

- **Foreword**

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The Action Strategy Sub Committee of Donegal Action for Cancer Care identified the need for a common source of information for cancer patients, their families and friends. In recognition of this need, the group decided to produce this booklet ***“You Are Not Alone”***.

We are aware that we cannot answer all your questions about the subject but we hope that this booklet will provide both initial support information and help signpost the road towards wellness. The booklet was written to help you understand the journey from diagnosis through to treatment and onwards to recovery. It may help you to understand the changes that can happen in your life and assist you and your family to deal with your feelings about cancer.

This booklet outlines the considerable supports, financial and other, that are available and in general terms gives information as to how these can be availed of by providing contact information. The specific detail of these may vary from year to year as a result of governmental budgetary changes.

The treatment of cancer has advanced considerably over the recent past and health professionals all over the world are developing new and better treatments. Most cancers can now be treated successfully and the future is certainly much more optimistic than ever before.

It is very important to remain positive. Use all support available to you from your family, your friends, and, other formal support services. Remember,

*“Together we stand at life’s crossroads  
And view what we think is the end  
But God has a much bigger vision  
And He tells us it’s only a bend.”*

Noel A Coyle on behalf of the Action Strategy Sub Committee 2007

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## • **What is this booklet about?**

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### **Introduction**

Donegal Action for Cancer Care (DACC) was formed in April 2005 to provide a platform for cancer patients, their relatives and supporters including members of the health care professions. All members are committed to evidence based health policies and infrastructure planning. DACC has as the primary aim to ensure that those diagnosed with cancer in Donegal, have equal access to care services and treatments. DACC campaigns to ensure that Letterkenny General Hospital (LGH) retains and develops its cancer services and for equal and improved access to radiotherapy treatment services for Donegal patients. DACC's motto is "Equal access for equal need."

DACC is made up of people living in County Donegal who have been or are related to those who have been diagnosed and treated for cancer. The need for clear and comprehensive information has been identified by individuals with cancer, and their families, across the county through support groups, DACC meetings and events. In response to this need the DACC Strategy Group supported by the Citizens Information Board has developed this information booklet for those who have been diagnosed and their family and friends.

We are very aware that one source or piece of information will not answer all your questions but hope that this booklet will provide both initial support information and a signpost in the

right direction. This information was written to help you understand the journey from diagnosis through to treatment and onwards to recovery. It may help you to understand the changes that may happen in your life. It also may help you understand and deal with feelings you and your family may have about cancer.

When people were asked what has helped them most on this journey, all have said the help and support of their family and friends.

The one thing we would ask in return for this valuable resource is if you have found this book and the information within it useful; please pass it on to someone else when you're finished with it.

*I believe we should pass on what we glean as we go through life, for others to build on and turn into meaning for themselves.*

*Cancer Survivor, 2006*

## • What happens at Diagnosis?

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### Introduction

When either you or your GP are concerned about symptoms you may be having, or something shows up after a screening test, it is then that you are referred on for further diagnostic tests.

*The earlier the cancer is detected the earlier relevant therapy can commence and the longer period you'll have without cancer. My suggestion to you is to take an overview of yourself and your health right now – if anything is not feeling to you as it should be, resolve to approach your doctor and discuss it with him or her. Don't ignore physical changes and think they're just normal; don't ignore pain and hope it will go away. I ignored pain in the sense that I rationalised it away in my own mind over many years. I was particularly reticent about insisting that recurring physical changes be taken seriously by those whom I did approach about them.*

*Cancer Survivor, 2005*

### Diagnostic Methods

Techniques and methods used to detect and diagnose cancer have improved dramatically in recent times with progress in technology. The most common methods of detecting abnormal cells are as follows:

- **Self examination and self-awareness:** knowing the warning signs and becoming familiar with your body

- **Screening:** where you are proactive and undergo screening tests for particular cancers
- **Detailed medical examination:** carried out by a GP or specialist doctor
- **Pap Smear:** inserting a small instrument into the vagina and taking a scraping of cells from the wall of the cervix – these are then examined by a pathologist
- **Magnetic Resonance Imaging (MRI):** revolutionary methods which works on different magnetism of different molecules
- **PET Scans:** after being given a radioactive substance a camera takes images of the body to detect size and location of tumour
- **X-rays and other imaging techniques:** such as Ultrasound, Mammograms, Bone Scans or CT Scanning. For example CT Scanning taking repeated x-rays with clearer images after injection of dye and/or barium is drunk
- **Endoscopy:** using internal telescope instruments to view internal organs – different telescopes (tube with camera) can be used through the mouth, stomach and back passage and viewed on screen
- **Biopsy:** Surgically removing a small section of suspected tissue which will be examined by a pathologist for abnormal cells
- **Blood and Urine Tests:** General measure of health status and marker tests for certain types of cancer

Following the appropriate diagnostic tests, your Consultant Oncologist/ Haematologist will arrange an appointment to see you and to go through the results. Here you may talk about the types, the severity and grade, prognosis and treatment options. At this appointment or where a second appointment may have been arranged you will discuss what treatment would be recommended and all relevant details. This may also include other specialists, surgeons and physicians.

***Remember,  
everyone hears  
something  
different so bring  
a friend***

*Prepare for the first consultation with the Consultant Oncologist. Arm yourself with as much good and accurate information as possible so as to maximise good results for yourself in the long term.*

*Cancer Survivor, 2006*

***Talk to  
positive  
people***

The treatment determines the road to recovery and so individuals need as much information as they can take in. Some suggested questions that you could ask your doctor:

- How long will I have to wait for surgery/treatment and how long treatment will last?
- Who is the Consultant that I will be dealing with?
- Where will the treatment take place – for example are there travel issues?
- Are there side effects and what are they?
- Are there alternative treatments?

- Are there other supports available such as counselling services, information on Support Groups and clinical nurse specialist services?

This is a huge amount of information to take in and you will have many different feelings when absorbing the initial shock. You may find yourself on a rollercoaster of emotion at this point experiencing shock and fear of the unknown.

### **Tips and Hints**

- For all consultations it is advised to have your questions written down in advance and also to bring a pen and paper to take notes
- Don't go alone to the consultations because it is good to have someone else, maybe even two others there to listen and ask questions
- Remember everyone hears something different
- Know your own family history
- Consider keeping a diary from your first visit to the end of treatment and afterwards
- Talk to positive people with the experience of a similar journey

## • What exactly is cancer?

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### Introduction

There are over 200 different types of cancer, and each has a specific name, treatment and chance of being cured. It begins in [cells](#), the building blocks that form the nerve cells, muscle, blood cells or connective tissue (e.g. skin) and these in turn make up the [organs](#) of the body.

Cancer is a term used to describe a group of illnesses, many of which have certain common characteristics. For example, many include an over-growth of cells, which forms a tumour<sup>1</sup>. Tumours cause medical problems either directly by pressing on and damaging other nearby organs or indirectly by breaking off and invading other distant tissues and organs. Tumours can be [benign](#) or [malignant](#).

***Don't be  
afraid to ask  
questions***

Benign tumours are not cancer:

- Benign tumours are rarely life-threatening
- Generally, benign tumours may be removed surgically or treated with drugs and/or radiation to reduce their size and they usually do not grow back
- Cells from benign tumours do not invade the tissues around them
- Cells from benign tumours do not spread to other parts of the body
- Benign tumours only cause problems in the organ where they occur

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<sup>1</sup> Not always for example leukaemia.

Malignant tumours are cancer:

- Malignant tumours are generally more serious than benign tumours. They may be life-threatening
- Malignant tumours often can be removed, but sometimes they grow back
- Cells from malignant tumours can invade/damage nearby tissues and organs
- Cells from malignant tumours can spread (metastasise) to other parts of the body. They spread by breaking away from the original ([primary](#)) tumour and entering the bloodstream or [lymphatic system](#). The cells can invade other organs, forming new tumours that damage these organs
- Tumours can cause health problems by blocking internal ducts, or by pressing against other organs, preventing them from working properly

### What are the different types?

Most cancers are named from where they start. For example, lung cancer starts in the lung, and breast cancer starts in the breast. [Lymphoma](#) is cancer that starts in the lymphatic system and [leukaemia](#) starts in white blood cells ([leukocytes](#)). When cancer spreads and forms a new tumour in another part of the body, the new tumour has the same kind of abnormal cells and the same name as the primary tumour. For example, if prostate cancer spreads to the bones, the cancer cells in the bones are actually prostate cancer cells. This is then metastatic prostate and not bone cancer. For that reason, it is treated as prostate cancer. Doctors sometimes call the new tumour "distant" or "metastatic".

There are three broad types: carcinomas, sarcomas and haematological cancers (i.e. leukaemia, lymphoma and myeloma).

1. Carcinomas are malignant tumours that arise from cells lining the surfaces of the body. For example, a cancer of the lining of the stomach is termed a carcinoma, as is cancer arising from cells lining the breast ducts. These are often just called cancers.
2. Sarcomas are malignant tumours that arise out of cells in the supporting structures of the body (e.g. bone, muscle and cartilage).
3. Leukaemia, lymphoma and myeloma are all malignancies that arise from blood cells or from cells that go to make up blood. These cancers are also known as haematological malignancies.
4. Brain tumours and other rare types of cancers.

