Understanding Hodgkin Lymphoma

Caring for people with cancer
Understanding Hodgkin lymphoma

This booklet has been written to help you understand more about Hodgkin lymphoma. It has been prepared and checked by cancer doctors, nurses, radiation therapists, other relevant specialists and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and management, and the key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can make a note below of the contact names and information that you may need quickly.

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

If you like, you can also add:
Your name
Address
The Irish Cancer Society is the national charity for cancer care, dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer. This booklet has been produced by Nursing Services in the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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Introduction

This booklet has been written to help you understand more about Hodgkin lymphoma. By reading it you can learn more about its diagnosis and treatment. We hope it answers some questions you may have and encourages you to discuss them with your doctor and nurse too. We cannot advise you about which treatment to choose. This decision can only be made by you and your doctor when all your test results are ready. Even so, we can help you find out more about some methods used to treat this lymphoma and any side-effects that may occur when treatment is given.

This booklet also discusses some of the feelings you and those close to you may have when a diagnosis of lymphoma is made. At the end of the booklet you will find a list of books you may find useful to read. There is also a list of websites and special groups to help and support you at this time.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freephone National Cancer Helpline 1800 200 700 to discuss any aspect of cancer and people who can help. Or you can also contact Lymphoma Support Ireland at email: info@lymphoma.ie or website: www.lymphoma.ie

If you have found the booklet helpful, perhaps you could pass it on to your family and friends who might find it useful too.

What if the amount of information puts me off?

When first diagnosed with Hodgkin lymphoma you may be overwhelmed with all the information to take in. Instead of wanting to know everything about it, you may prefer to know as little as possible. This can happen to patients at this time and is quite normal. Often too it can be hard to concentrate on reading, especially if you are feeling anxious or worried.

As things happen to you, it can help to read the relevant section or what interests you. Take it slowly at first and read when you feel relaxed and want to know more.

What does that word mean?

Abdomen  The part of the body that lies between the chest and the hips. Sometimes known as the belly or tummy.

Adjuvant treatment  Treatment given soon after surgery when a diagnosis of cancer is made.

Alopecia  Loss of hair. No hair where you normally have hair.

Anaemia  When there are less red blood cells in your blood. This can cause tiredness and shortness of breath.

Antibody  A protein made by the body that attacks and kills organisms, such as bacteria and viruses, or cells that cause disease.

Anti-emetic  A tablet, injection or suppository to stop you feeling sick or vomiting.

Autologous  The use of a person’s own tissue, e.g. when cells are taken from your bone marrow or blood.

Benign  Not cancer.

Biopsy  When a small amount of tissue is taken from your body and looked at under a microscope to see if lymphoma cells are present.

Cells  The building blocks that make up your body. These are tiny and can only be seen under a microscope.

Chemotherapy  Treatment with anti-cancer drugs.

Diaphragm  The thin muscle under the heart and lungs that separates the chest from the abdomen.

Fatigue  Severe tiredness.
Intravenous
Into a vein.

Lymph
A clear watery fluid that carries material through the lymphatic system.

Lymph node
A small oval or round gland found along lymphatic vessels that removes bacteria and foreign particles from your body.

Lymphatic vessels
Tubes carrying lymph that connect to lymph nodes.

Malignant
Cancer.

Medical oncologist
A doctor who treats cancer with chemotherapy and other drugs.

Metastasis
The spread of cancer from one part of the body to other tissues and organs.

Monoclonal antibody
Treatment using a manmade antibody to fight disease.

Nausea
Feeling sick or wanting to be sick.

Neutropenia
When there are less white blood cells called neutrophils in your body. As a result, you develop infections easily.

Oncology
The study of cancer.

Radiotherapy
The treatment of cancer using high-energy X-rays.

Radiation oncologist
A doctor who specialises in treating cancer using radiotherapy.

Radiation therapist
A radiographer who plans and gives the radiotherapy treatment.

Staging
A series of tests that measure the size and extent of cancer.

Thrombocytopaenia
When there are less platelets in your blood. This can cause you to bleed and bruise easily.

Before diagnosis

What is cancer?

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

The organs and tissues of the body are made up of tiny building blocks called cells. All cancers are a disease of the body’s cells. In healthy tissue these cells replace or repair themselves when they get worn out or injured. Where there is cancer, the cells do not behave as normal and keep on growing even when there is no need.

These abnormal cells can form a tumour. Tumours can either be benign or malignant. Benign tumours do not spread to other parts of the body so are not called cancer. Malignant tumours are made up of cancer cells that can spread from where they started and can go on to damage other tissues and organs. This may happen when a cell or group of cells breaks away and travels through the bloodstream or lymphatic vessels to form a new tumour somewhere else in the body. This is called a metastasis or secondary tumour.
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Lymph nodes are found in groups throughout your body such as in your neck, armpits and groin. Sometimes you may become aware of these glands if they become swollen or enlarged. More of these lymph nodes are grouped together in the chest and abdomen. Other parts of the lymphatic system include the spleen, thymus, tonsils and bone marrow.

What is Hodgkin lymphoma?

Hodgkin lymphoma is a cancer of the lymphatic system. It is a type of lymphoma named after the doctor who first recognised it. Previously it was known as Hodgkin’s disease. There are two types of lymphomas: Hodgkin lymphoma and non-Hodgkin lymphoma. Most lymphomas are non-Hodgkin, whereas about 1 in 5 is Hodgkin.

The difference between the two types depends on the appearance of the lymphoma cells under the microscope. The cells of Hodgkin lymphoma are called Reed Sternberg cells. These large cells contain B lymphocytes which have become abnormal. In the body B lymphocytes are a type of white blood cell that normally make antibodies to fight infection. Non-Hodgkin lymphomas do not have Reed Sternberg cells.

In general lymphoma cells grow in lymph nodes (glands) and enlarge them. Hodgkin lymphoma often begins in the lymph nodes in the neck, armpit or chest. Sometimes the cancer may spread to other lymph nodes nearby or cells may enter the bloodstream and be carried to other organs. However, some lymphomas begin in organs, such as the stomach or bowel, and up to one-third of cases occur in places other than lymph nodes.

The treatment of Hodgkin lymphoma, even if it has spread to other tissues, is very successful. Most people can be cured or their disease controlled for many years.

To sum up

- Cancer is a disease of the cells of the body.
- With cancer, the cells do not behave as normal and keep on growing even though there is no need.
- If a tumour is malignant, cells can break away and be carried by the bloodstream or lymph glands to form a new tumour somewhere else. This is called a metastasis or secondary tumour.

What is the lymphatic system?

The lymphatic system transports substances around the body like the bloodstream. Everyday the body must defend itself against infection and has many ways to do so. The lymphatic system is just one of these ways. It is made up a network of tiny tubes, like blood vessels, which pass through almost all the tissues in your body. These vessels carry a clear watery fluid called lymph. This fluid has cells called lymphocytes that fight infection.

Along this network are hundreds of small bean-shaped glands called lymph nodes. Their job is to filter the fluid for foreign particles as it passes through. They also allow the lymphocytes to protect the body against infection.

Lymph nodes are found in groups throughout your body such as in your neck, armpits and groin. Sometimes you may become aware of these glands if they become swollen or enlarged. More of these lymph nodes are grouped together in the chest and abdomen. Other parts of the lymphatic system include the spleen, thymus, tonsils and bone marrow.
Because Hodgkin lymphoma affects the immune system, you will have problems fighting infections.

Sometimes people have lymphoma in other areas of the body. In these cases the symptoms can be quite different. For example, if you have lymphoma in the bowel or stomach, you may experience abdominal pain, diarrhoea or indigestion.

Remember that all of these symptoms can be caused by conditions other than lymphoma. But do get them checked out by your doctor, who will decide what to do.

**How does the doctor make the diagnosis?**

Most people begin by visiting their family doctor (GP). If your doctor has concerns about you, he or she will refer you to a hospital for further tests. Usually it is not possible for your GP to confirm a diagnosis of lymphoma. At the hospital the doctor will ask you questions about your health before doing a physical exam. A blood test and a chest X-ray will be taken to check your general health. The blood tests will include a blood count to see how many red cells, white cells and platelets are in your blood. You may also have blood tests to check your kidney or liver function.

The doctor may have to remove a lymph node and examine it under a microscope. This is called a **lymph node biopsy**. It will confirm if you have lymphoma or not. This test can sometimes be done under local anaesthetic, but in most cases a general anaesthetic is needed.

**Lymph node biopsy**

Before the test you may be given a mild sedative to help you relax while the test is being carried out. A local anaesthetic is used on the skin to numb the area. A small cut is then made through the skin and the lymph node is removed for examination under a microscope.

A couple of stitches are generally needed at the biopsy site. This test can be uncomfortable but only takes 5–10 minutes to do. As soon as
the sedation has worn off you will be able to go home. But you will have to arrange for someone to take you home, as you will be feeling sleepy. You will not be able to drive for 24 hours after the test.

A general anaesthetic may be needed if the lymph node is not easy to locate. In this case you will not be allowed to eat or drink for a few hours before the test. You may also be given a sedative. This will help you feel more relaxed when going to theatre. The test takes about 15–20 minutes to do. After the test you will not be allowed to eat or drink anything for at least 4 hours. You should be allowed home the next day.

