

Understanding

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# Low-Grade Non-Hodgkin Lymphoma

Caring for people with cancer

## Understanding

# Low-Grade Non-Hodgkin Lymphoma

This booklet has been written to help you understand more about low-grade non-Hodgkin lymphoma. It has been prepared and checked by haematologists, cancer doctors, nurses and patients. The information is an agreed view on lymphoma, 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 list below any contact names and information you may need.



|                       |              |
|-----------------------|--------------|
| Specialist nurse      | Tel:         |
| Family doctor (GP)    | Tel:         |
| Haematologist         | Tel:         |
| Medical oncologist    | Tel:         |
| Radiation oncologist  | Tel:         |
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| Hospital day ward     | Tel:         |
| Emergency number      | Tel:         |
| Treatments            | Review dates |
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If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services in the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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- *Clinical Practice Guidelines in Oncology: Non-Hodgkin's Lymphomas*. National Comprehensive Cancer Network, 2013.
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## Introduction

This booklet has been written to help you learn more about the low-grade form of non-Hodgkin lymphoma. It describes what it is and how it is diagnosed and treated. The booklet is divided into five parts.

- **Part 1** gives an introduction to lymphomas, including symptoms and diagnosis.
- **Part 2** discusses the different treatments used for low-grade non-Hodgkin lymphoma, and possible side-effects.
- **Part 3** discusses the different subtypes of low-grade non-Hodgkin lymphoma in more detail.
- **Part 4** discusses how you can cope with your feelings and the emotional effects of having lymphoma.
- **Part 5** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites.

We hope the booklet 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. This decision can only be made by you and your doctors when all your test results are ready. If you have the high-grade form of lymphoma, call the National Cancer Helpline on 1800 200 700 for a copy of the booklet, *Understanding High-Grade Non-Hodgkin Lymphoma*. You can also visit a Daffodil Centre or download a copy from [www.cancer.ie](http://www.cancer.ie)



### Reading this booklet

Remember you do not need to know everything about low-grade lymphomas. There are so many different subtypes that it can all be very confusing. Read about the subtype that is relevant to you. If you cannot remember what type you have, ask your doctor or nurse to write it down for you. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.

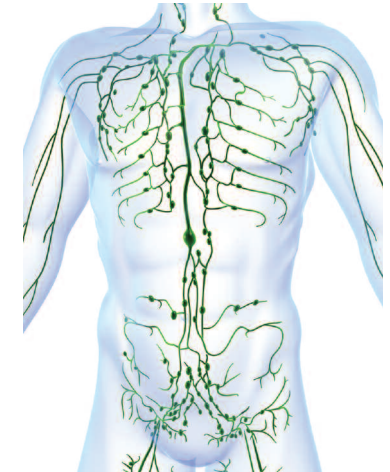
If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline on Freephone 1800 200 700 for information. It is open Monday–Thursday 9am–7pm and Friday 9am–5pm. You can also visit a Daffodil Centre if one is located in your hospital. See page 70 for more about Daffodil Centres.



## About lymphoma

### What is the lymphatic system?

The lymphatic system is an important part of your immune system that helps you fight infection. It refers to the tissues and organs that make, store and carry white blood cells.

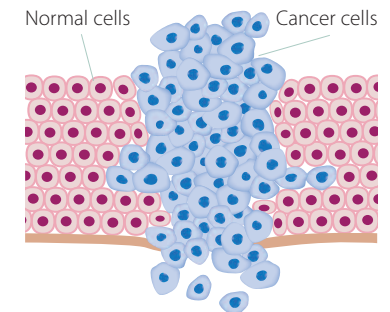


Lymphatic system

Like your blood system it is made up of a network of tiny tubes that pass all around your body. These tubes contain a clear fluid called lymph that has white blood cells to fight infection. These white blood cells are called lymphocytes. They destroy and remove viruses, bacteria and fungi from your body. The lymphatic system is made up of your bone marrow, tonsils, spleen, thymus and lymph nodes. Throughout your body, there are hundreds of small glands called lymph nodes. Larger glands can also be found in your neck, armpit, chest and abdomen. You may only become aware of them if they become swollen or enlarged.

### What is lymphoma?

Lymphoma is cancer of the lymphatic system. 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 your body healthy.



In lymphoma, the cells that are affected are lymphocytes. These white cells grow out of control and do not die off as they naturally would. The abnormal cells start to collect in your lymphatic system, particularly in your lymph nodes. They in turn cause swellings known as lymphomas. Sometimes lymphomas begin in organs such as your stomach or thyroid. One in three lymphomas occurs in places other than lymph nodes.

For information about the types of lymphoma, see page 12.

### How common is lymphoma?

In Ireland, non-Hodgkin lymphoma is the fifth most common cancer in men and the eighth in women. Each year about 306 women and 420 men are diagnosed with it. It affects men slightly more than women and in general can occur at any age, but usually over 60.

### What causes lymphoma?

The exact cause of lymphoma is unknown. Even so, research continues to look for possible causes. Lymphoma is not inherited, but some people may be at greater risk of developing it. For example:

- **Reduced immunity:** Lymphomas are more likely to develop if your immunity is reduced due to an illness (like HIV) or if taking medication to prevent rejection after an organ transplant. It may also occur if you have been treated for another cancer.
- **Chemicals:** In a small number of cases, working with chemicals such as insecticides and herbicides seems to increase the risk of developing lymphoma.
- **Immune system conditions:** If you develop conditions that affect your immune system, you may be more at risk of getting lymphoma later in life. These conditions include rheumatoid arthritis, haemolytic anaemia, coeliac disease, Sjögren's syndrome, lupus and psoriasis.
- **Viruses and bacteria:** Certain viruses can help lymphoma to develop. For example, Epstein-Barr virus, hepatitis C, and human T-cell leukaemia virus 1. Bacterial infections like *Helicobacter pylori* can also be responsible for certain types of lymphoma. But like other cancers, lymphoma is not infectious and cannot be passed on to other people.

### What are the symptoms of lymphoma?

Often with low-grade lymphoma there may be few or no symptoms at all. You might get enlarged lymph nodes in one or more places in your body, for example, your neck, armpit or groin. These lumps or painless swellings may come and go. Other symptoms, known as B symptoms, may include the following:

- Night sweats – these can be drenching
- High temperatures or fevers
- Loss of appetite
- Unexplained weight loss
- Feeling tired all the time (fatigue)
- Itchy skin
- Skin rash

Sometimes you might have lymphoma in other areas of your body, for example, your stomach, bowel, skin or brain. In these cases the symptoms can be quite different. For example, with lymphoma in your bowel or stomach, you may experience breathlessness, abdominal pain, diarrhoea or indigestion.

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



### To sum up

- The lymphatic system is an important part of your immune system that helps you fight infection.
- Lymphoma is cancer of the lymphatic system.
- In Ireland, lymphoma is the fourth most common cancer in men and the sixth in women.
- The exact cause of lymphoma is unknown. Risk factors include reduced immunity, exposure to chemicals, immune system conditions and viruses.
- You may have little or no symptoms at first.
- The main symptom of lymphoma is usually a lump or painless swelling in your neck, armpit or groin.

## How is lymphoma diagnosed and staged?

Most people begin by visiting their family doctor (GP). If your doctor has concerns about you, he or she will refer you to a hospital for further tests. In most cases it is not possible for your GP to confirm a diagnosis of lymphoma. At the hospital your doctor will ask you questions about your health before doing a physical exam. The following tests will be done:

- Blood tests
- Lymph node biopsy

**Blood tests:** These blood tests will include a blood count to see how many red cells, white cells and platelets are in your blood. Blood tests to check if your kidneys and liver are working well will be done too. Blood tests can also show if you have any infections and can give information on how your lymphoma might behave.

**Lymph node biopsy:** Your doctor may have to remove a lymph node or take a biopsy from another area and examine it under a microscope. A biopsy will confirm if you have lymphoma or not. This test can sometimes be done under local anaesthetic, but in most cases a general anaesthetic is needed.

Before the test you may be given a mild sedative to help you relax. A local anaesthetic is used on your skin to numb the area. A small cut is then made through your skin and the lymph node is removed and sent to the laboratory to be examined. A couple of stitches are generally needed at the biopsy site. This test can be uncomfortable but only lasts about 5–10 minutes. As soon as the sedation has worn off you can go home. But you will have to arrange for someone to take you home, as you will be feeling sleepy. You cannot drive for 24 hours after the test.

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

If the enlarged lymph nodes are in your chest or abdomen, you may need open surgery to get a suitable sample to examine. If the biopsy shows that you have lymphoma it will also show the type of lymphoma.

