chronic fatigue, which means long lasting. Most people get back to their normal energy levels from between 6 months to a year after the end of cancer treatment, but it can take longer.

Radiotherapy and fatigue

Most people feel tired while they are having radiotherapy, particularly if they are having treatment over several weeks. This is because the body is repairing the damage to healthy cells, or tiredness can be due to low levels of red blood cells (anaemia).

You may also feel weak and as though you don't have the energy to do your normal daily activities. This may last for a few weeks after the treatment ends. Rest if you need to and try to exercise a little when you can. This may help to reduce the tiredness.

Fatigue in cancer is common

Fatigue is very common in people with cancer. It can be the most troubling symptom. It affects between 7 and 9 out of every 10 people (70 to 90%). Many people with cancer say that it is the most disruptive side effect of all. In the past, doctors and nurses haven't always appreciated the long-term effects of fatigue on people with cancer. But there is now a lot of research into this area. Things are improving and there are ways of relieving fatigue.

You are not imagining your cancer fatigue. It is very real and can have a big impact on your life. If you have symptoms of fatigue, let your doctor or nurse know. There are ways of managing fatigue and your medical team will try to help you.

Learning to manage fatigue

You can do many things in your everyday life that will help to save your energy. Taking short cuts on some things or getting help from other people may help you feel less tired.

- Try not to rush – plan ahead where possible.
- Allow plenty of time for travel, and avoid the rush hour if possible.
- Put chairs around the house so that you can easily stop and rest if you need to.

- Sit down to dry off after your bath or shower, or simply put on a towelling dressing gown and let that do the work.
- Have some hand rails fitted in your bathroom to hold on to when you get in and out of the shower or bath (the hospital can help to arrange this for you).
- Prepare your clothes and lay them out in one place before you dress.
- Get dressed sitting down, as far as you can.
- Try not to bend too much – rest your foot on your knee to put socks and shoes on.
- Fasten your bra at the front first and then turn it to the back.
- Wear loose fitting clothes, and things with few buttons to do up.
- Where possible do household tasks sitting down – for example, peeling vegetables or washing up.
- You can also do ironing sitting down or buy clothes that don't need ironing.
- Use a duster on a long stick and sit to do dusting.
- Write a shopping list and go when the shops are quiet; or do your grocery shopping online.
- If you have children, play games that you can do sitting or lying down – reading, puzzles, board games or drawing.
- Ask family and friends for help with shopping, housework or collecting the children from school.
- Have plenty of nutritious snacks and drinks in, so you can have something quickly and easily whenever you feel like eating.
- Don't forget to do things that you enjoy – it will take your mind off your cancer and make you feel more relaxed.

Coping with the financial implications of cancer

Benefits for people who are sick or have a disability

There are a number of social welfare payments for people who are sick or who have a disability. Payments are made either by the Department of Social Protection or the Health Service Executive (HSE). To qualify for a social welfare payment because you are sick or have a disability you must be certified as sick or disabled by a doctor.

You can qualify for certain payments if you are sick for just a short time. For other payments you need to show that you have an illness or disability that will last longer than one year. Some social welfare disability payments are based on your PRSI contributions. If you do not have enough PRSI contributions you may qualify for a similar social assistance payment, however, you must pass a means test.

- Illness Benefit is intended for those with a short-term illness.
- Invalidity Pension is a long-term payment.

Illness Benefit and Invalidity Pension are both social insurance payments based on your PRSI contributions.

Partial Capacity Benefit

This is a scheme which allows you to return to work (if you have reduced capacity to work) and continue to receive a payment from the Department of Social Protection. To qualify for Partial Capacity Benefit you need to be getting either Illness Benefit (for a minimum of 6 months) or Invalidity Pension.

Disability Allowance

This is a long-term social assistance payment for those aged 16-65 with a disability expected to last at least one year.

Supplementary Welfare Allowance

If you are sick and do not qualify for any payment you may be eligible for Supplementary Welfare Allowance.

Generally, social welfare payments are made up of a personal payment for yourself and extra amounts for your dependent spouse, civil partner or cohabitant and your dependent children.

Other payments

If you are getting a social welfare payment you may qualify for additional financial support because of your illness or disability, for example, under the Supplementary Welfare Allowance Scheme you can apply for a Heating Supplement, if you have exceptional heating expenses due to ill-health or infirmity.

You may also be eligible for:

- The Long Term Illness Scheme;
- The Drug Payment Scheme
- A Medical Card; or
- a GP Visit Card.

Apply to your Local Health Office in the Health Service Executive.

Driving and home benefits

There are concessions for disabled drivers and passengers and local authority grants to adapt your home.

Tax benefits

There are also tax benefits available to people that are sick or have a disability.