***Cancer is not contagious - you can't "catch" it from someone who has it.***

Some people are at an increased risk of getting particular cancers and they could consider ways of reducing that risk. For example, if you smoke you are at a far higher risk of developing lung cancer. The contraceptive pill and hormone replacement therapy (HRT) may both slightly increase a woman's risk of breast cancer or a diet containing a lot of fat and meat and not enough fruit and vegetables may increase the risk of getting bowel cancer. In summary, it is clear that giving up smoking, eating a balanced diet, avoiding

sunburn/sunbeds, exercising moderately and maintaining a healthy weight will all promote wellness for you and can lower such a risk.

A very small number are also believed to be hereditary and it is good to discuss this with your GP. For example, if you have a close relative who developed cancer at a young age or if there are two or more with the same cancer. Screening and lifestyle changes may be advised.

It is not contagious – you can't "catch" it from someone who has it. It does not spread like chicken pox or the flu. You can't catch it from being with a person who has cancer or by drinking from the same glass as that person.

### **When a child has cancer**

Thankfully, childhood cancer is relatively rare. For those diagnosed, there are different types, with varying treatment options and cure rates. Among all age groups, the most common childhood cancers are leukaemia, lymphoma and brain cancer. As children enter their teen years, there is also an increase in the incidence of bone cancer.

Typically, the factors that can trigger cancer in children are usually not the same factors that may cause cancer in adults, such as smoking or exposure to environmental toxins. Childhood cancers tend to arise from non-inherited changes in growing cells and because these errors occur randomly and unpredictably, there is currently no effective way to prevent them.

It can be difficult to tell symptoms from those caused by other childhood illnesses such as swollen glands, bruises, fever and frequent infections. Because of this, it is not uncommon for both doctors and parents to suspect other childhood illnesses when cancer symptoms first appear.

Once cancer has been diagnosed, it is important for parents to seek help for their child at a medical centre that specialises in paediatric oncology, or treatment for childhood cancer. The treatment of cancer in children can include chemotherapy, radiation, and surgery including bone marrow transplants. The type of treatment needed depends on the type and severity of cancer and the child's age.

Children with cancer are generally treated by specialists. Medical professionals who have expertise in diagnosing and treating children with cancer include paediatric oncologists, pathologists, haematologists, radiotherapists, surgeons, radiographers, and others; all who work closely together, often in dedicated children's cancer centres.

The primary goal when treating children with cancer is to cure them; this takes priority over all other aspects of care. However, there are many medications and therapies that can make children more comfortable while undergoing treatment for cancer.

When possible, older children should be involved with their own cancer treatment. Facts about the specific type of cancer and its effects should be explained in language that is suitable for the child's age level. However, when cancer

affects younger children – toddlers and those younger than age 4 – simply telling them that they are "sick" and need "medicine" to get better is often enough explanation. For all age groups, the goal is to prevent fear and misunderstanding. For example older children may feel guilty, as if the cancer is somehow their fault and will need reassuring and supports to help them with their feelings. Replacing fear and misunderstanding with compassion and information is a goal in helping a child with cancer cope with the illness.

Thanks to medical advances, more and more children with cancer are finishing successful treatment, leaving hospitals, and growing up just like everybody else.

### **Support Services for Children**

**Canteen Ireland** – Nationwide Support Group for young people who have or have had cancer, their brothers, sisters and friends. Tel: 01 8722012. E-mail: [canteen@oceanfree.net](mailto:canteen@oceanfree.net)  
Website: [www.canteen.ie](http://www.canteen.ie)

**Rainbows**, Pastoral Centre, Letterkenny – this is a peer support group for young people who would like the chance to talk about how it has been to have a death in the family or a parent leave home. Tel: 074 9131245

### **Books available**

There are story books for young children and colouring books that help parents explain the diagnosis of cancer and treatment. These can be obtained free of charge from Letterkenny General Hospital, telephone 074 9125888, bleep 674.

## • You have cancer – What next?

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### Introduction

“You have cancer” – these are the words everyone dreads. But take heart, your chances of fighting and overcoming it in today’s world is good. New improved ways of detecting it have led to decreases in mortality and now in most cases, cancer is not a death sentence. If detected early, survival and quality of life after treatment is greatly improved.

### Coming to terms with the news

There are many different ways to think and feel about having cancer. It is important to remember that people can learn to adjust to changes in their lives. Sometimes it takes a little work, but you can almost always find some thing or someone who can help you when you need it. Keep trying and do not be afraid to ask for help. Friends and relatives can be very supportive. Also, many people find it helps to talk with others who have it. This is an opportunity to share what they have learned about coping with the illness and the effects of treatment.

*Cancer is a very scary word. It brings to mind many stories - most of them untrue. In fact nowadays most cancers can be cured.*

Living with a serious illness is not easy. You may worry about caring for your family, keeping your job, or continuing daily activities. Concerns about treatments and managing side effects, hospital stays, and medical bills are also common.

Any illness changes family life for a while. It can be very scary. Different reactions may be fear or anger that this has happened; nervous about the future; tense and worried. But it is important to know that more people are living with it now than ever before, and new ways to treat cancer are being discovered. A lot of research is being done, and ways of treating it are getting better.

***Reactions differ from one person to another - there is no right or wrong way to feel.***

Having cancer does not necessarily mean a person will die from it. In many cases, treatment can cause a remission, which means that there are no more signs of the cancer. A remission can last for months or years and often lasts so long that the person is considered cured. But sometimes it comes back. If this happens, it is called a relapse or recurrence. When that happens, treatment usually starts again.

***For many there is life after cancer and it is important to be positive and take hope from significant survival statistics.***

*Keep positive – get interested in something else, something other than yourself, your cancer and your treatment.*                      *Cancer Survivor, 2007*

## This affects more than me

Once diagnosed the decision about who to tell is on many people's minds. Questions this raises could be:

- How do I tell my family?
- Children of different ages – how to tell them and what to tell them
- Who else do I tell?
- Who is going to take care of my family?
- How will my family be affected?
- How do we as a family deal with this?
- How can my family/friends help me?
- Who else locally can I talk to about my illness?

There are many different circumstances and many issues for different types of families depending on the support structure available, ages of children, etc. For example there may be someone in the community who has been through this and it is good to share how others have coped and get some insights into what to expect. Consider beginning counselling, which is offered in the Haematology/Oncology services in Letterkenny General Hospital and paid for by the Irish Cancer Society.

Let the information about the diagnosis sink in for a while and then start to think about what you want people to know, then decide who needs to know. Many survivors say that after receiving the diagnosis they would begin to think about the practical implications – “how are we going to get through this with some semblance of normality” and others say their heads

are spinning about things like “will I ever get insurance again?” or “how can I afford to be sick?”

This is where clear information about health entitlements, Medical Card availability and insurance are critical, finding out about sick cover in the workplace and Social Welfare Entitlements. Other issues such as possible overnight stays, transport costs, actual health charges for treatment, home help/family income support/carers allowances are all uncertainties. The financial implications of treatment can be daunting and knowing where to look for help can be a maze.

### **Tips and Hints**

- If you feel you are waiting too long between diagnosis and treatment ask your doctor about the Treatment Purchase Scheme. This is a scheme where you can be treated in another jurisdiction or in a private hospital.
- Parking for Cancer patients is free of charge at Letterkenny General Hospital
- Find out what state supports you are entitled to through your local Citizens Information Centre or Social Welfare Office
- Check out if you have Serious Illness Cover
- Ask your oncology team about emotional supports that might be available such as counselling and Support Groups

## • What are the treatment options?

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### Introduction

There are over 200 different types of cancer. Each type has its own name (such as lung or breast cancer, leukaemia), its own treatment, and its own chances of being cured. Each type is different from the others in many ways, but every cancer is the same in this way: certain cells become abnormal and grow out of control.

### What are the treatment options?

With this, treatment for each type is different. Also, there may be more than one way of treating a type of cancer, so people who have the same kind may not even get the same treatment. Treatment will depend on how physically well the patient is, whether it has spread to other places in the body, and what the doctors think is best for each patient.

*People with similar cancers may not necessarily get the same treatment*

Treatment will usually follow a protocol, which is a plan for treating cancer. However, even if two people have the same type and the same treatment, the treatment may not work the same way for both of them, as each person is different and can have a different reaction to treatment.

Some people might prefer to leave the treatment options to their doctors, however it is helpful to take the time to understand what your treatment will involve and how it will affect you and those around you.

### Treatment Questions you could ask your Consultant:-

- What treatments are available for my type of cancer?
- How effective is the treatment likely to be?
- How will treatment affect my lifestyle, physical ability to work, drive, fly?
- How long will it take and what does it involve?
- Will I have to stay in hospital for this?
- What are the possible side effects and what can be done about these?
- What will happen if I don't want treatment?
- What other choices do I have?

There are three main kinds of treatment and these are:

1. **Surgery** - Depending on the type, an operation is performed to remove cancerous tissue from the body. In cancer surgery, all or part of the tumour may be removed. Sometimes healthy tissue around the tumour is also removed. When people have surgery, they often have to stay in the hospital until they are strong enough to go home. When they do, they may still be weak from the surgery. There may be some things they should not do for a while, like lifting heavy things or climbing stairs, because the body needs time to heal after surgery.
2. **Chemotherapy** - treatment with anticancer drugs. These drugs go into the blood stream and are carried to cancer cells anywhere in the body. Chemotherapy is usually given many times for several weeks or months. Chemotherapy is most often taken through a needle

inserted into a vein, called an intravenous drip (or IV for short), or into a muscle (a shot) or by mouth (liquid or pills) or very rarely administered in a cream. Many different drugs are used in chemotherapy. Doctors decide which drug or groups of drugs to use depending on what type of cancer the person has.

