Coping with Advanced Bowel Cancer

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

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About this booklet

This booklet is about coping with advanced bowel cancer.

It looks at the symptoms you might experience, the strong emotions you may feel and difficulties that you might encounter during the last months or weeks of life.

Not everyone is ready to read about what happens when someone is dying. Some of the information here can be upsetting and difficult to cope with. If you do read on, we suggest you have someone close by to support you.

We hope that we can give you some of the practical information, support and comfort you may need during a very emotional and difficult time.

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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.

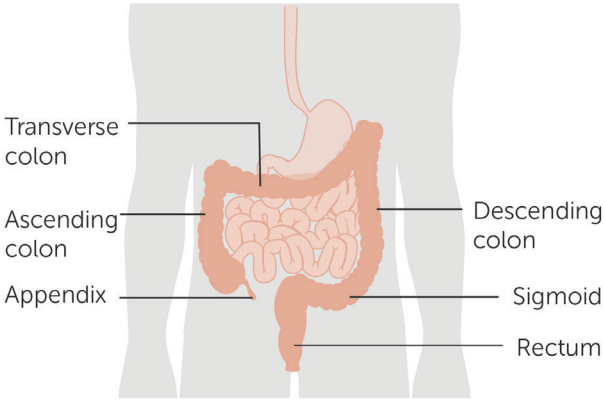

Figure 1: The parts of the colon, also called the large bowel or the large intestine

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 examination, 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**etastasis.

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

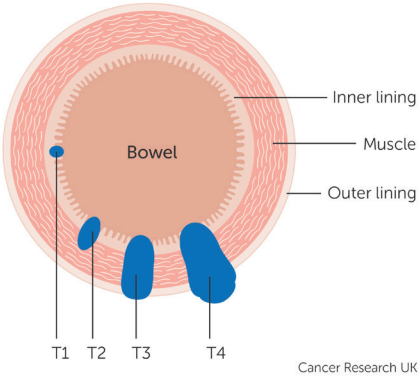

Figure 2: The T stages of bowel cancer
Image courtesy of Cancer Research UK

There are 4 stages of tumour size in bowel cancer:

- T1 means the tumour is 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 T4, N2, M1. This means:

- The tumour has grown through the outer lining of the bowel wall
- There are cancer cells in 4 or more of the nearby lymph nodes
- The cancer has 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,MO

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.

What is advanced bowel cancer?

Advanced bowel (colorectal) cancer means that the cancer has spread to other parts of your body from where it started in the large bowel (colon) or back passage (rectum). Your cancer may be advanced when it is first diagnosed. Or the cancer may come back some time after you were first treated. When cancer comes back after treatment it is called recurrent cancer. The cancer can spread:

- Locally into tissue close to the bowel; or
- To other parts of the body, such as the liver or lungs.

Local cancer spread

Local spread means the cancer has broken through the wall of the bowel and so cancer cells have spread into surrounding tissue in the abdomen or pelvis.

Secondary spread (metastasis)

Cancer that has spread to another part of the body is called secondary cancer or metastatic cancer. The bowel cancer cells have travelled through the lymphatic system or bloodstream to another part of the body. The cells have then settled and started to grow there.

Remember the most important thing is where the cancer started. Having bowel cancer cells in your liver doesn't mean that you have liver cancer. You have bowel cancer that has spread – it is also called secondary bowel cancer. This is important because your doctor needs to use treatments that work on bowel cancer cells – not treatment for liver cancer.

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.

Treatment for bowel cancer can be hard. 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' on page 44.

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. Please see the section 'Physical effects and sexuality' on page 36 for an explanation of these terms if you are not sure what they mean. 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' on page 36 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, on page 33 of 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 on page 41 of 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 cancerous 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 team 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;
- Palliative care; and
- Biological therapy

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.'

Treatments for advanced bowel cancer

Once bowel cancer has spread to another part of the body it is unlikely to be curable. But treatment can often keep it under control for quite a long time, and help people live longer. For some people with bowel cancer that has spread to the liver or lungs, it may be possible to cure it with chemotherapy and surgery.