### Further tests

If the biopsy shows that you have non-Hodgkin lymphoma, your doctor will refer you to a specialist, either a haematologist or a medical oncologist. The specialist will want to do further tests. This is known as staging. These extra tests are important because they will show if the disease is found in other tissues. It will also help your doctors to decide on the best treatment for you. The staging tests will show:

- The number and location of affected lymph nodes.
- If the affected lymph nodes are above or below your diaphragm. Your diaphragm is the thin muscle under your lungs and heart that separates your chest from your abdomen.
- If the disease is found in your bone marrow or in places outside the lymphatic system, such as your liver.

Tests may include:

- Chest X-ray
- CT scan
- Ultrasound scan
- PET scan
- Bone marrow biopsy
- MRI scan
- Lumbar puncture

**Chest X-ray:** Usually a chest X-ray is done to check your general health.

**CT scan:** This is a special type of X-ray that builds up a detailed picture of the tissues inside your body. For the test, you lie still on a table which moves your body into a doughnut-shaped machine. You will not feel a thing as the scan is painless. For some CT scans you may be asked to fast for 4 hours beforehand.



CT scan

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

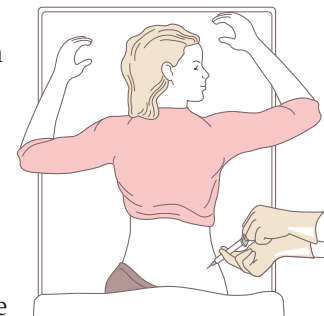
**Ultrasound scan:** This is a special scan that builds up a picture of the tissues inside your liver and upper abdomen using sound waves. You will be asked to lie on your back and a gel will be spread over the area to be scanned. A small device like a microphone, which makes sound waves, is used to take the scan. The sound waves are then changed into a picture by a computer. This test is painless and only lasts about 10 minutes. It is done in the X-ray department of the hospital.

**PET scan:** PET or positron emission tomography is the latest form of scanning to be used in the staging of lymphomas. It is also a useful way of seeing how you are responding to treatment. PET uses a low dose of radioactive sugar (glucose) to measure activity in your cells.

A CT scan is usually done together with the PET scan. Once you are relaxed, the sugar is 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 located. After an hour, the scan is taken and can show if the lymphoma is found in other tissues and organs. Before the test, you may have to fast for a few hours and the scan itself may take up to 1 hour. PET is safe to use and there are no side-effects.

**Bone marrow biopsy:** You may have a bone marrow aspiration and biopsy as part of the staging. Aspiration means removing some bone marrow fluid, whereas biopsy means removing a small piece of bone with marrow cells in it. Both samples are examined under a microscope to see if there are any lymphoma cells present. The samples are usually taken from the back of your pelvis at the hip bone.

Before the test you will be given a local anaesthetic to numb the area. After that, a needle is passed through your skin into your bone marrow. A tiny sample of the bone and bone marrow is then taken. You will feel some discomfort during it but it usually takes just 15–20 minutes to do. 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.



Bone marrow biopsy

**MRI scan:** This special type of scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but it can be noisy. You will be given earplugs to wear during the scan. Before the scan you 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, are usually not suitable for the test. Your doctor will advise you about this. Most people can go home afterwards.

**Lumbar puncture:** You might have a lumbar puncture done before starting treatment. This test will show if there are any lymphoma cells in the spinal fluid around your brain and within your spinal cord. You will be asked to lie down on one side with your knees curled up under your chest. A local anaesthetic will be injected into the lower part of your back. A thin needle will then be put in and a small amount of spinal fluid withdrawn. Usually some chemotherapy is given into the spinal fluid after the sample has been removed.

Your doctors will look at the sample under a microscope to see if any lymphoma cells are present. This test is not painful, but you may feel discomfort during it. You will not be allowed to sit up or get out of bed for 1–2 hours afterwards. This can vary, so your nurse will tell you what to do before you have the test. Repeated lumbar punctures and injections of chemotherapy may be needed as part of your treatment.



## Waiting for results

It may take at least a few weeks for all the test results to be completed. Naturally, this can be an anxious time for you. Do talk to your doctor, specialist nurse or GP if you need further information. You might find it helpful to talk to a relative or close friend during this time too. Or you may wish to call the National Cancer Helpline on 1800 200 700 to speak to one of our specially trained nurses or a patient volunteer. You can also visit a Daffodil Centre.



## To sum up

- Lymphoma is diagnosed by a lymph node biopsy and blood tests.
- Depending on the biopsy results, you may need other tests:
  - Chest X-ray
  - CT scan
  - Ultrasound scan
  - PET scan
  - Bone marrow biopsy
  - MRI scan
  - Lumbar puncture

## How are lymphomas classified?

Lymphoma is classified or grouped in different ways. There are two main types: Hodgkin lymphoma and non-Hodgkin lymphoma. Even though they are very alike in many ways, their treatment is not the same. The only way to tell the difference is by looking at the cells under the microscope. In Hodgkin lymphoma the cells have a particular appearance and are called Reed-Sternberg cells. Any lymphoma that does not have these Reed-Sternberg cells is called non-Hodgkin lymphoma.

**Types of lymphocytes:** The white blood cells that are affected in lymphoma are lymphocytes. There are two types of lymphocytes: B-cells and T-cells. B-cells are made in your bone marrow and make antibodies to fight infection. T-cells are made in your thymus gland behind your breastbone and help your immune system fight infection and disease in other ways. So you can have either a B-cell lymphoma

or a T-cell lymphoma. B-cell lymphomas are more common in non-Hodgkin lymphoma. T-cell lymphomas occur more rarely, mainly in children and young adults.

**Low grade or high grade:** Lymphomas can be broadly divided into high and low grades. The appearance of the cells under the microscope tells how quickly they are growing. Some non-Hodgkin lymphomas are very slow growing and need little or no treatment for many years. These are low-grade lymphomas, which are also called indolent lymphomas. Others grow rapidly and may cause serious ill health if not treated quickly. These are known as high-grade lymphomas or aggressive lymphomas.

The classification of your lymphoma will give your doctor more information, in particular about:

- What type of lymphocyte has become cancerous
- How quickly it is growing
- What parts of your body might be affected
- What is the most suitable treatment for it

Treatment for lymphoma, even at an advanced stage, can be very successful. Many people can be cured or their disease controlled for many years.

## What does low-grade non-Hodgkin lymphoma mean?

These lymphomas tend to have small cells grouped together. They grow very slowly and may need little or no treatment for months or even years. The speed of their growth might change over time and there may be times when the disease is more active.

After treatment, low-grade lymphomas usually get smaller or even disappear altogether. Some types can be completely controlled with treatment. If they do return, they can be treated again.

**Subtypes:** There are many subtypes of low-grade non-Hodgkin lymphoma. See page 45 for more details about the most common ones.



**Transformation:** Lymphoma cells can sometimes change gradually over time. Some of the small cells can grow larger, giving rise to a mixture of cells. These larger cells are more likely to be faster growing and signal your disease is becoming more like a high-grade lymphoma. This is called transformation. It is more common in B-cell than T-cell lymphomas. If any part of your lymphoma has transformed, you will be treated as having high-grade lymphoma.

Do ask your doctor or nurse for more information about your grade or subtype of non-Hodgkin lymphoma. You can also contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

## What are the stages of non-Hodgkin lymphoma?

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

|                |  |
|----------------|--|
| <b>Stage 1</b> | One group of lymph nodes is affected on one side of your diaphragm or a single organ |
| <b>Stage 2</b> | Two or more groups of lymph nodes are affected on one side of your diaphragm         |
| <b>Stage 3</b> | Lymph nodes are affected on both sides of your diaphragm                             |
| <b>Stage 4</b> | Lymphoma can be found in organs outside your lymphatic system or in your bone marrow |

Doctors also use a letter code – either A or B – to say if you have symptoms other than swollen glands or not. For example, weight loss, fever, night sweats. If you have no symptoms, your disease will be classified as A. If you do have symptoms, 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 (standing for extranodal).

- **Early stage:** This includes stage 1 and possibly stage 2.
- **Advanced stage:** This is usually stage 2, 3 or 4.

Once your doctors know the subtype of lymphoma and the stage and grade, they can plan the best treatment for you. If you need more information, do ask your doctor or nurse. They can explain the stages of non-Hodgkin lymphoma in more detail.



### To sum up

- There are two main types of lymphoma: Hodgkin and non-Hodgkin.
- There are two types of lymphocytes, giving rise to a B-cell lymphoma or a T-cell lymphoma.
- Non-Hodgkin lymphomas can be high grade or low grade. The grade depends on the appearance of the cells under the microscope.
- High-grade types grow more quickly and are called aggressive.
- Low-grade types grow slowly and are also called indolent.
- Staging refers to how much of your body is affected by the disease. There are four stages of lymphoma (1 to 4).