*In most cases the side effects go away when the treatment ends or soon after.*

- 3. Radiation therapy** – treatment of cancer with high-energy rays to kill or damage cancer cells. This treatment can come from a machine or from materials put in or near the cancer. The high-energy rays from radioactive substances are aimed at a malignant tumour. This damages the cancer cells. They die because they cannot divide. Some normal cells close to the tumours may be damaged. But most healthy cells are protected by special lead shields that cover the parts of the body not being treated. To be sure the radiation is aimed right at the cancer, dye or felt-tip markers are used to mark the target area on the skin. These marks are needed until treatments are finished. Radiation therapy does not make the patient radioactive. In some cases, radiation is not beamed through a machine but instead comes from radioactive material placed in or near the tumour. Surgery is used to insert radiation implants in the tumour. Then cancer cells will be destroyed from inside the body.

Other treatments include biological therapy, hormone treatment, blood cell and bone marrow transplantation, immunotherapy and cancer drugs. Also sometimes, people with cancer are treated in studies that test different types of cancer treatment. You may hear someone in your family talk about "clinical trials"; these are carefully designed studies that test new and promising treatments. Essentially, these treatments are used to destroy cancer cells or slow down the growth of cells and bring about a remission or an improvement of symptoms. In some cases only one treatment is used and in others, a combination may be used. This all depends on the type and grade you have and how early it has been detected.

***Drink plenty of water and liquids***

There can be side effects to these treatments such as nausea, loss of appetite, hair loss and weakness.

### **Where will treatment take place?**

Your doctor will advise where you will go for treatment – if you can be treated locally in Letterkenny or Sligo (for people living in South Donegal) or have to travel to other specialist treatment centres in for example Dublin, Galway, or Belfast. Referrals to other treatment centres may mean travelling long distances and it is important to consider this when deciding on the best treatment for your particular circumstances. For example, you may receive treatment faster through the Treatment Purchase Scheme. It is also important to get the phone number of the hospital where you will be treated to give to family and friends so that they can make contact for advice on local accommodation, etc.

## Who are the Specialists involved in Treatment?

From diagnosis to treatment you will come across a number of different specialists throughout diagnosis and treatment as follows:

- **General Practitioner (GP):** your family doctor who would be familiar with your medical history and is usually your first point of contact
- **Haematologist:** a doctor who is a specialist in the study and treatment of blood diseases
- **Oncologist:** a doctor who is a specialist in treating people with cancer
- **Oncology Nurse:** A nurse who is specialised in oncology.
- **Pathologist:** a doctor who is a specialist in the study of cells and tissues removed from the body and in making a diagnosis based on changes in these cells.
- **Pharmacist:** a chemist who will make and supply the appropriate treatment drugs
- **Radiation oncologist:** a doctor who is a specialist in using radiation to treat cancer
- **Radiologist:** a doctor who is a specialist in making and explaining pictures of areas inside the body – these pictures are made with x-rays, sound waves, or other types of energy
- **Radiographer:** a technician who will operate the machinery to take the pictures
- **Surgeon:** a doctor who is a specialist in performing operations

## What are some of the side effects of treatment?

All treatments have potential long-term and/or short-term side effects. It is a person's right to know everything about the treatments so that they can make fully informed decisions about what is best for them.

There are dangers and potential side effects with all surgery and your doctor will outline these to you beforehand. Other patients' experiences have identified that patients should be prepared before surgery by building up their strength to aid the healing process, and for a long road to recovering from major surgery, by taking time and rest in abundance to ensure a successful recovery. Immediately following surgery, bowels may not function normally for a number of days and the patient may not be able to move about comfortably for some time. Energy levels may be low, largely due to anaesthesia and other medications, coupled with stress of the major operation.

In some cases, coming to terms with the wound, scarring and loss of particular organs can take some time and support. In some cases counselling may be needed to overcome these major life changes.

Chemotherapy works mainly on the cancer cells. But healthy cells, especially those that also divide quickly, can be harmed as well. This can cause unwanted side effects, and almost all people receiving chemotherapy will have side effects. Most side effects don't last long and will gradually go away after treatment is stopped. For example, this treatment can cause

nausea and vomiting. Sometimes, people lose their appetite. If they have sores on the tongue, gums, or inside your mouth, it is hard to eat, especially if the food is too hot, cold, or spicy. People often lose some weight because of these side effects.

Temporary hair loss is another common side effect of chemotherapy. Sometimes the hair falls out all at once, and other times it slowly thins out. There's no way of knowing whether all the hair will come out, or if some parts of the body will lose more hair than others. Even if hair is lost, it usually grows back after treatment has stopped. Some people wear a wig, cap, hat or scarf until their hair grows back, and others choose not to cover their head.

Some people may be tired, pale, or cranky. Others may be more likely to get sick and may need to stay out of crowded places or away from people who have something they could catch such as a cold, the flu, or chicken pox.

***Remember that treatment can make life a great deal better for you once you're a few months over it all***

Some people find that during and following treatment they may bruise or bleed easily, for example, nosebleeds. Some people may feel depressed or nervous, very hungry, or not hungry at all. Some may feel the need to urinate frequently. The side effects people have depend on the treatment they get. They may have some or none of the side effects mentioned here, or they may have others. The side effects of chemotherapy are not pleasant for some people, but they do not last forever. Once

chemotherapy is over, the hair usually grows back, and the bone marrow produces the normal amount of new blood cells, and patients begin to feel and act like themselves again.

When undergoing radiation therapy, while it is not painful, it can cause unwanted side effects also. You may be more tired than usual. The skin where radiation is aimed may feel like it has been sunburned and will need to be protected from the sun. In addition your hair may fall out, but only in the area receiving radiation. If the radiation therapy is aimed at the stomach, the person may have nausea or vomiting, diarrhoea, or a loss of appetite. People who have radiation treatments to the head or neck may have a sore throat, headaches, difficulty swallowing, loss of appetite, loss of taste, or a changed sense of smell. Again these side effects will go away when treatment stops.

*Hope mixed with medicine makes both the hope and the medicine stronger!*

### Tips and Hints

- Ask your doctor or Oncology Nurse about the side effects there could be for your particular treatment plan
- Keep notes on your side-effects and what makes them worse such as too much activity
- Ask your Oncology nurse about options for hair loss, oral health and nutrition
- Ask you doctor about the need for contraception during treatment
- More information is available on [www.hse.ie](http://www.hse.ie) or call the Health Information Line 1850 636 313
- Make sure you drink plenty of water and liquids

### Complementary and Alternative Medicine

As outlined by the Irish Cancer Society of Ireland, the therapies used to treat cancer are generally based on orthodox western medicine, which uses scientific experimentation to prove the benefits of a particular treatment. The majority of patients receive such conventional treatments for their illness. However some people choose to use [complementary and/or alternative medicine](#) or therapies.

***Complementary medicines or therapies are used along with standard treatment.***

Complementary medicine or therapies are used along with standard treatment. These can include: acupuncture, reflexology, aromatherapy, magnetic therapies, massage

therapy, herbal products, vitamins or special diets, visualization, meditation, colour therapy, exercise, yoga, and spiritual healing.

Alternative medicine or therapies are usually substitutes used instead of conventional treatment. These can include: diet and megavitamin therapy and immune boosting therapies. This is by no means an exhaustive listing.

Many people say that these help them feel better, however, some types may change the way standard treatment works. These changes could be harmful even if used alone. We would advise that before embarking on any treatment that you talk about it with your doctor and possibly ask your doctor and specialists these questions:

- What benefits can I expect from this therapy?
- What are its risks?
- Do the expected benefits outweigh the risks?
- What side effects should I watch for?
- Will complimentary and alternative therapy change the way my treatment works? Could this be harmful?
- Is this therapy under study in a clinical trial? If so, who sponsors the trial?
- Will my health insurance pay for this therapy?

### **Nutrition and your diet**

Your [diet](#) is an important part of your treatment. Eating the right kind of food before, during, and after your treatment can help you feel better and stay stronger. If possible seek the

advice of a [registered dietician](#), as this is your best source of information about your diet. Your doctor or nurse can also give you helpful advice and can refer you to a registered dietician. Consider the benefits of an improved diet and explore nature's healing foods, nutritional and vitamin supplements and beneficial minerals.