The choice of treatment for advanced bowel cancer depends on:

- The type of cancer you have;
- The size and number of secondary cancers and where they are in the body;
- The treatment you have already had; and
- Your general health and fitness.

Chemotherapy

You are most likely to have chemotherapy. Chemotherapy drugs slow the process of cancer cells growing or multiplying. 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 (Campto).

In some circumstances you may have surgery. If you have areas of cancer in the liver, your doctor may recommend one of the specialised surgical techniques. 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).

Biological therapies, such as monoclonal antibodies, can help some people with advanced bowel cancer.

Palliative chemotherapy

Chemotherapy to shrink a cancer and control symptoms is called 'palliative chemotherapy'. To be told that treatment will be palliative can be very distressing and sometimes patients can fear that this means that they are at the very final stages of life. However, ideally palliative care is in place early in a patient's treatment plan as it has been shown to help patients live comfortably for longer and with greater dignity. If you have any concerns or fears, talk to your nursing and medical team.

To treat advanced bowel cancer, you have chemotherapy either into a vein or as a tablet. If the first type of chemotherapy you have (called 1st-line treatment) does not control your cancer, you can usually have a different type of chemotherapy (2nd-line or 3rd-line treatment). The chemotherapy drugs you may have have been listed under the chemotherapy section. You may have one or a combination of these drugs for 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 be able to take your chemotherapy tablets at home.

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;
- Diarrhoea and constipation;
- Depression;
- Hand and foot syndrome;
- Peripheral neuropathy

Radiotherapy

Doctors sometimes use external beam radiotherapy to shrink a lump or tumour in the bowel that is causing pain. This is called palliative radiotherapy. You are more likely to have radiotherapy for rectal cancers than colon cancers.

Your specialist may suggest a type of internal radiotherapy called selective internal radiation therapy (SIRT) for secondary cancer in the liver. This has been approved by the National Institute for Health and Care Excellence (NICE) as a treatment for people who cannot have their liver secondaries surgically removed.

Radiotherapy can also be used before surgery to shrink a tumour so it is easier to remove. In some cases, it is used after surgery to destroy any small amounts of cancer cells that may be left.

Surgery for advanced bowel cancer

Your specialist may suggest surgery to treat advanced bowel cancer:

- To slow the cancer;
- When the bowel is blocked; or
- To remove secondary cancer.

If the tumour in your bowel is causing symptoms your doctor may want to operate, to remove as much of it as possible. This type of operation is called ‘debulking’.

Specialised surgical treatments for liver secondaries

Specialised surgical treatments may be able to destroy bowel cancer that has spread to the liver (liver secondaries). These treatments include:

- Hepatic artery chemoembolisation – blocking liver blood vessels to give a high chemotherapy dose to the cancer;
- Radiofrequency ablation – using radio waves to destroy the cancer cells
- Cryotherapy – freezing the cancer cells;
- Microwave ablation – using micro waves to destroy the cancer;
- Laser therapy – using a laser to destroy the cancer cells;
- Alcohol injection – injecting alcohol into the cancer to destroy the cells;

Biological therapies for advanced bowel cancer

Biological therapies are drugs that help the body to control the growth of cancer cells. Research shows that some biological therapies can help some people with advanced bowel cancer to live longer when added to standard chemotherapy treatment. It can also improve quality of life.

Doctors usually give biological therapies such as Bevacizumab (Avastin), cetuximab (Erbitux) and panitumumab (Vectibix) for advanced bowel cancer along with the chemotherapy drugs:

- Fluorouracil (FU or 5FU);
- Oxaliplatin (Eloxatin); or
- Irinotecan (Campto).

Deciding about treatment

It can be difficult to decide which treatment to try, or whether to have treatment at all, when you have an advanced cancer. You will need to consider your quality of life while you are having the treatment. The side effects of treatment, as well as stresses such as travelling back and forth to the hospital, can have a big effect on your quality of life.

Your doctor will explain what they hope to achieve with the different treatments they offer you. Some people feel they would like to get an opinion from a second doctor before deciding on their treatment. If you would like a second opinion, you can ask your specialist or GP to refer you.