## Treatment and side-effects

### How is low-grade non-Hodgkin lymphoma treated?

Your type of treatment will depend on where the lymphoma is, the subtype you have and the stage. Your doctor will also take into account your age and general health. Your test results will help your doctors when planning the best treatment for you. A team of specialists will be involved in planning your treatment.

#### Aims of treatment

The aim of treatment is to get a long-term remission. Remission means the lymphoma is no longer active and is under control. It has been reduced or got rid of completely. Remission can be either partial or complete. A complete remission means there are no visible signs of the lymphoma after treatment. With partial remission, the lymphoma has been reduced by at least a half but is not completely gone. A relapse is when the disease comes back after treatment.

It is more usual to say your disease is in remission rather than cured, as low-grade non-Hodgkin lymphoma can recur. If it does relapse, it can be treated again with chemotherapy, radiotherapy or antibody therapy.

#### Early stage

In early stage disease, usually one or two groups of lymph nodes in just one part of your body are affected. After the first course of treatment, there is a good chance of getting a complete remission and the lymphoma not recurring. People diagnosed with early stage disease are fairly rare.

- **Watch and wait:** No treatment may be given if you have no symptoms. See page 19 for more details.
- **Radiotherapy:** Radiotherapy can be given to the small area of affected lymph nodes and nearby nodes. See page 30 for more details.
- **Chemotherapy or antibody therapy:** There is a risk that some lymphoma cells may be left behind after radiotherapy, increasing the risk of the disease relapsing. In this case, a short course of

chemotherapy or antibody therapy given either before or after radiotherapy might work well. Steroids may also be given as well. See pages 21, 27 and 29 for more details.

Surgery to remove the affected lymph nodes is usually not done, as it is less successful.

If the affected lymph nodes are not close to each other or the lymphoma is affecting other organs, it will be treated like an advanced low-grade lymphoma. Likewise, if your lymphoma relapses in the future it will be treated as an advanced low-grade lymphoma. Another period of remission can then follow. It is possible to control the lymphoma in this way for many years.

### Advanced stage

Most people will have advanced stage disease when diagnosed. This means that lymph nodes are affected in several places in your body. It is often hard to get rid of advanced stage lymphoma completely. It is likely to recur. In fact, it often behaves like a chronic condition. There may be times when the disease flares up and needs treatment to bring it under control and get a remission. The aim is to control the lymphoma by giving treatment at intervals when it does recur (relapses).

- **Watch and wait:** No treatment may be given if you have no symptoms. See page 19 for more details.
- **Chemotherapy:** A number of chemotherapy drugs may be given to bring about a remission. Over the years you may receive several courses of treatment, sometimes a repeat of the same treatment or a different drug. Steroids may also be given as well. See pages 21 and 27 for more details.
- **Antibody therapy:** These drugs use your immune system to target the lymphoma cells. It is also called biological therapy. See page 29 for more details.
- **Radiotherapy:** Radiotherapy might be given to the small area of affected lymph nodes and nearby nodes. See page 30 for more details.
- **Stem cell transplant:** If you are young and fit, you may be suitable for a stem cell transplant. See page 32 for more details.

With newer treatments, people are now getting better quality remissions that are much longer. The average length of remission is 2-3 years, getting shorter if repeated courses of treatment are needed. This means a better quality of life if you are living with this chronic condition. Many experts believe that in time it will be possible to cure advanced stage low-grade lymphoma.

### What if I am unsure about which treatment to have?



Before starting treatment your doctor will explain why you need the treatment and what its aims are. You may be asked to sign a consent form giving your permission for the treatment to be given to you. Before you sign, make sure you are aware of the advantages and disadvantages of the treatment and any other options available to you. Give yourself time to think about the decision. If you are unsure or confused, do ask your nurses and doctors to explain it again.

You are free not to have the treatment either, but it is best to discuss any of your concerns with your doctor before you come to this decision. He or she will explain what might happen if you did not have the treatment. Even though the possible benefits of each treatment may vary slightly between patients, in general, chemotherapy and radiotherapy can cure your lymphoma or put it into remission. If you are still unsure and would like a second opinion, discuss it with your doctor. Most doctors are willing to refer patients to another haematologist or medical oncologist for a second opinion.

### Watch and wait

Sometimes your doctors may prefer to hold off treatment and watch how the lymphoma behaves. This approach is called watch and wait. It is also known as active surveillance or active monitoring. It is not a treatment as such but a way of managing your disease. This is because there may be little or no benefit to treatment at this stage. It may be the best option for you as you will still be closely monitored,

especially if the lymphoma is very slow growing and not causing any problems. Watch and wait can last for months if not years.

**Check-ups:** During this time, you will have regular check-up visits and all the support you need. Your doctors will check your condition with physical exams, blood tests and possibly scans. Based on these results, they can decide when it's time to start treatment and look at your options.

**Worrying about your condition:** It is natural to feel uneasy and worried if you are not receiving treatment. In fact, you may feel that your doctors are doing nothing about your lymphoma. You may even think that you are too old to treat or that the disease is too advanced. Remember watch and wait is a recognised standard of care if you have no symptoms. It also means you avoid any harmful side-effects of treatment. Treatment can be delayed as long as you are feeling well generally.

**Looking after yourself:** During this time it can help to take good care of yourself, like having a healthy lifestyle. For example, eat a healthy diet, take regular exercise, reduce your alcohol intake, and stop smoking.

**What should I look out for?** Watch for any B symptoms like high temperatures or fevers, night sweats, weight loss or poor appetite, and an itchy rash. These might mean the lymphoma is becoming active. Do talk to your doctor and nurse about it.

**When does treatment begin?** Your doctor might start treatment when symptoms develop. For example, if your lymph nodes are getting larger or new ones are affected. You might also need treatment if your blood cell count has decreased, and you feel unwell, or your bone marrow or other organs are affected.

## Chemotherapy

Chemotherapy is a treatment using drugs that can control lymphoma. These drugs can be used on their own or with each other. Whether you get chemotherapy or not will depend on the type and stage of your disease, and if you have other symptoms, such as fevers or night sweats. Chemotherapy can also be given before or after radiotherapy. It is likely that you will need more chemotherapy over the years as low-grade lymphomas tend to relapse.

The drugs used in chemotherapy are carried in your bloodstream to almost every part of your body. It is not possible to get all the treatment you need during one visit to hospital, so you may have to attend hospital regularly for 3–6 months. There is usually a rest period between each treatment visit to allow your body time to recover from the effects of the drugs.

Normally each visit to the hospital where chemotherapy is given is called a cycle. The number of cycles you have will depend on the stage of the lymphoma and how well it is responding to treatment.

### How is chemotherapy given?

Chemotherapy can be given as an infusion (drip), injection or tablet. A number of drugs may be used with each other. For low-grade lymphoma you may be given chemotherapy in tablet form. Infusions and injections are usually given in the day hospital, while tablets can be taken at home. Treatments are often given over several months.

If you have lymphoma cells in your spinal fluid or your doctor thinks you may be at high risk, you will need extra treatment. You may be given special chemotherapy injections into the spinal fluid. To do this, a series of lumbar punctures will be done and the chemotherapy given at the same time.

**Central line:** If your treatment involves injections or infusions, it may help to have a central line put into a large vein. This device can be left in place throughout your treatment. It will make it much easier for you to get treatment and spare you the discomfort of repeated needle jabs. A central line is a narrow flexible plastic tubing (a catheter) that

is put into a main vein and brought out through your chest or arm. You will be given a local anaesthetic beforehand. In most cases, it takes about 10–15 minutes to put in. Removing it is very simple, sometimes needing a small local anaesthetic.

**Portacath:** There are other ways to have easy access to your veins for taking blood samples and giving treatment. Sometimes the tube is attached to a port called a portacath. This is a small round plastic or metal disc placed under your skin. 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.



Central line

### What chemotherapy drugs are used?

There are many chemotherapy drugs used to treat lymphoma. You may be given one drug or a combination of them. Most treatment schedules include steroids. The drugs most commonly used include:

- Doxorubicin (Adriamycin®)
- Cyclophosphamide
- Vincristine
- Bendamustine

All these drugs can be used in combination with each other. The most common combinations are:

- CVP – cyclophosphamide, vincristine and prednisolone (a steroid)
- CHOP – cyclophosphamide, doxorubicin, vincristine and prednisolone

In recent years, a new drug called rituximab has been developed and is now used in the treatment of most B-cell lymphomas. It is an antibody which specifically targets cells that carry a marker on their surface known as CD20. It is usually combined with the drugs listed above, though it can sometimes be used on its own. See page 29 for more details.

