This booklet has been written to help you understand more about Hodgkin lymphoma. It has been prepared and checked by haematologists, radiation oncologists, nurses, radiation therapists, other relevant specialists and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and 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 also make a note below of contact names and information you may need.

<table>
<thead>
<tr>
<th>Contact</th>
<th>Tel:</th>
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<tbody>
<tr>
<td>Specialist nurse</td>
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<tr>
<td>Family doctor (GP)</td>
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<tr>
<td>Haematologist/Medical oncologist</td>
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<tr>
<td>Radiation oncologist</td>
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<tr>
<td>Radiation therapist</td>
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<td>Medical social worker</td>
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<tr>
<td>Emergency number</td>
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</table>

If you like, you can also add:

Your name
Address

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43/45 Northumberland Road, Dublin 4
Tel: 01 231 0500   Fax: 01 231 0555
Email: info@irishcancer.ie   Website: www.cancer.ie

Freefone National Cancer Helpline 1800 200 700
Open Monday to Thursday 9am–7pm; Friday 9am–5pm
Email: helpline@irishcancer.ie

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

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Introduction

This booklet has been written to help you understand more about Hodgkin lymphoma. It describes how it is diagnosed and treated and ways of coping with it. We hope it answers some of your questions and encourages you to discuss them with your doctors and nurses. We cannot advise you about which treatment to choose. Only you and your doctors can make this decision when all your test results are ready.

The booklet also discusses some of the feelings you and those close to you may have after a cancer diagnosis. At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.

About Hodgkin lymphoma

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 an individual type of treatment and chance of being cured. In your body, your organs and tissues are made up of tiny building blocks called cells. All cancers are a disease of the body’s cells. In healthy tissue, most cells replace or repair themselves when they get worn out or injured. With cancer, the cells do not behave as normal and keep on growing, or stop being removed when they should be.

These groups of abnormal cells can form a lump or tumour. Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body and so are not called cancer. Malignant tumours are cancer cells that can spread from where they first grew. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to form a new tumour elsewhere in your body.

What is the lymphatic system?

The lymphatic system helps your body defend itself against infection and is part of your immune system. Like your bloodstream, it carries waste material around your body from your tissues. It is made up of a network of tiny tubes that pass through most of the tissues in your body. These tubes carry lymph,
What is Hodgkin lymphoma?

Hodgkin lymphoma is a cancer of your lymphatic system. Previously it was known as Hodgkin’s disease.

The difference between Hodgkin and non-Hodgkin lymphoma depends on the appearance of the lymphoma cells under the microscope. Hodgkin lymphoma is identified by the presence of Reed-Sternberg cells, named after two scientists called Reed and Sternberg. They identified the presence of a particular cell in all cases of Hodgkin lymphoma that was not present in other lymphomas.

How common is Hodgkin lymphoma?

Hodgkin lymphoma is a rare cancer that can affect both men and women. About 113 people are diagnosed with it in Ireland each year.

What are the types of Hodgkin lymphoma?

Hodgkin lymphoma is divided into two types by the World Health Organisation (WHO). These types describe the disease in more detail, such as what the affected nodes look like under the microscope and what other cells are present. In each type, Reed-Sternberg cells are present. These are abnormal lymphocytes that are much larger and have two nuclei. The amount of Reed-Sternberg cells can vary between the various subtypes of lymphoma and can be mixed with many normal cells.

The two types of Hodgkin lymphoma are:
- Classical Hodgkin lymphoma
- Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

Classical Hodgkin lymphoma

Most cases of Hodgkin lymphoma are of the classical type. This is further divided into four subtypes:
- Nodular sclerosing
- Mixed cellularity
- Lymphocyte rich
- Lymphocyte depleted

What is lymphoma?

Lymphoma is a cancer of your lymphocytes, a type of cell that forms part of your immune system. It is not just one illness but a word that describes a wide range of diseases that all start with a cancerous lymphocyte. Lymphomas were first identified by Dr Thomas Hodgkin in the 19th century. They are described as either Hodgkin lymphoma or non-Hodgkin lymphoma. Most lymphomas are non-Hodgkin, whereas about 1 in 5 is Hodgkin.

a clear watery fluid that is leaked into your tissues and returned to your body. This fluid has cells called lymphocytes that fight infection.

Along the network are hundreds of small glands and nodes that remove the lymph. They are mainly found in your neck, armpit and groin. More of these lymph nodes are grouped together in your chest and abdomen. Some body organs also form part of your lymphatic system. For example, your tonsils, adenoids, thymus, spleen and bone marrow.

The lymphatic system works to keep your body healthy in the following ways:
- It fights infection.
- It drains any leaked fluid in your tissues back into your bloodstream.
- It filters the lymph as it passes through your lymph nodes.
- It filters your blood as it passes through your spleen.
Understanding Hodgkin lymphoma

The nodular sclerosing type is the most common subtype and mainly occurs in younger adults and women. Mixed cellularity occurs more commonly in men than in women. The lymphocyte-rich type is quite rare and occurs mostly in children, while lymphocyte depleted often occurs in older people.

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

This subtype of lymphoma is very rare. It is usually diagnosed at an early stage and is not very aggressive. It tends to occur more in men and often diagnosed in people under the age of 35. When seen under the microscope, there are some abnormal cells that look like popcorn but few Reed-Sternberg cells.

For more information about types of Hodgkin lymphoma, call the National Cancer Helpline on 1800 200 700. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

What causes Hodgkin lymphoma?

The exact cause of Hodgkin lymphoma is unknown. Even so, research continues to look for possible causes. There are certain things called risk factors that can increase your chance of getting the disease. For example:

- **Gender**: It is more common in men than in women.
- **Age**: It occurs most often in young people between the ages of 15 and 30 and sometimes in the over 60s, but it can occur at any age.

- **Family history**: Brothers and sisters of those with Hodgkin lymphoma have a higher chance of developing the disease, although the likelihood is still small.
- **Poor immunity**: Anyone whose immune system is damaged or not working fully may be at risk. This includes those taking drugs to prevent rejection after an organ transplant or due to other treatments. Anyone born with an immune condition, for example, rheumatoid arthritis, may be more at risk too.
- **Viruses**: Certain viruses, like Epstein Barr (glandular fever) and HIV, may lead to an increased risk of developing Hodgkin lymphoma.

Remember that many people with risk factors do not get Hodgkin lymphoma and many who are diagnosed have no known risks. Like other cancers, Hodgkin lymphoma is not infectious and cannot be passed on to other people.

To sum up

- **Cancer** is a disease of the cells of your body.
- The lymphatic system helps your body defend itself against infection.
- **Lymphoma** is a cancer of the lymphatic system.
- Hodgkin lymphoma has abnormal cells called Reed-Sternberg cells.
- Hodgkin lymphoma is a rare cancer. It affects about 113 people in Ireland each year.
- There are several subtypes of Hodgkin lymphoma.
- The exact cause of Hodgkin lymphoma is unknown. Possible risk factors are gender, age, family history, poor immunity and certain viruses like Epstein Barr and HIV.

National Cancer Helpline 1800 200 700
Understanding Hodgkin lymphoma

What are the symptoms of Hodgkin lymphoma?

The main symptom of Hodgkin lymphoma is a lump or swelling in your neck, armpit or groin. These swellings are enlarged lymph nodes that are usually painless but might sometimes ache.

Other symptoms

Other symptoms may include any of the following:
- Drenching night sweats
- High temperatures or fevers
- Unexplained weight loss (more than a tenth of your total weight)
- Loss of appetite
- Feeling tired all the time (fatigue)
- Itchy skin

The most common of these symptoms are fever, sweating and weight loss, which are described as ‘B’ symptoms. Sometimes you might develop lymphoma in other areas of your body. If this happens, the symptoms can be quite different. For example, if you have lymphoma in your bowel or stomach, you may experience abdominal pain, diarrhoea or indigestion.