**Surgery**
If the enlarged lymph nodes are in your chest or abdomen, you may need to have an operation to get a suitable sample for examination. If these nodes are found only in your abdomen, you will need a general anaesthetic to biopsy them. However, this is not very common. Your doctor will discuss it with you if it is needed.

**Further tests**
If the biopsy shows that you have Hodgkin lymphoma, your doctor will refer you to a specialist, either a [haematologist](https://example.com) or a [medical oncologist](https://example.com). The specialist will want to do further tests. This is known as **staging**. These extra tests are important because they will show if the disease has spread to other tissues. It will also help doctors to decide on the best treatment for you.

The staging tests will show:
- The number and location of affected lymph nodes.
- If the affected lymph nodes are above or below the diaphragm. (The diaphragm is the thin muscle under the lungs and heart that separates the chest from the abdomen.) See the diagram on page 8.
- If the disease has spread to the bone marrow or to places outside the lymphatic system like the liver.

Tests may include:

**CT scan (CAT scan):** This is a special type of X-ray that builds up a detailed picture of the inside of your body. You lie still on a table which moves your body into a doughnut-shaped ring machine. You will not feel a thing as the scan is painless. For some CT scans you may be asked to fast for 4 hours beforehand. For others, you may be given a special drink or injection which helps show up certain parts of your body on the scan. It is important to let the radiographer know if you have asthma or are allergic to iodine before you take the drink or injection.

At first the injection may make you feel hot all over for a few minutes. The preparation for a CT scan can vary between hospitals but your doctor or nurse will tell you what to do. This test is usually done as an outpatient in the X-ray department.

**Ultrasound scan:** This is a special scan that builds up a picture of the inside of your liver and upper abdomen using sound waves. You will be asked to lie on your back and a gel will be spread over the area to be scanned. A small device like a microphone, which produces sound waves, is used to take the scan. The sound waves are then converted into a picture by a computer. This test is painless and only takes about 10 minutes to do. It is done in the X-ray department of the hospital.
MRI scan: This special type of scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but it can be noisy. You will be given earplugs to wear during the scan. Before the scan you may have an injection to show up certain areas of your body. During the scan you cannot wear metal jewellery and patients who have certain medical devices implanted in their body, like pacemakers, are not suitable for the test. Your doctor in the hospital will advise you about this. Most people can go home after the scan.

PET scan: PET or positron emission tomography is the latest form of scanning to be used in the staging of lymphomas. It is also a useful way of seeing how you are responding to treatment. PET uses a low dose of radioactive sugar (glucose) to measure activity in your cells. CT scanning is usually done together with the PET scan. Once you have relaxed, the glucose is injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the glucose, there will be more radioactivity where the cancer cells are located. After an hour, the scan is taken and can show if the lymphoma has spread to other tissues and organs. Before the test, you may have to fast for a few hours and the scan itself may take up to 1 hour. PET is safe to use and there are no side-effects.

Bone marrow biopsy: You may have a bone marrow aspiration and biopsy as part of the staging. Aspiration means removing some bone marrow fluid while biopsy means removing a small piece of bone with marrow cells in it. Both samples are examined under a microscope to see if there are any lymphoma cells present. The samples are usually taken from the back of the pelvis at the hip bone. Before the test you will first be given a local anaesthetic to numb the area. After that, a needle is passed through your skin into your bone marrow. A tiny sample of the bone and bone marrow is then taken. You will feel some discomfort while this is being done but it usually takes just 15–20 minutes to do. The area may feel tender and sore for a few days after the test. You may need to take a mild painkiller for a day or two.
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What are the stages of Hodgkin lymphoma?

Hodgkin lymphoma is defined as stages 1 to 4, depending on how many lymph nodes or organs are involved.

**Stage 1** One group of lymph nodes is affected on one side of the diaphragm.

**Stage 2** Two or more groups of lymph nodes are affected on one side of the diaphragm.

**Stage 3** Lymph nodes are affected on both sides of the diaphragm. For example, the chest and the abdomen.

**Stage 4** Lymphoma can be found in organs outside the lymphatic system like the liver or bone.

The diaphragm is the sheet of muscle that lies just under the ribcage.

Doctors also look at your symptoms when staging Hodgkin lymphoma. They use a letter code, either A or B, to say if you have symptoms like fever, night sweats or weight loss. If you have no symptoms your disease will be classified as A; if you have any symptoms of Hodgkin it is B. So for example your disease could be staged as 2B or 1A, etc.

If you need more information do ask your doctor or nurse. They can explain the stages to you in more detail.

Waiting for results

It may take at least a week for all the test results to come back. Naturally, this can be an anxious time for you. You might find it helpful to talk to a relative or close friend during this time. You may want to call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses or a patient volunteer.

To sum up

Hodgkin lymphoma is diagnosed by a biopsy of the lymph node. Depending on the results of the biopsy, you may need to have:

- CT scan
- Bone marrow biopsy
- Ultrasound scan of liver and abdomen
- MRI scan
- PET scan

These tests will show the extent of the disease and help your doctor decide on the best treatment for you.

What are the types of Hodgkin lymphoma?

There are about four main types of Hodgkin lymphoma. When looked at under a microscope after a biopsy, they all contain Reed Sternberg cells. As the lymphoma develops, more Reed Sternberg cells are found.

The types are:

- Nodular sclerosing
- Mixed cellularity
- Lymphocyte rich
- Lymphocyte depleted

The most common type found in young people is nodular sclerosing.

If you would like more information on the different types, talk to your doctor or nurse. You can also call the National Cancer Helpline 1800 200 700.

If the disease comes back after having treatment, it is called recurrent lymphoma. This too can be treated successfully.
Treatment and side-effects

What kind of treatment will I need?

It is now possible to treat Hodgkin lymphoma very successfully. Your type of treatment will depend on where the disease is, what part of your body is affected, and the stage of the disease. Your doctor will also take into account your age, gender, general health and if you have other symptoms such as weight loss or fever.

A team of specialists will plan your treatment. Usually radiotherapy and chemotherapy are used alone or together to treat Hodgkin lymphoma. With these treatments, this type of cancer is curable in most cases or it will have no signs of active disease (remission). The aim of treatment is to cure the cancer while causing as little damage as possible to other tissues and organs.

What is remission?

Remission means that the lymphoma is no longer active. It has been reduced or got rid of completely. This can be either partial or complete. With partial remission, the lymphoma has been reduced significantly but not removed completely. A complete remission means that the disease is no longer there. The longer you are in remission, the less likely it is for the lymphoma to come back.

Individual treatment

You may notice that other people with Hodgkin lymphoma are getting different treatment to you. Their cancer may not be the same type or at the same stage as yours so their treatment needs may be different.

At this time you may be anxious about what is going to happen next. Do not be afraid to ask your doctor about it. You may want to use the fill-in page at the back of this booklet to write down your questions and the answers you receive. Your doctor will talk to you and tell you about your treatment choices.
Radiotherapy can also be used if the lymph nodes are very swollen and causing you discomfort or pain. Hodgkin lymphoma tends to spread in an orderly way from one lymph node to the next. In most cases radiotherapy is not only given to the affected lymph nodes but to lymph nodes close by as well.

Planning your treatment

Before any radiotherapy is given, your doctor, radiation therapists and other specialists plan how best to give the treatment to you. They work out how to give you the right amount of treatment for the lymphoma with the least damage to normal cells.

You may need radiotherapy to your head or neck. The head is one of the most difficult parts of the body to keep steady during treatment. Therefore, a mould of your head is made for you to wear during each visit for treatment. The mould is attached to the couch you are lying on during treatment. This will make sure that the radiotherapy is given to the same area each day. The areas for treatment will be marked on the mould by ink.

Making the mould

On your first visit to the radiotherapy department you will be asked to lie on a couch. A quick-setting cream will be put on your face or neck, depending on which area is to be treated. Holes are left around your
eyes, mouth and nose so that you can breathe. The cream will be lifted off as soon as it has set and a mould will be made of the impression.

Sometimes a mould can be made by heating plastic in a water bath and moulding this to your face and neck.

When the mould is ready the next part of treatment planning will take place.

Simulation
Before treatment can go ahead, you will have a CT scan and asked to lie under a machine called a simulator that takes X-rays of the area to be treated. Once this is done, the treatment field or area will be marked by the radiation therapist. By doing this, the X-rays can be aimed at the same area each day. If you have a mould the area to be treated will be marked on the mould by ink.

If you need radiotherapy to another part of the body such as the chest, you will be marked on the skin where the treatment is to be given. This may be with ink or a permanent tattoo.

The ink marks are temporary, tiny and barely noticeable. They should not be washed off until treatment is over.

Treatment planning is a very important part of radiotherapy so it may take a few visits before your treatment can go ahead. Before starting radiotherapy you will be told how to look after your skin during and after treatment.