Your doctor will talk to you about all the options. There may also be a counsellor or specialist nurse at the hospital you can talk to. You may also want to discuss things with a close relative or friend. It can be helpful to talk over difficult decisions with someone outside your circle of family and friends.

Ask your nurse

If you have questions about your illness or treatment, your Clinical Nurse Specialist can help. He or she will be supporting you through your diagnosis and treatment plan so ask them about any questions or speak to them about any concerns you have.

Supportive personnel

Specialist surgeons

Surgical oncologists are surgeons who devote most of their time to the overall management and treatment of cancerous 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 (CNS)

Clinical Nurse Specialists (CNS) support you through your diagnosis and treatment. They:

- 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 families 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.

Palliative specialists

Most people, when asked about dying, will say that what they want is a peaceful and pain free death. This is usually possible with the right care and treatment. This makes the thought of death far less frightening. Your GP, district nurses, and hospital doctors and nurses will all try to control any symptoms that you have and keep you as comfortable as possible. They may also refer you to a palliative care team for specialist care. This can be in the hospital setting as well as at home. The Irish Cancer Society has a night nursing service which provides end of live care for cancer patients and their families in their own home. This service can provide support and rest for your family during this difficult time. Ask your palliative care nurse about this service and make it part of your plan.

The palliative care team work together to give you relief from pain and other symptoms of your cancer. They will offer you a support system that aims to allow you to live your life as fully as possible until you die. They will also support your friends and relatives to help them cope during your illness, and after you die.

Palliative care offers relief, support, and comfort to patients and their family and friends. It involves caring for your physical, emotional, psychological, and spiritual needs in the best way possible. The palliative care team is made up of:

- Specialist doctors and nurses;
- Social workers;
- Volunteers;
- Pastoral care workers; and
- Other health care professionals, such as dieticians, physiotherapists and counsellors.

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@gkcancersupport.com
Greystones Cancer Support	La Touche Place, Greystones, Co Wicklow	01-287 1601	info@GreystonesCancerSupport.com

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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

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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

There is no right or wrong way to react when you are told your cancer is too advanced to cure. Everyone responds in their own way. For most of us, of course, this is very shocking news. Even if you thought it might happen, hearing it from your doctor can still be devastating.

Some people become silent. They cannot believe what they are hearing and don't know what to say or do. Some start to cry and feel as though they won't be able to stop. Others may become very angry and scared. Some people feel numb and as though they have no emotions. These are all very common reactions. You might find that many questions come into your mind. Why me? Do I deserve this? Why can't you find a treatment to help me? There must be something that will stop this cancer – can't you just try anything?

It is natural to feel desperate, upset, angry, or that you don't believe the news. Be sure to give yourself the time and space to take in what is happening. You may want to be on your own. Or you may need to spend time with your partner, family or friends to help you deal with the news. Of course they may also be very upset and feel that they don't know what to say. Even if all you can do at first is get upset together, that can be a huge help.

You may find that you have different feelings from other people with cancer. 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 help you.

Shock

Shock is often the first reaction when a doctor tells someone they have life-threatening 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. You may remember small amounts of information but do ask again if you cannot remember details.

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 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 makes your overall situation even worse, you may need professional help from a psychologist or counsellor.

Sharing your feelings

Sharing your fears and sadness with people you love and trust may be a great relief for you.

Many people say that talking about their feelings helps them to cope. It also helps your friends and family to understand more about your situation. In turn, this will help them to help and support you. Other people find sharing their thoughts and emotions too difficult, and would rather keep things to themselves. It is important to do whatever feels best for you.

Don't let other people pressure you into talking if you don't feel ready. This is a very personal, emotional time. You can choose how you handle things. If you would like to talk, make sure you choose people you can talk to easily, who will understand how you feel and be able to support you.

If, after some time, you still feel overwhelmed and that you can't cope, try speaking to someone outside your immediate family and friends.

If you are by yourself

If you don't have people nearby to help with practical things, you can ask for help. One of your health care team may be able to arrange volunteers to help out at home, or come to visit you in hospital. Ask your specialist cancer nurse or doctor about this.