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

The side-effects of chemotherapy vary from one person to another and depend on the drugs used. These unwanted effects happen because the chemotherapy can affect both the lymphoma cells and normal cells. In many cases side-effects can be well controlled with medication.

Before you start your treatment ask your doctor about any possible side-effects. Do tell your doctor about the way you are feeling during your treatment as most side-effects can be eased with medication. In most cases, the side-effects go away once the treatment ends or soon afterwards. Your doctor or nurse can give you something to stop most of them or make them easier to cope with.

Side-effects may include:

- |                       |  |
|-----------------------|--|
| ▪ Infection           | ▪ Diarrhoea                                      |
| ▪ Bruising            | ▪ Constipation                                   |
| ▪ Tiredness (fatigue) | ▪ Numbness or pins and needles in hands and feet |
| ▪ Nausea and vomiting | ▪ Hair loss (alopecia)                           |
| ▪ Sore mouth          | ▪ Infertility                                    |
| ▪ Loss of appetite    |  |

**Infection:** Chemotherapy can make you more likely to get infections. This happens because most chemotherapy drugs affect the bone marrow that makes the white blood cells that fight infection. If you do not have enough white cells, even minor infections such as a cold or sore throat could make you quite ill. During treatment cycles you will have regular blood tests to make sure you have enough white blood cells. If they are low (neutropenia), your doctor might decide to give you growth factors. These are hormones that occur naturally and can help to control how blood cells are made. The most common one is G-CSF, which stands for granulocyte colony-stimulating factor. It can boost the number of white cells made.

You will be asked to watch out for signs of infection at all times, especially if your white cells are low. These signs could include feeling shivery and unwell or running a high temperature of 37.5°C or higher. If this happens tell your doctor straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly.

Check this out with your nurse or doctor before you start treatment. If you have a high temperature or feel unwell, you will need a blood test. You may need antibiotics to treat the infection.

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

**Bruising:** Platelets in your blood help to clot and stop any bleeding if you hurt yourself. If there are not enough platelets in your blood (thrombocytopenia), you may bleed or bruise more easily, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily or if you notice tiny red spots under your skin, which can look like a rash (petechiae). He or she will give you advice on what to do.



### Tips & Hints – anaemia, infection, bleeding



- Take plenty of rests and breaks if you are feeling tired or fatigued.
- Avoid close contact, such as hugging or kissing, with people who have colds, flu's and other infections, especially chickenpox, shingles or measles.
- Wash your hands often during the day, especially before eating and after going to the toilet.
- Take care to avoid injury. Use an electric razor when shaving. Wear thick rubber gloves when gardening to protect yourself from cuts.
- Contact the hospital immediately if you have a temperature of 37.5°C (99.5°F) or higher, shortness of breath or bleeding that cannot be stopped.

**Tiredness (fatigue):** You may feel very tired during treatment. This tiredness can last for some months after treatment has ended. If this happens do take things easier. Do less than you normally would and rest as much as you can. Ask your family or friends to help you at work or at home. The tiredness can also be due to having fewer red blood cells

(anaemia) because of changes in your bone marrow caused by chemotherapy. See page 40 for more information about feeling tired and fatigue. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet, *Coping with Fatigue*, or download it from [www.cancer.ie](http://www.cancer.ie)

**Nausea and vomiting:** Not everyone feels sick with chemotherapy. But if you do it can happen before, during or after treatment. It may last for several hours or for a few days after treatment. There is medication available that prevents or reduces nausea and vomiting. These are called anti-emetics. Ask your doctor to give you medication to stop you feeling sick and follow his or her instructions while you are on treatment.

**Sore mouth:** Some drugs used to treat lymphoma can cause a sore mouth. They can also cause little ulcers to 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. Clean your teeth after each meal, using a very soft toothbrush. If you have dentures remove them if your gums are sore. There are special mouthwashes that you can use too. Your nurse will show you how to use them properly.

**Loss of appetite:** It is good to eat as best you can while on chemotherapy. Eat smaller amounts more often. If you do not feel like eating during treatment, you could try replacing some meals with special food supplements. The hospital dietitian will be available to help you. You can also call the National Cancer Helpline on 1800 200 700 for a copy of the booklet, *Diet and Cancer*. Or you can visit a Daffodil Centre or download a copy from [www.cancer.ie](http://www.cancer.ie)

**Diarrhoea:** Passing watery bowel motions more than three times a day is known as diarrhoea. You might also have cramping or abdominal pain. Tell your doctor, as he or she can give you medication to prevent this. Drink plenty of clear fluids. Let your doctor know if the diarrhoea lasts for longer than 24 hours.

**Constipation:** Chemotherapy may slow down the movement of your bowel and your regular bowel habit may change. As a result, you may have difficulty passing a bowel motion. This is called constipation.

If this occurs let your doctor or nurse know as soon as possible. You may need to drink more clear fluids or take a laxative. In some cases your doctor may have to adjust your treatment.

**Numbness or pins and needles in hands and feet:** Some 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 almost always temporary and goes away after treatment stops. But do tell your doctor or nurse if this happens, as some changes may need to be made to your treatment. For a free factsheet on peripheral neuropathy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

**Hair loss (alopecia):** The drugs may also cause some hair loss. The amount of hair loss depends on the drugs you are given. Your hair might just thin out a little bit. If you do lose your hair, it can happen about 2–3 weeks after your first cycle of chemotherapy. You may get a tingling sensation in your scalp a day or two beforehand. Try not to worry as your hair will grow again once treatment ends.

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 with hair loss. You might like to wear a wig, hat, scarf or turban. The staff can give you names of hairdressers and wig suppliers. Ask them too if you can get financial assistance towards the cost of a wig. For some patients the amount of hair loss is small and a wig may not be needed. For more information, especially on wig suppliers, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the free factsheet called *Hair Loss and Cancer Treatment*. You can also download one from [www.cancer.ie](http://www.cancer.ie)

National Cancer Helpline Freefone 1800 200 700



### 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 pulls 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, curling tongs and curlers. Pat your hair gently after washing it.
- Use a gentle, unperfumed moisturiser on your scalp if it becomes dry, flaky or itchy. Natural oils such as almond oil or olive oil are suitable.
- If you are likely to lose your hair, ask your doctor or nurse about wigs early on, so that the wig will be as close a match to your normal hair.
- You may like to wear a hat or scarf when you go out. There are also turbans which can be worn in the house.

**Infertility:** Some of the drugs used to treat non-Hodgkin lymphoma may cause infertility. It may be temporary or permanent. See page 36 for more information.

### Other side-effects

If you have a side-effect or symptom other than those listed above that concerns you, tell your doctor or nurse straight away. He or she will tell you what to do. For more information about chemotherapy and its side-effects, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet *Understanding Chemotherapy* or download it from [www.cancer.ie](http://www.cancer.ie)

### Steroid therapy

Steroids are drugs often given with chemotherapy to help treat non-Hodgkin lymphoma. They can kill the lymphoma cells and improve your symptoms. They are also given to help with some of the side-effects you might experience. In fact, they can help you feel better

quite quickly. In most cases, steroids for non-Hodgkin lymphoma are given for short periods with chemotherapy.

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

- Increased appetite
- Feeling more energetic
- Difficulty in getting to sleep
- Stomach upset

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

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

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

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

**Long-term effects of steroids:** Sometimes treatment for non-Hodgkin lymphoma involves taking steroids for a long time. The effects of this can include increased weight and lowered resistance to infection.

You will notice that you put on weight, especially on your face, waist and shoulders. Your face will fill out and appear more rounded. You may also have a lowered resistance to infection. Try to avoid close contact with people who have colds, flu or any kind of infection while you are taking steroids. Do remember that all these side-effects are temporary and will gradually disappear once you are no longer taking steroids.

It is important that you keep taking the exact dosage your doctor prescribes. He or she will explain your steroid medication to you in more detail.



## To sum up

- Chemotherapy is a treatment using drugs to cure or control lymphoma.
- 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.
- Steroids are drugs often given with chemotherapy to help treat non-Hodgkin lymphoma. They can kill lymphoma cells and improve your symptoms.

## Antibody therapy (biological therapies)

Biological therapies use your body's immune system to control or destroy cancer cells. There are many different types of biological therapies. Antibody therapy or immunotherapy is the kind used in lymphoma. The drugs are called monoclonal antibodies and they can find a particular type of cancer cell in your body. They attach themselves to a protein on the surface of the lymphoma cells and destroy them.

Monoclonal antibodies can be used alone with chemotherapy or with radiotherapy. The treatment can be given as part of the first treatment or if the disease recurs. The most common monoclonal antibody is rituximab (MabThera®). The treatment can be given in different ways. You might have it on its own by weekly infusion into a vein.