Getting your radiotherapy
Treatment with radiotherapy is quite straightforward. You will be asked to come for treatment every day during the week with a rest at weekends. Your course of treatment can go on for 4–6 weeks. Each treatment session only takes a few minutes. In all it takes about 10–15 minutes between setting up the machine and having the treatment itself. You will not feel any pain but you will have to lie still during treatment. How much radiotherapy you need will depend on the size and number of lymph nodes involved. Your doctor will discuss this with you.

What happens each day?
Each time you arrive for treatment you will go into a radiotherapy room. The radiation therapist will ask you to lie or sit in a certain way under the radiotherapy machine. When you are ready he or she will leave the room. The machine will then be turned on and your treatment given.

Even though you are on your own in the room, the radiation therapist will be able to see you all the time through a closed circuit television. You can talk through an intercom to the radiotherapy staff if you need to. You will not feel anything when the machine is working.

External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends. For more information about radiotherapy, contact the National Cancer Helpline 1800 200 700 for a free copy of the booklet Understanding Radiotherapy.
Will I have any side-effects?

Radiotherapy is given directly to the site of the lymphoma and nearby lymph nodes. As a result, the side-effects that occur are related to the part of the body being treated.

Some people have only mild symptoms, while for others the side-effects can be more severe. It depends on how much treatment you need and what part of the body is being treated.

The most common side-effects that may occur are:

**Difficulty swallowing or sore throat**

If you have radiotherapy to the neck or chest, you may notice after a week or two of treatment that your chest feels tight and you have difficulty swallowing. It may feel like you have a lump in your throat all the time. Your throat may also feel dry and sore. This is a common reaction to treatment. You may find it helpful to eat soft foods. If you find it difficult to eat your normal foods, high-calorie liquid supplements may help. Your doctor may also give you medicine to take before meals to make swallowing easier. Usually the discomfort gets better on its own after about 5 to 8 weeks.

**Sore mouth**

Radiotherapy to the glands in the neck may cause a sore mouth. Little ulcers may appear on the tongue, gums and inside the cheeks of your mouth. Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after each meal. It can also help to use a very soft toothbrush. If you have dentures remove them if your gums are sore.

There are also special mouthwashes that you can use. Your nurse will show you how to use them properly. You may also notice that your mouth feels dry and you have a loss of taste or a metallic taste in your mouth. This is because your salivary glands may make less saliva than usual during treatment.

Radiation may also increase your chances of getting cavities in your teeth. For that reason, do go to your dentist for regular check-ups. This will help reduce the risk of tooth decay.

**Feeling sick or getting sick**

Your nurse can give you tablets to help prevent feeling sick (nausea) or vomiting. Take them 1 hour before treatment. It is best to eat small amounts often.

**Diarrhoea**

If you have radiotherapy to the abdomen or pelvis you may get diarrhoea. Passing watery bowel motions more than twice a day is known as diarrhoea. You may also have cramping and/or abdominal pain. If this happens drink plenty of clear fluids. This will help to replace the fluid you are losing. Let your doctor, nurse or radiation therapist know if the diarrhoea lasts for longer than 24 hours. There is medication that can stop this side-effect of treatment.
Weight loss
If you have problems with eating or sickness you may begin to lose weight. It is best to try to eat as well as you can while on treatment. Ask to see a dietician if you are losing weight. He or she will give you advice on the best foods to eat.

Skin changes
During radiotherapy your skin in and around the treated area may become red and sore. It may look a little like sunburn. A special cream can be used for this problem. But only use creams recommended to you by the nurses or the radiation therapist.

If you need to wash the area use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. If you shave use an electric razor. Avoid perfumed creams or powders. Check with your radiation therapist or nurse before putting anything onto your skin.

Tips & Hints – skin care
■ Do not scratch or rub the treated area as it may become sore.
■ Avoid soaps, talcum powders, deodorants, lotions, perfumes as they may irritate the treated area.
■ Apply simple moisturisers like E45 cream or aqueous cream to the area.
■ Do not apply creams, lotions, dressings, herbal remedies unless prescribed or recommended by your specialist.
■ Do not wet shave within the treated area or use an electric razor. Do not use shaving lotion or hair removal products on the treated area.
■ Wash the area gently with lukewarm water and pat it dry.

Tiredness
Tiredness can build up over the course of your treatment. It may be due to the treatment itself or due to travelling long distances for treatment, if you live far from the hospital. Rest as much as you can. It is best to cut down on the things you normally do while you are on treatment.

Shortness of breath
After radiotherapy to the chest you may develop a dry cough and shortness of breath. Radiotherapy can affect the supply of oxygen to the lungs. This condition is known as radiation pneumonitis. It can happen several months after treatment has ended. Do tell your doctor as soon as possible if you develop these symptoms. He or she may want to treat you with medication.

Hair loss (alopecia)
Hair loss will happen if you have radiotherapy to any part of the body where there is hair. Before treatment starts ask your doctor if you are likely to lose your hair. You will only lose hair within the treated area. You may find that the hair loss is patchy. If you are having radiotherapy to the head, you may have hair loss from the scalp. If this happens it will fall out quickly, but try not to worry, as your hair will start to grow again when treatment ends. It is best to let your hair grow down over the area being treated. For most patients, the amount of hair loss is small, and a wig is not needed.

You may feel upset at the thought of losing your hair. Talk to your nurse, radiation therapist or social worker about your feelings. He or she will help you find ways to cope with hair loss. If this happens you can get a wig/hairpiece or you may prefer to wear a scarf or hat. For more information, contact the National Cancer Helpline 1800 200 700 for a factsheet called Hair Loss and Cancer.

If you prefer to wear a wig it is better to organise one before treatment starts. By doing this you will get a better match to the colour and style of your hair. Your social worker or nurse may be able to arrange a wig for you. If your hospital does not have a social worker, ask if they have the name of a wig fitter you could go to see. Your local hairdresser may be able to help. In some cases it is possible to get financial assistance towards the cost of a wig. Ask your social worker or nurse for more details about this.
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Chemotherapy can be used on their own or with each other. Most people with Hodgkin who need chemotherapy will get a combination of three or four drugs. Chemotherapy can also be given before or after radiotherapy.

Because it is not possible to get all the treatment you need during one visit to hospital, you may have to attend hospital at regular intervals for 3–6 months. There is usually a rest period between each treatment visit to allow your body time to recover from the effects of the drugs. Each visit to the hospital for treatment is called a cycle. The number of cycles you have will depend on the stage of your cancer and how well it is responding to treatment.

How is chemotherapy given?
Chemotherapy can be given as an injection into a vein in your arm or by intravenous infusion (drip). It may also be given in tablet form. Depending on the type of chemotherapy you get, you may have to spend some time in hospital for treatment. However, most treatments can be given in day care. Some treatments are given once every 3 or 4 weeks for about 6 months.

Central line
If your treatment involves injections or intravenous infusions, it may help to have a central line put in. This device can be left in place throughout your treatment. It will make it much easier for you to get treatment and spare you the discomfort of repeated needle jabs.

A central line is a narrow flexible plastic tubing (a catheter) that is put into a main vein and brought out through your chest or arm. You will be given a local anaesthetic before the line is put in. In most cases, it takes about 10–15 minutes to put in. Removing it is very simple, sometimes needing a small local anaesthetic.
Chemotherapy for cancer that recurs or has spread

Many people have no further problems after their first treatment for Hodgkin lymphoma. But for some the cancer does come back. It may also have spread to other parts of the body. There are times when the cancer may have already spread by the time the diagnosis is made.

It is important to know that, even if the cancer extends to other parts of the body or recurs, it can still be treated. In many cases chemotherapy will cure the disease or at least help people to live longer with better control of their symptoms.

Sometimes, if the lymphoma has come back after the first course of treatment, the treatment may only be able to control it. This can improve your symptoms and give you a better quality of life. When deciding your treatment, your doctor will consider your general health and where the lymphoma is located. He or she will also take into account the kind of treatment you have had in the past.

What are the side-effects of treatment?

The side-effects of chemotherapy vary from one person to another and depend on the drugs used. These unwanted effects happen because while the chemotherapy is working on the cancer cells it can affect normal cells too. In many cases it is possible to have this treatment and have side-effects that are well controlled with medication.

Before you start your treatment ask your doctor about any possible side-effects. Do tell your doctor about the way you are feeling during your treatment as most side-effects can be eased or stopped with medication. In most cases, the side-effects go away once the treatment ends or soon afterwards.

Side-effects may include:

**Infection**

Chemotherapy can make you more likely to get infections. This happens because most chemotherapy drugs affect the bone marrow that makes the white blood cells that fight infection. If you do not have enough white cells even minor infections such as a cold or sore
throat could make you quite ill. During treatment cycles you will have regular blood tests to make sure that you have enough white blood cells.

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

While on treatment you will be more at risk of picking up infections. Try to avoid close contact (such as hugging or kissing) with people who have colds or flu and other infections such as chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections. Wash your hands often during the day, especially before you eat and after going to the bathroom. Try to avoid crowds. Infection can be a very serious complication of chemotherapy. It needs to be treated as soon as possible. Talk to your doctor or nurse, who will give you more information.