Other people being in denial

Sometimes you may find denial happens the other way around. 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.

But 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 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 very intense.

Understanding your feelings

Having negative feelings is very normal especially at diagnosis and 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. Having an open and frank discussion can help some people to become closer, more understanding and are therefore in a position to support you even more.

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 after your diagnosis and during treatment. They will be ready to listen to you and give you support.

It is also worth finding out what support is available at your local hospice. Going to a hospice does not mean that you are about to die. Hospices offer skilled, compassionate care for people of all ages in calm, comforting environments. They often have lovely grounds and tranquil gardens. 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).

To be admitted to a hospice or to access hospice home care, a patient must be referred by their GP or hospital consultant. If the matter has not yet been raised and you are wondering about it, don't be afraid to bring it up yourself with your doctor or nurse. Hospice care is provided free of charge, regardless of the patient's circumstances. Where patients have private medical insurance, their insurer may be asked to contribute towards the cost of their 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

You will find that your digestion may be upset during bowel cancer treatment. Some foods can upset the way your bowel works. Treatment may mean that high fibre foods, such as fruit and vegetables, give you loose stools. You may need to go to the toilet much more often than normal. You may have had a colostomy and a combination of treatments that affect how your bowel works. 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 go home after an operation, you may be on a low fibre diet for about 6 weeks. You may then be able to 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.

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.

You should also:

- 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; and
- Drink peppermint water – it 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, let your doctor know.

You may need to take diarrhoea medicines. Your doctor or nurse will advise you about how much you need and for how long you need to take it.

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 when you are not having chemotherapy.

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.

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.

Diet with an ileostomy

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. You lose more fluid through an ileostomy, so it is important to drink plenty.

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 your 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 bags 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

As mentioned earlier, 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 can also affect 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. 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.

Physical activity

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. Exercise along with proper nutrition and good sleep are essential to maintaining your wellbeing. Be sure to speak to your medical team before starting any exercise and keep them informed of how you are getting on.

“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.

If someone is enduring the side effects of their treatment, the last thing they may be thinking about is exercise. However, if you are exercising, even in the most gentle way, you can improve how you are feeling, your quality of life, your self-esteem, lower the risk of being anxious and depressed, lessen nausea and lessen the symptoms of tiredness and fatigue.

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.

Even if you are in bed, it is still possible to do gentle exercises, moving your legs, ankles, arms and wrists. This can help to reduce the risk of clot formation, improve your circulation and prevent your joints from becoming stiff.

Nutrition is equally important, though this can be difficult to maintain because of side-effects. You may find it hard to eat your daily allowance of calories, protein and other nutrients. You may need to take a protein supplement while you recover from treatments. You may find it helpful to speak to a dietitian if you are concerned about your dietary intake and/or your weight.

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.

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 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.

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/

Planning ahead

You can read more about planning ahead for financial matters as well as other legal, practical and medical matters in the section starting on page 57.

Coping with terminal illness

Finding out you have advanced cancer

When cancer is advanced it means that it can't be cured and is likely to cause death within a limited period of time. The amount of time is difficult to predict, but it could be weeks to several months. Doctors might also say that the illness is 'terminal'. This distressing news can affect you and the people close to you in different ways.

If you don't feel like talking straight away, just tell the people around you. As hard as it can be, try not to push your emotions aside completely. If you can manage it, it is better to express how you feel and allow your emotions to come to the surface – even if that is uncomfortable and hard to cope with.

Feelings you may have

Over the first few days, you may go through a range of very strong emotions. The emotions may change very quickly and sometimes you may feel numb or as though everything is happening to someone else. Some people say they feel very calm and detached when they are first told they don't have long to live.

At times, you will probably feel shock, anger, and sadness. These emotions can feel overwhelming at times. This news will mean that you can't plan your future in the way you had hoped. Dying may mean leaving behind a partner, children, and other important people in your life. You may wonder how they will cope and won't want to see them upset.