### What are the side-effects?

Usually most people notice no side-effects when given a monoclonal antibody on its own. But allergic reactions to them can happen. If they occur, it is usually during the first infusion. For this reason, the first dose is given slowly over a number of hours. But you will be watched closely during this time. Symptoms include:

- Fever and chills
- Low blood pressure
- Flu-like symptoms



Do tell your doctor or nurse if you get a swollen feeling in your tongue or throat, irritation of your nose, breathing problems, wheeze, cough, skin itching or rash. You will also be given medication before treatment begins to make these side-effects less likely. This medication might make you drowsy, so it is best not to drive home afterwards. These symptoms normally go away once the infusion is slowed down or when it ends.

**Delayed side-effects:** These are rare. But your white cell count may drop (neutropenia), making you more prone to infection. Your doctor and nurse will explain this treatment to you in more detail.

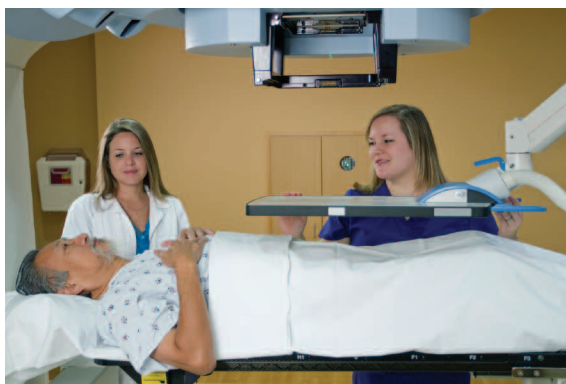


## To sum up

- Antibody therapy uses your body's immune system to control or destroy cancer cells.
- The ones used most often to treat lymphoma are monoclonal antibodies.
- They attach themselves to the cancer cells and destroy them.
- The most common monoclonal antibody is rituximab (MabThera®).

## Radiotherapy

Radiotherapy is not used very often for low-grade lymphomas. It is a treatment where high-energy X-rays are aimed at a cancer to cure or shrink it. In non-Hodgkin lymphoma the X-rays are usually delivered through a machine called a linear accelerator. This is known as external beam radiotherapy.



External beam radiotherapy

Radiotherapy is a local form of treatment. The beams are only aimed at the lymphoma. It may be used on its own when the lymphoma is found in one or two groups of lymph nodes in the same part of your body. It may also be given after a course of chemotherapy.

Radiotherapy can also be used if the lymphoma has affected the fluid around your brain or if there is a high risk that it may develop there. Treatment planning is a very important part of radiotherapy so it may take a few visits before your treatment can go ahead.

## What are the side-effects of treatment?

Radiotherapy is given directly to the site of the lymphoma and nearby lymph nodes. As a result, the side-effects that occur are related to the part of your body being treated. Some people have only mild symptoms, while for others the side-effects can be more severe. It depends on how much treatment you need and what part of your body is being treated. The most common side-effects that may occur are:

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

For more information about the side-effects of radiotherapy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet *Understanding Radiotherapy* or download it from [www.cancer.ie](http://www.cancer.ie)



## To sum up

- Radiotherapy is where high-energy X-rays are aimed at the lymphoma to cure or shrink it.
- It only affects the lymphoma in the area being treated.

## Stem cell transplant

There are a few situations where you might benefit from a stem cell transplant after high-dose chemotherapy. These include:

- If there is a high risk of the lymphoma coming back after treatment.
- If your first treatment has failed, that is, the disease has not responded (refractory).
- If the lymphoma has returned (relapsed).
- If you are involved in a clinical trial.

If this is relevant to you, your doctor and nurse will discuss it with you.

Healthy stem cells can be collected and removed from your body before treatment and returned to you afterwards. These stem cells can restore or rescue the bone marrow destroyed during the high-dose treatment. The stem cells are taken from blood or bone marrow. When your own stem cells are used it is called an autologous transplant. If stem cells are taken from a donor, it is called an allogeneic transplant.

There are various stages or steps when having a stem cell transplant. Your doctor and nurse will explain each step as it happens. For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklets, *Understanding Stem Cell Collection* or *Understanding Autologous Stem Cell Transplants*. You can also download them from [www.cancer.ie](http://www.cancer.ie)



### To sum up

- High-dose treatment with a stem cell transplant can be given if there is a high risk of the lymphoma returning or it has relapsed, or if treatment has failed.
- By taking stem cells from your body before treatment and returning them afterwards, your bone marrow can be rescued and allowed to make new blood cells.



## Research – what is a clinical trial?



Research into new ways of treating lymphoma goes on all the time.

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

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.

### Phases of research

There are many stages or phases when research is being done. If a drug or treatment looks as if it might be useful in treating lymphoma, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and which lymphomas can be treated. If early studies suggest that a new drug may be both safe and effective, more 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 lymphoma and new treatments. There is no need for worry as you will be carefully monitored during and after the study. You might also receive a treatment that later proves to be better than the current best standard treatment.

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 factsheet called *Cancer and Clinical Trials*, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## After treatment

### What follow-up do I need?

Once your treatment is finished you will have to come back for regular check-ups. This is known as follow-up. In the beginning these will be quite often. The visits will include seeing your doctor and having tests such as X-rays, scans and blood tests. These will continue for a number of years but will become less frequent as time goes by.

These visits are important as they will allow your doctor to check for signs of recurrence and to follow up on any ongoing side-effects that you may have. He or she can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given. If you are between check-ups or you have a symptom or problem that worries you, let your doctor know as soon as possible.

If the lymphoma does return it can be treated again with chemotherapy, radiotherapy or monoclonal antibodies. Another period of remission can then follow. It is possible to control the lymphoma in this way for many years.

### Getting back to normal

**Tiredness:** It can take at least a year for you to get over the effects of treatment. You may still feel tired and lacking in energy. You may not feel ready to lead as active a life as you did before treatment. It is better not to fight these feelings but to allow your body the time it needs to recover.

**Work and activities:** You may have problems to solve or decisions to make which you deferred because of treatment. These issues may include changing jobs, getting back to work or study and if you can have children or not. If you stopped working during treatment, you can start to go back to your job. But you might want to take it slowly at first by working part-time or reduced hours. You can also resume other activities such as sport, hobbies and other pastimes.

**Taking care of your health:** Watch out for any signs of infection or other problems. In particular, some people may experience pneumonia

or other lung problems. You may find that you have excess mucus, coughing, pain, blocked sinuses or the sniffles. It is best to get the flu vaccine each winter too and the pneumonia vaccine every 5 years. Also, take good care of your mouth, teeth or dentures, as they can be a source of infection. If you develop any bowel problems, such as ongoing abdominal pain, diarrhoea, bleeding or constipation, contact your doctor as soon as possible.

**Cancer risk:** Having lymphoma puts you at a higher risk of developing other cancers. For example: bladder, lung, stomach and myeloid leukaemias.

**Holidays and insurance:** You may decide to go on a holiday once your treatment is over. Check with your doctor first about any special precautions to take or vaccinations you may need. It is best to have travel insurance too. Some insurance companies now provide cover for lymphoma patients. Contact the National Cancer Helpline on 1800 200 700 for more details.

### Should I quit smoking?

It is never too late to quit smoking. If you quit, it reduces your chances of developing other cancers and illnesses. These include emphysema, heart disease, stroke and osteoporosis. Smoking can also affect the treatment of cancer. For example, it can reduce how well chemotherapy or radiotherapy works. It can also make their side-effects worse. Sometimes it may cause rarer side-effects such as breathing and heart problems. This is because radiotherapy can make body organs like the lungs more sensitive to tobacco smoke.

Like many others, you may find giving up smoking hard. But with the right information and support you can do it. If you would like advice or support on quitting, call the National Smokers' Quitline on CallSave 1850 201 203. It is open Monday to Saturday from 8am to 10pm.

If you would like further personal support locally, the helpline can put you in touch with the smoking cessation officer in your area. For more information on giving up smoking, see [www.quit.ie](http://www.quit.ie). Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.

## Will treatment affect my sex life?

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

One common fear is that lymphoma can be passed on to your partner during sex. But this is not true. It is perfectly safe for you to resume having sex. There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routines your interest in sex should return too. If you have a supportive partner, you may find that talking about your feelings will help ease your anxiety.

Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If not having sex becomes a problem for you, do seek help. Do not feel guilty or embarrassed to talk to your doctor or nurse about what is troubling you. He or she may refer you for specialist counselling if you think that would be helpful.