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### Bruising

Chemotherapy may cause you to bruise easily. Bruising easily or for no obvious reason is known as purpura. In the blood, platelets help to make your blood clot and stop any bleeding if you hurt yourself. If there are not enough platelets in your blood (thrombocytopenia), you may bleed or bruise more easily, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily or if you notice tiny red spots under your skin, which can look like a rash (petechiae). He or she will give you advice on what to do. You may need a platelet transfusion.

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### Feeling very tired

It is not uncommon to feel very tired. This tiredness can last for some weeks after treatment has ended. If this happens take things easier. Do less than you would normally do. Rest more if you can. Ask your family or friends to help you at work or at home.

The tiredness can also be due to having fewer red blood cells (anaemia) because of changes in the bone marrow caused by chemotherapy. You may need a blood transfusion if your red blood cell count is low. See page 49 for more information about feeling tired and fatigue.

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### Tips & Hints – blood changes

- Take plenty of rests and breaks if you are feeling tired or fatigued.
- Avoid close contact, such as hugging or kissing, with people who have colds, flu and other infections, especially chickenpox, shingles or measles.
- Wash your hands often during the day, especially before eating and after going to the toilet.
- Take care to avoid injury. Use an electric razor when shaving. Wear thick rubber gloves when gardening to protect yourself from cuts.
- Contact the hospital immediately if you have a temperature of 38°C (100.4°F) or higher, shortness of breath or bleeding that cannot be stopped.

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### Feeling sick (nausea) or getting sick

Not everyone feels sick with chemotherapy, but if you do it can happen before, during or after treatment. It may last for several hours or for a few days after treatment. There are very effective drugs available that prevent or reduce nausea and vomiting. Ask your doctor to give you medication to stop you feeling sick and follow his or her instructions while you are on treatment.

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There is medication available that prevents or reduces nausea and vomiting.
Diarrhoea
Passing watery bowel motions more than twice a day is known as diarrhoea. You may also have cramping and/or abdominal pain. Tell your doctor, as he or she may be able to give you tablets to prevent this. Drink plenty of clear fluids. Let your doctor know if the diarrhoea lasts for longer than 24 hours.

Constipation
Chemotherapy may slow down the movement of the bowel and your regular bowel habit may change. As a result, you may have difficulty passing a bowel motion. This is called constipation. If this occurs let your doctor or nurse know as soon as possible. You may need to drink more clear fluids and/or take a laxative. In some cases your doctor may have to adjust your treatment.

Not wanting to eat
It is best to eat as much you can while on chemotherapy. Eat smaller amounts more often. If you do not feel like eating during treatment, you could try replacing some meals with special food supplements. Talk to the dietician in the hospital, who will be available to help you.

Sore mouth
Some drugs used to treat Hodgkin lymphoma can cause a sore mouth. They can also cause little ulcers to appear on the tongue, gums and inside the cheeks of your mouth. Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after each meal. Use a very soft toothbrush. If you have dentures remove them if your gums are sore. There are special mouthwashes that you can use. Your nurse will show you how to use them properly. See page 25 for hints and tips about mouth care.

If you do not feel like eating during treatment, you could try replacing some meals with special food supplements.

Keep your teeth, gums and mouth very clean, as it will reduce the risk of getting a mouth infection.

Numbness or pins and needles in hands and feet
Some chemotherapy drugs used to treat cancer can cause tingling or a burning sensation in your hands and feet. This is known as peripheral neuropathy. You may also have trouble picking up small objects or buttoning up a shirt or cardigan. This effect is almost always temporary and goes away after treatment stops. However, do tell your doctor or nurse if this happens, as some changes may need to be made to your treatment.

Hair loss (alopecia)
This is a common effect of some of the drugs used to treat lymphoma. Hair loss usually happens about 2–3 weeks into treatment. Hair loss can be complete or partial. Your hair will grow again once treatment stops.

You may feel upset at the thought of losing your hair. Talk to your nurse about your feelings. He or she will help you find ways of coping with hair loss. You can get a wig when this happens or you may prefer to wear a hat or scarf.

If you would like a wig, organise this before your hair starts to fall out so that you can get a good colour and style match to your own hair. Your social worker or nurse may be able to arrange for a wig specialist to visit you in hospital. If this is not possible ask if they have the name of a wig fitter you could go to see. Your local hairdresser may also be able to help. In some cases it is possible to get financial assistance with the cost of a wig. Ask your social worker or nurse for more information. For some patients the amount of hair loss is small, so a wig may not be needed.

Tips & Hints – hair care
- If your drugs are likely to cause hair loss, it can help to have your hair cut short before treatment. The weight of long hair pulls on the scalp and may make the hair fall out faster.
- Use gentle hair products.
Infertility
Some of the drugs used to treat Hodgkin lymphoma may cause infertility. It may be temporary or permanent. See page 44 for more information.

Other side-effects
If you have a side-effect or symptom not listed above that concerns you, tell your doctor or nurse straight away. He or she will tell you what to do. For more information about chemotherapy and its side-effects, contact the National Cancer Helpline 1800 200 700 for a free copy of the booklet Understanding Chemotherapy.

Children and chemotherapy
Infection is a major concern when children have chemotherapy. Even though you may be trying to keep life as normal as possible for your child, do avoid large crowds. That said, it is important not to isolate your child either. Tell the parents of your child’s friends of your concerns about infections such as chickenpox or measles. Ask them to let you know if their child is in contact with or develops them. If your child has been in contact with these infections, contact the hospital as soon as possible for advice.

Do not perm your hair during chemotherapy, or for 3 months afterwards.
If you colour your hair, use a mild vegetable-based colourant. Ask your chemotherapy nurse or hairdresser for advice.
Try not to brush or comb your hair too roughly – use a soft or baby brush.
Avoid using hair dryers, curling tongs and curlers. Pat your hair gently after washing it.
Use a gentle, unperfumed moisturiser on your scalp if it becomes dry, flaky or itchy. Natural oils such as almond oil or olive oil are suitable.
If you are likely to lose your hair, ask your doctor or nurse about wigs early on, so that the wig will be as close a match to your normal hair.
You may like to wear a hat or scarf when you go out. There are also turbans which can be worn in the house.

To sum up
- Chemotherapy is a treatment using drugs to cure or control cancer.
- The drugs can be given in tablet form, directly into a vein as an injection or through an intravenous infusion (drip).
- The side-effects vary depending on the drugs used. Most side-effects are well controlled with medication.

Steroid therapy
Steroids are drugs that are often given with chemotherapy to help treat Hodgkin lymphoma. They are also given to help with some of the side-effects you might experience. In fact, they can help you feel better quickly. In most cases, steroids for Hodgkin lymphoma are given for short periods with chemotherapy.
Side-effects of steroid therapy

There are a number of side-effects to steroids. In the short term these include:

- Increased appetite
- Feeling more energetic
- Stomach upsets
- Finding it hard to get to sleep.

It is better to take steroids as early in the day as possible. Take them no later than 4 o’clock in the afternoon if getting to sleep is a problem.

Other side-effects

If you have to take steroids for some time, you may have some other temporary side-effects. These may include:

- Puffiness of the eyelids, hands, fingers and feet
- Raised blood pressure
- Increased level of sugar in your blood.

If you develop high blood sugars your doctor will prescribe treatment. This will need to be taken daily to bring your blood sugar back to normal. Your doctor may also reduce the amount of steroids you are taking.

Long-term effects of steroids

Sometimes treatment for Hodgkin lymphoma involves taking steroids for a long time. This effect of this can include:

- Increased weight
- Low resistance to infection.

You may notice that you put on weight, especially on your face, waist and shoulders. Your face will fill out and appear more rounded. You may also have a lowered resistance to infection. Try to avoid close contact with people who have colds, flu or any kind of infection while you are taking steroids. It is important to remember that all these side-effects are temporary and will gradually disappear as the steroid dose is reduced.

Doctors recommend that if you have been taking steroids for a while it is better to come off them slowly. This will allow your body to slowly get used to not having them anymore. The sudden withdrawal of steroids could make you feel unwell.

Your doctor or nurse will explain your steroid medication to you in more detail. You should always carry a card with you stating that you are taking steroids. This information would be very important if you suddenly became ill.

Always carry a card with you stating that you are taking steroids. This information is very important if you suddenly became ill.

High-dose treatment with stem cell support

For some patients, even though they have been treated for Hodgkin lymphoma, there is still a high risk of the cancer coming back. Others may need more treatment as the first treatment has failed. In this case high-dose chemotherapy or radiotherapy may be given.

Because high-dose treatment would destroy the bone marrow that makes the blood cells that are essential for good health, bone cells that can restore the marrow need to be removed and then replaced after treatment is given. This can be done by collecting cells from blood or bone marrow before treatment begins and giving these cells back to you after treatment.

Peripheral blood stem cell transplantation (PBSCT)

The cells are usually got from the bloodstream. These cells, normally found in the bone marrow, are called stem cells and are the basic cells from which all other blood cells grow. Before these stem cells can be collected from the bloodstream they must be moved out of the bone marrow. This occurs when the bone marrow is made to produce a lot of stem cells. The bone marrow gets overcrowded and the extra stem cells spill over into the bloodstream. To make this happen your doctor will give you chemotherapy and/or a special drug called a growth factor. The stem cells are then collected from the bloodstream. This procedure is called peripheral blood stem cell transplantation (PBSCT).
Understanding Hodgkin lymphoma

Moving the cells into the bloodstream
To move the cells into the bloodstream, chemotherapy is usually given over a couple of days. The growth factor needs to be given daily for 10–14 days in a small injection under the skin. You can either do this yourself or your doctor or nurse can do it for you.