### **Tips and Hints**

- Be Positive – the mind is a powerful tool
- You can ask questions – this is about you
- For any prescriptions it is good to stick to the same local pharmacist
- Keep all your treatment medication together away from other medication at home
- If you have a fear of needles or injections ask your local GP practice if the nurse can do this
- Buy a digital thermometer to keep an accurate check on your temperature
- Think about eating smaller amounts more regularly during treatment
- Have an overnight bag ready in case you need an overnight or day or two stay in the hospital
- Use a cotton handkerchief to cover any creams you receive after radiation treatment – this will protect your clothes

## Personal Care Checklist

In compiling this information, people made suggestions for a personal care checklist and these include:

- ✓ Drink lots of water
- ✓ Look after your hair and scalp. If you lose your hair look for a good wig. But if you choose not to wear a wig maybe consider nice hats, caps and scarves or simply go 'al fresco'
- ✓ Look after your teeth and maintain oral hygiene
- ✓ Don't be alarmed – there may be either weight loss and/or gain
- ✓ Treat your nails, feet and hands to a good cream and beauty treatment
- ✓ Look after your skin to avoid dryness
- ✓ Consider using an electric razor to avoid cuts with razor blades
- ✓ Rest whenever you can to counteract fatigue and try to keep a regular sleep pattern

## Tips and Hints

- During your treatment try to avoid unnecessary visits to areas with risk of infection such as crowded places, places with air conditioning, hospitals and nursing homes – especially take care with any cuts/wounds to avoid infection
- If you have any signs of an infection such as a rash or a temperature above 38°C, it is vital you go to your GP or local hospital as you will need to have your bloods and temperature checked and to prevent a more serious infection
- You are entitled to privacy and dignity throughout your care and treatment
- Don't be afraid to ask for anything you need such as extra pillows and blankets when in hospital
- To make a comment or complaint about the Health Services Executive, call 1 850 24 1850 or email: [yoursay@hse.ie](mailto:yoursay@hse.ie) or visit [www.hse.ie](http://www.hse.ie)
- Check-Up Clinics – when the doctors from specialist hospitals visit your local hospital for out-patients clinic – if you're not feeling very well, let them know and you can be moved up the list so that you will be seen quicker
- When you go home, don't be afraid to phone the Hospital if you have any concerns or worries (*see pages 67 and 68*)
- Think about taking time out from work and caring at this time – be sure to call on family and friends for support
- Think about counselling support – the Irish Cancer Society and Derry Well Woman provide a counselling service
- Throughout your treatment retain your independence as much as possible
- Try to remember that treatment can make life a great deal better for you once you're a few months over it all.

# What supports are available?

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## Introduction

As well as the treatment options other supports will be needed throughout this journey. This will include both emotional needs such as the need to have someone to talk to, to learn from others' experiences and to draw on your inner strength. There are also very practical needs such as how much will this cost, what am I entitled to and how will my day-to-day life change.

## Emotional supports

People diagnosed, and their families, face many challenges that may leave them feeling overwhelmed, afraid, helpless and alone. It can be difficult to cope with these challenges or to talk to even the most supportive family members and friends.

Joining a Support Group can help people to feel less alone and can improve their ability to deal with the uncertainties and challenges that this illness brings. Support Groups give people, who are affected by a similar illness, an opportunity to meet and discuss ways to cope with the illness. Support Groups are designed to provide a confidential atmosphere where patients can discuss the challenges and issues that accompany the illness with others who may have had similar experiences.

People who have been diagnosed sometimes find they need assistance coping with the emotional as well as the practical aspects of their illness. In fact, attention to the emotional burden is something that should be part of a patient's

treatment plan, so ask about available counselling and social services supports.

Family and friends are also affected when cancer touches someone they love, and they may need help in dealing with stresses, such as, family disruptions, financial worries, and changing roles within relationships. To help meet these needs, some Support Groups are designed just for family members of people who have been diagnosed, other groups encourage families and friends to participate along with the patient.

#### **Tips and Hints**

- Make contact with a local Cancer Support Group – see pages 73, 74 & 75 for details
- Look up the Irish Cancer Society website and send for their books and leaflets. [www.cancer.ie](http://www.cancer.ie)

### **Practical Supports<sup>2</sup>**

When people have had some time to absorb the information from diagnosis and make some sense of what is happening to them, many begin to think about the practical implications of being diagnosed and embarking on a treatment plan. For example, what support from the state are patients entitled to, how will medical care, travel, costs, etc. be covered. The next few pages outline very specific detail of entitlements and supports available and all rates and details were accurate at the time of going to print in September 2007.

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<sup>2</sup> Information supplied by Donegal Citizens Information Service

## 1. Medical Costs

Entitlement to health services for those with cancer is the same as for all patients.

(i) **Medical cards** are issued by the Health Services Executive (HSE). Entitlement to a medical card is generally means-tested. However, there are some exceptions. Everyone, normally resident in Ireland, who is over 70 years of age, is entitled to a medical card regardless of means. Frontier workers, for example, people who live in the Republic of Ireland, and who work in any other EU country, including N.I. are also entitled to a medical card, without a means-test, provided they have *no* income from the Republic of Ireland.

If you have a medical card (full eligibility), you are entitled to free GP services; prescribed drugs and medicines; in-patient public hospital services; out-patient services and medical appliances. You can choose a GP from a panel. The GP must generally have his/her practice within seven miles of where you live. Your GP must accept you as a patient. Persons with no income other than a social welfare payment will normally qualify for a medical card. Lone parents with dependants are assessed under the income limits for married persons. However, a card may be issued on *compassionate grounds* to an individual or a family who does *not* satisfy the means-test.

The **GP Visit Card** is in place since 2005 as an initiative to assist those who did *not* qualify for a medical card on income grounds. It covers the cost of GP visits only.

## (ii) Hospital Services

Entitlement to in-patient hospital services for cancer patients is the same as for all other citizens. Holders of medical cards (full eligibility) do *not* have to pay hospital charges for public beds in HSE hospital. People with G.P. only cards or *no* medical card will incur daily in-patient and out-patient charges and some long-term stay charges.

**Hospital services includes:**

- **Out-patients'/Emergency Medical services in public hospitals:** There is no charge for medical card holders with *full* eligibility. Without a referral from your GP you may be charged €60. This is a one-off charge for that illness/accident. In cases of excessive hardship, a HSE Area may provide the service free of charge. You can be referred by your family doctor to the out-patients department of a public hospital for specialist assessment by a consultant or for diagnostic assessments. If you attend this service as a public patient, you will *not* have to pay for this service. If you are admitted to the hospital under the care of a consultant where you do *not* require the use of a bed overnight, you are receiving day services.
- **In-patient charges in public hospitals:** If you are in a public ward under the care of a consultant for treatment and you remain overnight, you are receiving in-patient services. The charge for in-patient/day services is €60 per day, up to a maximum of €600 in any 12-month period.
- **Private/semi-private Patients in public or voluntary hospitals:** If you are in a private/semi-private bed in a

public or voluntary hospital, you must pay the set charge. These charges are *in addition* to the public hospital in-patient charges. As a private patient, you must pay for any consultants involved in caring for you.

- **Private treatment in a private hospital:** If you opt for private care in a private hospital, you must pay the full cost of treatment and maintenance. Access is through referral from your family doctor. It is not possible to avail of public services in a private hospital. Your private health insurance may cover some or all of the costs involved.

## 2. Community Care Services

(i) **Home Help:** The Health Services Executive (HSE) may provide home help services to people who need them. Home help services are provided in order to assist people to remain in their own home and to avoid the necessity of entering into care. The HSE either provides the home help service directly or makes arrangements with voluntary organisations to provide them. Home helps usually assist people with normal household tasks although they may also help with personal care. Home helps do *not* provide nursing or medical care.

Home help service is means-tested, so you may have to make a contribution towards the cost, even if you hold a medical card. You should apply to your local public health nurse, who will assess your need for the service and then process the application to the HSE. Each application is considered on its own merit and a number of factors will be taken into account

including income, other family support available and remoteness from services.

**(ii) Public Health Nurses:** Health Service Executive Areas are obliged to provide a free nursing service to medical card holders. The service is not necessarily confined to medical card holders, although they get priority as they have a legal entitlement. The services provided by the public health nurses vary from area to area and they frequently act as a point of access for other community care services.

**(iii) Physiotherapy/Occupational Therapy:**

Physiotherapy/Occupational Therapy services are generally provided in the community and are free to medical card holders. There may be waiting lists for these services.

**(iv) Technical Aids:** The HSE is obliged to provide medical and surgical aids and appliances such as wheelchairs and walking aids, free of charge, to medical card holders. If you do *not* have a medical card, you may get such aids and appliances free, if they are part of hospital treatment. If you have private health insurance, you may be covered for some or part of the costs.

**(v) Respite Care:** Respite care or temporary care is provided at various centres. There is a charge for respite care (even for medical card holders). For details of charges, you should contact the care centre involved or your nearest Citizens Information Centre.

**(vi) Day Centres:** Day Centres provide a range of different services and access is usually by referral. Eligibility conditions may vary with means test applying in some cases.

**(vii) Home Care Grant:** The Home Care Grant is available to people who are 65 years of age, are currently in receipt of

community support services and wish to remain living at home but cannot do so without financial assistance to pay for additional community supports and/or services. The grant is available to persons deemed to be of high or maximum dependency level and a needs assessment is carried out by the Public Health Nurse to help determine the level of care required. A Home Care Package is tailored to meet the individual's assessed needs and will not normally exceed a six week period.

The Home Care Package differs from normal delivery of care in the community as it allows for the provision of enhanced services, beyond the normal levels available in the community on a time limited basis, to assist with the transition period between hospital and home or to prevent or delay admissions to Acute Hospital, Community Hospital or Continuing Care.

### **3. Travel**

#### **(i) Subsidised air travel for cancer patients from Derry City/Carrickfinn Airports to Dublin Airport.**

Available to medical card holders and in certain circumstances to non-medical card holders. Spouse/relative/friend may also travel at subsidised rate, which in July 2007 is €25.40 and is sponsored by the HSE. Funding for overnight stays/subsistence is not covered through above service.