These thoughts may be too painful to cope with at times. You might feel as if you are going mad. You may be unable to stop crying and worrying. All this is perfectly normal and understandable.

You may find it difficult to look around and see life going on as normal for most people. It can feel very strange to watch people going about their daily lives as usual – shopping, driving and working. Coping with this roller coaster of feelings can be very exhausting. You may feel as if you are stuck under a huge black cloud and that there is no point in doing anything.

Most people will have some or all of these emotions. This usually changes gradually. Many people say that the intensity and distress lessens in time. This doesn't mean that you stop worrying or feeling upset. But the feelings get more bearable. You will most likely be able to think about your situation a little more calmly and plan what you want to do.

Talking about dying

Sharing your fears and sadness with people you love and trust may be a great relief for you.

Many people say that talking about their feelings helps them to cope. It also helps your friends and family to understand more about your situation. In turn, this will help them to help and support you. Other people find sharing their thoughts and emotions too difficult, and would rather keep things to themselves. It is important to do whatever feels best for you.

Don't let other people pressure you into talking if you don't feel ready. This is a very personal, emotional time. You can choose how you handle things. If you would like to talk, make sure you choose people you can talk to easily, who will understand how you feel and be able to support you. You may have different types of conversations with different people, depending on your relationship with them. With some people, you may have an in-depth, serious discussion while with others you might have a more open discussion while watching TV. You can decide based on what makes you comfortable.

If, after some time, you still feel overwhelmed and you can't cope, try speaking to someone outside your immediate family and friends.

If you are by yourself

If you don't have people nearby to help with practical things, you can ask for help. One of your health care team may be able to arrange volunteers to help out at home, or come to visit you in hospital. Ask your specialist cancer nurse or doctor about this.

If you need help with personal care, such as washing or dressing, social services may be able to help. They can arrange a care package for you.

You may be wary of letting people you don't know into your life, but most people find that they do need support at some stage from other people or organisations. The people that you are put in touch with will be understanding and aware of your feelings and need for personal space. They will want to support you in the best possible way they can.

You might find help and support at your religious organisation or through other organisations you are involved with.

Difficult questions and important decisions

It can be helpful to find out what support is available. Some people want to make plans about what they would like to do before they die. You may like to ask your doctor about:

- How to control cancer symptoms;
- What is likely to happen; and
- Who to talk to about your concerns.

Having some idea about what to expect can help you feel less anxious. You may also want to think about where you want to be at the end of your life.

What happens in the final days

Knowing that you, or a loved one, is close to dying can be very difficult for everyone involved. People often ask questions about how someone will die, especially relatives and friends. They often worry that they will not be able to cope, or know what to do when the person they are caring for dies.

It is very difficult to give exact details of how someone will die. Each person is different and will die in their own unique way, but here is some general information about what may happen and what a carer can do to support you through the process of dying.

Physical changes

The body begins its natural process of slowing down all its functions. How long this takes varies from person to person – it may take hours or days. The dying person will feel weak and sleep a lot. When death is very near the dying person may have:

- Sleepiness and difficulty waking (semi-conscious);
- Difficulty swallowing or not wanting to eat or drink at all;
- Loss of control of bladder and bowel;
- Restless movements;
- Changes in breathing;
- Noisy breathing;
- Cold feet, hands, legs and arms;

- Confusion and disorientation;
- Complete loss of consciousness.

For carers, it can be emotionally very difficult to watch someone go through these physical changes. But they are part of a natural dying process and don't mean that the person is uncomfortable or in distress.

The doctors and nurses looking after you during this time will be checking regularly for these changes. They will do all they can to make you as comfortable as possible during your death. If you are being looked after at home while you are dying, your carer should have support from a specialist palliative community nurse, district nurses, and the GP. They can answer their questions and help to make home nursing easier.

Sleepiness and difficulty waking (semi-conscious)

People who are dying often sleep a lot and may not respond when someone tries to wake them. But this doesn't mean they can't hear someone talking to them. Hearing may be one of the last senses to be lost. So it is important that people continue to talk and comfort you.

They can sit close to you and hold your hand. They should not say anything to you that they would not want you to hear. It's also a good idea for them to tell you when they enter or leave your room.