Carer's payment

If someone is providing you with full-time care they may qualify for a carer's payment.

Medical card application form

Your illness may mean you are entitled to a Medical Card. You can apply for a Medical Card online at:

- www.sspcrs.ie/portal/medapponline/

People who hold a Medical Card are entitled to a range of Health Services free of charge.

To apply for a Medical Card, you can download and print an application form from this website, fill it in, and return it to the HSE Client Registration Unit, P.O. Box 11745, Dublin 11.

Call the HSE customer care team at the Client Registration office on Call Save 1890 252 919 for any other questions you have about Medical Cards. They can also post an application form to you, or help you in filling in the form or making your application.

Non-medical card holders

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 a 12-month period. Higher rates apply for semi-private or private care.

If you do not have a medical card, you may have to pay some in-patient and out-patient hospital charges.

You may be entitled to some community care and personal social services.

Mortgages, loans, pensions and insurance

Mortgages and loans

You may be experiencing short-term payment difficulties with your mortgage, due to your illness, and you may be worried about losing your home. Talk to your lender. If you can't – talk to MABS, the state money advice service.

MABS now has a dedicated confidential, free, and independent mortgage arrears service. It is a state-funded service for mortgage debt advice and referral.

You can call MABS on 0761 07 2000 for independent information, advice and referral.

If you are unable to make payments on other loans you can contact MABS for help on this too. It is the same phone number 0761 07 2000.

You can also send an email to helpline@mabs.ie if you have any queries. MABS does not offer financial advice on investments or on specific financial products. Remember that MABS also does not give out money.

Pensions

You may be worried about taking a break from paying into a private or occupational pension scheme. For information about your scheme, contact:

- The trustees in an occupational (workplace) pension scheme; and
- The provider in a private scheme.

They will tell you if the scheme allows you to take a break and how this may affect your final pension payout.

The Department of Social Protection can tell you how a break in employment may, or may not, affect your final state pension. See more information on their website at:

- www.welfare.ie/en/Pages/home.aspx

Health insurance

If you have bowel cancer and you have private health insurance, check with your provider what cover you have for inpatient and outpatient services before you attend hospital.

Taking out health insurance

If you take out health insurance when you are ill, the health insurance company may not cover you for existing or previous illnesses for some years. The amount of time you have to wait before you are covered for pre-existing conditions varies from company to company.

Travel insurance

It can be very hard for people who have cancer to get travel insurance. This can apply if you have had cancer in the past or if you are receiving treatment at present.

Before you look for insurance, ask your doctor for a letter to say you are fit to travel. Before you book your tickets, check the cost of travel insurance as it may be so expensive that you cannot afford the trip.

When asked, you must give the travel insurance company all the information they need about current and past illnesses. They will use this information to decide how much of a risk you are, and how much they will charge. They may refer you to a special phone line that will ask you questions to medically screen you.

If you fail to give the insurance company all the relevant information, and you later make a claim, the insurance company may say the policy is invalid and refuse to pay out on it.

Financial implications: useful contacts

	Phone	Website
Medical card forms	Phone HSE customer care team at the Client Registration office Call Save 1890 252 919	www.sspcrs.ie/portal/medapponline/
Free advice, Money advice and budgeting service (MABS)	0761 07 2000	www.mabs.ie
Citizens' information Service	0761 07 4000	www.citizensinformation.ie/en/

Returning to work after treatment

You cannot set in stone when you will return to work. Everyone's experience will be different, and unfortunately some people may feel under financial pressure to return to work before they really feel fit enough.

If possible, agree a flexible plan with your employer where you can fit in medical appointments and treatment and possibly work flexi-hours or part time. It can give you confidence and help you return to work more easily if you can make these arrangements in advance of your treatment.

You may also need to return to less physically demanding or stressful work until you are fully recovered.

The law requires your employer to take reasonable steps to accommodate your needs while you are ill. They must make 'reasonable accommodation' and this might be some modification to the way your work is organised including the:

- Tasks or structure of your job or workplace; and
- Working time arrangements.

It's a good idea to arrange a conversation with your employer at least a couple of weeks before you plan to return to work. This will give you enough time to discuss and identify any adjustments that you need to be able to return to work.

Every person with bowel cancer is different and employers should not make assumptions about your fitness or about what reasonable adjustments will or won't be needed.

Ask your employer to arrange a smooth return, and avoid situations where you come back to a mountain of work. Also check that your employer has told your colleagues that you are returning. If your colleagues don't already know about the nature of your illness, it is up to you if you want them to be told. You should agree with your employer whether you tell them, or if someone else should do it.

If you feel it will be helpful, ask your union representative to help you make arrangements about sick leave and returning to work.