Collecting the stem cells
Around about day 10 of the injections, when your blood is ready, the stem cells can be collected. This takes about 3–4 hours each day for 2 or 3 days. It some cases it is possible to collect all the stem cells needed in one day. The stem cells are collected from a central line or from intravenous lines placed in large veins in your arms. Blood is taken out through the drip into a machine that separates the stem cells from the rest of your blood. This is called a leucopheresis machine. The stem cells are collected into a bag and the rest of the blood is returned to you.

The stem cells are then frozen until you have had the high-dose chemotherapy.

Returning the stem cells
Once you have had the high-dose chemotherapy, the stem cells are thawed out and returned to you through a drip or central line. These stem cells will help your bone marrow recover from the effects of treatment. This normally takes about 2 weeks. However, it may take 6–12 months before you are fully recovered from the effects of high-dose chemotherapy. You may need to stay in hospital for several weeks due to infection or other effects of treatment.

Autologous bone marrow transplant (ABMT)
If the cells are taken from your own bone marrow, this is called an autologous bone marrow transplant (ABMT). The bone marrow is usually taken from your hips. A general anaesthetic is given beforehand. You will not be allowed to eat or drink anything for several hours before the anaesthetic. You may be given a sedative before going to theatre. This will help you feel more relaxed.

Taking the bone marrow
When you are asleep a thin needle is passed through your skin into your hip bone. The bone marrow is then drawn up through the needle into a syringe and stored until needed. It is usually necessary to take bone marrow from different places in both hips to make up the amount needed. The procedure takes about 30–40 minutes in total.

You will not be allowed to eat or drink anything for at least 4 hours after coming back from theatre. Your hips may feel tender and sore for a few days afterwards. Ask your nurse for painkillers if you need them.

Returning the bone marrow
After your high-dose treatment of chemotherapy, the bone marrow is returned by intravenous infusion (drip). The bone marrow can be returned through a central line or other types of access by vein. It will take your bone marrow about 4 weeks to recover and resume its role of fighting infection. However, it may take 6–12 months before you are fully recovered from the effects of high-dose chemotherapy. You may need to stay in hospital for several weeks due to infection or other effects of treatment.

Consenting to treatment
Before consenting to either of the above treatments, make sure you understand why you should have it and what its chances of success are. You will also need to know about the side-effects of such treatment and how long they will last. Talk to your doctor or nurse. Ask them to go over the procedure with you in detail. Write down your questions if necessary.

It is more and more common to have a modified stem cell/bone marrow transplant from a donor in certain circumstances where high-dose therapy is needed. You will need advice on this from your doctor and the experts in bone marrow transplantation.

The Bone Marrow Transplant Support Group is available to help and support you at this time and throughout treatment. Call the National Cancer Helpline 1800 200 700 for more information.

Cancer Helpline 1800 200 700
Follow-up

No matter what treatment you receive for your cancer, once it is over you will have to come back for regular check-ups. In the beginning these will be quite often. These visits may include seeing your doctor and having some tests such as X-rays, scans and blood tests. These will continue for a number of years but will become less frequent as time goes by.

These visits are most important, as they will allow your doctor to check for signs of recurrence and to follow up on any ongoing side-effects that you may have. He or she will also be able to check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that effective treatment can be given.

If you are between check-ups or you have a symptom or problem that worries you, let your doctor know by making an appointment to see him or her as soon as possible.

Will treatment affect my sex life?

There is no medical reason why you cannot have sex while getting chemotherapy or radiotherapy if you feel like it. However, coming to terms with the fact that you have cancer can take quite a while. Your emotions are likely to be turned upside down. You may find it hard to relax when you have a lot on your mind. You may also be feeling tired from the effects of treatment or travelling to the hospital. As a result you may lose interest in sex. This is a normal way to feel at this time.

One common fear is that cancer can be passed on to your partner during sex. But this is not true. It is perfectly safe for you to resume a sexual relationship.

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine your interest in sex should return. If you have a supportive partner, you may find that talking about your feelings will help ease your anxiety.

Research – what is a clinical trial?

Research into new ways of treating lymphoma goes on all the time. Some look at new anti-cancer treatments, while others look at new ways to stop or slow the spread of cancer. The best time to give chemotherapy and radiotherapy is also being studied. Doctors are also studying the use of high-dose treatments in groups of patients who, in the past, were not thought to be suitable for this type of treatment.

When a new treatment is being developed, it goes through stages of research called phases. If the treatment looks as if might be useful in treating cancer, it is then given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and identify which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, more trials are done. These aim to:
- Find out if the treatment is better than existing ones.
- Find out if extra benefits result when the new treatment is given together with existing ones.
- Compare the new treatment with current best standard treatments.

Your doctor may ask you to try a new treatment. There are many benefits in doing this. You will be helping to improve knowledge about cancer and the development of new treatments. You will also be carefully watched during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of lymphoma, your doctors may ask your permission to store some samples of your cells or blood.

If you would like more information, a booklet called Understanding Cancer Research Trials (Clinical Trials) is available. Call the National Cancer Helpline 1800 200 700 for a copy.
Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

You should not feel guilty or embarrassed to talk your doctor or nurse about what is troubling you. He or she may refer you for specialist counselling if you think that would be helpful.

### Will treatment affect my fertility?

Many couples go on to have normal healthy babies after one or other partner has been treated for Hodgkin lymphoma. However, some treatments for lymphoma and sometimes the disease itself can cause infertility. This infertility may be temporary or permanent. Before you start treatment your doctor will talk to you about this in more detail.

If you have a partner, you may find it helpful if you see the doctor together so that you can both talk about your fears and worries.

#### For women

**Chemotherapy**

Some of the drugs used to treat Hodgkin lymphoma can affect the ovaries. This means that your periods may stop during or for a few months after treatment. You may get hot flushes, a dry vagina or other symptoms of the menopause. If it is temporary your periods may return to normal after a few months. This happens in about one third of women who have short-term infertility brought on by chemotherapy. In general the younger you are, the more likely it is that regular periods will return and you will still be able to have children.

**Early menopause**

The nearer a woman is to her menopause the more likely it is that chemotherapy will stop her periods permanently. Most of the effects of the menopause can be prevented or reversed by replacing the hormones the ovaries normally produce. However, it will not be possible to restore your fertility.

Your doctor may prescribe hormone replacement therapy (HRT) for you. This treatment can be given in different ways. For example, in tablet form, through a device put under the skin or by a slow release patch worn on the arm or the leg. Often a simple lubricant such as KY gel, which can be bought from most chemists, can help to ease any discomfort during sex. Talk to your doctor if this is an ongoing problem for you.

**Contraception**

As periods usually stop during treatment you may not know if you are fertile or not. If you are having sex and are still young enough to have children you must use a reliable method of contraception throughout your treatment and for some time afterwards. This is because there is a risk of miscarriage or birth defects in children conceived during or just after treatment.

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If you are having sex and are still young enough to have children, you must use a reliable method of contraception throughout your treatment and for some time afterwards.

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**Getting pregnant**

Many doctors believe it is better not to get pregnant for 2 years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment and by this time the likelihood of the disease coming back is much less. When you have finished treatment there are blood tests that can be done to show if you are fertile or not. Talk to your doctor or nurse if you need more information. They will answer your questions in more detail.

**Radiotherapy**

Most radiotherapy treatments have no effect on your ability to have children. If the lower part of your body is being treated, special shields can be used to protect your ovaries. However, many specialists recommend that women wait for 2 years after radiotherapy before

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Most radiotherapy treatments have no effect on your ability to have children.
If the eggs are successfully collected (harvested), they are stored for a maximum of 10 years or to age 45. However, you can make a request in writing to extend this period. The eggs will only be stored while you are alive, so it is important you keep in touch with the HARI Unit every year. Do inform them of any change in your address.

The egg freezing service (oocyte cryopreservation) at the HARI Unit is free for all cancer patients living in Ireland.

If you would like to find out more about egg freezing, talk to your doctor or nurse. You can also call the National Cancer Helpline 1800 200 700.

**For men**

For some men, the lymphoma itself can cause infertility. Sperm tests carried out before treatment starts will show if you are infertile or if your sperm count is low. Some types of treatment can also cause infertility. This may be temporary or permanent.

**Thinking about infertility**

The prospect of infertility can be a difficult issue to come to terms with. If you are young you may not have considered the thought of having children. You may also want to get started on treatment straight away. At times like this knowing if you will be able to have children or not may not be a priority.

However, as many lymphomas can be completely cured, it is most important that you give yourself some time to think about the future. It may help to talk to a member of your family or a close friend about your concerns. Ask your doctor or nurse for advice on what you should do.