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

The main symptom of Hodgkin lymphoma is a lump or painless swelling in your neck, armpit or groin.

How is Hodgkin lymphoma diagnosed?

Most people begin by visiting their family doctor (GP). If your doctor has concerns about you, he or she will refer you to a specialist for further tests. At the hospital the doctor will ask you questions about your general health and do a physical exam. The following tests will be done:
- Blood tests
- Chest X-ray
- Lymph node biopsy

Blood tests: The blood tests will include a blood count to see how many red cells, white cells and platelets are in your blood. Other blood tests can check how well your kidneys and liver are working.

Chest X-ray: A chest X-ray may be taken to check your general health and see if there are any enlarged nodes in your chest.

Lymph node biopsy: In most cases the lymph node containing the lump is removed and a sample (biopsy) sent to the laboratory to be examined under a microscope. A biopsy is the only way to tell if you have lymphoma or not. The test may be done under a local or general anaesthetic.

If the enlarged lymph nodes are deep in your chest or abdomen, you may need open surgery to get a suitable sample to examine.

Further tests

If the biopsy shows that you have Hodgkin lymphoma, your doctor will refer you to a haematologist or medical oncologist for further tests. These tests are known as staging. They will show what areas of your body are involved and so help your doctors 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 your diaphragm. (Your diaphragm is the thin muscle under your lungs that separates your chest from your abdomen.)
- If the disease has spread to your bone marrow or to places outside the lymphatic system such as your liver.

Tests may include:
- CT scan
- PET scan
- Ultrasound scan
- Bone marrow biopsy
- MRI scan

CT scan: This is a special type of X-ray that builds up a detailed picture of the tissues inside your neck, chest and abdomen.
Understanding Hodgkin lymphoma

For the test, you lie still on a table which moves your body into a machine shaped like a doughnut. 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. Do 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. Some people get anxious about this test and are afraid they may feel claustrophobic during it. If you do feel anxious, contact the medical team in the hospital the day before. They may be able to give you medication to help you to relax on the day.

PET scan: Positron emission tomography (PET) can help to stage 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. A CT scan is usually done together with the PET scan. Once you are relaxed, the sugar is injected into a vein in your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are located. After an hour, you lie on a scanning table that will move through a scanning ring, which takes pictures of the tissues inside your body. It shows where the lymphoma is in your body. Before the test, you may have to fast for a few hours and the scan itself may take up to 1 hour. PET does not hurt and is safe to use with no side-effects. PET scanners are not available in all hospitals, only specialised centres.

Ultrasound scan: This is a special scan that builds up a picture of the tissues inside 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 makes sound waves, is used to take the scan. The sound waves then appear as a picture on a computer screen. This test is painless and only lasts about 10 minutes. It is done in the X-ray department of the hospital.

Bone marrow tests: You might have a bone marrow aspiration and biopsy as part of the staging. Your bone marrow is a jelly-like substance found in the centre of your large bones. Bone marrow is responsible for making your blood cells. A bone marrow aspiration takes a sample of bone marrow cells, which is the liquid part of your marrow. A bone marrow trephine (biopsy) takes a piece of whole bone. Both can be done at the same time. The samples are usually taken from the back of your pelvis at your hipbone.

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 marrow is then taken. You will feel some discomfort during it but the test usually lasts 15–20 minutes. 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. The sample is examined under a microscope to see if there are any lymphoma cells present.
**Understanding Hodgkin lymphoma**

**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, though it can be quite noisy. But you will be given earplugs to wear during it. Before the scan you might 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, might not be suitable for the test. Your doctor will advise you about this.

**Waiting for results**
It may take at least a week or longer 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. Or you may wish to call the National Cancer Helpline on 1800 200 700 and speak to one of our specially trained nurses. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

**How is Hodgkin lymphoma staged?**
The stage of Hodgkin lymphoma refers to how much of your body is affected by the disease. Knowing the type and the extent of the cancer helps your doctors to decide on the right treatment for you. Hodgkin lymphoma is defined as stages 1 to 4, depending on how many lymph nodes or organs are involved.

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>One group of lymph nodes is affected on one side of your diaphragm</th>
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<tbody>
<tr>
<td>Stage 2</td>
<td>Two or more groups of lymph nodes are affected on one side of your diaphragm</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Lymph nodes are affected on both sides of your diaphragm. For example, your chest and abdomen</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Lymphoma can be found in organs outside your lymphatic system or in your bone marrow</td>
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</table>

Remember your diaphragm is the sheet of muscle that lies just under your ribcage and separates your chest from your abdomen.

When staging Hodgkin lymphoma your doctors will also look at your symptoms. They use a letter code, either A or B, to say if you have symptoms, such as fever, night sweats or weight loss, or not. If you have no symptoms your disease will be classified as A; if you have any symptoms of Hodgkin lymphoma, it is B. Sometimes lymphomas can occur at unusual places outside your lymph nodes, for example in your stomach. This is called extranodal lymphoma and the stage will include the letter E.

Stages 1 to 2 are known as early stage disease, while stages 3 to 4 are advanced stage disease. If the disease comes back after treatment, it is called recurrent or relapsed lymphoma. This too can be treated successfully. If you need more information about staging, do ask your doctor or nurse. They can explain the stages to you in more detail.

Your doctor or nurse will explain the different stages in more detail.

**To sum up**
- The main symptom of Hodgkin lymphoma is a painless lump or swelling in your neck, armpit or groin.
- Hodgkin lymphoma is diagnosed by a biopsy of the lymph node.
- Depending on the results of the biopsy you may need other tests to stage the cancer. These find out the extent of the lymphoma and helps your doctor decide on the best treatment for you.
- Staging tests include CT scan, PET scan, ultrasound scan, bone marrow biopsy, and MRI scan.
Treatment and side-effects

How is Hodgkin lymphoma treated?

It is now possible to treat Hodgkin lymphoma very successfully. The type of treatment you receive will depend on:
- The stage of the disease
- Your age
- Your general health
- If you have 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, the lymphoma is curable in most cases or it will show 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.

Types of treatment

Some people only need one type of treatment, while others need a combination of treatments. These treatments can include:
- Chemotherapy
- Radiotherapy
- Biological therapies
- High-dose treatment and stem cell support

Chemotherapy: Chemotherapy is the use of drugs to cure or control cancer cells. It can be given on its own or with other treatments. See page 22 for more details.
Understanding Hodgkin lymphoma

Radiotherapy: Radiotherapy uses X-rays to destroy the cancer cells. See page 30 for more details.

Biological therapies: These are newer drugs that use your body’s own immune system to fight cancer. The type used is called monoclonal antibodies. For example, rituximab. Biological therapies are not commonly given in Hodgkin lymphoma and more research is being done to see if they are effective in treating the disease. See page 37 for more details.

High-dose treatment and stem cell support: This treatment might be given if Hodgkin lymphoma comes back after first treatment or if the cancer has not responded to the treatment. It allows high doses of chemotherapy to be given to kill the lymphoma cells. See page 38 for more details.

Stage of disease and treatment
Your treatment can also vary depending on the stage of the disease.

Early stage lymphoma: Some people with early stage Hodgkin lymphoma will have chemotherapy alone. The duration of this chemotherapy will depend on your individual situation. In some cases, the course of chemotherapy is followed by radiotherapy. A typical course of radiotherapy lasts about 2–3 weeks.

Advanced stage lymphoma: If you have advanced Hodgkin lymphoma, you will be treated with chemotherapy over 6 months. In some cases, the course of chemotherapy is followed by radiotherapy.

Relapsed/refractory: For a small number of people, the Hodgkin lymphoma may not respond well enough to treatment (refractory) or it may return (relapse). In this case, more chemotherapy and possibly radiotherapy may be suggested. Sometimes high-dose chemotherapy with stem cell support may be discussed.

Deciding on treatment
Treatment options: Your doctor and nurse will explain your treatment options to you. Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers.