#### **(ii) Bus Service**

Bus Service to Dublin for cancer patients: Bus service is available from Letterkenny General Hospital, Lifford and Mc Clay's Corner, Stranorlar to all hospitals in Dublin. This

service is available at subsidised cost to both medical card and non-medical card holders (€12.50 return).

**(iii) Reimbursement of transport costs to hospital/outpatient appointments (within the HSE-NW area) for those deemed entitled to it**

Contact your local Community Welfare Officer (CWO) for financial assessment form as there is a means-test involved. Application should be made prior to visit/appointment. A letter will be required from your G.P. stating that client requires a subsidy due to financial constraints. If you use a taxi service, your receipt should be retained. The taxi must be registered. 50% of the cost is reimbursed. 'Waiting time' charged by taxi is not reimbursed. For reimbursement you should retain your notification letter from hospital/outpatients clinic. You should get the letter stamped by hospital/outpatients' secretary, confirming your attendance. Where a family member/friend takes you to your appointment by private car, the costs will be reimbursed at rate of €4 per 35 miles. A comprehensive list of all CWOs in County Donegal and clinic times is available from Citizens Information Centres.

**(iv) Disabled Person's Parking Cards**

These cards are available to people living in Ireland with certain disabilities, whether they are drivers or passengers. The card may be used by a disabled person, in any vehicle in which he/she is travelling. The card is valid for two years from date of issue and costs €25. You will automatically qualify for

a parking card if you hold a Primary Medical Certificate, however, you must still formally apply for the card.

**NOTE:** In some HSE regions special transport arrangements can be made for people who are not financially well off. These are outlined within the HSE Transport Policy Document. This is not currently available to patients in the North West.

#### 4. Social Welfare Entitlements

(i) **Illness Benefit:** Illness Benefit (Disability Benefit) is a payment for insured people who cannot work due to illness. You may qualify if you:

- Are under – 66 years of age
- Are unable to work due to illness, and
- Satisfy the PRSI conditions

Your payment is made up of a personal rate for yourself with extra amounts for – any qualified adult and/or – children. Details of current rates of payment are available from your nearest Citizens Information Centre or Social Welfare Office. You may get half the personal rate of Illness Benefit for a limited period, if you are claiming:

- One-Parent Family Payment
- Widow's/Widower's Contributory/Non-Contributory Pension
- Deserted Wife's Benefit/Allowance

Illness Benefit is a taxable source of income. If you have a total of 260 weeks (5 years) paid PRSI contributions, since starting work, you may get Illness Benefit for as long as you are unfit for work, satisfy the social welfare requirements, and you are under age 66. If you have between 52 – 259 PRSI

contributions, you may qualify for Illness Benefit for up to 52 weeks.

To apply contact your GP and get a first medical certificate, which includes an application form (MC1). This form is *only* available from your doctor. Complete the MC1 form and declaration. Forward it to the nearest Social Welfare Office or PO Box on form. You must send in a medical certificate each week for as long as you are ill, unless told otherwise.

Anyone on any sick payment can be asked to sit a medical board where they will be examined by a doctor employed by the Department of Social and Family Affairs. This doctor will decide whether you are capable or not of returning to work. If he/she decides you are capable of returning to work, your payment will cease. In this case, you can supply further medical information to appeal the decision.

People on sick payments should never commence work or training courses without first getting appropriate approval/exemption (Rule 5) from the Department of Social and Family Affairs. Approval or exemption may be granted for work of a rehabilitative or therapeutic nature, for training courses or for non-paid voluntary work. Contact your local Citizens Information Centre for further information.

**(ii) Invalidity Pension:** Invalidity Pension is a payment for people who are permanently incapable of work because of illness or incapacity and who satisfy the contribution conditions. To qualify you must satisfy both medical and

social insurance conditions. You can also use social insurance contributions paid in countries covered by EU regulations or countries with which Ireland has a Bilateral Social Security Agreement to help you qualify.

Your payment is made up of a personal rate for yourself and extra amounts for a qualified adult and child dependants. You will continue to get Invalidity Pension as long as you are under 66 years of age and you are incapable of work. Payment will stop if you get any other payment from the Department (except Disablement Pension). You will automatically be transferred from Invalidity Pension to State Pension (Contributory) when you reach 66 years of age.

**Extra Benefits:** If you qualify for Invalidity Pension and are living in the State, you are automatically entitled to a Free Travel Pass. You may also qualify for:

- Household Benefit Package
- Assistance under the Supplementary Welfare Allowance Scheme
- Fuel Allowance (subject to certain conditions)
- A medical card from the HSE

**(iii) Disability Allowance:** Disability Allowance is a weekly allowance for people with a disability aged between 16 and 66yrs. Your disability must be expected to last for at least one year. You must pass a medical examination and a means test to get the allowance. Entitlement to full-rate Disability Allowance has (from January 2007) been extended to all

people resident in institutions. The capital<sup>3</sup> disregard for Disability Allowance is €50,000. You may get Disability Allowance for as long as you satisfy the conditions, except if you are awarded another pension or allowance.

**Extra benefits:** You are entitled to free travel automatically when you get Disability Allowance. You may also qualify for:

- A Free Companion Pass, which allows you to have a companion aged 16 or over join you when travelling
- The Household Benefit Package
- Assistance under the Supplementary Welfare Allowance Scheme
- Fuel Allowance subject to a means test and certain conditions
- A medical card from the HSE

To apply, complete application form DA 1 which is available from your local Social Welfare Office, Citizens Information Centre or online at [www.welfare.ie](http://www.welfare.ie).

**(iv) Living Alone Allowance:** The Living Alone Allowance is a supplementary payment for people in Ireland on various social welfare pensions who are living alone. If you are under 66 you may qualify if you live alone and are in receipt of Disability Allowance, Invalidity Pension, Incapacity Supplement and Blind Pension. If you are over 66, you can qualify on a wider range of payments.

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<sup>3</sup> Capital can include for example, value of your savings.

**(v) Carer's Allowance:** Carer's Allowance is a means-tested payment for carers on low incomes who look after certain people in need of full-time care and attention. You will qualify if you the carer:

- Are aged 18 or over
- Satisfy a means test
- Are caring full-time for the person
- Are not employed/self-employed outside the home for more than 15hrs per wk
- Are caring for somebody who:
  - Is so disabled as to need full-time care and attention (a medical certificate is needed)
  - Does not normally live in hospital, home or other institution

It was announced that a new additional means-tested payment equivalent to up to half of the Carer's Allowance for certain people with another Social Welfare entitlement will be introduced in September 2007.

The requirement to provide full-time care and attention is assessed on an individual basis. Carer's are not expected to provide round the clock care. You the carer may:

- Attend an educational or training course or take up employment or self-employment for up to 15 hours a week
- Work part-time as a Home Help with the HSE for up to 15 hours a week. Income from this employment is not assessed as means.

You can get Carer's Allowance for as long as you are caring for the person(s) and satisfy the qualifying conditions.

**Extra Benefits:** All people getting Carer's Allowance qualify for:

- A free travel pass
- The Household Benefit Package
- An annual Respite Care Payment each June of €1,500 for each person being cared for.

You can apply for a Carer's Allowance by completing **CR 1** available from your local Citizens Information or Social Welfare Office or download form from [www.welfare.ie](http://www.welfare.ie).

Notes: Carer's Allowance is disregarded income when calculating entitlement to Family Income Supplement (FIS) and Medical Card. Also you may get credited contributions (credits) for the period of caring. These may help you qualify for a range of social welfare benefits including State Pension (Contributory). You should enquire about credits at your local social welfare office.

**(vi) Carer's Benefit:** Carer's Benefit is a payment for people who have made social insurance contributions and who have recently left the workforce, or decided to take time off, and are looking after somebody in need of full-time care and attention. You will qualify if you, the carer:

- Are aged 16 or over,

- Have been employed for eight weeks in the twenty six week period immediately before applying for the Carer's Benefit
- Satisfy the PRSI conditions
- Give up employment \* to care full-time \*\* for somebody
- Are *not* employed or self-employed outside the home while caring
- Are caring for somebody who is so disabled as to need full-time care and attention (a medical certificate is needed)
- Are caring for at least 16 hours a week or 32 hours a fortnight.

Notes: If you share the care of a person with somebody else, only one of you can claim Carer's Benefit.

You may be regarded as providing full-time care and attention and still:

- Attend an educational or training course or take up voluntary or community work for up to 15 hours per week
- Engage in employment or self-employment for up to 15 hours per week

There is a limit on earnings from employment or self-employment.

Payment is made up of a weekly personal rate for yourself and extra amounts for qualified children. There is no qualified

adult increase. You also qualify for a Respite Care Grant on the first Thursday in June each year.

You can get Carer's Benefit for two years (104 weeks) for each person you are caring for. You may claim it in a single continuous period or in separate periods adding to a total of 2 years (104 weeks). There is no minimum period for claiming Carer's Benefit.

You can apply for Carer's Benefit by completing application form CARB 1. This form is available from your local Social Welfare Office, Citizens Information Centre (CIC) or download a form from [www.welfare.ie](http://www.welfare.ie).

**(vii) Carer's Leave:** By law, you may qualify for temporary unpaid leave from your employment to provide full-time care and attention to another person.