**Sperm banking**

If the tests show that your sperm count is satisfactory it may be possible before treatment begins to store sperm for use at a later date. Sperm banking is done at the HARI Unit in the Rotunda Hospital, Dublin. To do this you will be asked to give several sperm samples. There will be a couple of days’ break between each sample to make sure good samples are obtained. The sperm will be frozen and stored until needed.

Your own health will take priority over egg freezing.
Understanding Hodgkin lymphoma

You may worry that the process of banking sperm may cause a delay in starting treatment. This is seldom the case as it can be done while tests are being carried out and the results of tests awaited. If you want to find out more about sperm banking talk to your doctor or nurse. He or she will give you more information. Call the National Cancer Helpline 1800 200 700 to talk to a nurse who will tell you what services are available.

If you want to find out more about sperm banking talk to your doctor or nurse.

Chemotherapy
Chemotherapy may cause infertility. It may be temporary or permanent. Even though doctors know that some chemotherapy drugs may cause infertility it is very difficult to say if and when this will happen. You may be on treatment 2–3 months before your sperm count is reduced. If you are having sex and your partner is still young enough to have children you must use a reliable method of contraception throughout your treatment and for some time afterwards. There is a risk of miscarriage or birth defects in children conceived during or just after treatment. Many doctors believe it is better for your partner not to get pregnant for 2 years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment and by this time the likelihood of the disease coming back is much less.

Radiotherapy
Most radiotherapy treatments have no effect on your ability to have children. However, sperm production may be reduced if the testicles are near the area being treated. Nowadays it is possible to avoid giving radiotherapy to the testicles in most treatments. Special shields can also be used to protect the testicles during treatment.
If your partner is still young enough to have children, you must use a reliable method of contraception throughout your treatment and for some time afterwards. This is because there is a risk of miscarriage or birth defects in children conceived during or just after treatment. Many specialists recommend that you wait for 2 years after radiotherapy before trying to start a family or have more children. This time gives your body a chance to get over the effects of the cancer and its treatment.

How can I cope with fatigue?

Fatigue is something that lots of people complain of from time to time, even if they are not ill. For most people, it is nature’s way of telling them to slow down and take some rest. Fatigue is a common symptom of cancer and is often described as an overwhelming tiredness. You may find it difficult to concentrate or make decisions.

The reason for the fatigue can be hard to identify. Fatigue may be caused by anxiety when a diagnosis of cancer is made and the additional stress caused by treatment. It can also be a side-effect of treatment or due to anaemia.

It is important to know that even though you may find it hard to identify the reasons for your tiredness there is action you can take that may help.

Fatigue can be caused by anaemia, treatment or anxiety.

What can I do?

- **Side-effects to expect:** For many patients treatment may help by relieving symptoms such as fever and feeling unwell, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.
- **Sleep:** If you are feeling worried and find it hard to sleep at night tell your doctor or nurse. He or she may be able to help. Try talking to your close family or friends about your concerns. If you find this hard, ask to see a counsellor. He or she will help you to find ways to cope.

Cancer Helpline 1800 200 700
Understanding Hodgkin lymphoma

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

Conventional therapies

Conventional therapies are treatments which doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy and hormone treatments. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

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

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

Many people find complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that cancer can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used instead of conventional treatments. These therapies include:

- Diet therapy
- Megavitamin therapy
- Herbalism.

Most doctors do not believe that such treatments can cure or control cancer.

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them helpful and beneficial during their illness. In many countries the way cancer is treated depends on the culture and environment in which you live. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted.

Physical exercise: If your illness allows you to take part in physical exercise, try to do some on a regular basis. For example, 10 minutes’ exercise 2–3 times a day might be a realistic goal and will boost your morale when you achieve it.

Losing weight: You may notice that you have lost weight. This may be due to the cancer or the treatment you are getting. Sometimes when you are feeling weak and tired you may lose interest in your food. Ask for help in preparing your meals. Eat your favourite foods. Take plenty of clear fluids such as water and fruit juice.

Ask for help: Get others to help you around the house, with travelling to hospital, with the children or with shopping.

Working: Whether you work or not during treatment depends on the kind of work you do and how you are feeling. It is probably better to make this decision when you have had one or two courses of treatment or some radiotherapy. Only then will you have a clearer picture of how the treatment affects you.

Studying: If you are in full-time education think about putting your studies on hold until your treatment is over. Use the extra free time to do something that you especially enjoy.

A useful booklet called Coping with Fatigue is available free of charge. If you would like a copy, call the National Cancer Helpline 1800 200 700.
If you decide to have complementary or alternative treatments…

Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, it is important to talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don’t be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

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

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

Coping and emotions

How can I cope with my feelings?

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

Some of the more common reactions include:
- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation.

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet called Understanding the Emotional Effects of Cancer is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

Shock and disbelief

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss your cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same...
questions over and over again. Or else you may accept the news calmly and say nothing because you don’t really believe what is happening to you.

**Fear and uncertainty**

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But nowadays many cancers can be cured or controlled with modern treatments. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers. You may also have fears that your experience of cancer will change who you are and that people with reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look.

You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer recurs. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Discuss your concerns with your doctor, who will give you advice and help. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

**Loss of control**

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don’t know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will ‘fall to pieces’ or ‘go crazy’. You may even lose hope. It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can help you feel more in control of your illness.

>>> **Learning more about your illness and treatment can help you feel more in control.**

**Sorrow and sadness**

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you’ve let down, and for any changes to your body that arise from treatment.

Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

**Denial**

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem absurd, it is a valid way of coping. As a result, people may not wish to mention or discuss their illness. Or else they may talk as if their illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at
least for the time being. Your doctors and nurses will also understand if you don’t want to hear any information about your cancer until you’re ready.

**Anger**

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with your God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you. Your family and friends may not always be aware that your anger is really about your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

**Resentment**

It is natural that you might be resentful and unhappy because you have cancer, while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have. You may resent having to change your lifestyle in some way. Sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

**Blame and guilt**

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don’t torture yourself at this time. Don’t feel guilty if you can’t keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is also no evidence that your attitude will affect your health or cancer. Regret and guilt serves no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

**Withdrawal and isolation**

There is no doubt that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is a normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready. If you would like more information on how to talk about your cancer,
there is a useful booklet available called *Who Can Ever Understand? – Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline 1800 200 700.

**Learning to cope**

No matter what treatment you have for cancer, it can take some time to come to terms with your emotions. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, many people are able to live a normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling, they can give you more support.

**Positive emotions**

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

**How can my family and friends help?**

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

**How to talk to someone with cancer**

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

Don’t withdraw because you’re afraid of what might happen to your relative or friend in the future.

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

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

*Lost for Words – How to Talk to Someone with Cancer* is a useful booklet written for relatives and friends of people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.
How can I talk to my children?

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

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

Be honest

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

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

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

It is best to prepare children for what to expect from the side-effects of treatments and to answer their questions simply and honestly. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

Coping with children’s emotions

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

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

What can I do?

Many people feel helpless when they are first told they have cancer. They think there is nothing they can do other than hand themselves over to the doctors and hospital. This is not true. There are many things that you can do at this time.

If you and your family understand your illness and its treatment you will be better able to cope.

- Always ask for information that is personal to you from your own doctors.
- Follow your doctor’s instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor. Write down the answers if you want.
- Let your doctor know if you have any problems or worrying side-effects. He or she can decide what to do to help you. If you say nothing a small problem can become more serious.
- After 3 or 4 cycles of treatment you may feel much better. You may
question the need for further treatment. Finishing your course of
treatment with as few delays as possible between cycles is most
important. Not completing the treatment may leave some cancer
cells untreated. This may affect the outcome of treatment.

- At times you may not be able to do the things you used to take for
  granted. 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. Many people talk about ‘fighting their cancer’. This can
  help some people feel more in control of what is happening to
  them. You can do this by becoming involved in your illness.

- Try to eat as well as you can. Eat little and often using lots of
different types of foods with plenty of fresh fruit and vegetables.

- Think about joining a support group. These groups allow you to
talk through your feelings with others who have been diagnosed
and treated for cancer. Lymphoma Support Ireland (LSI) is the
support group for patients with Hodgkin and non-Hodgkin
lymphoma. It provides patients and relatives with information,
advice and emotional support at time of diagnosis, throughout
treatment and afterwards. See pages 77–78 for more information.

- Join a relaxation class or listen to relaxation tapes.

- Take some regular exercise. Take it easy at first, building up the
amount you do, as you feel stronger.

- Some people find it helpful to talk to a counsellor.

- If the idea of changing your diet or taking exercise does not appeal
to you, don’t do it. Just do whatever suits you. Some people find
pleasure in keeping to their normal routine as much as possible.
Others prefer to take a holiday or spend more time on a hobby.

Life after treatment

Many patients are delighted when the treatment ends and they are
told that they no longer have Hodgkin lymphoma. However, they are
often surprised at how long it takes to regain their strength and to get
back to normality. It is important to know that it can take at least a
year for you to get over the effects of treatment. You may still feel
tired and lacking in energy. You may not feel ready to lead as active a
life as you did before treatment.