Difficulty swallowing or not wanting to eat or drink at all

There will come a time when you will not want to eat or drink anything. It is important that no one tries to force you to eat or drink. This would make you uncomfortable. If you are still awake people can give you small pieces of ice to suck or sips of fluid to keep your mouth moist. They can put vaseline or lip balm on your lips to help stop them getting dry and sore.

If you really can't take anything into your mouth, your carer can moisten your lips and mouth every 1 to 2 hours with lemon and glycerine swabs or water. Your GP or community nurse can get you the swabs.

Loss of bladder and bowel control

The dying person may lose control of their bladder and bowel. This happens because the muscles in these areas relax and don't work as they did. The nursing staff will do all they can to protect the bed and keep you as clean and comfortable as possible.

If you are being cared for at home, the district nurses and specialist nurses can arrange for your carer to have draw sheets or pads to protect the bed. They may also be able to arrange a laundry service for you, if necessary. As people become very close to death and are not eating or drinking, the amount of urine and stools they produce gets less and less.

Some people have a tube inserted to drain the bladder which makes them more comfortable. If this is needed, the GP will organize it.

Restless movements (as though in pain)

Many people who are dying, and the people around them, worry that they will be in pain. Not everyone dying of cancer has pain. But if they do, it can usually be well controlled and people can be kept very comfortable. The doctors and nurses looking after the dying person will do all they can.

Sometimes restlessness is a sign of being in pain. If you can't communicate very well and your carer thinks you are in pain, the most important thing they should do is to tell your doctor and nurses. They will want you to be pain free, so your carer should talk to them. This will help them plan the best way of controlling the pain and keep you comfortable.

Changes in breathing

When someone is dying their breathing often changes. It may become noisy and irregular. There may be times when they stop breathing for a few seconds. This is called Cheyne Stoke (pronounced chain stoke) breathing. They may breathe with their mouth open and use their chest muscles to help them catch a breath.

It can help if your carer raises the head of the bed with pillows or cushions. Just sitting with you, speaking gently, and holding your hand can be very reassuring for you. If someone is having difficulty breathing, a doctor or nurse may suggest giving a small dose of morphine, even if they are not otherwise in pain. Morphine can help to make breathing easier.

Noisy breathing

You may make gurgling or rattling sounds as you take each breath. This is coming from your chest or the back of your throat. It is because there is a buildup of mucus and saliva and you don't have a strong enough cough reflex to cough it up. If your carer raises your head and turns it to the side, gravity may help to drain the secretions. Sometimes the fluid can be sucked out through a thin tube put down into your windpipe, but this is not usually needed. Medication can help to relieve this also, so your carer can let the nurses know. Hearing these gurgling sounds can be upsetting for your carers, but they do not usually seem to cause distress to the dying person.

Cold feet, hands, arms and legs

The dying person's face, hands, arms, feet and legs often become cold to touch. Their skin may also become pale and look blotchy or mottled. This happens because there is less blood circulation to these parts of the body. Your carer should keep you warm with blankets, but they shouldn't use an electric blanket as this may become too uncomfortable. Thick socks can help to keep your feet warm. The room shouldn't be overheated as this can make it stuffy. It should just be kept at a comfortable temperature.

Confusion and disorientation

Your carer may hear you say things that make no sense. You may not know what day it is or may not appear to know who your carer is. You may even say things that are totally out of character. For example, you may shout at your carer or physically push them away. This can be very hurtful and upsetting. But your carer will know that you don't mean it and are not aware that you are doing these things.

This happens partly because of the chemical changes going on inside your body.

Complete loss of consciousness

At the end of life, the chemical balance of the body becomes completely upset. The dying person then slips into unconsciousness. This is usually right towards the end, maybe only a few hours or days before death. Breathing becomes irregular and may become noisy. Your carer won't be able to wake you at all. Your breathing will stay irregular for some time and will at some point stop.

Emotional and spiritual changes

Everyone will feel different emotions when they are dying. A lot will depend on:

- The type of person you are;
- Your age;
- How much support you have;
- Your religious and spiritual beliefs; and
- The experiences you have had in life.