**(viii) The Respite Care Grant:** The Respite Care Grant is an annual payment for full-time carers who look after certain people in need of full-time care and attention. The payment is not means tested but is subject to certain conditions. One Respite Care Grant is paid for each person in need of full-time care and attention. There is no need to apply if you are getting one of the Carer's Payments. You will qualify if you:

- Are aged 16 or over
- Care for the person on a full-time basis (this period of care must include the first Thursday in June)
- Either live with the person you are looking after, or have a direct line of communication with them

You will **not** qualify if you are:

- Employed or self-employed outside the home for more than 15 hours a week, or
- Getting Jobseeker's Benefit or Jobseeker's Allowance or signing for Jobseeker's Credits

Respite Care Grant is paid once a year, by cheque, and can be paid retrospectively for people who fulfil the conditions. You can apply for the Respite Care Grant by completing the application RCG 1.

**(ix) Domiciliary Care Allowance:** The Domiciliary Care Allowance is a monthly means-tested payment made to the carer of a child with a severe disability. It is paid by the HSE. In order to qualify, the child must have a severe disability that is likely to last at least one year and:

- Must be aged under 16
- Must live at home
- Must need substantially more constant care and attention than a child of the same age who does *not* have a disability

A Medical Assessment is carried out by the Senior Area Medical Officer in the Health Services Executive (HSE), and the Senior Area Medical Officer determines whether or not a child with a particular condition qualifies for the Allowance.

The means test applies only to the means of the child and not to that of the carer. Entitlement to Child Benefit is *not* affected and a carer may also qualify for Carer's Allowance or

Carer's Benefit if he/she meets the other conditions. The carer is also eligible for a Respite Care Grant, which is paid automatically each year during the month of June.

**(x) Exceptional Needs Payments (ENPs):** Exceptional Needs Payments are made under the Supplementary Welfare Allowance Scheme. This scheme is administered by the Health Services Executive (HSE). An Exceptional Needs Payment is a single payment to help meet essential, once-off, exceptional expenditure, which a person could not be reasonably expected to meet out of their weekly income. For example, the payments can be made for special clothing for a person who has a serious illness, visiting relatives in hospital, or other miscellaneous items. The payment is means tested. Important: Keep receipts and letters about appointments that come from the Hospital or treatment centre. Each application is decided on its merits by the Community Welfare Officer.

## **5. Tax Relief Available**

**(i) Incapacitated Child Tax Credit:** This can be claimed by a parent for a child who is permanently incapacitated either physically or mentally from maintaining him/herself and had become so before reaching age 21 or finishing full-time education.

**(ii) Dependant Relative Tax Credit:** This can be claimed by a person who maintains an incapacitated or elderly relative or a spouse's relative, a widowed mother or mother-in-law or a child on whom he or she is dependant.

**(iii) Incapacitated Person (Allowance for employing a Carer):** This can be claimed where an individual employs a person to

take care of a family member who is permanently incapacitated.

**(iv) Child Oncology Patients and Children with Permanent Disabilities:** In the case of child oncology patients and children with permanent disabilities, tax relief may be claimed on a number of health expenses. These include:

1. **Telephone** – where the child is treated at home, a flat rate of €270 to include telephone rental and calls may be claimed where the expenses are incurred for purposes directly connected with the treatment of the child.
2. **Overnight Accommodation** – payments made by the parent/guardian to a hospital, hotel or B & B in respect of overnight accommodation in or near the hospital where the child is a patient where such overnight stay is necessary for the treatment of the child.
3. **Travel** – the cost incurred in travelling (unlimited journeys) to and from any hospital in respect of the patient and accompanying parent/guardian's and parents/guardians of the patient where such trips are shown to be necessary for the treatment of the child.
4. **Hygiene products and special clothing** – the cost incurred – these items are subject to a maximum of €500 per year.

**(v) Medical Expenses Relief:**– Using a MED 1 form you can claim tax back on medical expenses. There is an excess on this relief for individuals and families. Expenses could include:–

- Un-reimbursed nursing home fees
- Cost of doctors'/Consultants' visits
- Maintenance or treatment in a hospital
- Transport by ambulance
- Kidney patients' expenses
- Specialised dental treatment
- Certain items of expenditure in respect of a child suffering from a serious life threatening illness

Relief is also available for the following, where prescribed by a doctor:–

- Drugs and medicines
- Diagnostic procedures
- Orthoptic or similar treatment
- Hearing Aid
- False Eye
- Where qualifying health care is only available outside Ireland, reasonable travelling and accommodation expenses can also be claimed.
- Cost of gluten-free foods for coeliacs
- Orthopaedic bed/chair
- Wheelchair/Wheelchair lift (no relief is due for alteration to the building to facilitate a lift)
- Glucometer machine for a diabetic
- Engaging a qualified nurse in the case of serious illness
- Physiotherapy or similar treatment
- Cost of a computer, where it is necessary to alleviate communication problems of a severely handicapped person.

**(vi) What income is exempt from tax?**

- **DIRT (Deposit Interest Retention Tax) Exempt Accounts:** for those aged 65 or over or permanently incapacitated – the Finance Act 2007 introduces a new scheme to allow the operation of DIRT-free savings accounts. To qualify, there are two simple conditions: you must be aged 65 or over (either you or your spouse) and your total income must not exceed 19,000 Euro (individual) or 38,000 Euro (married couple). Application form/information leaflet DE1. Permanently incapacitated – this concession will be available to those who are, or their spouse is, permanently incapacitated. Application form DE2.
- **VAT:** If you live in Ireland and have a disability and as a result, need to use certain aids and appliances you can avail of a refund of VAT (Value Added Tax). People with both physical and/or mental disabilities can avail of these VAT refunds. The aid or appliance must be owned by and for the exclusive use of the person with the disability. *Examples of eligible aids and appliances include:-*
  - Walk-in baths designed for people with disabilities
  - Commode chairs
  - Lifting seats and specified chairs designed for people with disabilities
  - Tele-text and Braille books
  - Hoists and Lifts designed for incapacitated people, including stair lifts.

Apply using Claim Form VAT 61A that you can download from Revenue Website at [www.revenue.ie](http://www.revenue.ie)

**(vii) Tax Concessions for Disabled Drivers and Passengers:** To enter the scheme the person with the disability must be in possession of a Primary Medical Certificate. The medical criteria for entry to the Scheme are that the person must be severely and permanently disabled and fall within a number of clearly defined categories. For example in some cases of treatment for Lymphoedema patients may qualify. The vehicle must be specially constructed or adapted to take account of the person's disability. Relief may apply to a new or second-hand vehicle.

There are three categories of applicants for admission to the Scheme as follows:

- Drivers with Disabilities
- Passengers with Disabilities
- Family Members of a person with a disability

What does the scheme cover?

- Repayment of VAT
- Remission of Vehicle Registration Tax (VRT)
- Exemption from road tax
- Refund of excise duty on fuel

## **6. Housing**

**(i) Disabled Person's Grant:** A local authority may make a grant available for the provision of additional accommodation or the necessary works to adopt a house to meet the needs

of a member of the household who has a disability. The grant is not means-tested. The amount of the grant cannot exceed 90% of the approved cost of the works subject to a maximum grant of €20,320. Possible works covered include:-

- New bathroom
- New bedroom
- Adapt existing bathroom (level deck shower etc.)
- Stair Lift
- Conversion of store/garage to bedroom
- Contribution towards heating
- Contribution towards pathway (disabled access)

Application forms are available from your local authority. A Medical report is required from GP/Consultant. A Tax Clearance Certificate is required if grant awarded is in excess of €10,000.

Note: This grant scheme is being reviewed at present and changes are expected, including the introduction of a tapered means test and an increase in the maximum allowance. Check with Donegal County Council or your local Citizens Information Centre.

## Tips and Hints

- There is a lot of detail here – read through it and take notes on what you think you may be entitled to
- Contact your local Citizen Information Centre on your rights and entitlements
- Keep all receipts and all hospital appointments letters and cards
- Contact you local Social Welfare Office to get information on your entitlements
- Contact the Revenue Commissioners to get information on tax relief available to you
- Contact the HSE Information Line to find out what supports are available

## • The Road to Recovery

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### Introduction

This has been some journey and now you are on the road to recovery. Throughout this you have tried to remain as positive as possible and remembered that you are important. You have had great support from those around you: partner, children, family, friends, medical and care personnel, those in your community, etc. Keep the communications open and keep in touch with people because it is so important to talk about your experience, share your knowledge and support others embarking on a similar journey.

*Think positive -  
look forward,  
and think about  
your future*

### What you can do

One important part of your life now is follow-up care. Here's a guide to the steps you can take once your treatment ends, to help ensure you receive the care you will need.

### Getting Follow-up Medical Care

Everyone should have follow-up care. Knowing what to expect in the future helps you and your family make plans, lifestyle changes and important decisions. When you go for your first post-treatment visit, ask your doctor to design a schedule of follow-up care appointments for you. Ask someone to come with you to your doctor visits. Make a list of questions ahead of time and bring it with you, and ask the doctor to explain what he or she said in terms you understand. Ask for booklets or other materials to read at home.

Some common questions you may have are:

- Should I tell the doctor about symptoms that worry me?
- Which doctors should I see after treatment?
- How often should I see my doctor?
- What tests do I need?
- What can be done to relieve pain, fatigue, or other problems after treatment?
- How long will it take for me to recover and feel more like myself?
- Is there anything I can or should be doing to keep me healthy?