## Will treatment affect my fertility?

Many couples go on to have healthy babies after one or other partner has been treated for lymphoma. However, some treatments for lymphoma, and sometimes the disease itself, can cause infertility. This infertility may be temporary or permanent. Before you start treatment your doctor will talk to you about this in more detail. If you have a partner, you may find it helpful to see the doctor together so that you can both talk about your fears and worries.

### For women

**Chemotherapy:** Some drugs used to treat non-Hodgkin lymphoma can affect your ovaries. This means that your periods may stop during or for a few months after treatment. You may get hot flushes, a dry vagina or other symptoms of the menopause. If it is temporary, your periods

may return to normal after a few months. This happens in about a third of women who have short-term infertility brought on by chemotherapy. In general the younger you are, the more likely your regular periods will return and you can still have children.

**Early menopause:** The nearer you are to the menopause the more likely it is that chemotherapy will stop your periods permanently. Most of the effects of the menopause can be prevented or reversed by replacing the hormones your ovaries normally make. But it will not be possible to restore your fertility.

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

**Contraception:** As periods usually stop during treatment you may not know if you are fertile or not. If you are having sex, 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.

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

**Radiotherapy:** Most radiotherapy treatments have no effect on your ability to have children. If the lower part of your body is being treated, special shields can be used to protect your ovaries. However, many specialists recommend that you wait for 2 years after radiotherapy before trying to get pregnant to give your body a chance to get over the effects of the lymphoma and its treatment. You should 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:** If there is a risk that your treatment will cause long-term infertility, do discuss it with your doctor. You might have the option of freezing your eggs (oocytes) before treatment begins. The HARI Unit at the National Fertility Centre in the Rotunda Hospital, Dublin provides a service where eggs can be frozen and stored for later use. But remember for most patients with lymphoma it is not possible to delay treatment. It could take 6–8 weeks before your eggs are frozen and this timeframe is not practical. Also, there is no guarantee that egg freezing will be a success for lymphoma patients. Do ask your doctor for more information. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



## For men

For some men the lymphoma itself can cause infertility. Sperm tests carried out before treatment starts will show if this is the case. Some types of treatment can also cause infertility. This may be temporary or permanent.

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

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 family member 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 to store your sperm before treatment for use at a later date. Sperm banking is done at the HARI Unit at the National Fertility Centre in the Rotunda Hospital in Dublin. To do this you will be asked to give several sperm samples. There will be a couple of days' break between each sample to make sure good samples are got. 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 and the results of tests awaited. If you wish to find out more about sperm banking, talk to your doctor or nurse. He or she will give you more information. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can talk to a nurse who will tell you what services are available.

**Chemotherapy:** Chemotherapy may cause infertility. It may be temporary or permanent. Even though doctors know that some chemotherapy drugs may cause infertility it is very difficult to say if and when this will happen. You may be on treatment 2–3 months before your sperm count is reduced.

If you are having sex, you must use a reliable method of contraception throughout your treatment and for some time afterwards. There is a risk of miscarriage or birth defects in children conceived during or just after treatment. Many doctors believe it is better for your partner not to get pregnant for 2 years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment and by then the chances of the disease coming back are much less.

**Radiotherapy:** Most radiotherapy treatments have no effect on your ability to have children. But you might make less sperm if your testicles are near the area being treated. Nowadays it is possible to avoid giving radiotherapy to the testicles in most treatments. Special shields can also be used to protect them during treatment.

You must use a reliable method of contraception throughout your treatment and for some time afterwards. This is because there is a risk of miscarriage or birth defects in children conceived during or just after treatment. Many specialists recommend that you wait for 2 years after radiotherapy before trying to start a family or have more children. This time gives your body a chance to get over the effects of the lymphoma and its treatment.

## How can I cope with fatigue?

Fatigue is a common symptom of lymphoma and is described as an overwhelming tiredness. Often it is not relieved by rest. You may find it hard to concentrate or make decisions. Fatigue may also be caused by anxiety when a diagnosis of cancer is made and the added stress caused by treatment. It can also be a side-effect of treatment or due to anaemia.

### What you can do

- **Side-effects to expect:** For many patients treatment may help by relieving symptoms such as fever and feeling unwell, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

- **Sleep:** If you are feeling worried and find it hard to sleep at night tell your doctor or nurse. He or she may be able to help. Try talking to your close family or friends about your concerns too. If you find this hard, ask to see a counsellor. He or she will help you to find ways to cope.
- **Physical exercise:** If your illness allows you to take part in physical exercise, try to do some regularly. For example, 30 minutes of exercise 2–3 times a week might be a realistic goal and will boost your morale when you achieve it.
- **Losing weight:** You may notice that you have lost weight. This may be due to the lymphoma or the treatment you are getting. Sometimes when you are feeling weak and tired you may lose interest in your food. Ask for help in preparing your meals. It can help to eat your favourite foods too. Take plenty of clear fluids such as water and fruit juice.
- **Asking for help:** Get others to help you around the house, with travelling to hospital, with the children or with shopping.
- **Working:** Whether you work or not during treatment depends on the kind of work you do and how you are feeling. It is probably better to make this decision when you have had one or two courses of treatment. Only then will you have a clearer picture of how the treatment affects you.
- **Studying:** If you are in full-time education, think about putting your studies on hold until your treatment is over. Use the extra free time to do something that you especially enjoy.

A useful booklet called *Coping with Fatigue* is available free of charge. If you would like a copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## 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 in which you live. In Ireland, cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

### Conventional therapies

Conventional therapies are treatments which doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, biological therapies and hormone therapy. 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:

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

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

## Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy 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. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download a copy from [www.cancer.ie](http://www.cancer.ie)



## Subtypes of low-grade non-Hodgkin lymphoma

### What are the different subtypes?

There are many subtypes of low-grade non-Hodgkin lymphoma. The most common ones are:

- Follicular lymphoma
- Chronic lymphocytic leukaemia / small lymphocytic lymphoma
- Lymphoplasmacytic lymphoma
- MALT lymphoma
- Splenic marginal zone lymphoma
- Nodal marginal zone lymphoma
- Cutaneous lymphoma

If your subtype of lymphoma is not listed here, do talk to your doctor or nurse. They can give you more information and advice about it.

**Symptoms:** Along with enlarged lymph nodes in your neck, armpit or groin, you may experience B symptoms such as:

- Night sweats
- Fevers
- Unexplained weight loss
- Loss of appetite
- Itchy skin
- Skin rash
- Fatigue
- Flu-like symptoms
- Infection
- Aches and pains
- Breathlessness
- Pale skin
- Bleeding and bruising

More specific symptoms are listed with each subtype.

**Treatment:** The main treatment is chemotherapy and antibody therapy using a number of drugs. If the disease relapses it can be treated again.



## Follicular lymphoma

**Why is it called follicular lymphoma?** The cells in the lymph nodes tend to grow in a cluster or circular pattern. They are irregular in size and shape and replace the normal cells there. It is a cancer of the B-cells. Usually the cancer cells have a protein called CD20 on their surface. This protein is targeted in antibody therapies.

**How common is it?** It is the most common type of low-grade lymphoma. In Ireland, it makes up about half of all low grades and about one-fifth of all non-Hodgkin lymphomas. It is more common in people over 50 with most people being diagnosed aged 60 and over. It rarely affects people under 20. It is slightly more common in women.

**How quickly do the cancer cells grow?** Follicular lymphoma usually grows slowly and causes few symptoms in its early stages. In general it behaves like a chronic condition where it flares up from time to time. Most patients have advanced disease by the time symptoms develop. About 4 in 5 have follicular lymphoma at stage 3 or 4 when first diagnosed. Gradually the cancer cells grow and large numbers can be found in your body. Most of these are a mixture of small and large cells. The smaller the cells, the slower your disease is likely to be.

Sometimes follicular lymphoma will be graded from 1 to 3. These grades refer to the various amounts of small and large cells. Grade 3 tends to grow more quickly than grade 1 or 2. The grade of your lymphoma may change and might become fast growing over time.

**What other symptoms might I have?** It usually causes few symptoms in the early stages.

**When is treatment given?** Doctors may decide to watch and wait at first. Many people live with follicular lymphoma for years without treatment and enjoy fairly good health. Treatment might be given if the disease changes, gets worse or causes problems in your major organs.

**How is it treated?** Very early stage disease is treated with radiotherapy. For those diagnosed with stage 1 and 2, the lymphoma might be cured completely. Advanced disease is often treated with

chemotherapy along with the antibody therapy, rituximab (MabThera®). After chemotherapy, if you are in remission, rituximab may still be given as a maintenance treatment. This is done to prolong the remission. This treatment will last 2 years if it is working and not causing any side-effects. Other milder forms of chemotherapy in tablet form might be considered if you are less fit. Nowadays the time between treatments is getting longer, often lasting many years.