Someone dying in their 20s is likely to feel very different to someone who is 80. If the person dying is leaving behind young children, they will have different worries from someone whose children are grown up and able to take care of themselves.

Before the final stages of death you may want to complete any unfinished business. This may mean:

- Sorting out any problems with personal relationships, or deciding not to;
- Visiting certain places;
- Buying gifts for people;
- Sorting out personal belongings and giving special things away to family and friends;
- Getting your will and financial business in order; and
- Seeing a religious leader.

As death gets closer you may begin to let go and seem more at peace with things. Others may become very anxious, fearful or angry. Some people may appear to withdraw even from the people they love and care about. But this doesn't mean that they don't care anymore. These events are all very normal and a natural part of dying.

Even if the physical body is ready to shut down, some people may resist death. You may still have issues you want to resolve or relationships you want to put right. It is important that your loved ones let you know they are there for you and will help you with any of these issues.

You and your relatives and friends are likely to feel some very strong emotions during the time you are dying. Often all people can do is to give you a lot of support and comfort during this difficult time. Friends and relatives should:

- Allow you to share any memories or feelings you have; and
- Reassure you that it is all right to let go and die whenever you are ready.

Some people who are dying will hold on until people close to them say it is alright to go whenever they are ready. So letting you go can be one of the most important and loving things they can do for you.

If those close to you need some support when you are dying it may help them to speak to:

- The doctor or nurses on the ward;
- A religious leader;
- A counsellor;
- Close friends and relatives ; or
- The palliative care team if at home

Your carers should try not to worry that they are going to do the wrong thing. Just being with you and letting you know they love and care for you is the most important thing.

Planning for end of life

It can be upsetting to think about the future when you have advanced cancer. However, many people find it gives them peace of mind to have medical plans in place and legal and practical matters in order, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not. These are ways for you to lessen decision-making burdens on your family, and for you to know that your wishes will be respected.

'Think ahead'

You may want to talk to your solicitor about appointing one person to manage your financial affairs on your behalf.

The 'Think ahead' form allows you to fill in details about:

- Bank accounts;
- Insurance policies – home, property, car etc;
- Life assurance;
- Credit cards;
- Tax affairs;
- Pensions;
- Mortgage documents;
- House deeds;
- Other assets; and
- Any debts.

The ‘Think Ahead’ scheme can help you record and register your preferences about what you want if you are very ill or dying. This scheme was devised by the National Council of the Forum on End of Life in Ireland.

The programme gives people control and choice. It can help you be responsible for what happens in the future.

Family members may want to prolong your life at all costs. That may not be what you want. There are lots of care preferences that you can consider.

- How do you feel about your quality of life compared to the length of your life?
- If you are dying, do you want chemotherapy or radiotherapy?

If you are very ill, you are not going to recover and you have very poor quality of life and a lot of suffering, you may feel you want to say ‘thus far and no further’.

If you can write down your preferences while you are still able to, it can save a huge amount of conflict, heartache and hassle.

If you take part in the ‘think ahead’ project, it means you will get the type of care that you want. It can make what is a very difficult time for everyone that bit easier.

‘Think ahead’ lets you answer questions like:

- Who would you like included in discussions about your medical condition or care?
- Are there cultural preferences or religious beliefs that you would like the healthcare staff to consider in caring for you?

The form lets you say what your care preferences would be if you are so ill that you cannot speak for yourself.

It allows you to set out your preferences about medical treatments you do not want to receive in the future in case you cannot speak for yourself.

It also allows you to name someone, called a ‘Patient-Designated Healthcare Representative’, who can speak on your behalf.

You should speak to a healthcare professional before completing the form as they may be the best person to give you the information you need when deciding about the care and treatment you would like.

You can print out a free 'Think ahead' form to fill in your preferences at: http://www.thinkahead.ie

Hospice Foundation and other palliative services

The Irish Hospice Foundation runs a Hospice Friendly Hospitals Programme to make sure that end of life, palliative and bereavement care are central to the everyday business of hospitals.