### **What is Follow-up Care?**

Follow-up care means seeing a doctor for regular medical check-ups. At these visits your doctor will:

- Review your medical history
- Give you a medical examination

Your doctor may run follow-up tests such as:

- Blood tests
- X-rays or scans

### **Develop a Long Term Wellness Plan**

Ask your doctor what you can do between check-ups to stay healthy. A wellness plan might include getting regular exercise, but remember that sometimes you won't feel like exercising, and that's ok. Don't feel guilty. Do what you can, but know that rest is important to your recovery as well.

Decrease stress, quit smoking, if you choose to drink alcohol, keep it to a minimum, and maintain a healthy weight. Vary your diet to include lots of fruit and vegetables, as well as whole grains. If you are concerned about getting all the

vitamins you need, ask your doctor if taking a daily multivitamin is right for you.

These steps can help your body heal after treatment. A wellness plan should also include keeping your mind healthy, which might involve joining a support group or a prayer group, or trying meditation or yoga.

Do what you can. While you fear it will take an entire overhaul of your lifestyle to achieve all these goals, do what you can and make changes slowly. Easing into a healthy diet or regular exercise will make it more likely that you will stick with these changes for the rest of your life.

### **Tips and Hints**

- Take care of your body
- Go to all of your follow-up appointments
- Be open about your fears
- Keep busy
- Keep a record of all your appointments

At times you may not be able to do the things you used to take for granted. But as you begin to feel better you can set yourself some simple goals and slowly build your confidence again. Take one step at a time. Don't feel you need to do everything at once. Take time for yourself as you try to get your daily routine back on track. Try exercising, talking with other survivors and taking time for activities you enjoy. Devise your own plan for coping with your emotions. You know what

works best for you. Have an open mind and try different strategies to find out what brings you the most peace.

While cancer is a major event for all who are diagnosed, it brings with it the chance for growth. As hard as treatment can be, many survivors have told us that the experience led them to make important changes in their lives. Many say they now take time to appreciate each new day. They also have learned how to take better care of themselves and value how others care for them. Others draw from their experience to become advocates to improve cancer research, treatment, and care.

*Having cancer has made me take the time to stop, see what I have and enjoy every moment.*

*Cancer Patient, 2007*

We hope this information has been of some use to you, the reader, as we truly believe that knowledge is the key. With information and experiences shared by others we have the power to question, to talk openly and to seek answers. Best wishes and have a happy and healthy future!

### **Tips and Hints**

- Suggest that there is a comment/suggestion card at Oncology Unit so that patients can write down suggestions on how to improve services.
- Consider the benefits of Health Insurance.
- Everyone should have an annual health check.

## Words Used when Talking about Cancer

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**Benign:** Not cancer.

**Biological therapy:** treatment to improve the ability of immune cells to fight infection and illness.

**Biopsy:** A test where a piece of tissue (a group of cells) is taken from a person's body and looked at through a microscope to see if the cells are normal. This is one way to see if a person has cancer. A biopsy also can tell what type of cancer a person has.

**Cancer:** Illness where cells that are not normal grow and divide rapidly. They crowd out and destroy normal cells the body needs. Cancer can also spread to other parts of the body.

**Chemotherapy:** treatment with anticancer drugs

**Clinical trials:** Research studies that involve patients and new treatments.

**Haematology:** The study of the blood, the parts of the body where blood is formed, and blood illness.

**Immune cells:** Cells in the body that protect a person from infection and illness.

**Intravenous:** Into the vein. Also called IV. A common way of getting medicines into the bloodstream is by having them drip down from a container through a tube and needle and into a vein. Medicine also can be injected into the vein through a syringe (veins are tubes that carry blood back to the heart

from all parts of a person's body). After surgery, blood or fluids to help a patient recover can be given through IVs.

**Lump:** A thickness or bump under the skin that can be felt by the fingers, either by the person who has it or by a doctor. Lumps can be a sign of cancer, but most lumps are not cancerous.

**Lymphatic system:** Certain tissues and organs of the body that make and store cells that fight infection and disease (immune cells). These cells are carried throughout the body in an almost colourless fluid called lymph. Lymph and the vessels that carry lymph fluid also are part of this system.

**Malignant:** Cancer.

**Metastasis:** The spread of cancer from one part of the body to another. Metastasis also is the word used for a new tumour caused by the spread of cancer cells.

**Oncology:** The study and treatment of cancer.

**Prognosis:** What might happen to a person who has an illness.

**Protocol:** A detailed plan that doctors follow when treating cancer patients.

**Radiation therapy:** treatment of cancer with high-energy rays to kill or damage cancer cells. This treatment can come from a machine or from materials put in or near the cancer. Radiation therapy does not make the patient radioactive.

**Recurrence:** The return of cancer cells and signs of cancer after a remission.

**Relapse:** Recurrence.

**Remission:** The disappearance of cancer symptoms and cells. When this happens, the illness is said to be "in remission."

**Side effects:** Problems caused when cancer treatment affects healthy cells in the body. The most common side effects are hair loss, being tired, and having nausea, vomiting, and mouth sores.

**Surgery:** An operation done to remove cancerous tissue from the body.

**Tissue:** A group of cells that performs a specific function.

**Tumour:** An abnormal mass of tissue.

**Vein:** Tubes that carry blood back to the heart from all parts of the body.

## ● For Further Information

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### DACC Information and Contact Details

DACC continues to lobby for a number of core developments that are needed for people living in County Donegal. These include:

1. The permanent appointment to Letterkenny General Hospital of a Consultant Breast Surgeon; A Consultant Colorectal Surgeon and a Consultant Radiation Oncologist;
2. The retention of breast cancer services in LGH;
3. The immediate introduction of Breastcheck;
4. The provision of 70 new beds for LGH;
5. The establishment of a satellite radiotherapy unit at LGH;
6. Urgent designated funding to assist patients and families who have to travel for treatment.

### Contact details

13 St Columba's Terrace

Letterkenny

Co Donegal

Ph: 074 9128400

Email: [equal@dacc.ie](mailto:equal@dacc.ie)

Website: [www.dacc.ie](http://www.dacc.ie)

## Contact details for Citizen Information Centres in Co Donegal

<b>Location</b>	<b>Address and Telephone No</b>
Letterkenny.	Public Services Centre, Blaney Road 074-9194281
Carndonagh,	Public Services Centre, Malin Road, 074-9373741
Buncrana,	Lower Main Street 074-9363496
Milford ,	Public Services Centre, Lower Main Street 074-9153901
Donegal Town	Public Services Centre, Drumlonagher 074-9724460
Dungloe,	Public Services Centre, Gweedore Road 074-9561360
Ballyshannon,	Public Services Library Building 074-9851666
Health Information Line, North West	1850 636 313
Citizens Information – National Lo-Call Number	1890-777-121
(This line is staffed 09.00hrs 21.00hrs Mon-Fri.)	
Citizens Information On-line:	<a href="http://www.citizensinformation.ie">www.citizensinformation.ie</a>

## Some useful numbers

NowDoc (out of hours GP service)	1850 400 911
Irish Cancer Society Helpline ( <a href="http://www.cancer.ie">www.cancer.ie</a> )	1800200700
Action Breast Cancer	1800309040
Prostate Cancer information Service	1800380380
Quitline	1850201203
Health Information Line (HSE)	1850636313
Ulster Cancer Foundation <a href="http://www.ulstercancer.org">www.ulstercancer.org</a>	048 90663286
CLIC – Support for Childhood Cancer Marie Keating “Comfort Fund” <a href="http://www.mariekeating.com">www.mariekeating.com</a>	www.clic.uk.com 01 6283726
Derry Well Woman ( <a href="http://www.derrywoman.org">www.derrywoman.org</a> )	048 71360777
Donegal Hospice, Letterkenny	074 9177256
Foyle Hospice, Derry	048 71351010
Mayo Cancer Support Centre, Castlebar	094 9038407
Cancer Care West, Galway City	091 529609
Tuam Cancer Care Centre, Tuam	093 28522

## Hospital Telephone Numbers

Letterkenny General Hospital	074 91 25888
Sligo General Hospital	071 91 71111
Carndonagh Community Hospital	074 93 74164
Donegal Community Hospital	074 97 21019
Dungloe Community Hospital	074 95 22261
Altnagelvin Hospital, Derry	048 71 345171
The Cancer Centre, Belfast City Hospital	048 90 329241
University College Hospital, Galway	091 544544
St. Luke’s Hospital, Dublin	01 406 5000
St. James’ Hospital, Dublin	01 410 3000

Beaumont Hospital, Dublin	01 837 7755
James Connolly Memorial Hospital, Dublin	01 821 3844
Mater Misericordiae Hospital, Dublin	01 803 2000
St. Vincent's University Hospital, Dublin	01 269 4533

### Some contact details for the Health Service Executive (HSE)

Further information on any of the community services is available from:

HSE – Ballybofey                      074 – 9131391

HSE – Manorhamilton              074 – 9820400

Your local Citizens Information Centre will also have this information

Home Care Grants Section, Subvention Office, Navenny House, Navenny Street, Ballybofey, Co. Donegal. Tel. (074) 9189168 or Carer's Support Worker – Marie O'Neill at 087-9839514

### Medical Card Means Test

For information on how the means-test is conducted or for an application form (**MC1** or **MC2** for those *over 70*), you can contact the *HSE – medical card section at Community Care Office, Ballybofey 074 – 9131391*. Alternatively, you can contact your local Community Welfare *Officer (CWO)* or your *Citizens Information*. You can download an application form for a medical card at [www.hse.ie](http://www.hse.ie). Details of all incomes must be submitted with the application as well as details of various outgoings e.g. rent/mortgage, travel costs to work, childcare costs, ongoing medical expenses, necessary home improvement loans.