Case study: Jim Ferris

Jim Ferris, a self-employed financial adviser, was diagnosed with bowel cancer some years ago. He was treated with radical surgery and did not need chemotherapy or radiotherapy.

He had his first surgery in the January, a few weeks after being diagnosed following a colonoscopy. Jim then had a second surgery the following October, and went back to work, at first three days a week, the following May.

“I was very lucky, I didn’t have any financial difficulties, because I had critical illness insurance cover. It meant I could take two years’ out and not miss the income,” says Jim.

However, Jim now thinks that he went back to work a little too soon.

“The surgeries combined took a long time to settle. It probably took me nearly three years to recover from them. My recovery process was aided by the fact that I had an ileostomy bag. Many people dread this, but my attitude was, ‘I’m alive. Without this, I wouldn’t be’. I regarded it as my best friend.

“I think a good time to think of going back to work is as soon as you have recovered from the surgery.

You have to want to go back to work. It depends of course on whether it is physical work or office work.

“Confidence is very important. I used visualisation – a technique I learnt back in 1965 to help my athletic career. Right through the whole process I did visualisation twice a day for 10 minutes: seeing myself walking around normally, seeing myself better. I also used self-hypnosis, with the blessing of the hospital.

“I walked every day. And I bought a 250cc scooter as a distraction from it all. I went out on it every day for a couple of hours. While on the scooter I just had to focus on the road. I went from Dublin to Donegal on the scooter.

“You do it alone, but you need support. I had my wife and my children. And my siblings and colleagues were all there for me. They came to visit me or go for coffee with me. My dad was fantastic. Humour, however macabre, was also very helpful.

“I had a note on the hospital door which said: ‘If you’re not smiling coming in, don’t come in’. I didn’t want sympathy, I just wanted people around me who were also positive.

“I was scared, but we laughed and cried our way through it – 75% was laughter.”

Physical activity during and after treatment

The importance of being active

Marie Murphy, former Irish Olympian, and consultant exercise and nutrition specialist, has done extensive research into the effect of exercise during and after treatment for cancer, and particularly for bowel cancer.

The research shows that exercise helps boost your immunity, which helps your recovery and reduces your chance of cancer recurring. So exercise along with proper nutrition and good sleep are essential to making a good recovery.

“The most important thing is to stay active both during treatment and after treatment, within the ability of the individual and how they are feeling,” says Marie.

Exercise will counteract the fatigue that most cancer patients feel during treatment. During treatment the amount of exercise is down to the individual and the energy levels that they have.

“If someone is enduring the side effects of their treatment, the last thing they may be thinking about is exercise, but if they are not moving they are not changing anything,” says Marie.

They key is to take it slowly and do the same level of exercise for three weeks before increasing how much you do. This could start at as little as five minutes a day. People do need to avoid anything that will over-exert the body and to protect their blood count.

The guidelines for the general population recommend that people do 2.5 hours’ exercise per week.

“For a person going through treatment, that seems like a marathon. So the idea is small amounts, 5 minutes first once a day, for three weeks; then twice a day, for three weeks; and then moving up to 10 minutes. Slowly build up,” says Marie.

In the long-term to prevent recurrence of cancer, research recommends that people do at least 2.5 hours a week. However, the pace you exercise at is very important and if you are very unfit, you will need to do more than 2.5 hours a week to get the protective effect. The slower your pace, the more time you will need to spend exercising to reap the same rewards.

For people with bowel cancer, the research has shown that if the individual with average fitness did one hour more than the 2.5 hours' recommended it reduced recurrence of cancer by a further 6%.

Nutrition is equally important and this can be difficult because due to side-effects, people may find it hard to eat their daily allowance of calories, protein and other nutrients. They may need to take a protein supplement while they recover.

How to be active during treatment

Most cancer patients will experience fatigue and loss of energy during treatment, however, exercise can break this cycle!

- Engage in low-intensity exercise at first, such as a slow walk around the block.
- Avoid vigorous exercise when your blood count is low or if you are at risk of infection.
- Be active when you feel your best (even for 5 or 10 minutes).

How to stay active after treatment

- Gradually build up to moderate intensity for 30 minutes a day, 5 days a week.
- Moderate intensity activities (an activity that takes as much effort as a brisk walk) can reduce the risk of cancer recurrence and help you live longer.
- Start with light-intensity exercises and progress slowly.
- Keep in mind that a low-to-moderate-intensity exercise may feel like a higher-intensity exercise following cancer treatment.

Before beginning an exercise programme, talk with your doctor about your symptoms and treatment so that you can choose the physical activities that are best for you.

How the Marie Keating Foundation can help you

The Marie Keating Foundation's aim is "making cancer less frightening by enlightening".