Time to think: When faced with a life-threatening illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You might also feel under pressure to make a decision. In this case, you might want more time to think things through. However with lymphoma, it is best to start treatment as soon as possible.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor will refer you to another specialist if you feel this would be helpful. But remember it is best not to delay treatment in the case of lymphoma.

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you wish to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The most important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment
You may be asked to sign a consent form saying that you give permission for the treatment to take place. No medical treatment can be given without your consent. Before treatment, you should know:
• The type of treatment you are advised to have
• The benefits and risks of the treatment
• Any other treatments that may be available
• Any major side-effects of the treatment

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.
Individual treatment

You may notice that other people with Hodgkin lymphoma are not getting the same treatment as you. This does not mean that you are not getting the best treatment. Remember everyone’s treatment needs will be different. Do ask your doctor about your own treatment.

To sum up

- The aim of treatment is to cure the Hodgkin lymphoma while causing as little damage as possible to other tissues and organs.
- Treatment will depend on the stage of the disease, your age, general health and if you have symptoms such as weight loss and fever.
- Hodgkin lymphoma can be treated with chemotherapy, radiotherapy, biological therapies, and high-dose treatment and stem cell support.
- Treatments can vary for early stage, advanced stage or relapsed/refractory stage.

Who will be involved in my care?

Some of the following health professionals may be involved in your care. Usually, a team of specialists will decide your treatment.

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
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<tbody>
<tr>
<td>Haematologist</td>
<td>A doctor who specialises in disorders of the blood and lymphatic system.</td>
</tr>
<tr>
<td>Medical oncologist</td>
<td>A doctor who specialises in treating cancer patients using chemotherapy and other drugs.</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>A doctor who specialises in treating cancer patients using radiotherapy.</td>
</tr>
<tr>
<td>Clinical nurse specialist</td>
<td>A specially trained nurse with knowledge and expertise in caring for patients with cancer.</td>
</tr>
<tr>
<td>Liaison oncology or haematology nurse</td>
<td>A specially trained nurse with knowledge and expertise in caring for patients with cancer, who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.</td>
</tr>
<tr>
<td>Radiation therapist</td>
<td>A person specially trained in giving radiotherapy and radiotherapy-related advice to cancer patients.</td>
</tr>
<tr>
<td>Medical social worker</td>
<td>A person specially trained to help you and your family with all your social and practical needs. They are skilled in giving counselling and emotional support at times of change and loss. They can also give advice on practical and financial supports available to you when you go home.</td>
</tr>
<tr>
<td>Psychologist</td>
<td>A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.</td>
</tr>
<tr>
<td>Counsellor</td>
<td>A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness. The Irish Cancer Society provides a counselling service. For details, call the National Cancer Helpline on 1800 200 700.</td>
</tr>
</tbody>
</table>
Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. The type of chemotherapy you get will depend on the type and stage of your Hodgkin lymphoma.

Chemotherapy drugs can be used on their own or with each other (in combination). Most Hodgkin patients who need chemotherapy will get a combination of drugs.

What chemotherapy drugs are used?

There are many chemotherapy drugs used to treat Hodgkin lymphoma. ABVD and BEACOPP are the most common treatment schedules (see table below). Most treatment schedules include steroids as well (see page 29).

<table>
<thead>
<tr>
<th>Treatment schedule</th>
<th>Drugs</th>
</tr>
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<tbody>
<tr>
<td>ABVD</td>
<td>Doxorubicin (Adriamycin*), bleomycin, vincristine and dacarbazine</td>
</tr>
<tr>
<td>BEACOPP type</td>
<td>Bleomycin, etoposide, doxorubicin (Adriamycin*), cyclophosphamide, vincristine (Oncovin*), procarbazine and prednisolone</td>
</tr>
</tbody>
</table>

Before any chemotherapy is given your doctor will discuss your treatment options with you. For more information on chemotherapy, call the National Cancer Helpline on 1800 200 700 and ask for a copy of the booklet Understanding Chemotherapy. For more about specific drugs, visit [www.cancer.ie/cancer-information/treatments/chemotherapy/drugs](http://www.cancer.ie/cancer-information/treatments/chemotherapy/drugs)

How much chemotherapy do I need?

How much chemotherapy you need will depend on the extent of your Hodgkin lymphoma. Treatment usually lasts from 3 to 6 months. The frequency of treatment depends on special guidelines called a protocol. Your doctors and nurses will discuss this protocol with you in more detail.

How is chemotherapy given?

Chemotherapy is usually given into a vein or as a tablet. If given into a vein, it can be as an injection or through a drip (infusion). 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.

Central line: If your treatment involves injections or 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 long, thin flexible tube that goes from a main vein in your body and out through your chest or arm. The plastic tube is also known as a catheter. You will be given a local anaesthetic before it is put in, which usually takes about 10–15 minutes. Removing it is very simple, sometimes needing a small local anaesthetic.

Peripheral line: When the line is threaded from your arm to a large vein in your chest, it is called a PICC line. This stands for peripherally inserted central catheter. This may be done if you have good veins and you can receive chemotherapy this way each time you have treatment.

Portacath: There are also other ways to have easy access to your veins for taking blood samples and giving treatment. Sometimes the central line is attached to a device called a portacath. This is a small, round plastic or metal disc placed under your skin, which can be attached to plastic tubing. The port can be used for as long as is needed. Talk to your doctor or nurse, who will explain the different options to you.
Understanding Hodgkin lymphoma

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 or unwell or running a high temperature of 37.5°C or higher. If this happens, contact the hospital where you are being treated straight away. They 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, as infection can be a serious complication of chemotherapy. Talk to your doctor or nurse, who will give you more information.

Tiredness (fatigue): Fatigue can be due to the lymphoma itself or a side-effect of treatment. For example, sometimes your blood count can drop, in particular haemoglobin, which is the iron part of your blood. Remember fatigue can affect you both physically and emotionally. It can be very frustrating, as it may not be eased by rest. But do rest as much as you can and take things easier. Simple stretching or a range of motion exercises or a short walk can give you more energy, while not tiring you out. Fatigue can remain for up to 6 months after your treatment has finished or even longer for some people. See page 40 for more details or contact the National Cancer Helpline on 1800 200 700. Ask for a copy of the free booklet, Coping with Fatigue.
Numbness or pins and needles in hands and feet: Some chemotherapy drugs 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 usually temporary and goes away after treatment stops. But do tell your doctor or nurse if it happens, as your treatment may need to be changed slightly. Call the National Cancer Helpline on 1800 200 700 for more advice or a copy of our free factsheet on peripheral neuropathy.

Hair loss: Not all chemotherapy drugs cause hair loss. Some may thin your hair while others do not affect it at all. You may lose all body hair including your eyelashes and pubic hair, which can be very distressing. Your doctor or nurse will let you know if the drugs you are receiving will cause hair loss. Your hair can begin to fall out within a few weeks of your first chemotherapy treatment. You might feel a tingling sensation in your scalp a day or two before your hair begins to fall out. But remember your hair will start to grow back a few weeks after your last treatment.

If choosing a hair wig, do pick one before your own hair falls out, as this will help you match it to your usual colour and style. Remember it is normal to feel upset at the thought of losing your hair. Talk to your nurse or medical social worker about your feelings. He or she will help you to find ways to cope both emotionally and practically.

For more information, call the National Cancer Helpline on 1800 200 700. Ask for a copy of the free factsheet Hair Loss and Cancer Treatment.
**Understanding Hodgkin lymphoma**

**Tips & Hints – hair care**
- If the drugs are likely to cause hair loss, it can help to have your hair cut short before treatment. The weight of long hair will pull on your scalp and may make your hair fall out faster.
- Use gentle hair products.
- 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 and straighteners. 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, bandana or scarf when you go out. There are also turbans that can be worn in the house.

**Infertility and birth defects:** Some of the drugs used to treat Hodgkin lymphoma may cause infertility. It may be temporary or permanent. If you are younger and fertile, chemotherapy can cause birth defects. See page 42 for more information.

**Bruising:** Platelets help to stop bleeding by clotting your blood. If your platelet count is low (thrombocytopenia), you will be more prone to bruising and bleeding. Usually this rarely happens with Hodgkin lymphoma. Let your doctor know if you have unusual or prolonged bleeding or if you notice a rash on your body. Your platelet count will be measured regularly and you may need a platelet transfusion.

**Other side-effects**
If you have a side-effect or symptom from those listed above that concerns you, tell your doctor or nurse straight away. Certain chemotherapy drugs might also weaken your heart muscle. In this case, you might need an ECHO scan before treatment to check how well your heart is working. Sometimes the drugs may affect your lungs and cause a cough, chest pain or shortness of breath. Your doctor will give you more advice if these happen. For more information on chemotherapy, contact the National Cancer Helpline on 1800 200 700. Ask for a copy of the free booklet, *Understanding Chemotherapy*, or the DVD called *A Guide to Chemotherapy*. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

**Steroid therapy**
Steroids are hormones made naturally in your body. Some treatments are more successful when steroids are given along with chemotherapy drugs. They can also help with some of the side-effects you might experience. In fact, they can help you feel better rather quickly. In most cases, steroids for Hodgkin lymphoma are given for short periods with chemotherapy. 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 as possible in the day. Take them no later than 4 o'clock in the afternoon if getting to sleep is a problem at night.

**Other side-effects**
If you have to take steroids for some time, there may be other temporary side-effects. For example:
- Puffy eyelids, hands, fingers and feet
- Raised blood pressure
- Increased sugar in your blood
- Mood or personality changes, such as euphoria and anger

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. For this and other side-effects, the dose of steroids you are taking may need to be reduced.

Sometimes your treatment might involve taking steroids for a longer time. This can lead to weight gain and low resistance to infection. But remember that all these side-effects are temporary and will gradually disappear as the steroid dose is reduced. Usually you come off steroids gradually to allow your body to slowly get used to being without them.

Do ask your doctor or nurse for more information about steroids. 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.
Planning your treatment

Before radiotherapy your doctor, radiation therapists and other specialists plan how best to deliver your treatment. This team will first make sure that the treatment area includes all the cancer cells and areas that might be hiding cancer cells. They aim to avoid targeting healthy cells. This is called planning and it usually takes place in a CT scanner. The scan helps your doctor to decide the exact area within your body that needs treatment. The CT scan is usually taken with you lying on your back, but this can vary depending on where the lymphoma is or was. Sometimes other devices are used to help keep you still.

**Masks:** Lymphoma often affects the lymph glands around your head, neck and upper chest. When giving radiotherapy to this region, an immobilisation shell or mask is needed. This helps to keep you very still during treatment. To make this mask, warm plastic material is moulded directly on your skin and allowed to set. The material may be slightly warm but will not feel too hot. Do not worry as most people cope very well and help is available if you need it. There are holes in the mask for you to breathe and see through.

The mask helps you to keep still so treatment is given to the same area each day. It is an important part of planning and may take some time to complete. The mask is not a shield or barrier to the effects of radiation. If you do not need radiotherapy to your head or neck region, a mask will not be necessary.

**Skin marks:** If you do not need a mask, the radiotherapy team may make one or two small permanent skin marks instead. These marks are about the size of a small freckle. They help to accurately line up the radiation treatment each day. It is done by placing a drop of dark purple ink into your skin with a small needle. This does not take long but it can be slightly uncomfortable. These marks are called tattoos.
When will treatment begin?
Your treatment will usually start 2–4 weeks after your radiotherapy planning visit. If there is any change to this plan, the team will let you know.

During the treatment
At each treatment the radiation therapists will take you into the treatment room and make sure you are in the right position. When they are satisfied with the position, they will leave the room for a short while so the treatment can be given. You will not feel anything but you may hear a bleeping sound. This is normal and means that the treatment is happening. During the treatment, the radiation therapists will watch you on a television screen and can talk to you over an intercom. They can also hear you. Each treatment may take 10–20 minutes. During radiotherapy, you might notice some changes in the way the radiation therapists give you your treatment. For example, they might take a scan, a measurement or change the angles of the machine. This is all part of the process and done to make sure that radiotherapy is given to exactly the right area each day. It is important that you lie still in exactly the same position for each treatment.

External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends afterwards. The radiations therapists will also tell you how to look after your skin during and after treatment. For more information about radiotherapy, contact the National Cancer Helpline on 1800 200 700. Ask for a copy of the booklet Understanding Radiotherapy or the DVD called Radiation Therapy: A Patient Pathway.

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

The most common side-effects that may occur are:
- Difficulty swallowing or sore throat
- Sore mouth
- Nausea and vomiting
- Diarrhoea
- Weight loss
- Skin changes
- Tiredness (fatigue)
- Shortness of breath
- Hair loss

Difficulty swallowing or sore throat: If you have radiotherapy to your 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 or that it is dry and sore. This is a common reaction to treatment. You may find it helpful to eat soft foods often. If you find it difficult to eat your normal foods, high-calorie liquid supplements may help as well. Your doctor may also give you medication to take before meals to make swallowing easier. Usually the discomfort gets better on its own within about 2 to 4 weeks. Do ask your hospital dietitian for advice too. For more information, contact the National Cancer Helpline on 1800 200 700 and ask for a copy of the booklet Diet and Cancer.

Sore mouth: Radiotherapy to the glands in your neck may cause a sore mouth. Little ulcers may appear on your 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. Remember to clean your teeth after each meal using 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 radiation therapist and nurse will advise you and show you how to use them properly. You may also notice that your mouth feels dry and sometimes has a metallic taste. This is because your salivary glands might make less saliva than usual during treatment. Radiotherapy can also increase your chances of getting cavities in your teeth. For that reason, do visit your dentist for regular check-ups. This will help reduce the risk of tooth decay.
Skin changes: During radiotherapy your skin in and around the treated area may become red and sore. It may even look a little like sunburn. A special cream can be used for this problem. Remember to only use creams recommended by your nurses or radiation therapists. 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, do use an electric razor. Avoid perfumed creams or powders. Check with your radiation therapist or nurse before applying anything to your skin.

Tiredness (fatigue): Tiredness can often build up over the course of your treatment. This can last for some weeks or months after treatment has ended. It may be due to the treatment itself or due to travelling long distances for treatment. It is best to rest as much as you can and take things easier. Simple stretching or a range of motion exercises or a short walk can also give you more energy. Yet these will not tire you out at the same time. See page 40 for more about fatigue.

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

Nausea and vomiting: Nausea or vomiting usually only occurs if you need radiotherapy to your abdominal area. Your nurse can give you medication to help prevent you feeling sick (nausea) or vomiting. Take it 1 hour before treatment. It is also best to eat small amounts often.

Diarrhoea: If you have radiotherapy to your abdomen or pelvis, you may get diarrhoea. Passing watery bowel motions more than three times a day is known as diarrhoea. You might also have cramping or abdominal pain. If this happens, do 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 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 dietitian if you are losing weight. He or she will give you advice on the best foods to eat. For more information, contact the National Cancer Helpline on 1800 200 700 and ask for a copy of the booklet Diet and Cancer.
Understanding Hodgkin lymphoma

Biological therapies

Biological therapies use your body’s immune system to fight cancer. They can be given together with chemotherapy. The most common type of biological therapy used in Hodgkin lymphoma is monoclonal antibodies.

The drug rituximab is one example and may be given in some cases. It depends on the type of Hodgkin lymphoma you have and it is normally given into a vein through a drip. For this reason, you will need to stay in the hospital day ward while receiving it. Unlike chemotherapy, biological therapies target cancer cells directly and do not harm normal cells. So you experience fewer side-effects. The following side-effects can occur:

- Infusion reaction – fever and chills
- Flu-like symptoms
- Headaches
- Changes in blood pressure
- Fatigue

The above side-effects are mild and your doctor and nurse will help ease any discomfort. Remember to tell your doctors and nurses straight away if you experience any of the above side-effects or others not listed above. These drugs do not cause any hair loss. Call the National Cancer Helpline on 1800 200 700 for more information. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

To sum up

- Biological therapies use your body’s immune system to fight cancer.
- Unlike chemotherapy, biological therapies target cancer cells directly and do not harm normal cells.
- The drug rituximab is given into a vein through a drip.
- You will have to attend the hospital day ward to receive the drug.
- Some side-effects include infusion reactions, flu-like symptoms, and headache.

Hair loss (alopecia): Hair loss will happen if you have radiotherapy to any part of your 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 notice that the hair loss is patchy. If you are having radiotherapy to your head, you may have hair loss from your 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. Talk to your nurse, radiation therapist or medical social worker about coping with hair loss. See page 27 for more about hair loss.

Other side-effects

If you develop other side-effects or any symptom that is worrying you, do tell your doctor, nurse or radiation therapist. Any side-effects you develop will be watched very carefully during the radiation treatments. Your doctor or nurse will give you information on how to prevent or reduce side-effects and medication will be prescribed if needed. Most of these side-effects should go away once treatment is over, but do let your doctor know about them if they continue.

For more information about the side-effects of radiotherapy, contact the National Cancer Helpline on 1800 200 700. Ask for a free copy of the booklet Understanding Radiotherapy or the DVD called Radiation Therapy: A Patient Pathway. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

To sum up

- Radiotherapy uses high-energy X-rays to cure or shrink the lymphoma.
- The radiotherapy machine is called a linear accelerator.
- A lot of preparation is involved before you receive the actual treatment.
- Each session only takes a few minutes and does not hurt.
- Treatment may continue for 2–4 weeks, depending on the type of lymphoma.
- Some side-effects of radiotherapy are difficulty swallowing, sore throat and mouth, nausea and vomiting, and fatigue.
High-dose treatment with stem cell support

For a small number of patients there is a high risk of the cancer coming back, despite treatment. Others may need more treatment if the first treatment has failed. In this case, high-dose chemotherapy may be given to kill off the lymphoma cells completely. However, giving high-dose chemotherapy will also destroy all your healthy blood cells in your bone marrow. But by collecting stem cells from your blood or bone marrow before the treatment and returning them to you after treatment, they can grow into new blood cells.

Peripheral blood stem cell transplant (PBSCT)

In this method, the stem cells are usually taken from your bloodstream. Stem cells are normally found in your bone marrow and are the most basic cells from which all other blood cells grow. For example, red cells, white cells and platelets. Before these stem cells can be collected from your bloodstream they must be moved out of your bone marrow. Drugs are usually given to make your bone marrow produce a lot of these stem cells. For example, chemotherapy and a special drug called a growth factor. As your bone marrow gets overcrowded, the extra stem cells spill into your bloodstream. They are then collected from your bloodstream using a special machine. This method is called a peripheral blood stem cell harvest (PBSCH).

Moving stem cells into your bloodstream: Chemotherapy is usually given for a day or so to move the stem cells into your bloodstream. The growth factor is injected under your skin until there are enough stem cells to be collected. You can give the injections yourself or your doctor or nurse will do it for you.

Collecting the stem cells: When your blood is ready, the stem cells can be collected. This takes about 4–5 hours. Usually it takes one day to collect all the stem cells but sometimes a second day is needed. The stem cells are collected using a central line or a drip 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. After that, the stem cells are frozen and stored until you have had the high-dose chemotherapy.

Returning the stem cells: After 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 3–12 months before you are fully recovered. You may need to stay in hospital for 2–3 weeks due to infection or other effects of treatment.

Consenting to treatment

Before treatment, make sure you understand why you need it and its chance of success. You will also need to know about the side-effects of treatment and how long they will last. Do talk to your doctor or nurse for advice. You may be asked to sign a consent form, allowing the treatment to go ahead.

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 transplants.
How can I cope with fatigue?

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

**Effect on lifestyle:** The effect of fatigue on your lifestyle can be huge. It can also affect you both physically and emotionally. It may affect your appetite or prevent you from doing your favourite pastimes and activities. You may also find it hard to concentrate or make decisions. You may even have to stop working or take time out of college for a time. Discuss with your doctor about a suitable time to return to work. Do not drive until you are well enough to concentrate and feel confident to make a rapid movement like stopping quickly.

**Sleep and anxiety:** If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

**Exercise and support:** If your illness allows you to do physical exercise, get some regularly. For example, a 30-minute walk 3-5 days a week might be a realistic goal and will boost your morale when you achieve it. Get others to help you around the house, with travelling to hospital, at work, with childcare or with shopping. Use the extra free time to do something that you especially enjoy. A helpful booklet called Coping with Fatigue is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

National Cancer Helpline 1800 200 700

### Tips & Hints – fatigue

- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs such as ironing, etc.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Ask for help at work or around the house, especially with cooking, housework or childcare.
- Make sure your bedroom is quiet and not too hot or cold.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.
- Use relaxation techniques to get to sleep. For example, gentle exercise, relaxation CDs, etc.

### Will treatment affect my sex life and fertility?

**Sex and sexuality**

It is likely that treatment will have some effect on your sex life. The worry of a cancer diagnosis can turn your emotions upside down, making it hard to relax. You might also be feeling tired or have a lower sex drive from the effects of treatment or from your symptoms. As a result, you may lose interest in sex. Do not worry about this as it is quite normal.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your
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 your skin or by slow-release patch worn on your arm or leg. Often a simple lubricant such as KY gel, available in your local pharmacy, can help ease any discomfort during sex. Talk to your doctor if this is an ongoing problem for you.

Avoiding pregnancy: You may not know if you are fertile or not, as periods usually stop during chemotherapy. But it is still possible for you to become pregnant during treatment. Side-effects of chemotherapy like vomiting and diarrhoea can also make the contraceptive pill work less well. For this reason, you must use a reliable method of contraception throughout treatment and for some time afterwards. Barrier methods like condoms or the cap are usually best. Do not get pregnant as the drugs can cause serious birth defects, especially in the first 3 months of pregnancy. There can also be a risk of miscarriage.

Getting pregnant after treatment: Many doctors believe it is better not to get pregnant for at least 2 years after the end of chemotherapy. This gives your body 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. If the lower part of your body is being treated, special shields can be used to protect your ovaries. However, it is best to wait for 6 months after radiotherapy before trying to get pregnant. This allows your body get over the effects of the cancer and its treatment. Do 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.

Freezing your eggs: Usually treatment for Hodgkin lymphoma needs to start as quickly as possible. For most patients, freezing their eggs before treatment is not a realistic option. Any delay could seriously affect your survival chances. Sometimes it might be possible to freeze your eggs.
before treatment begins. This is done at the HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital in Dublin. You must be over 18 years, give informed consent, and be referred to the HARI Unit by your cancer specialist. For this reason, you should discuss this issue with your doctor before your treatment begins. It is important to remember that you may not be suitable for this method. The type and location of your cancer, your age, medical history, and viral status can affect your suitability.

You will also need to receive counselling as part of the service, as it will be a stressful time for you. The method itself is not simple. It is still experimental and not without risk. The time factor too is crucial. Your ovaries will need to be stimulated to make enough eggs before they can be stored. From the moment you are seen by a doctor at the HARI Unit and considered suitable for egg freezing, your treatment will start with your first menstrual period. It is expected that eggs will be collected within 3 weeks. You should be aware that your own health will take priority over egg freezing. And if this time interval is not available to you, due to the urgency of treatment, egg freezing cannot go ahead.

If the eggs are successfully collected (harvested), they are stored for 10 years or to age 45. But 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 to your address.

The egg freezing service at the HARI Unit is free for all cancer patients living in Ireland. Your cancer specialist will arrange for you to have a blood test to check for any viruses, for example, hepatitis B, hepatitis C, HIV or CMV. This needs to be repeated 6 months later. 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 on 1800 200 700.

Storing embryos may be a possibility for some women. It appears to be more successful than egg storage. However, it may not be possible to delay your treatment. Do talk to your doctor for more details.

Men and infertility

For some men, the lymphoma itself can cause infertility. Some types of treatment like chemotherapy can also cause infertility. This may be temporary or permanent. For his reason you will be offered sperm banking from the very start. Usually there is no time to carry out sperm tests beforehand.

Thinking about infertility: The prospect of infertility can be a difficult issue to come to terms with. If you are a young man, you may not have considered the possibility of having children. You might also want to get started on treatment straight away. At times like this whether you can 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 over a number of days. The sperm will be frozen and stored until needed.

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 or when waiting for results of tests. If you wish to find out more about sperm banking talk to your doctor or nurse. Or call the National Cancer Helpline on 1800 200 700 and talk to a nurse who will tell you what services are available.

Chemotherapy: Chemotherapy can cause infertility in men but it is very difficult to say if and when this will happen. It may be temporary or permanent. You may be on treatment 2–3 months before your sperm count is reduced. Again it is best to use a reliable method of contraception throughout your treatment and for some time afterwards. For more information, talk to your doctor or nurse. Or call the National Cancer Helpline on 1800 200 700 for a copy of the booklet, Understanding Chemotherapy.
aware of these as early as possible so that further treatment can be given. At these visits, be sure to tell your doctor about:

- Any new symptoms
- Pain
- Physical problems like fatigue or insomnia
- Any new problems such as heart disease, diabetes, high blood pressure
- Weight gain or loss
- If taking any new medications or vitamins
- Emotional concerns such as anxiety or depression

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

Life after treatment
Many patients are delighted when treatment ends and told they no longer have Hodgkin lymphoma. However, you might be surprised at how long it takes to regain your strength and get back to normal. Remember it can take at least a year to get over the effects of treatment. At first you may not feel ready to lead as active a life as you did before treatment. Do allow your body the time it needs to recover.

If your partner is still fertile, 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 6 months 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.

Coping with infertility
It is not easy to come to terms with infertility. You may feel devastated if told that you could not have a child in the future. It can bring deep feelings of sadness, anger and loss of identity. You may find it helpful to talk openly to your partner or a friend about these feelings. It is important to discuss it with your doctor or nurse too. He or she may arrange for you to speak to a trained counsellor or a specialist, especially if you cannot deal with any strong emotions that you might have. Do seek professional help if infertility is likely to trouble you. For more advice, call the National Cancer Helpline on 1800 200 700. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

What follow-up do I need?
No matter what treatment you receive, you will still need to come back for regular check-ups. This is called follow-up. At each outpatient visit, your doctor will examine you and blood tests will be done. Other tests, like X-rays and scans, can be arranged if needed. The visits will allow your doctor to check for any signs of recurrence and follow up any ongoing side-effects you may have. He or she can also check for new side-effects that may develop. It is better to be

Radiotherapy: Most radiotherapy treatment has no effect on your ability to have children. However, sperm production may be reduced if your testicles are near the area being treated. It is sometimes possible to avoid giving radiotherapy to the testicles by wearing special protective shields.

If your partner is still fertile, 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 6 months 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.

Allow your body the time it needs to recover.
Tips & Hints – a healthy lifestyle

- If you feel anxious about lymphoma recurring, do talk to your partner or a close friend. Support groups can also help. Do seek professional help if a problem overwhelms you.
- Take regular exercise to improve your energy levels. Begin slowly and gradually increase the amount.
- Think about quitting if you smoke. Call the National Smokers’ Quitline on CallSave 1850 201 203; Monday–Saturday 8am–10pm. Visit the websites: www.quit.ie to help you quit or www.thetribe.ie for young people dealing with smoking-related issues.
- Protect your skin from the effects of the sun, especially if you have had chemotherapy or radiotherapy. Wear a high protection factor suncream and cover up.
- Eat a variety of foods, including plenty of fruit and vegetables. Cut out sweets and cakes if you want to reduce weight put on during treatment.

Research – what is a clinical trial?

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

Your doctor will let you know if you and your type of lymphoma are suitable for a trial.

Phases of research

There are many stages or phases when research is done. If a drug or treatment looks as if it might be useful in treating cancer, it is given to patients in research studies called clinical trials. If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully monitored 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 cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

For a copy of our factsheet on clinical trials, call the National Cancer Helpline on 1800 200 700 or visit our website: www.cancer.ie/cancer-information/treatments/clinical-trials

Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.
Cancer and complementary therapies

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

Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone therapy and biological therapies. 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 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 it 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 and herbalism. The diet therapy can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition. Most doctors do not believe that such treatments can cure or control cancer.

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

Before you decide to change your treatment or add any methods of your own, do 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, do 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. Make sure 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 on 1800 200 700. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.
Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have cancer. Reactions can often differ from person to person. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, 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.

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet which discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy. Do talk to your medical social worker as well.

**Common reactions include:**

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

Shock and disbelief

‘It can’t be me.’ ‘Has there been a mistake?’ ‘Cancer happens to other people, not me.’

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 very shocked when it does. Even if your doctor and nurse discuss the 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 cannot really believe what is happening to you.
It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

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 due to treatment.

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

Denial

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

**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, do not torture yourself at this time.

Do not feel guilty if you cannot keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve 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**

It is true 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 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 on 1800 200 700.
Understanding Hodgkin lymphoma

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that are either great or small. You may feel that you do not want to upset your family life, or feel guilty that you cannot do activities with your children or that you are letting them down. These are all natural feelings to have at this time. Even so, it is best to keep family life as normal as possible. Continue with activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.

Be honest

Every family deals with cancer in its own way. But 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 family. It can put added pressures on them and lead to confusion. If you have very young children, they can be 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.

Lost for Words: How to Talk to Someone with Cancer is a useful booklet for relatives and friends of people with cancer. It is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

How can my family and friends help?

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

Learning to cope

After any treatment 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 can live a normal life during treatment. But 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.

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

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help.
It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news. Do prepare your family for the side-effects of treatment before they happen and answer their questions simply and honestly. For example, if you get hair loss due to treatment.

If you need some extra help in dealing with young 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 free copy, call the National Cancer Helpline on 1800 200 700. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

What else can I do?

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

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.

- **Live one day at a time:** Do not think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

- **Live well:** 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. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.

- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.

- **Keep an open mind:** Do not feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but do not feel guilty about it, as it will pass.

- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your lymphoma and treatment as possible. Follow your doctor’s instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones. Call 1800 200 700 for a free copy of the Journey Journal to help you keep track of your cancer treatment.

- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable talking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it is not working, be open to finding a new way to cope.

- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.

- **Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If these moods are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.
Spiritual care: When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 if you would like a free copy. Or if you prefer, you can visit a Daffodil Centre if one is located in your hospital.

**Caring for someone with lymphoma**

Being a carer of someone with lymphoma can be both a challenging and rewarding experience. In practice carers provide all sorts of emotional and physical support. It is true that caring for a loved one can bring great personal satisfaction. But there can be times when it is tiring, frustrating, distressing and isolating. You may become a carer overnight and feel that you are not experienced to handle the care of your relative or friend. And because lymphoma is an unpredictable illness, you may be worried or anxious about the future, have fears about the effects of treatment, of relapses, and about future tests. To keep your strength and spirits up, it is important to take good care of yourself. And remember to ask and accept help when you need it.
Support resources

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

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

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

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

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

Family doctor (GP): You may feel comfortable talking to your family doctor (GP) about your lymphoma too. He or she can discuss any of your queries and offer advice and support.
Community health services: When you go home, there are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. All these people in community health services can provide advice and support. More information on the services is available either from the medical social worker in the hospital before you go home or at your local health centre.

Cancer support groups and centres: 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. Cancer support centres and groups are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet.

Irish Cancer Society: The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters. For example, getting life insurance. We might also be able to put you in touch with one of our trained volunteers who has had Hodgkin lymphoma.

Call 1800 200 700 for information about any of the services outlined above or for 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 the following are given here:

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

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

Hospital cover

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

Outpatient cover

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

Medical card

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

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

GP visit card

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

**Drugs Payment Scheme**

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €132 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

**Private healthcare cover**

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

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

**Benefits and allowances**

Information on the following is given in this section:

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

For a free copy of *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*, contact the National Cancer Helpline on 1800 200 700. More information and application forms for the benefits below are available from your local social welfare office or from Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Local 1890 927 770. You can also download the forms from websites such as [www.welfare.ie](http://www.welfare.ie) or [www.citizensinformation.ie](http://www.citizensinformation.ie)

**Illness Benefit**

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

**Disability Allowance**

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

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

**Invalidity Pension**

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

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like
the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

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

**Carer’s Benefit**
If you are employed but wish to care for a sick relative full time, you might qualify for a carer’s benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home.

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

You can work while you are on carer’s leave for up to 15 hours a week.

But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection.

**Appliances**
For patients who have medical cards most appliances are free of charge or subsidised.

**Travel to hospital**
You may be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital. In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

See pages 75 and 76 for information on the Travel2Care and Care to Drive schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

**Further information**
Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

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

**For social welfare queries, contact:**
Dept of Social Protection – Tel: 1850 662 244
Information Service Leaflet line: 1890 202 325
Oisin House Email: info@welfare.ie
212–213 Pearse Street Website: www.welfare.ie
Dublin 2
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If you have queries about health and social services, contact the HSE office in your area:

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

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

**Citizens Information**
Citizen Information Telephone Service: 0761 07 4000
**Email:** info@ciboard.ie  **Website:** www.citizensinformation.ie

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**If you have financial worries…**

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

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 75 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 76 for contact details. A useful book for preparing low-budget nutritious meals is 101+ Square Meals. See page 82 for more information.

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**Irish Cancer Society services**

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

- **Cancer Information Service (CIS)**
- **Daffodil Centres**
- **Cancer support groups**
- **Survivors supporting survivors**
- **Counselling**
- **Night nursing**
- **Oncology liaison nurses**
- **Cancer information booklets**
- **Financial support**
- **Care to Drive transport project**

**Cancer Information Service (CIS)**

The Society provides a Cancer Information Service with a wide range of services. The National Cancer Helpline 1800 200 700 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. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. It is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

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

**Daffodil Centres**

Daffodil Centres are located in a number of Irish hospitals. These have been set up by the Irish Cancer Society in partnership with each
Night nursing
The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

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

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

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

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking.

Travel2Care: If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email travel2care@irishcancer.ie

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

**Financial Aid:** For this kind of help, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

See our website for more information: [www.cancer.ie](http://www.cancer.ie)

**Care to Drive transport project**

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.

For more information on any of the above services, call the National Cancer Helpline on 1800 200 700.

**Useful organisations**

**Irish Cancer Society**
43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline: 1800 200 700
Email: helpline@irishcancer.ie
Website: [www.cancer.ie](http://www.cancer.ie)

**All-Ireland Co-operative Oncology Research Group**
Website: [www.icorg.ie](http://www.icorg.ie)

**Citizens Information**
Citizen Information Service: 0761 07 4000
Email: info@ciboard.ie
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

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

**Health Promotion HSE**
Website: [www.healthpromotion.ie](http://www.healthpromotion.ie)

**Irish Oncology and Haematology Social Workers Group**
Website: [http://socialworkandcancer.com](http://socialworkandcancer.com)

**Money Advice and Budgeting Service (MABS)**
Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline: 0761 07 2000
Email: helpline@mabs.ie
Website: [www.mabs.ie](http://www.mabs.ie)

**Health insurers**

**AVIVA Health**
(formerly VIVAS Health)
PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: [www.avivahealth.ie](http://www.avivahealth.ie)

**Laya Healthcare (formerly Quinn)**
Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
Local: 1890 700 890
Email: info@layahealthcare.ie
Website: [www.layahealthcare.ie](http://www.layahealthcare.ie)

**Voluntary Health Insurance (VHI)**
IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSaver: 1850 44 44 44
Email: info@vhi.ie
Website: [www.vhi.ie](http://www.vhi.ie)

**National support groups**

**ARC Cancer Support Centres**
Dublin and Cork (see pages 78 and 80).

**I’ve Got What?!**
[Support for young adults affected by cancer]
C/o Cross Cause Charity Shop
Blackrock
Co Louth
Tel: 086 339 5690

**Lakelands Area Retreat & Cancer Centre**
Multyfarnham
Mullingar
Co Westmeath
CallSave: 1850 719 719
Email: info@larcc.ie
Website: [www.larcc.ie](http://www.larcc.ie)

**Connaught support groups & centres**

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

**Ballinasloe Cancer Support Centre**
Society Street
Ballinasloe
Co Galway
Tel: 090 964 5574 / 087 945 2300
Email: ballinasloe@ymail.com

**Cancer Care West**
Inis Aoi bhinn
University Hospital Galway
Costello Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: [www.cancercarewest.ie](http://www.cancercarewest.ie)

**Cara Iorrais Cancer Support Centre**
2 Church Street
Belmullet
Co Mayo
Tel: 097 20590
Email: caraiorrais@gmail.com

**East Galway Cancer Support Centre**
The Family Centre
John Dunne Avenue
Ballinasloe
Co Galway
Tel: 087 984 5574 / 087 945 2300
Website: [www.eastgalwaycancersupport.com](http://www.eastgalwaycancersupport.com)

**Gort Cancer Support Group**
The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220
Email: gcsupport@eircom.net
Website: [www.gortcs.ie](http://www.gortcs.ie)

**Mayo Cancer Support Association**
Rock Rose House
32 St Patrick’s Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: [www.mayocancer.ie](http://www.mayocancer.ie)
Understanding Hodgkin lymphoma

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

Sligo Cancer Support Centre
44 Wine Street
Sligo
Tel: 071 917 0399
Email: sccs@eircom.net
Website: www.sligocancersupportcentre.ie

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

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

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

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

Balbriggan Cancer Support Group
Unit 23, Balbriggan Business Park
Balbriggan
Co Dublin
Tel: 087 353 2872

The Bellarose Foundation
[Women with Cancer]
Merry Maid House
West Park Campus
Garter Lane
Citywest
Dublin 24
Tel: 086 879 3242
Email: thebellarosefoundation@gmail.com

Bray Cancer Support & Information Centre
368 Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@braycancersupport.ie
Website: www.braycancersupport.ie

Cuisle Centre
Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: info@cuislecentre.ie
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support
Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@doshasoffaly.ie
Website: www.doshasoffaly.ie

Dundalk Cancer Support Group
Philipstown
Hackballs Cross
Dundalk
Co Louth
Tel: 086 107 4257

Éist Cancer Support Centre Carlow
The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Support Centre
George’s Street
Drogheda
Co Louth
Tel: 041 980 5100 / 086 817 2473
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

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

Haven Cancer Support and Therapy Group
Haven House
68 Hazelwood
Gorey
Co Wexford
Tel: 053 942 0707 / 086 250 1452
Email: info@thehavengroup.ie
Website: www.thehavengroup.ie

HOPE Cancer Support Centre
22 Upper Wexer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Kilkenny Cancer Support Services
Walkin Street
Kilkenny City
Tel: 085 721 9280
Email: info@kilkennycancersupport.com
Website: www.kilkennycancersupport.com

Lakelands Area Retreat & Cancer Centre
Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larc.ie
Website: www.larc.ie

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

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

Tallaght Cancer Support Group
Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486
Email: cttallaght@yahoo.ie

Wicklow Cancer Support Centre
1 Morton’s Lane
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support groups & centres
Cancer Information & Support Centre
Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre
14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: cancersupport@eircom.net
Website: www.cancercare.ie
Understanding Hodgkin lymphoma

**Good and New Cancer Drop In Centre**
Unit 1, Portlink Business Park
Port Road
Letterkenny
Co Donegal
Tel: 074 911 3437

**Killybegs Cancer Support Group**
Killé
Kilicar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

**Living Beyond Cancer**
Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477

**Solace: Donegal Cancer Support Centre**
St Joseph’s Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

**Yana Cancer Support Centre**
Belturbet
Co Cavan
Tel: 087 994 7360

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**Useful contacts outside Republic of Ireland**

**Cancer Focus Northern Ireland**
40–44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Website: www.cancerfocusni.org

**Cancer Network Buddies**
Website: www.cancernetworkbuddies.org

**Cancer Research UK**
Tel: 0044 20 7274 0020
Website: www.cancerresearchuk.org
Website: www.cancerhelp.org.uk

**Healthtalkonline**
Website: www.healthtalkonline.org

**Lymphoma Association (UK)**
Tel: 0044 1296 619400
Email: information@lymphoma.org.uk
Website: www.lymphoma.org.uk

**Macmillan Cancer Support (UK)**
Tel: 0044 207 840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

**Macmillan Support & Information Centre**
Belfast City Hospital Trust
77–81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net
Website: www.macmillan.org.uk

**National Cancer Institute (US)**
Website: www.nci.nih.gov

**Northern Ireland Cancer Network**
Tel: 02890 565 860
Email: admin@ncan.n-i.nhs.uk
Website: www.cancerni.net

**Royal Marsden Hospital Foundation NHS Trust**
Website: www.royalmarsden.nhs.uk

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**Ulster support groups & centres**

**Cancer Support and Social Club**
Tiernaleague
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

**Crocus: Monaghan Cancer Support Centre**
The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965

**The Forge Cancer Support Group**
The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924

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

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**Suaimhneas Cancer Support Centre**
2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

**Suir Haven Cancer Support Centre**
Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

**Youghal Cancer Support Group**
161 North Main Street
Youghal
Co Cork
Tel: 024 92353 / 087 273 1121

**West Cork Cancer Support**
Community Work Department
HSE Skibbereen
Co Cork
Tel: 027 53485 / 086 862 5417

**Sláinte an Chláir: Clare Cancer Support**
Tir Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

**South Eastern Cancer Foundation**
Solas Centre
7 Sealy Close
Earls court
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net
Website: www.sec.ie

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**Cork ARC Cancer Support House**
Cliffdale
5 O’Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

**Cúnamh: Bons Secours Cancer Support Group**
Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

**Kerry Cancer Support Group**
124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@eircom.net
Website: www.kerrycancersupport.com

**Recovery Haven**
5 Haig’s Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.org

**Suaimhneas Cancer Support Centre**
2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

**Suir Haven Cancer Support Centre**
Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

**Youghal Cancer Support Group**
161 North Main Street
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Co Cork
Tel: 024 92353 / 087 273 1121

**West Cork Cancer Support**
Community Work Department
HSE Skibbereen
Co Cork
Tel: 027 53485 / 086 862 5417

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**For other support groups or centres in your area, call 1800 200 700.**
Helpful booklets/DVDs

Free booklets from the Irish Cancer Society:
- Understanding Chemotherapy
- Understanding Radiotherapy
- Understanding Cancer and Complementary Therapies
- Diet and Cancer
- Coping with Fatigue
- Understanding the Emotional Effects of Cancer
- Lost for Words: How to Talk to Someone with Cancer
- Who Can Ever Understand? Taking About Your Cancer
- Talking to Children about Cancer: A Guide for Parents
- Managing the Financial Impact of Cancer: A Guide for Patients and Their Families
- Journey Journal: Keeping Track of Your Cancer Treatment

Helpful DVDs
- Hope: A Personal Journey through Hodgkin and Non-Hodgkin Lymphoma
  Call 1800 200 700 for a copy.
- A Guide to Chemotherapy
  HSE/Mid-Western Cancer Centre/ICS, 2008
  Call 1800 200 700 for a copy.

Explaining cancer to children
The Secret C: Straight Talking About Cancer
Julie A Stokes
Winston’s Wish, 2000
ISBN 0953912302

What does that word mean?

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

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

Anaemia
Fewer red blood cells in your blood. It can cause tiredness and shortness of breath.

Antibody
A protein in your body that attacks and kills germs 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, for example, when cells are taken from your bone marrow or blood.

Benign
Not cancer. A tumour or growth that does not spread.

Biological therapies
A treatment that uses your immune system to fight cancer or other illnesses. For example, using antibodies. Also called targeted therapies.

Biopsy
Removing a small amount of tissue from your body to find out if lymphoma cells are present.

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

Chemotherapy
Treatment using drugs that cure or control cancer.

Diaphragm
A thin muscle under your heart and lungs that separates your chest from your abdomen.

Fatigue
Ongoing tiredness often not helped by rest.

Intravenous
Into a vein.
Questions to ask your doctor

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

- What 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?

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Lymph</td>
<td>A clear watery fluid that carries material through your lymphatic system.</td>
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<tr>
<td>Lymph node</td>
<td>A small oval or round gland found along the lymph vessels that removes bacteria and foreign particles from your body.</td>
</tr>
<tr>
<td>Lymphocytes</td>
<td>Small white blood cells that help to protect your body against infection and disease.</td>
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<tr>
<td>Lymph vessels</td>
<td>Tubes carrying lymph that connect to lymph nodes.</td>
</tr>
<tr>
<td>Malignant</td>
<td>Cancer. A tumour that spreads.</td>
</tr>
<tr>
<td>Medical oncologist</td>
<td>A doctor who specialises in treating cancer patients using chemotherapy and other drugs.</td>
</tr>
<tr>
<td>Monoclonal antibody</td>
<td>Treatment using a manmade antibody to fight disease.</td>
</tr>
<tr>
<td>Nausea</td>
<td>Feeling sick or wanting to be sick.</td>
</tr>
<tr>
<td>Oncology</td>
<td>The study of cancer.</td>
</tr>
<tr>
<td>Prognosis</td>
<td>The expected outcome of a disease.</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>A doctor who specialises in treating cancer patients using radiotherapy.</td>
</tr>
<tr>
<td>Radiation therapist</td>
<td>A radiographer who plans and delivers the radiotherapy treatment.</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>The treatment of cancer using high-energy X-rays.</td>
</tr>
<tr>
<td>Remission</td>
<td>When the lymphoma has been reduced or can no longer be found in your body.</td>
</tr>
<tr>
<td>Targeted therapies</td>
<td>Drugs that stop the growth of particular types of cancer cells using your immune system. Also known as biological therapies.</td>
</tr>
<tr>
<td>Staging</td>
<td>Tests that measure the size and extent of cancer.</td>
</tr>
<tr>
<td>Thrombocytopenia</td>
<td>Fewer platelets in your blood. This can cause you to bleed and bruise easily.</td>
</tr>
</tbody>
</table>
Your own questions

1
Answer

2
Answer

3
Answer

4
Answer

5
Answer

6
Answer

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Answer

8
Answer
Acknowledgements
We would like to extend a special word of thanks to the following for their invaluable contributions in this booklet and/or previous editions:
Prof Peter Daly, Consultant Medical Oncologist
Prof Donal Hollywood, Consultant Radiation Oncologist
Irish Oncology and Haematology Social Workers Group
Michael H Phillips, Illustrator

Would you like more information?
We hope this booklet has been of help to you. After reading it or at any time in the future, if you feel you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?
If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

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

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

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

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4
Tel: 01 231 0500 Email: info@irishcancer.ie Website: www.cancer.ie
The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life with three programme areas to achieve them: advocacy, cancer services and research.