See page 30 for more about radiotherapy, page 21 for chemotherapy and page 29 for antibody therapy.

## Chronic lymphocytic leukaemia (CLL) / small lymphocytic lymphoma (SLL)

**Other names:** small cell lymphocytic lymphoma.

**Why is it called chronic lymphocytic leukaemia or small lymphocytic lymphoma?** Leukaemia and lymphoma have many features in common and can affect your body in the same way. CLL and SLL are now believed to be the same condition. The abnormal cell called a small lymphocyte is found in both conditions but the difference is where this cell is located in your body. In CLL, the abnormal lymphocyte is found in blood and bone marrow, whereas with SLL it is found in the spleen and lymph nodes. It is a cancer of the B-cells. Chronic means it lasts a long time and does not fully go away. Lymphocytic means the white blood cells known as lymphocytes are affected. Leukaemia means a cancer of the blood cells.

**How common is it?** CLL/SLL is a rare disease and affects adults. It is more likely to be found in people aged over 60 but can happen at any age. It is more common in men.

**How quickly do the cancer cells grow?** The behaviour of CLL/SLL can vary from person to person. It generally flares up from time to time. In between those times nothing much happens. Some people have very slow-growing disease that lasts for long periods of time and needs no treatment. On the other hand, some might have a more aggressive form of the disease.

Occasionally, CLL/SLL can change and become more aggressive as time goes on. In this change, known as a Richter transformation, many of the cells become bigger. If this occurs, it might be treated like a high-grade lymphoma.

**What other symptoms might I have?** You might have few or no symptoms at the start. The condition is sometimes found during a routine blood test when you have no symptoms.

**When is treatment given?** Even with advanced disease, there may be no hurry to start treatment if you feel well. Your doctor may decide on a watch and wait approach and begin treatment if needed. For example, if you feel unwell or symptoms begin to appear.

**How is it treated?** Treatment may involve chemotherapy, such as cyclophosphamide and fludarabine, along with the antibody therapy rituximab (MabThera®). This is given through a vein. The condition can also be treated with other types of chemotherapy alone, with antibody therapy alone, and with steroids. If you are younger, you might be offered treatment with a bone marrow or stem cell transplant. The same might be given if you have CLL that has relapsed or is behaving more aggressive than usual.

For more about CLL, see the booklet *Understanding Chronic Lymphocytic Leukaemia*. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## Lymphoplasmacytic lymphoma

**Other names:** Waldenström's macroglobulinaemia.

**Why is it called lymphoplasmacytic lymphoma?** Lymphoplasmacytic describes the appearance of the cells under the microscope. Here the lymphocytes appear more like plasma cells, which are blood cells. The cells involved are B-cells. One type of lymphoplasmacytic lymphoma is Waldenström's macroglobulinaemia. Macroglobulinaemia refers to large abnormal proteins called globulins made by the lymphoma cells and found in blood.

**How common is it?** It is a very rare form of lymphoma. It is most commonly diagnosed in people over 60 years of age.

**How quickly do the cancer cells grow?** It is like CLL where lymphoma cells can be found in the bloodstream. It usually involves the bone marrow and often the spleen too. As a result, the growth of normal cells is reduced and it causes anaemia (low red blood cells) and thrombocytopenia (low platelets). The globulins that are made can enter your bloodstream, causing your blood to thicken. This is called hyperviscosity and you may need treatment for this. Sometimes the cells transform, where they start to grow larger and divide faster. In this case, the lymphoma behaves more like a high-grade lymphoma and is treated along those lines.

**What other symptoms might I have?**

- Bleeding and bruising, especially nosebleeds
- Blurred or loss of vision
- Confusion

Nosebleeds, confusion, blurred or loss of vision are caused by the thickened blood (hyperviscosity). This can raise the pressure in your smaller blood vessels as the blood tries to flow through. Your protein levels will also be checked regularly by your doctor. Sometimes a different type of globulin or no abnormal proteins are made, so the symptoms are milder.

**When is treatment given?** In some cases, if you have no symptoms, you may not need any treatment. Your doctors will continue the watch and wait approach and begin treatment if needed. Treatment can be given if you feel unwell or symptoms begin to appear. Or you might need more immediate drug treatment using chemotherapy with or without antibody therapy.

**How is it treated?** There are various ways to treat it, depending on your situation. It may include chemotherapy alone or with an antibody therapy like rituximab. Other treatments may be suggested by your doctor to manage some of your symptoms. Anaemia may sometimes be treated with blood transfusions. If your blood gets too thick, a plasma exchange called plasmapheresis may be advised. This is where the large plasma proteins are removed from your bloodstream allowing it to flow better through your blood vessels. This may have to be repeated as the proteins might build up again if the lymphoma is active.

## Marginal zone lymphomas

Marginal zone lymphomas can grow in many different places in your body. Most occur outside your lymphatic system. They all develop from the same type of cell called a marginal zone B-cell. They make up around 1 in 10 of all non-Hodgkin lymphomas. The most common types are MALT lymphoma and splenic marginal zone lymphoma. Both behave in a different way to the other types of low-grade lymphomas. A third type called nodal marginal zone lymphoma can also occur but is much rarer.

### MALT lymphoma

**Full name:** MALT stands for mucosa associated lymphoid tissue. The word extranodal is often placed before it, which refers to it being beyond the lymph nodes.

**Why is it called MALT lymphoma?** This type of lymphoma grows in your mucous membranes. These are the soft moist tissues that line many organs in your body. The lymphoma can develop in any part of your body where these membranes are found. It most often occurs in the stomach but also the salivary glands, lungs, tear ducts and other parts of the eye. MALT lymphomas in the stomach are also known as gastric MALT lymphoma.

**How common is it?** They make up just less than 1 in 10 of all B-cell non-Hodgkin lymphomas. Mostly they occur in adults aged 60 or over but can happen at any age. They are slightly more common in women. If you have an autoimmune disease like Sjögren's syndrome or Hashimoto's thyroiditis, you might be more at risk of developing a MALT lymphoma. There is also a clear link between MALT and the bacterial infection *Helicobacter pylori*.

**How quickly do the cancer cells grow?** Often the lymphoma may only be present in the tissue where it first started to grow. Or it may involve other lymph nodes and your bone marrow. But this happens less frequently than in other lymphomas.

### What other symptoms might I have?

- Indigestion and abdominal pain – if MALT is in your stomach
- Watery eye – if MALT is in your tear gland
- Cough or shortness of breath – if MALT is in your lungs

**When is treatment given?** This depends on where in your body the MALT has occurred. In some cases no treatment may be given at first. Your doctors will continue to watch and wait and only begin treatment if needed. In other cases, treatment may be more immediate.

**How is it treated?** Antibiotics are often used to treat MALT lymphomas of the stomach in the early stages. This is because the bacteria *Helicobacter pylori* may also be present in the stomach. As soon as the infection is treated, the MALT will often start to shrink back too. Your doctors will check the response of the MALT by doing regular endoscopy. This is where they place a long narrow tube in your stomach to see its tissues. You might need other treatments like chemotherapy, radiotherapy and antibody therapy if the MALT is found in several places at diagnosis or did not respond well to antibiotics. The treatment of MALT in other places will vary and depend on where they are found. Treatments may include radiotherapy, surgery and chemotherapy, with or without antibody therapy.

## Splenic marginal zone lymphoma

**Other names:** Splenic lymphoma with villous lymphocytes.

**Why is it called splenic marginal zone lymphoma?** It is called splenic marginal zone lymphoma because it occurs in the spleen. Your spleen is an organ found on the left side of your tummy (abdomen). It is important in your body's defence against infection. Its main function is to remove old blood cells from your bloodstream and store platelets. It is also called splenic lymphoma with villous lymphocytes because it refers to how the particular lymphoma cells look in your bloodstream.

**How common is it?** It is not as common as a MALT lymphoma. It most often occurs in later life. If you develop hepatitis C infection, you are more at risk of developing splenic lymphoma, though it may improve when the hepatitis C itself is treated.

**How quickly do the cancer cells grow?** The lymphoma is usually slow growing. It may be found only in your spleen or in other tissues, like your bone marrow or bloodstream.

**What other symptoms might I have?** If your spleen enlarges, you may develop anaemia and low platelets. These symptoms include:

- Abdominal pain
- Shortness of breath
- Fatigue
- Bleeding or bruising

An enlarged spleen is known as splenomegaly.

**When is treatment given?** Splenic lymphoma may be treated in many different ways. In some cases no treatment may be needed at first. Your doctors will continue the watch and wait approach and begin treatment if needed. In other cases, treatment may be more immediate.