It is better not to fight these feelings but to allow your body the time
it needs to recover. You may have problems to solve or decisions to
make which you deferred because of treatment. These issues may
include changing jobs, getting back to work or study and if you can
have children or not. Health-wise, there are things that you can do
which may speed up the process of recovery and help you to have a
good quality of life in the future.

Anxiety

You may find that you miss the regular contact with the people who
looked after you while you were getting treatment. You may also be
worried about the cancer coming back. This anxiety can be
overwhelming at times but it may help to talk about your feelings. Try
talking to your partner or a close friend. If you find this hard,
someone who has had the same illness may be able to help.
Lymphoma Support Ireland is the support group for patients with
Hodgkin lymphoma and non-Hodgkin lymphoma. It provides patients
and relatives with information, advice and emotional support. See
pages 77–78 for more information.

Tell your doctor or nurse if you have a problem that is worrying you.
If you are still anxious and upset, ask to speak to a medical social
worker or counsellor about your feelings, as it may help.

Lack of energy

You may continue to feel quite tired after treatment ends. This is very
common as it will be at least a year before your body gets over the
effects of treatment. Do not be in a rush to get back to your normal
routine with work. Just do as much as you feel comfortable with. If
you are trying to study you may find it hard to concentrate. It may be
helpful to limit your studies until you feel stronger.
Doing some regular exercise will help improve your energy levels. Take it easy at first, increasing the amount you do as you feel stronger.

Ask for help around the house or at work. Try to build rest periods into your day. Do not allow yourself to get overtired. If you are going somewhere special have a rest before you go out. Save your energy for doing the things you especially enjoy. As time goes on your energy levels should improve.

Fertility

It is not easy to come to terms with the prospect of infertility. It can take a while to sort out your emotions and be able to talk about them. When you are ready, it may be helpful to talk openly to your partner or a friend about these feelings. If they can understand how you feel it is often easier for them to offer help and support.

Doctors cannot always tell if the infertility is going to be temporary or permanent. Once you are over the effects of treatment it is possible to have tests done to show whether you are fertile or not. These tests are quite straightforward; you may need to have some blood tests. Your doctor can organise them for you.

If you can have children you may be worried that the cancer may be passed on to them. You may also be worried that they will be malformed as a result of your treatment. It is important to know that these fears are unfounded. Many couples go on to have healthy babies after treatment for Hodgkin lymphoma.

Healthy lifestyle

In rare cases, treatment for Hodgkin lymphoma may cause long-term damage to your heart and lungs. There is also a slight risk of developing a second cancer because of the treatment. Living a healthy lifestyle may help to lessen the chances of you developing such health problems in the future.

Stop smoking

Some organs in the body, such as the lungs, are more sensitive to the damaging effects of tobacco smoke if they have been exposed to radiation. There is help available if you smoke and would like to stop. The Irish Cancer Society Quitline offers support and assistance for smokers. You can talk to a specially trained stop smoking counsellor who will help you to prepare a plan and support you during this time. Call the Quitline Local 1850 201 203 Monday–Friday 9am – 5pm for more information. Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.

Skin protection

If you are out in the sun or going on a sun holiday after your treatment, you must protect your skin. Keep skin that has been exposed to radiation covered up and wear a high protection factor suncream at all times. The sun’s rays that cause sunburn can be extra harmful to skin that has been exposed to radiation. You may be more at risk of getting skin cancer.

Chemotherapy can also make your skin more sensitive to the damaging effects of the sun, especially if you have had treatment recently. You may get sunburn more easily. As a result, do not sunbathe for long periods. If you are out in the sun keep your skin covered up. Protect your skin by wearing a high protection factor suncream at all times.

Healthy diet

Try to eat a variety of foods. Eating plenty of fruit and vegetables and cutting out sweets and cakes may help to bring your weight back to normal if you have put on weight during treatment.
Follow-up
These visits are most important, as they will allow your doctor to check for signs of recurrence and to follow up on any ongoing side-effects that you may have. He or she will also be able to check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that effective treatment can be given.

If you are between check-ups or you have a symptom or problem that worries you let your doctor know by making an appointment to see him or her as soon as possible.

If you are between check-ups or you have a symptom or problem that worries you, let your doctor know.

Support resources

Who else can help?
There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Oncology liaison nurses
- Cancer nurse co-ordinators
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups
- Helpline nurses.

The medical social worker in your hospital can help in many ways. He or she provides support and counselling to patients and their families and can provide advice on benefits, entitlements and services available when you go home.

Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses provide support to patients and their families from the time of diagnosis and throughout treatment. These people along with other members of your medical team work together to meet your needs.

In some larger hospitals there are special units that provide psycho-oncology services. This means that psychological care and support is given to patients with cancer during diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists, nurses and doctors working closely together.

When you go home there are various community health services available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live in an area which is remote or far from the hospital where you have been treated, your community welfare officer can also help with practical issues such as financial worries, etc. All these people in community health services can provide advice and support. You can get more information on the
services available either from the social worker in the hospital before you go home or at your local health centre.

Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. You may find it easier to share your thoughts and feelings with someone who has a similar experience than with anyone else. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. A list of support groups is given at the back of this booklet.

Often you might need practical advice about your financial matters, e.g. getting a mortgage or travel insurance. The Irish Cancer Society Helpline nurses will be happy to discuss any concerns you or your family may have, at any stage of your illness. They can give you more information about any of the services outlined above and can also let you know about support services in your area.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of what this involves are given in the following pages. At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €60 a night charge up to a limit of €600 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €60. There is no charge if you are referred by a GP. This charge does not apply if you have a medical card or are admitted to hospital as a result of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services, and outpatient services and medical appliances. Every person aged 70 or over has a right to a medical card and no means test is required. It covers the applicant only and not their dependants.

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

GP visit card

If you do not qualify for a full medical card, you may be eligible for a new type of medical card, called the ‘GP visit card’. It covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependant children pay a limit of €85 each month to cover the cost of prescribed drugs, medicines and appliances. If you have not already received a DPS card for yourself and your family, you can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your pharmacy.
Private healthcare cover

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

Benefits and allowances

Illness Benefit

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

Disability Benefit

You may qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least a year. Disability allowance is a weekly allowance paid to people with a disability who are aged between 16 and 66. For this allowance you must satisfy a means test, normally live in Ireland and be medically suitable. To be medically suitable you should have an illness that has continued or may continue for at least 1 year. This means that you are unlikely to be able to work for at least a year due to your illness. You are allowed a free travel companion pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Invalidity Pension

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

Your eligibility will also depend on your PRSI contributions and you must normally live in Ireland. You are allowed a free travel pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 704 3314, Ext. 48728.

Carer’s Allowance

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

Application forms are available from your social welfare office or from the Carer’s Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or Dublin (01) 704 3000.

Carer’s Benefit

Under carer’s leave legislation, you may be entitled to unpaid temporary leave from your employment. Or if you are employed but wish to care for a sick relative full time, you may qualify for a carer’s benefit. This is
a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You should be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, normally live in Ireland, are not self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer’s Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 / Dublin (01) 704 3000.

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

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

Further information
Depending on your circumstances at the time of your illness, there are many other benefits and entitlements which may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:
- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries contact:
Information Service
Dept of Social and Family Affairs
Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1890 662 244
Leaflet line: 1890 202 325
Email: info@welfare.ie
Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area. In 2005 the health boards became the Health Service Executive based in four regions: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

HSE infoline: 1850 241 850; Email: info@hse.ie; Website: www.hse.ie

HSE East Coast Area
[Co Wicklow, South East Dublin]
Southern Cross House
Southern Cross Business Park
Boghall Road
Bray
Co Wicklow
Tel: 01 2014 200

HSE Northern Area
[North Dublin]
Swords Business Campus
Balheary Road
Swords
Co Dublin
Tel: 01 8131 800

HSE South Western Area
[Co Kildare, West Wicklow, South Dublin]
Oak House
Millennium Park
Naas
Co Kildare
Tel: 045 880 400

HSE Midland Area
[Counties Laois, Offaly, Longford, Westmeath]
Head Office
Arden Road
Tullamore
Co Offaly
Tel: 057 9321 868

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

HSE North Eastern Area
[Counties Cavan, Monaghan, Louth and Meath]
Head Office
Navan Road
Kells
Co Meath
Tel: 046 9280 500

HSE North Western Area
[Counties Donegal, Sligo, Leitrim and West Cavan]
Head Office
Manorhamilton
Co Leitrim
Tel: 071 9820 400 / 1850 636 313

HSE South Eastern Area
[Counties Carlow, Kilkenny, Wexford, Waterford, South Tipperary]
Head Office
Lacken
Dublin Road
Kilkenny
Tel: 056 7784 100

HSE Southern Area
[Counties Cork and Kerry]
Head Office
Wilton Road
Cork
Tel: 021 4545 011

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

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

Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 7 nights to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer Information Service (CIS)

The Society also provides a Cancer Information Service with a wide range of services: the National Cancer Helpline is a freephone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues such as prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put patients in contact with the various support services available in Ireland.