The programme aims to improve the standard of end-of-life care in hospitals. More than 40 public and private hospitals are now linked to the programme.

There are seven End-of-Life Coordinators in position in hospitals across the country.

Hospice care

Hospice care aims to improve the lives of people whose illness is no longer curable. It helps them to live as fully as possible to the end. It seeks to relieve the physical symptoms of illness while equally addressing the patient's emotional and spiritual needs. Hospice care also provides support to families and those who are important to the patient, and extends its reach into bereavement.

Hospice care can be provided in various care settings, such as a hospice, your home, a family member's home, a hospital or a nursing home.

Palliative care

The terms 'hospice care' and 'palliative care' are sometimes used interchangeably. Palliative care is the term generally used by those working in the health service.

Palliative Medicine is a recognised medical specialty in Ireland. A doctor specialising in this area is known as a Consultant Physician in Palliative Medicine or Palliative Care Consultant. Specially trained nurses working in hospices or as part of a specialist palliative care team in a hospital or in the community are Clinical Nurse Specialists (CNS) in Palliative Care.

Palliative care aims to improve the quality of life of patients and their families facing the problem associated with life-threatening illness. It does this by preventing and relieving suffering by:

- Identifying problems early;
- Assessing and treating pain; and
- Assessing and treating other problems – physical, psychosocial and spiritual.

End-of-life care

Not everyone means the same when they talk about 'end-of-life care'. The Irish Hospice Foundation uses this term to refer to all aspects of the care provided to a person with a life-limiting illness:

- From the time of diagnosis;
- Through the last months of life; and
- Up to and including the final hours.

For more information see:

Website: www.hospicefoundation.ie
Phone: 01-679 3188
Email, hfh@hospicefoundation.ie

Digital accounts

Email accounts, social networking profiles and photo sharing are seamlessly integrated into many of our everyday lives. Things like digital music libraries and photo albums may not translate to a euro amount but are certainly valuable so creating a plan for these assets is important. Consider making a password-protected list of your online accounts, that includes all the user identification, passwords, and account numbers. If you choose, you can provide the executor of your will with the instructions on where to obtain your password list and what should be done with it. Alternatively, you can give the list to a family member or friend that you trust and give them instructions on what to do with it. If you are on Facebook, you can pick a beneficiary of your Facebook account. You can set this up in your general Security setting tab under Legacy Contact. This legacy contact will manage your memorialised Facebook account after you have passed away.

Legal affairs

If you are very ill or dying you will probably want to organise your legal affairs. To do this you need to think about:

- Making a will;
- Making financial or other provisions for family members; and
- Appointing guardians for children under 18.

You may also wish to appoint an attorney under Enduring Power of Attorney, to make decisions on your behalf if you become unable to do so.

You may want to give your attorney the authority to refuse life-sustaining treatment on your behalf.

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 all the key cancers, including:

- Bowel cancer;
- Breast cancer;
- Cervical cancer;
- Lung cancer;
- Ovarian 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 by sending an email to info@mariekeating.ie or by completing a form online.

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.

The Marie Keating Foundation accepts applications on behalf of men, women and children. In 2015 alone, the Marie Keating Foundation's Comfort Fund helped more than 345 families through their cancer journey.

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). The Marie Keating Foundation does not accept applications directly from patients.

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.

Positive living

The Marie Keating Foundation provides workshops and seminars to help people with metastatic cancer adapt and cope. The Positive Living programme includes advice from experts on issues that people with metastatic cancer often face, including:

- Managing side effects, treatment plans and quality of life
- Changed nutritional needs
- Coping with emotions, feelings and end of life
- Managing stress and physical activity
- Mindfulness and positive appearance
- Sexuality and relationships

All courses and seminars are free to attend, but places are limited and registration is essential. If you would like find a course that is suitable for you, see contact details below.

For more information please contact:
Nursing Services Coordinator
The Marie Keating Foundation
Phone, 01-628 3726
Email info@mariekeating.ie

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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 225,000 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,

Marie Keating
FOUNDATION

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Roche