## Some more information on travel, transport and costs

Further information/applications for **subsidised flights**:

Mary Nolan – Inishowen area 086 6068757 –

10am – 3pm, Monday – Friday

Mary McGinley – North West Cancer Group – 074 95 42373  
(using Carrickfinn airport). Contactable between 10am – 4pm

Monday – Friday

For further information or to book **subsidised bus service**

Contact Ambulance Control at 071 9851888.

To apply for a **Parking Card** contact:

### Parking Card Section

The Disabled Drivers' Association	or	Irish Wheelchair Association
Ballindine		Ballinagappa Road
Co Mayo		Clane
Tel. 094 964054		Co Kildare
		Tel. 045 893094

Travel supports are limited but you should ask about the HSE Transport Policy Document and what is available in the North West.



## Some useful contacts for the Department of Social and Family Affairs and Social Welfare

For more details of Illness Benefit you can contact:

### **Illness Benefit Section**

Department of Social and Family Affairs

Aras Mhic Dhiarmada

Store Street

Dublin 1.

Telephone (01) 679 7777

For more details of Invalidity Pension you can contact:

### **Invalidity Pension Section**

Social Welfare Services Office

Government Buildings

Ballinalee Road

Longford

Telephone: (043) 40118/40045 or (01) 7043000

ext. 48818/48745

For more details of Disability Allowance you can contact:

### **Disability Allowance Section**

Social Welfare Services Office

Government Buildings

Ballinalee Road

Longford

Telephone: (043) 45211

For more details on Carer's Benefit you can contact:

**Carers' Benefit Section**

Social Welfare Services Office

Government Buildings

Ballinalee Road

Longford

Telephone: (043) 45211

To check if you qualify for carer's leave, contact the:

**Employment Rights Information Unit**

Department of Enterprise, Trade and Employment

Telephone: Dublin (01) 631 3131

LoCall 1890 201 615

You can get further information on carer's leave from the Department of Enterprise, Trade and Employment website – [www.entemp.ie](http://www.entemp.ie), or by e-mailing the Department at [erinfo@entemp.ie](mailto:erinfo@entemp.ie)

For information about Respite Care Grant contact:

**Respite Care Grant Section**

PO Box 10085

Dublin 2

Telephone (01) 6732222

Applications for all of the above Social Welfare benefits can be obtained from your local Social Welfare Office, Citizens Information), or the Department's website at [www.welfare.ie](http://www.welfare.ie) or from the Department's LoCall Leaflet Request Line on 1890 20 23 25.

## **Contact details to get information about your general tax entitlements**

Office of the Revenue Commissioners  
High Road,  
Letterkenny,  
Co. Donegal.  
Tel: 074 9121299

## **Further Information on tax concessions for disabled drivers and passengers**

The Office of the Revenue Commissioners  
Central Repayments Office  
Freepost  
Coolshannagh  
Monaghan  
Tel. 047 38010 Fax 047 82782

If you have any further queries  
contact your local Citizens Information Centre  
(see page 66)

## [Contact details for local Cancer Support Groups](#)

**Cancer Support Group, Carndonagh** – Perhaps you would benefit from a Cancer Support Group in Carndonagh. If so, contact Rita on 086 6028993 or Deirdre on 087 7634596 any time. All calls will be treated in the strictest confidence.

**EIST, Cancer Support Group, Serenity House, Moville** – We offer support to people with cancer, their families and friends and essential links to other organisations, which are available to help. Why not drop in to one of our monthly meetings for a cup of tea and a chat in a relaxed atmosphere. Group Meetings: Last Monday of each month at 7.30pm. Total Confidentiality. Tel: 074 9392945. Email: [eist2@eircom.ie](mailto:eist2@eircom.ie)

**Donegal Town Cancer Support Group** – support to people with cancer, their families and friends. We have a monthly meeting on the 1<sup>st</sup> Wednesday in each month from 8 – 10pm, each Monday from 7 – 9pm; Tuesday from 10.30am – 12.30pm; Thursday from 10.30am – 12.30pm. Or drop in and visit us at SOLACE, St Joseph's Avenue in Donegal Town. If you prefer you can e-mail us at [solacedonegal@eircom.net](mailto:solacedonegal@eircom.net) or pick up the phone and call us on 074 9740837. Telephone messages/enquiries can be recorded at any time and group members will respond as soon as possible.

**LGH Cancer Support and Education Group** – held monthly in a comfortable venue locally in Letterkenny Town. Some cancer nurses from LGH will be there to answer questions and give you support. There is a short talk on a relevant topic at each meeting. Friends and relatives welcome to come with you. For more details, contact 074 9125888, bleep 674 or Ext 4477.

**SPARC Group (Supporting a Positive Attitude to Recovery from Cancer)** is held every year and runs for 8 – 10 weeks, one evening per week in a local Hotel, in Letterkenny. Speakers on relevant topics for women who have completed surgery, chemotherapy or radiotherapy for breast cancer. No cost. Tel: 074 9125888, bleep 672 or Ext 2966 for details.

**Derry Well Women Centre** – 17 Queen Street, Derry. Tel: 048 71 360 777. Website: [www.derrywellwoman.org](http://www.derrywellwoman.org). Counselling service in their premises to women, men and their families. Cancer Support Group and a 12 week “Well Holistic Programme”.

**Letterkenny Women’s Centre** a supportive, caring and welcoming place for women which provides listening service, counselling service and Support Groups. Most services are free. Tel: 074 9124985

**Marie Keating Foundation** – provides information on all types of cancer for both women and men. They have a nurse in their office in Dublin, Monday – Friday, 9am – 5pm, if you wish to talk to her. Mobile units travel countrywide. They also provide a “Comfort Fund” for breast cancer sufferers where you can apply for a small grant through your local Breast Care Nurse or through the Irish Breast Care Nurses Association, eg. for the purpose of buying a hair piece. Tel: 01 624 6314. Email: [info@mariekeating.com](mailto:info@mariekeating.com), website: [www.mariekeating.com](http://www.mariekeating.com)

**Lymphoedema Support Group, Co. Donegal** – offers advice and support to individuals affected by lymphoedema (limb swelling) as a consequence of surgery or treatment. For details contact: Ms Jean Perry 074 9722531.

**Action Cancer** – provides lifesaving cancer prevention services, therapeutic support services and early detection services in Northern Ireland. Tel: Belfast 048 9080 3344 or Derry 048 7134 4114. Email: [info@actioncancer.org](mailto:info@actioncancer.org). Website: [www.actioncancer.org](http://www.actioncancer.org)

**Reach to Recovery Service** – this is a service run by volunteers who have had a breast cancer diagnosis. At your request and with your Nurse Specialist/Consultant approval, a volunteer will visit you to provide emotional support, advice and answer questions you may have. Tel: 1800 200 700 to avail of the service.

**Samaritans** – The Samaritans are available 24 hours to befriend those passing through personal crises. The telephone service is free. Tel: 074 9120999 or free phone 1850 609 090.

**Donegal Carers Association**, Ballyraine House, Letterkenny – voluntary organisation to cater and care for those involved in looking after those who are unwell at home. Tel: 074 9121586.

### **[For more information about Cancer and Supports](#)**

A highly recommended website for cancer information is [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk) – Cancer Concern? If you are living with a diagnosis of cancer and feel the need of support of others who are experiencing the same ordeal.

## Getting more information

The Irish Cancer Society has a wealth of information booklets and magazines – make contact and ask them to send out anything relevant to your situation. Tel: 1800 200 700 (free phone help-line). They also have a part-time counsellor funded by the Irish Cancer Society available for one-to-one counselling for individuals and their families. This is free and you can refer yourself. To avail of this service phone the Pastoral Centre 074 9121853 or ask one of the cancer nurses for details.

Information is also widely available on the Internet you can simply go into a search engine such as [www.google.ie](http://www.google.ie) or [www.yahoo.com](http://www.yahoo.com) and type words such as a particular type of cancer or treatment name. A word of caution however, some websites are commercial and there to make money – so be wary of false promises. A good place to start is the Irish Cancer Society [www.cancer.ie](http://www.cancer.ie) or other cancer societies across the world.

The Local Library – your local library will have a range of books and magazines available and can also order most books in from another library in Ireland. Some books people found useful included titles such as *The Choice* by Bernadette Bohan; *Survivors of Childhood and Adolescent Cancer – A Multidisciplinary Approach* by, Cindy L. Schwartz, Wendy L. Hobbie, Louis S. Constine and Kathleen S. Ruccione; *The China Study* by Colin T Campbell; or the *Everywoman and Everyman guides to health*. Some people found certain movies useful such as *The Miracle of the Cards*; *Lorenzo's Oil*; and *The Teddy Kennedy Story*.

For Keeping your Notes.....



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Mayoclinic.com

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May God heal me,  
body and soul.  
May my pain cease,  
may my strength increase,  
may my fears be released,  
May blessings, love,  
and joy surround me.  
Amen.