Information is also available from your local Citizens Advice Centre. A list of these centres is available from: Citizens Information Board (formerly Comhairle)

7th Floor, Hume House, Ballsbridge, Dublin 4
Tel: 01 605 9000
Citizen Information Service: 1890 777 121
Email: information@ciboard.ie
Website: www.citizensinformationboard.ie

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

Information Guide to Health Services (published by the Dept of Health and Children). Copies are available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers.

Guide to Social Welfare Services (published by the Dept of Social and Family Affairs). Copies available from the Dept of Social and Family Affairs. Tel: 1890 662 244. Email: info@welfare.ie. Website: www.welfare.ie

Entitlements for People with Disabilities published by Citizens Information Board (Comhairle). Available from Citizens Information Board (Comhairle). Tel: 01 605 9000. Email: information@ciboard.ie
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groups that are available. The helpline 1800 200 700 operates Monday to Thursday from 9 am to 7 pm, and every Friday from 9 am to 5 pm. A Prostate Cancer Information Service 1800 380 380 also operates at the same time.

All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie.

The walk-in caller service allows anyone with concerns about cancer to freely visit the Society to discuss them in private.

CancerForum is a bulletin board on our website (www.irishcancer.ie) that gives the public the chance to post their comments. The CancerChat service is a live chatroom with a link to a Cancer Information Service nurse.

Action Breast Cancer

Action Breast Cancer (ABC) is a project of the ICS that provides breast cancer information and support and also funds breast cancer research. Its services are free and confidential. They include a national helpline, publications, one-to-one support, breast awareness talks, and advocacy. The ABC helpline 1800 90 30 40 operates weekdays from 9am to 5pm.

Counselling

Coping with a cancer diagnosis can be very stressful at times. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the National Cancer Helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Cancer information booklets

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

Cancer support groups

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

Lymphoma Support Ireland (LSI), formerly the Hodgkin’s United Group (HUG), is the support group for patients with Hodgkin and non-Hodgkin lymphoma. LSI provides patients and relatives with information, advice and emotional support from time of diagnosis and for as long as is needed.

This support group consists of volunteers who have had treatment for Hodgkin or non-Hodgkin lymphoma. These men and women are carefully selected following recovery and are trained to provide information and reassurance at a time when you are most in need. This service is provided on a one-to-one basis and is confidential.

LSI hold meetings once a month and publishes a newsletter that is distributed free to patients and their families. LSI has books on lymphoma that may be taken out on loan by patients.

Patient grants

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial assistance to patients in need. If you would like to request this kind of help contact your oncology or medical social worker at the hospital where you have been treated. He/she should then make the request in writing to the Irish Cancer Society.

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

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Tel: 01 231 0500
Fax: 01 231 0555
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Lymphoma Support Ireland (LSI) [formerly HUG]
c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Email: info@lymphoma.ie
Website: www.lymphoma.ie

Citizens Information Board (formerly Comhairle)
7th Floor
Hume House
Ballsbridge
Dublin 4
Tel: 01 605 9000/1890 777 121
Email: information@ciboard.ie

Dept of Social and Family Affairs – Information Service
Oisin House
212–213 Pearse Street
Dublin 2
Tel: 1890 662 244
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted Reproduction Ireland)
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion Unit
Dept of Health and Children
Hawkins House
Hawkins Street
Dublin 2
Tel: 01 635 4000
Website: www.healthpromotion.ie

Health insurers
Quinn Healthcare (formerly BUPA)
Mill Island
Fermoy
Co Cork
Local: 1890 700 890
Fax: 025 42122
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

VIVAS Health
Paramount Court
Corrig Road
Sandyford
Dublin 18
Tel: 1850 717 717
Email: support@vivashealth.ie
Website: www.vivashealth.ie

Voluntary Health Insurance (VHI)
VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
Email: info@vhi.ie
Website: www.vhi.ie

Support groups & support centres
ARC Cancer Support Centre
ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arcancancersupport.ie
Website: www.arcancancersupport.ie

BMT Support
Bone Marrow Transplant Support Group
c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline 1800 200 700
Email: info@bmtsupport.ie
Website: www.bmtsupport.ie

Bray Cancer Support & Information Centre
368 Main Street
Bray
Co Wicklow
Tel: 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre
Mid-Western Regional Hospital
Doonadyle
Co Limerick
Tel: 061 482615
Website: www.mwhb.ie/cancercentre

Cancer Plus (support group for parents of children with cancer)
Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline 1800 200 700
Email: helpline@irishcancer.ie

CanTeen Ireland
Young Peoples’ Cancer Support Group
c/o Carmichael Centre
Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: canteen@oceanfree.net

Cork ARC Cancer Support House
Cliffdale
5 O’Donovan Rossa Road
Cork
Tel: 021 434 6688
Email: Karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

The Cuisle Centre
Cancer Support Group
2 Park Villas
Harper’s Lane
Mountmellick Road
Portlaoise
Co Laois
Tel: 0502 81492
Email: cuislecentre@eircom.net

Dóchas – Offaly Cancer Support
12 Henry Street
Tullamore
Co Offaly
Tel: 0506 28268
Email: dochasoffaly@hotmail.com

Donegal Cancer Support Group
Clar
Co Donegal
Tel: 074 974 0837

The Gary Kelly Support Centre
Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Fax: 041 980 5101
Email: info@garykellycentre.org
Website: www.garykellycentre.org

Greystones Cancer Support
La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: kk@kathleenkelleher.com

HOPE
Enniscorthy Cancer Support & Information Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 9238 555
### Helpful books

**Cancer Positive: The Role of the Mind in Tackling Cancers**  
Dr James Colthurst  
Michael O’Mara Books Ltd, 2003  
ISBN 1-85479-860-X

**Challenging Cancer: Fighting Back, Taking Control, Finding Options**  
(2nd edn)  
Dr Maurice Slevin & Nira Kfir  
Class Publishing, 2002  
ISBN 1-85959-068-3

**Hodgkin Lymphoma**  
Catriona Gilmour Hamilton  
Lymphoma Association, 2004  
0-95372-445-X

## Useful contacts outside Republic of Ireland

### Action Cancer

**Action Cancer**  
Action Cancer House  
1 Marlborough Park  
Belfast BT9 6XS  
Tel: 028 9080 3344  
Fax: 028 9080 3356  
Email: info@actioncancer.org  
Website: www.actioncancer.org

### American Cancer Society

**American Cancer Society**  
1599 Clifton Road NE  
Atlanta, GA 30329-4251  
Website: www.cancer.org

### Cancerbackup

**Cancerbackup**  
3 Bath Place  
Riverton Street  
London EC2A 3JR  
Tel: 020 7696 9003  
Helpline: 020 7392 2800  
Website: www.cancerbackup.org.uk

### CancerLink UK

**CancerLink UK**  
Macmillan Cancer Relief  
89 Albert Embankment  
London SE1 7UQ  
Tel: 0044 20 7840 7840  
Email: cancerline@macmillan.org.uk  
Website: www.macmillan.org.uk

### Cancer Research UK

**Cancer Research UK**  
Website: www.cancerresearchuk.org

### Cancerbackup

**Cancerbackup**  
3 Bath Place  
Riverton Street  
London EC2A 3JR  
Tel: 0044 207 696 9003  
Helpline: 0044 207 7392 2800  
Website: www.cancerbackup.org.uk

### Cancerbackup

**Cancerbackup**  
3 Bath Place  
Riverton Street  
London EC2A 3JR  
Tel: 0044 207 696 9003  
Helpline: 0044 207 7392 2800  
Website: www.cancerbackup.org.uk

### The Ulster Cancer Foundation

**The Ulster Cancer Foundation**  
40/42 Eglington Avenue  
Belfast BT9 6DX  
Tel: 048 906 63281  
Website: www.ulstercancer.co.uk

### Lymphomas – For People Affected by Hodgkin Lymphoma or Non-Hodgkin Lymphoma

Catriona Gilmour Hamilton  
Lymphoma Association, 2004  
0-95372-445-X

### The Key Model – A New Strategy for Cancer Recovery

Dr Sean Collins & Rhoda Draper  
Ardagh Clinic, 2004  

### What You Really Need to Know about Cancer

Dr Robert Buckman  
Pan, 1997  
**Frequently asked questions**

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

- What is Hodgkin lymphoma? Where exactly is it?
- What is the stage of the disease?
- What type of treatment do I need?
- How successful is this treatment for my cancer?
- Are there other treatment options? Why is this one best for me?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects or after-effects will I get?
- Do I need to use contraception during my treatment? What will happen if I, or my partner, get pregnant?
- Is there anything I can do to help myself during treatment?
- Should I eat special foods?

**Your own questions**

1. Answer
2. Answer
3. Answer
4. Answer
5. Answer
6. Answer
7. Answer
8. Answer
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Nicky Martin, Medical Social Worker

We hope that this booklet has been of help to you. If you have any suggestions as to how it could be improved, we would be delighted to hear from you. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

After reading this booklet or at any time in the future, if you feel you would like more information or someone to talk to, please call our nurses on the freephone National Cancer Helpline 1800 200 700.

Would you like to help us?

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

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.
Tel: 01 231 0500 Email: info@irishcancer.ie
The Irish Cancer Society is the national charity for cancer care, dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer.