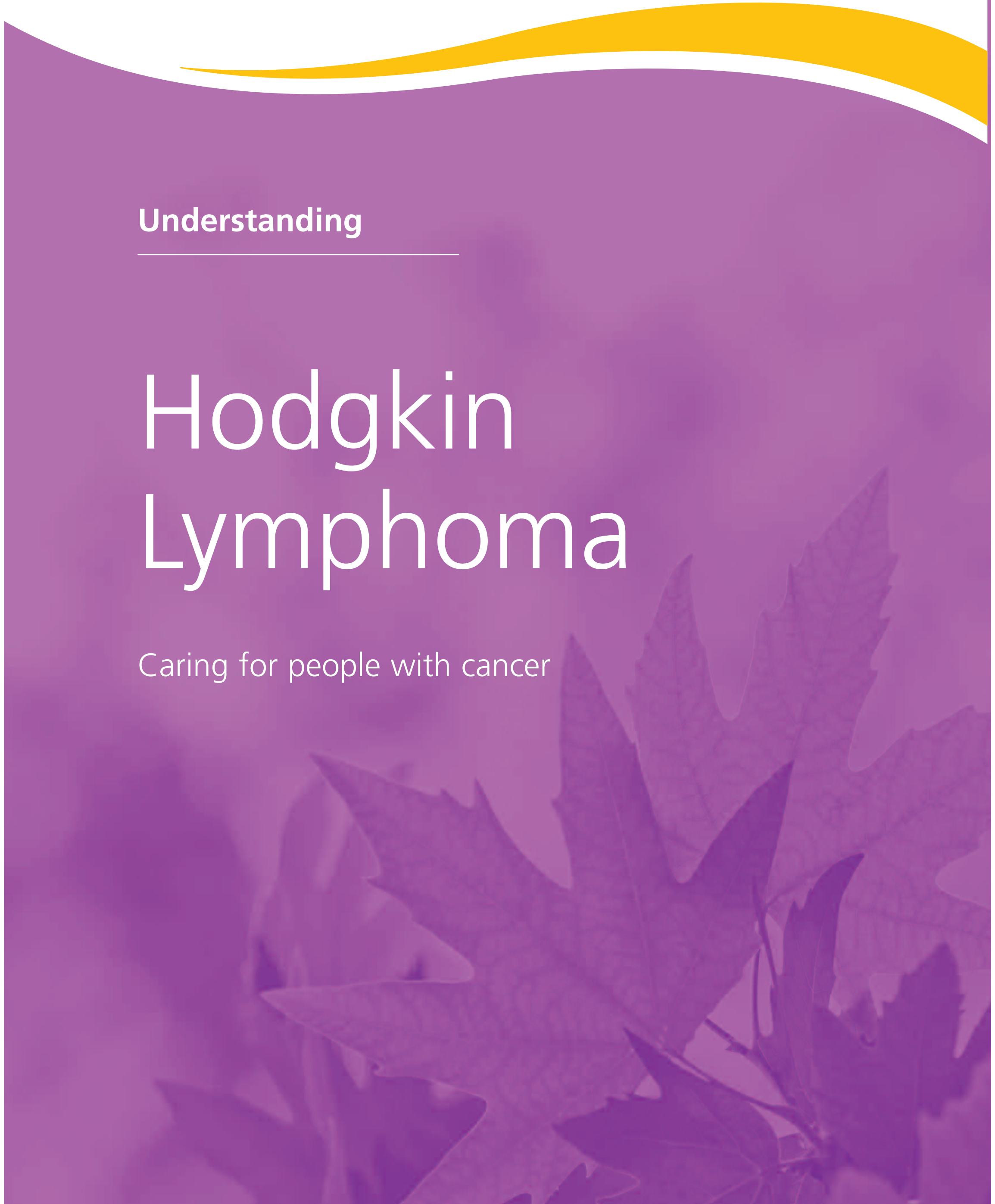
Irish Cancer Society



Understanding

Hodgkin Lymphoma

Caring for people with cancer

Understanding

Hodgkin lymphoma

This booklet has been written to help you understand more about Hodgkin lymphoma. It has been prepared and checked by consultants, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on Hodgkin lymphoma, its treatment and how it may affect you.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information that you may need.

	Name	Telephone
Specialist nurse		
Family doctor (GP)		
Haematologist		
Medical oncologist		
Radiation oncologist		
Radiation therapist		
Medical social worker		
Emergency		

This booklet has been produced by 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. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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Introduction

This booklet has been written to help you to learn more about Hodgkin lymphoma. The booklet is divided into 4 parts:

- **About Hodgkin lymphoma** gives an introduction to Hodgkin lymphoma.
- **Treatment and side-effects** discusses the different treatments used for Hodgkin lymphoma and possible side-effects.
- **Coping and emotions** discusses how you can cope with your feelings and the emotional effects of having cancer.
- **Support resources** gives information on where to get help and support. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

Reading this booklet

Remember you do not need to know everything about Hodgkin lymphoma straight away. Read a section about a particular item as it happens to you or if you are interested in it. Then when you want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at **cancernurseline@irishcancer.ie**. You can also visit a Daffodil Centre. See page 51 for more about Daffodil Centres. You can email **daffodilcentreinfo@irishcancer.ie** to find your local Daffodil Centre.

Helplines Partnership
MEMBER

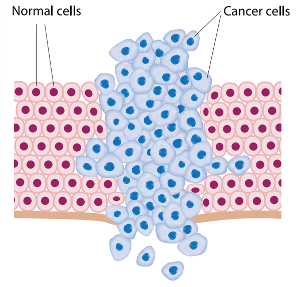
About Hodgkin lymphoma

What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer starts in cells in the prostate gland, breast cancer starts in cells in the breast.

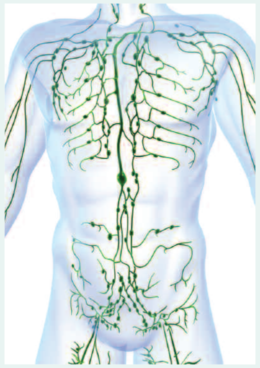
All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body, where they can form a secondary tumour. This is also called metastasis.



What is the lymphatic system?

The lymphatic system protects us from infection and disease. It is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



To sum up

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

What is lymphoma?

Lymphoma is a cancer that affects your lymphocytes. Lymphocytes are white blood cells that are part of your immune system.

There are different types of lymphoma. They all start with a cancerous lymphocyte cell.

Lymphomas are described as either Hodgkin lymphoma or non-Hodgkin lymphoma. Most lymphomas are non-Hodgkin. About 1 in 5 is Hodgkin lymphoma.

What is Hodgkin lymphoma?

Hodgkin lymphoma is a cancer of your lymphatic system, which is part of your body's immune system. Abnormal lymphocyte cells are produced, which can form lumps in lymph nodes. For more about the lymphatic system see page 5.

Hodgkin lymphoma used to be known as Hodgkin's disease, after the doctor who discovered it. Hodgkin lymphoma is identified by the way the lymphocyte cells look under the microscope. With Hodgkin lymphoma, cells called Reed-Sternberg cells can be seen. These are abnormal lymphocytes that are much larger and have two nuclei.

The cells are named after two scientists called Reed and Sternberg. Reed-Sternberg cells are only found with Hodgkin lymphoma.

What are the types of Hodgkin lymphoma?

Hodgkin lymphoma is divided into two types: Classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

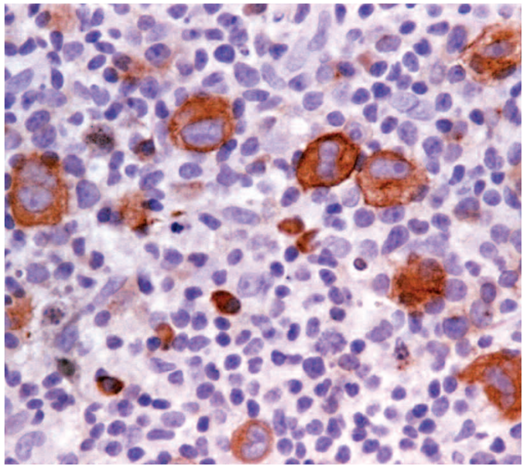
These types describe the disease in more detail, such as what the affected lymph nodes look like under the microscope and what other cells are present. In each type, Reed-Sternberg cells are present. The amount of Reed-Sternberg cells can vary between the various types of lymphoma and can be mixed with many normal cells.

>>> Knowing the type of Hodgkin lymphoma you have will help the doctors to decide on which treatment will work best for you.

Classical Hodgkin lymphoma

Most cases of Hodgkin lymphoma are of the classical type. Classical Hodgkin lymphoma is divided into four subtypes:

- **Nodular sclerosing:** The most common subtype. Mainly occurs in younger adults and women
- **Mixed cellularity:** More common in men than in women
- **Lymphocyte rich:** Quite rare. Occurs mostly in children
- **Lymphocyte depleted:** Often occurs in older people


Classical Hodgkin lymphoma with Reed-Sternberg cells (in brown)

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

This type of lymphoma is very rare. It is usually diagnosed at an early stage and is usually slow growing. It tends to occur more in men and is 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 the types of Hodgkin lymphoma, call our Cancer Nurseline on 1800 200 70 or visit a Daffodil Centre.

How common is Hodgkin lymphoma?

Hodgkin lymphoma is a rare cancer that can affect both men and women. It affects mostly younger people between the ages of 15 and 30. About 137 people are diagnosed with it in Ireland each year.

What are the risk factors for Hodgkin lymphoma?

The exact cause of Hodgkin lymphoma is unknown. But there are certain things called risk factors that can affect your chances of getting the disease.

Having a risk factor doesn’t mean you will definitely get Hodgkin lymphoma. And sometimes people without any known risk factors develop Hodgkin lymphoma.

Some things that can increase your risk of Hodgkin lymphoma are:

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: Close relatives (parents, children, sisters or brothers) of people who have had Hodgkin lymphoma have a slightly increased risk of getting the disease. It is not known if this is due to genetics or to them having similar lifestyles.

Poor immune system: 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.

To sum up

- The lymphatic system helps your body to defend itself against infection.
- Lymphoma is a cancer that affects the lymphatic system.
- Hodgkin lymphoma has abnormal cells called Reed-Sternberg cells.
- Hodgkin lymphoma is a rare cancer. It affects about 137 people in Ireland each year.
- There are several types 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.

Being diagnosed with Hodgkin lymphoma

Hearing that you have Hodgkin lymphoma can be a huge shock. You may be feeling:

- **Upset** and overwhelmed by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Scared** about the future

Everyone reacts differently to a cancer diagnosis. However you feel, you are not alone. There are many people who can help and support you at this time.

If you need to talk to someone, or if you want more information or advice:

- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with cancer. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website **www.cancer.ie**

Telling people about your diagnosis

It can be hard to tell other people the news that you have been diagnosed with cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people's reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet can help you find ways to talk about your cancer and to ask for the help and support you need.

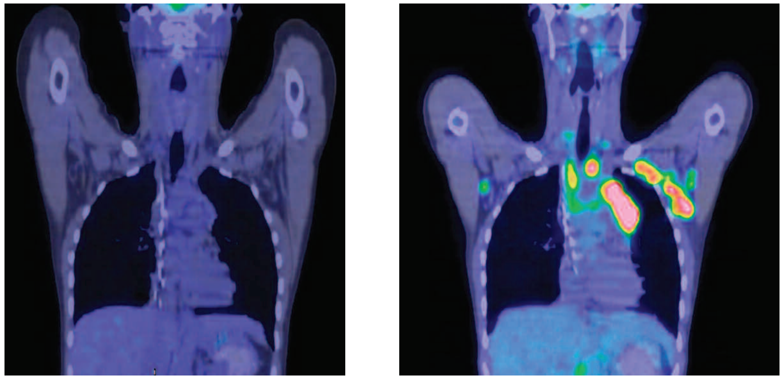
What tests will I have?

After being diagnosed with Hodgkin lymphoma, you may have more tests to find out more about your cancer and your general health.

Tests you may have include:

Blood tests: Your blood will be tested 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. These tests will also be done regularly if you are having chemotherapy, to check the effects of the treatment on your body.

PET scan: PET uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into 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 found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. During the scan, you will lie on a table which moves through a scanning ring. Before the scan, you may have to fast (not eat) for a few hours.



Left: A PET scan with no lymphoma cells.
Right: PET scan showing lymphoma cells (in pink) in left armpit and upper chest

CT scan (CAT scan): This is a special type of X-ray that gives a detailed picture of the tissues inside your body. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It is painless and takes between 10 and 30 minutes. You might be asked not to eat (fast) for a few hours before the test.

You may also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary, but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

Bone marrow tests: You might have a bone marrow aspiration and biopsy. 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. Sometimes with Hodgkin lymphoma, abnormal lymphocyte cells can spread to the bone marrow.

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 the test. The test usually lasts 15–20 minutes. The area may feel tender and sore for a few days afterwards. 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.

MRI scan: This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic during the MRI scan. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. An MRI can also be noisy, but you will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

Ultrasound scan: This is a scan which uses sound waves to create a picture of the inside of your body. It is done in the X-ray department of the hospital. The scan is painless and only takes a few minutes. Some gel is first put on your abdomen (tummy), which is then scanned to see if your liver is affected by the cancer.

Waiting for results

It usually takes about a week for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Staging Hodgkin lymphoma

The tests you have after diagnosis are usually done to help the doctor to stage your cancer. Staging for Hodgkin lymphoma describes if you have any symptoms and how many places in your body are affected by the cancer. Staging is very important, as it helps your doctor to decide the best treatment for you.

How is Hodgkin lymphoma staged?

Hodgkin lymphoma is defined as stages 1 to 4, depending on how many lymph nodes or organs are involved. Your disease will also be given a letter code: A, B, E or S.

What do the letter codes mean?

A: No symptoms.

B: You have symptoms of Hodgkin lymphoma, such as fever, night sweats or weight loss.

E: Lymphoma is found in unusual places outside your lymph nodes, for example in your stomach. This is called extranodal lymphoma.

S: The lymphoma is in your spleen.

What do the number stages mean?

Early stage disease

Stage 1: One group of lymph nodes is affected on one side of your diaphragm (either above the diaphragm or below the diaphragm). Your diaphragm is the sheet of muscle that lies just under your ribcage and separates your chest from your abdomen.

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

Advanced stage disease

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

Stage 4: Lymphoma can be found in organs outside your lymphatic system or in your bone marrow.

In general, the lower the number, the less the cancer has spread. Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

Recurrent or relapsed lymphoma

This is when the disease comes back after treatment. This can be treated successfully, depending on the stage of the disease.

>>> Staging allows your doctor to decide the best treatment for you.

To sum up

- You may need to have tests such as a PET scan, CT scan or bone marrow biopsy.
- These tests can help to stage the cancer.
- Staging cancer means finding out where it has spread in the body.
- The stages of Hodgkin lymphoma are described using the numbers 1-4 and the letters A,B, E and S.

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

It is not always easy for doctors to answer a question about life expectancy, as the answer is based on a 'typical' experience. In reality, everybody is different and experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

- **Think about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment and side-effects

How is Hodgkin lymphoma treated?

Hodgkin lymphoma can be treated very successfully. The type of treatment you receive will depend on:

- The stage of the disease (see page 13)
- Your age and general health
- If you have symptoms, such as weight loss or fever

In most cases the lymphoma is curable or it will show no signs of active disease (remission).

What is remission?

Remission means the lymphoma has been reduced or cannot be found in your body.

Partial remission means the lymphoma has been reduced significantly but not completely removed.

Complete remission means the lymphoma is no longer found in your body. The longer you are in complete remission, the less likely it is that the lymphoma will come back.

Types of treatment

Some people only need one type of treatment, while others need a combination of treatments. Most treatments are outpatient treatments, so you will not need to stay in hospital overnight.

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

Radiotherapy: Radiotherapy uses X-rays to destroy cancer cells. See page 26 for more details.

Biological therapies: These drugs work with your body to fight cancer. Biological therapies are not commonly used for people newly diagnosed with Hodgkin lymphoma. See page 29 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 30 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. In some cases, the course of chemotherapy is followed by radiotherapy. Or you may have radiotherapy on its own. 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, biological therapies, more chemotherapy and possibly radiotherapy may be suggested. Sometimes high-dose chemotherapy with stem cell support may be discussed.

Specialist cancer centres

Hodgkin lymphoma is treated in specialist cancer centres in Ireland. The staff at these centres have great expertise in managing patients with Hodgkin lymphoma. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

Deciding on treatment

Multidisciplinary team: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a haematologist, specialist nurse, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

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. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

Time to think: When faced with a serious 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 may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you to decide about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

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 want to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Any other treatments that may be available

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 still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Individual treatment

You may notice that other people with Hodgkin lymphoma are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Treatment decisions can also depend on any previous treatments you have had and your general health. Don't be afraid to ask your doctor about your treatment.

Who will be involved in my care?

Some of the following health professionals may be involved in your care.

Haematologist	A doctor who specialises in disorders of the blood and lymphatic system.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiation therapist	A person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.
Oncology or haematology liaison nurse / clinical nurse specialist	A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.
Medical social worker	A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.
GP (family doctor)	Your GP can be a great support to you. You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.
Psycho-oncology team	These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.
Counsellor	A person trained to give you emotional support and advice when you find it difficult to come to terms with your illness.
Community health services	This includes family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Chemotherapy

Chemotherapy is a treatment using drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

The type of chemotherapy you get will depend on the type and stage of your Hodgkin lymphoma. Most Hodgkin lymphoma patients who need chemotherapy will get a combination of drugs. Your doctor will discuss your individual treatment plan with you.

How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments to give your body time to recover. You will have blood tests before each chemotherapy treatment to check you are well enough to have your planned treatment. The number of cycles can vary, depending on the stage of your cancer and how well it is responding to treatment. For Hodgkin lymphoma treatment normally lasts from 3 to 6 months.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). It may also be given in tablet form. Usually your treatment will be given in the chemotherapy day care unit.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat Hodgkin lymphoma. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or in combination with each other. Often with Hodgkin lymphoma your doctor will advise a combination of 4-7 different chemotherapy drugs. Usually you will be given steroids as well (see page 25).

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

- **Fatigue.** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 33.
- **Nausea and vomiting.** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments available that work well to prevent nausea and vomiting.
- **Infection.** Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature, having a cough, or pain passing urine.
- **Anaemia.** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.
- **Bleeding and bruising.** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help to make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.
- **Mouth and throat problems.** Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.
- **Hair loss (alopecia).** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.
- **Constipation and diarrhoea.** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).
- **Skin and nail changes.** Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

- **Peripheral neuropathy.** Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.
- **Changes in kidney function.** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.
- **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 36 for more information.

Tips & Hints – avoiding infections

- Avoid close contact, such as hugging or kissing, with people who have colds, flus or other infections, especially chickenpox, shingles or measles.
- Wash your hands often during the day, especially before eating and after going to the toilet.
- Contact the hospital immediately if you have a temperature of 37.5°C (99.5°F) or higher or shortness of breath

Other side-effects

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. An echocardiogram, or 'echo', is a type of ultrasound scan used to look at the heart and nearby blood vessels.

Sometimes the drugs may affect your lungs and cause a cough, chest pain or shortness of breath. You may have breathing tests (pulmonary function tests) to measure how well your lungs are working before you start treatment. These usually involve you breathing into a measuring device. Your doctor will give you more advice.

If you feel unwell or have any symptoms that are troubling you, tell your doctor or nurse straight away. He or she will tell you what to do.

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding Chemotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Steroid therapy

Steroids are hormones that are 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. They often help you to feel better 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 pm if you find it hard to sleep 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 feeling very happy, excited or angry.

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. 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.

To sum up

- Chemotherapy is a treatment using drugs to kill cancer.
- The drugs are often given in combination.
- The drugs can be given in tablet form, directly into a vein as an injection or through an infusion (drip).
- The side-effects vary depending on the drugs used. Most side-effects are well controlled with medication.
- Some common side-effects are infection, fatigue, nausea and vomiting, hair loss and sore mouth.
- Some treatments are more successful when steroids are given along with chemotherapy drugs.

Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells. Radiotherapy is most useful when the Hodgkin lymphoma is only in one part of the body. Often radiotherapy is give with chemotherapy to make the treatment work better.

If a cure is not likely, radiotherapy can also be used to control and relieve symptoms you may have. This is called palliative radiotherapy.

External beam radiotherapy is used for Hodgkin lymphoma. This means the radiation comes from machines that aim rays directly at the tumour site. The machines are called linear accelerators.

Planning your treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells.

In external radiotherapy an important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. You may have extra scans or X-rays taken, but this is to plan your treatment only. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Masks: Lymphoma often affects the lymph glands around your head, neck and upper chest. If you are having radiotherapy to your head or neck region, you will need to wear a mask to keep your head completely 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. There are holes in the mask for you to breathe and see through. The treatment area will be marked on the mask. Making the mask is an important part of planning and may take some time to complete.

Getting your treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit every day and going home after each treatment.

Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. These centres need highly trained staff and space for the large equipment involved. As a result, the centre may be some distance from the hospital where you were first treated.

How much radiotherapy do I need?

Treatment for Hodgkin lymphoma generally involves between 10 and 20 treatments and lasts between 2 and 4 weeks.

External radiotherapy does not make you radioactive. It is completely safe for you to mix with family and friends. Pregnant women or children are not at risk.

For more information on radiotherapy or a copy of our booklet Understanding Radiotherapy, call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Side-effects of treatment

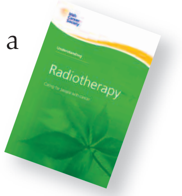
Radiotherapy is given directly to the site of the cancer. Therefore, most of the side-effects that occur are related to the part of your body being treated. The most common side-effects are:

- Difficulty swallowing or sore throat
- Sore mouth
- Nausea (feeling sick) and vomiting
- Diarrhoea
- Weight loss
- Skin changes
- Tiredness (fatigue)
- Shortness of breath
- Hair loss

How severe these side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment. Some side-effects are long-term or may even be permanent.

If you feel unwell or have any other side-effects or symptom, tell your doctor, nurse or radiation therapist.

For more information on the side-effects of radiotherapy or a copy of the booklet *Understanding Radiotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Radiotherapy uses high-energy X-rays to kill the lymphoma cells
- The radiotherapy machine is called a linear accelerator.
- A lot of preparation is involved before you receive your radiotherapy 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.
- Side-effects of radiotherapy include difficulty swallowing, sore throat and mouth, nausea and vomiting, and fatigue.

Biological therapies

Biological therapies work with your body. They can help fight cancer, stop it spreading or control side-effects from other cancer treatments. Biological therapies are not usually used for Hodgkin lymphoma. They may be used for Hodgkin lymphoma that has come back after treatment or when other treatments haven't worked.

Different types of biological therapies work in different ways. For example:

- **Cancer growth inhibitors** block the chemical signals that trigger cancer cells to divide and grow.
- **Monoclonal antibodies** trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.
- **Angiogenesis inhibitors** interfere with the blood supply to the cancer cells.
- **Immunotherapy** boosts your body's immune system to fight cancer.

Some treatments fit into more than one of these groups. Monoclonal antibodies are the type of biological therapy usually used to treat Hodgkin lymphoma. For example, rituximab, which can be used for nodular lymphocyte-predominant Hodgkin lymphoma (see page 8).

Some drugs are given in tablet form. Others are given into a vein through a drip. You may be given a biological therapy together with chemotherapy.

New biological therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a biological therapy as part of a clinical trial (see page 32). Ask your doctor if there are any biological therapies available to treat your cancer or if there are any trials that are suitable for you.

Side-effects

Biological therapies only target the cancer cells and leave normal cells alone. This means you usually get fewer side-effects than with chemotherapy.

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include:

- Flu-like symptoms
- Headaches
- Changes in blood pressure
- Fatigue

Your doctor and nurse will explain your treatment in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if any symptoms are troubling you.

For more information on biological therapies and their side-effects, call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

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.
- Some side-effects include infusion reactions, flu-like symptoms, and headache.

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 leukapheresis 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.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

When a drug is being used in a clinical trial it has already been carefully tested to make sure it is safe to use in a clinical trial.

More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, **www.cancer.ie**. You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

What if the Hodgkin lymphoma comes back?

Many people have no further problems after their first treatment for Hodgkin lymphoma. Even if it does come back (recur), it can still be treated with chemotherapy and usually cured.

Sometimes treatment may only be able to control the Hodgkin lymphoma. In this case, it can improve your symptoms and give you a better quality of life. When deciding on treatment, your doctor will consider your general health and where the lymphoma is located.

He or she will also take into account the kind of treatment you have had in the past.

Your doctor may advise different chemotherapy drugs or biological therapies that may help. There may also be treatments that you can have as part of a clinical trial (see page 32). Your doctor will tell you if there are any clinical trials that might be helpful for you.

In many cases, treatment can help you to live longer with better control of your symptoms. Your doctor will discuss the best treatment option for you with the healthcare team. Your doctor may refer you to specialist palliative care doctors and nurses, who are experts in managing the symptoms of advanced cancer. Palliative care also offers emotional support and comfort to patients and their families.

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer.

Fatigue when you have cancer can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Finding out what is causing your fatigue makes it easier to treat. For example if you have a low red blood cell count a transfusion can make you feel better. If you are not eating well a dietitian may be able to give you some advice to help you.

Tips & Hints – fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy.

Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments…
Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. Others can interfere with standard treatment or cause serious side-effects.

More information

If you want to know more about the different complementary and alternative therapies, read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. To get a copy, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website **www.cancer.ie**

Will treatment affect my sex life and fertility?

Sex and sexuality

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery. Once you return to your usual routine your interest in sex should return too. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

Many specialists recommend that you wait for up 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor's advice about contraception or if you are thinking about having children after treatment.

Asking for advice

If you have any queries about how treatment may affect your sex life, you can ask your doctor or nurse. Don’t be put off by thinking the question is small or trivial or that you’ll be embarrassed. Your doctor and nurse are well used to taking about these matters and will give you advice. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Fertility

Many couples go on to have normal healthy babies after one of them has been treated for Hodgkin lymphoma. However, some treatments for lymphoma and sometimes the disease itself can cause infertility. This infertility may be temporary or permanent.

If you were planning to start a family or have more children in the future, try to talk to your doctor as soon as possible. Your doctor will tell you if your treatment is likely to cause infertility and if there is anything that can be done so that you can try to have children later on. If you have a partner, you can visit the doctor together, so that you both understand any options open to you and have a chance to discuss any fears or worries.

It may be possible to freeze your eggs or sperm before you start treatment. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use. Sometimes there may not be time to freeze eggs before treatment starts, as the process can take a few weeks. Many lymphomas can be cured if treatment starts early enough, and so the doctors will be keen to start your treatment as soon as possible. Sperm banking (freezing sperm samples) takes less time than freezing and storing eggs.

Coping with infertility

Dealing with infertility may not be easy, depending on your age and if you have had children. It can bring feelings of sadness, anger and loss of identity. It can help to share your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

What follow-up do I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. The visits will allow your doctor to check for any signs of recurrence and follow up any ongoing side-effects you may have.

At first you will see your consultant every 3 months but these check-ups will become less frequent over time.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget what you wanted to say.

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

Staying healthy after treatment

Many people want to make positive changes to their lives after their treatment has ended. Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Cope better with the side-effects of treatment
- Keep up your energy and strength

Research suggests that a healthy lifestyle may also lower your risk of the cancer coming back. A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also go to our website **www.cancer.ie** for tips and publications on healthy living.

Coping and emotions

How can I cope with my feelings?

People react in different ways when they find out they have cancer. There is no right or wrong way to feel and there is no set time to have any particular emotion.

Common reactions include:

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

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it's important to get help. It is not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and learn ways to cope better.