The Foundation is now a leading voice in cancer awareness and information for both men and women in Ireland.

We provide information on the most common cancers in Ireland, including:

- Bowel cancer;
- Breast cancer;
- Cervical cancer;
- Lung cancer;
- Skin cancer;
- Prostate cancer; and
- Testicular cancer.

We do not receive any Government funding and all of our services are provided free of charge.

Ask the nurse

Our 'Ask the nurse' service means you can get information about any aspect of bowel cancer from a qualified, expert nurse. You can submit your question on line at:

- www.mariekeating.ie/cancer-information-services/ask-the-nurse/

Our nurse will respond to you in complete confidence to the email address or phone number that you supply.

Marie Keating Foundation Comfort Fund

We provide financial help to people who are receiving treatment for any kind of cancer and who find themselves in financial difficulty as a result. A diagnosis of cancer can lead to:

- Increased medical costs such as consultant fees and expensive medications;
- Additional expenses from activities such as increased travel to medical appointments that may be some distance from home;
- Increased utility bills due to extra time at home while recovering from treatment; and
- Reduction in earnings where a patient and perhaps their family members have to take time off work.

Many people can find themselves overwhelmed by these costs and this adds to the stress associated with their cancer diagnosis. We hope to reduce that burden.

Through the Comfort Fund, the Foundation helps people who are undergoing treatment for cancer for who are struggling financially. Applications are accepted on behalf of men, women and children. In 2015, over 350 families received Comfort Fund grants.

How does it work?

The Marie Keating Foundation works in partnership with health care professionals, mainly Medical Social Workers (MSWs) and Clinical Nurse Specialists (CNSs). Applications must be made by the health care professional involved directly in your care. If you do not know who this is, ask in the centre in which you are receiving treatment and they will refer you. The Marie Keating Foundation cannot accept applications directly from patients or their family members.

The Comfort Fund only provides 'once-off' assistance. The Foundation will consider only one application per patient.

If you are a healthcare professional or a social worker and would like more details on the Comfort Fund, please email info@mariekeating.ie or call 01 628 3726.

Survive and Thrive

The Marie Keating Foundation provides workshop programmes and seminars to help cancer survivors adapt to the 'new normal'. Facilitated by specialists in tandem with a Marie Keating Foundation nurse, these courses offer advice from experts on issues that cancer survivors often face including:

- Coping with emotions;
- Fatigue and other symptoms;
- Changing nutritional needs;
- Coping with feelings and change; and
- Managing stress and physical activity.

The Survive and Thrive workshops and seminars also include an introduction to mindfulness.

Sometimes the courses are for men or women only and sometimes they are mixed. Attendees are welcome to bring a friend or family member to support them through the course or day.

All courses and seminars are free to attend, but places are limited and registration is essential. Please visit www.mariekeating.ie to see if there are any upcoming Survive and Thrive courses or seminars in your area.

Other useful organisations and resources

Name	Phone	Email	Website
Citizens Information	0761 07 4000	You must first contact them by phone.	www.citizensinformation.ie
Family carers	Freefone: 1800 240 724	info@carersireland.ie	http://familycarers.ie/
Money Advice and Budgeting Service (MABS)	Helpline: 0761 072 000	Helpline@mabs.ie	www.mabs.ie
Irish Stoma Care and Colorectal Nurses Association			www.isccna.org
Irish Nutrition & Dietetic Institute	01 280 4839	info@indi.ie	www.indi.ie
Medical card application	Call Save 1890 252 919		www.sspcrs.ie/portal/medapponline/

About the Marie Keating Foundation

Following their mother Marie's death in 1998, the Keating family promised that they would do everything they could to bring an end to cancer. They committed to provide all Irish people with the necessary information to prevent cancer or detect it at its earliest stages. Their collective aim was **"making cancer less frightening by enlightening"**.

Through its community information service, the Foundation's dedicated nurses have enlightened over 210,000 people of the causes and risk factors of cancers. The Foundation is continuing to expand its awareness campaigns on the most common cancers affecting men and women in Ireland, at local level through its community outreach approach as well as through national campaigns.

Through its Comfort Fund, the Foundation provides financial assistance to people who are currently receiving treatment for any kind of cancer and who, as a result, find themselves in financial difficulty. In 2015 alone, over 350 families received assistance from the Comfort Fund.

On 2 February 1998, our mother, Marie died from breast cancer. Throughout her illness, we could do nothing to help the amazing person who had done everything for us, all our lives. We, the Keating family, have set up this charity in her name to try to prevent others going through what our family went through. This is also ensure that such a wonderful person did not die in vain.

Take care,

The Keating Family



Marie Keating
FOUNDATION

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