Free counselling is available at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie A list of counsellors funded by the Irish Cancer Society is available at **www.cancer.ie**

Ways to get support

Find out about cancer support services in your area. There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 53 for more about cancer support services.

Ask about psycho-oncology services at the hospital. Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

Join a support or educational group. Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Get online support. There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

Talk things through. It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support. For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

Learning to cope

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 with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. 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, most people are able to adjust to life during treatment.

How can I help myself?

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 cancer.

Use your support network. Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don't be afraid to ask for help from those who want to support you or to use the support services available.

Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involve your family and close friends. Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

Gather information about your cancer and treatment. Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

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

Get some exercise. Exercising is a great way to boost your mood and sense of well-being. Exercise can also improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

Try relaxation and stress management techniques. Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Try complementary therapies. Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 34 for more information on complementary therapies.

Accept change in your life. Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs. Sometimes people feel they have to be brave or positive all the time, but it is normal to have bad days. Get help if you are finding it hard to cope.

Keep busy. Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

Try to cope day by day. Don't 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.

Express yourself. Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

Practical planning. It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website **www.cancer.ie** for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.

Positive emotions

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

How can my family and friends help?

Your family and friends can support 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 friend best.

Advice for carers

Caring for someone who has had treatment for Hodgkin lymphoma can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

Coping with both the practical and emotional issues of treatment can be hard. Here are some things that can help to make life a little easier.

Caring for someone with cancer

Learn about cancer: Learn more about Hodgkin lymphoma, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your relative or friend.

Visit our website **www.cancer.ie** or call our Cancer Nurseline for a free copy of our publications.

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If any medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

Encourage your relative or friend: At first your relative or friend may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

Support for you

Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information.

Looking after yourself

Share worries: You may feel tired with the worry and extra work that can come with being a carer. Make sure you share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you don't always feel like it.

Take regular breaks: Try to take a break each day, even if it's just a walk to the shops. Ideally, try to organise a longer break as well, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don't want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

Find carers support organisations or local cancer support centres: Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline on 1800 200 700 and ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at **www.cancer.ie**

Talking to children and teenagers

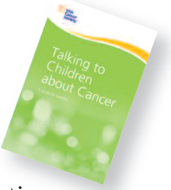
Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, or feel guilty that you can’t do activities with your children, or that you’re letting them down. You may also worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

Saying nothing

You may feel it is best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It is best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.



The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It is also available on our website **www.cancer.ie**.

Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Life after cancer

Being told your treatment has been successful is wonderful news. But it can take some time to adjust to life after cancer treatment. It isn’t unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

- **Fear of cancer coming back** and worrying about every small symptom
- **Loneliness** without the company and support of your medical team and fellow patients
- **Stress** at having to deal with concerns such as your finances, going back to work and family issues that may have been on hold during your treatment
- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready
- **Anxiety and self-doubt** about sexual and romantic relationships
- **Anger** at what has happened and the effect on you and your loved ones
- **Depression or sadness**

There is more about how to cope with these feelings and adjusting to life after cancer on our website **www.cancer.ie/coping/life-after-cancer-treatment**

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 40 for other ways to get support.

Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It is important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 07 4000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, 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 help towards travel costs. See page 52 for more details of our Volunteer Driving Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

For a free copy of the booklet, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: **www.cancer.ie**

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

- **Our Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at **www.cancer.ie**

  For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

- **Our Daffodil Centres.** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

- **Our Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 53 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

  To access either of these services please contact your hospital healthcare professional.
- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

If you would like more information on any of the above services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's Strides for Life walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at **http://www.cancer.ie/support/support-in-your-area/directory**

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: **www.cancer.ie**.

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue

Coping and emotions

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

A Time to Care: Caring for Someone Seriously Ill at Home

Managing the Financial Impact of Cancer. A Guide for Patients and their Families.

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.

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

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?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

Notes

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it is like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions. Please email **reviewers@irishcancer.ie**.

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

Irish Cancer Society
43/45 Northumberland Road, Dublin 4

T: 01 231 0500
E: info@irishcancer.ie
W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700
Email: cancernurseline@irishcancer.ie

Find us on Facebook
Follow us on Twitter: @IrishCancerSoc

The National Cancer Charity

Irish Cancer Society