**How is it treated?** Surgery may be an option if your enlarged spleen is causing you symptoms. This is called a splenectomy. You may be more prone to picking up infections afterwards and will be prescribed a small dose of protective antibiotics. If surgery is not suitable or the lymphoma is found in your bone marrow, other treatments may be discussed with you. These include an antibody therapy like rituximab (MabThera®), which can be given on its own or possibly with chemotherapy. Radiotherapy to the spleen is another option. Blood transfusions may help to ease the symptoms of anaemia.

## Nodal marginal zone lymphoma

**Why is it called nodal marginal zone lymphoma?** This type of lymphoma has no signs of disease in the spleen, stomach or other organs. But the lymph nodes look the same as those involved in the other types of marginal zone lymphomas. It usually affects the B-cell lymphocytes.

**How common is it?** It is a very rare type of lymphoma.

**How quickly do the cancer cells grow?** It normally develops very slowly. In some people, it may change into a high-grade non-Hodgkin lymphoma. This means it will need more intensive treatment.

**What other symptoms might I have?** None specific.

**When is treatment given?** Nodal marginal zone may be treated in many different ways. In some cases no treatment may be needed at first. Your doctors will continue to watch and wait and begin treatment only when needed. In other cases, treatment may be more immediate.

**How is it treated?** If treatment is needed, it can be done in the same way as follicular lymphoma. This usually involves chemotherapy alone or with the antibody therapy rituximab (MabThera®).

## Cutaneous lymphoma

**Other names:** cutaneous T-cell lymphomas; mycosis fungoides; Sézary syndrome.

**Why is it called cutaneous lymphoma?** Cutaneous refers to anything related to your skin. Some types of low-grade lymphoma develop in the lymphocyte cells in the lymphoid tissue of your skin. Cutaneous T-cell lymphomas (CTCL) are the most common type of skin lymphoma and they develop from the T-cells. The most common type is mycosis fungoides, which makes up half of all skin lymphomas. Sézary syndrome is a more advanced form of mycosis fungoides.

**How common is it?** Skin lymphomas are rare. They are more common in men than women.

**How quickly do the cancer cells grow?** Many are slow growing and may take years before they cause any bother. Often they look like common skin conditions, such as eczema or psoriasis. They can be difficult to diagnose and may need repeated skin biopsies over a period of time to confirm the diagnosis. Many behave more like a chronic type of skin condition and may affect widespread areas of your body.

**What other symptoms might I have?** With mycosis fungoides:

- Red skin patches or plaques
- Patches can be flat, dry, scaly and itchy
- Appearance of patches may change over time
- Found mainly on the buttocks or trunk, but can occur anywhere on skin

**When is treatment given?** This can vary. It depends on the type of skin lymphoma and how much of the skin is involved and if any other parts of your body are affected, for example, lymph nodes. In some cases, no treatment may be needed at first. Your doctors will continue to watch and wait and only begin treatment when needed. In other cases treatment may be more immediate.

**How is it treated?** There are various ways of treating cutaneous lymphoma. Treatments may be applied directly to your skin like steroid creams, chemotherapy lotions, ultraviolet light and radiotherapy. Other treatments like chemotherapy drugs, steroids and antibody therapy may also be used.

### More information

If you would like more information on your subtype or others, talk to your doctor or nurse.



## 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 too. 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 the later stages of your illness that your emotions hit hard.

#### Common reactions include:

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



Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet that discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. For a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre or download one from [www.cancer.ie](http://www.cancer.ie). Your medical social worker in the hospital is also available to support you.

#### 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 totally 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 yet believe what is happening to you.

### Fear and uncertainty

*'I'm going to die.'*  
*'Will it be painful?'*  
*'Will I become a different person?'*

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. No one knows how long anybody will live, but having cancer is likely to shorten your life. It can be very difficult to face an uncertain future and feel you are no longer in control. One way to reduce the stress of uncertainty is to make your plans day by day. Letting go of the past and not worrying about the future allows you to live fully in the present.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, finances, job, and lifestyle.

Do discuss your concerns with your doctor, nurse or medical social worker, as they can advise and help you. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

### Loss of control

*'I can't cope with this.'* *'I'll never get through it.'*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about cancer at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident making any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

### Sorrow and sadness

*'I used to be so healthy.'* *'I had so many plans.'* *'I've let my family down.'*

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 life may be affected by treatment to varying degrees. 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

*'I'm fine, really.'*  
*'I don't have cancer.'*

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 don't want to hear any information about your cancer until you're ready.

### Anger

*'Why me? I always took care of my health.'* *'Why did this happen now?'*

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with God for allowing

cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

Your family and friends may not always be aware that your anger is really at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor. There is also an upside to anger. You can channel its powerful energy into fighting your illness. This could be in doing something creative like writing or a physical activity like exercise.

### Resentment

*'How can you talk, you don't have to deal with cancer.' 'How come I'm not getting better?'*

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have.

You may resent your healthy relatives or having to change your lifestyle in some way. On the other hand, sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

### Blame and guilt

*'I should've been more careful.' 'If only I had a more positive attitude, I wouldn't have got sick.'*

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty

because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is 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

*'I just need to be on my own.'*

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 to want 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 them, as they will want to share this difficult time with you. They may worry about you needlessly. Do 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 or visit a Daffodil Centre or download it from [www.cancer.ie](http://www.cancer.ie)

### 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. Others may gather up-to-date information on lymphoma to know what you can expect and what you are going through. Others again 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.



## 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.

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

### Be patient

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

*Lost for Words: How to Talk to Someone with Cancer* is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes of many kinds, great or small. Even so, it is best to keep family life as normal as possible. If you have young children, continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives. Every family deals with cancer in its own

way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or grandchildren or that you're letting them down. These are all natural feelings to have at this time.

### Be honest

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

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

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. For example, if you get scarring or hair loss due to treatment. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

### Coping with children's emotions

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



If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for discussing cancer with children. If you would like a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre, or download it from [www.cancer.ie](http://www.cancer.ie)

## How can I help myself?

Here is a list of things to help make you feel more involved and in control of your illness.

- Communicate with your family and close friends.
- Live one day at a time.
- Live well by eating well and taking exercise.
- Expect change in your life.
- Keep an open mind.
- Seek information about your cancer and treatment.
- Find what way of coping works for you.
- Build a support network.
- Seek professional help if you have low moods or strong emotions.
- Consider spiritual care.
- Express yourself through writing, music, dance or art.

### Journey Journal

It can help to keep a record of your cancer journey, including both physical and emotional aspects. Call the National Cancer Helpline on 1800 200 700 for a copy of *Journey Journal: Keeping Track of Your Cancer Treatment* or visit a Daffodil Centre. In this journal, you can record any of your tests like blood tests, X-rays and scans, as well as treatments, symptoms, side-effects, medications, and your general health. Write down any emotions you are feeling too, especially strong ones. It's a great way to express yourself without holding back.



## 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
- Support groups and cancer support centres
- Irish Cancer Society



**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.

**Haematology/oncology nurse specialists:** Some of the major cancer treatment hospitals have haematology/oncology units where there are specially trained nurses. These are called haematology/oncology liaison nurses and/or cancer nurse co-ordinators. They can support you and your family from the time of diagnosis and throughout treatment. The 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.

**GP (family doctor):** 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:** 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. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

**Support groups:** 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 are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. Useful websites, including patient forums, are also listed. You can also download the Irish Cancer Society's *Directory of Cancer Support Services* from **www.cancer.ie**

**Irish Cancer Society:** The staff of the Cancer Information Service 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.

Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for information about any of the services outlined above or for support services in your area.

>>> Remember that there are many people ready to help you.

## Health cover

Health cover falls into two groups – cover for medical card holders and cover for all other groups. Details of the following are given here:

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

At the end of this section there are also some useful telephone numbers and websites 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 emergency department 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 emergency department 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 €2.50 per item up to a limit of €25 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 €500 or less (€900 for couples), 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. This is known as a discretionary medical card. But it will depend on your financial circumstances and how long your treatment is expected to last. In this case, your spouse and children will not be covered if your means are over the limit. If you wish to apply for a medical card, you can download an application form and apply online (**www.medicalcard.ie**) or at your local health centre. LoCall 1890 252 919.

## 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 your hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online ([www.medicalcard.ie](http://www.medicalcard.ie)) or at your local health centre. LoCall 1890 252 919.

## Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 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 or 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, GloHealth, and other schemes. They provide cover for day care or 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

You or a family member may qualify for a number of benefits and allowances. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

More information on these is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a free copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

Application forms for the benefits are available from social welfare offices or the Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 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)

## Appliances

If you have a medical card most appliances are free of charge or subsidised. For example, if you have hair loss due to chemotherapy, you are entitled to 1–2 free or subsidised new hairpieces every year. The subsidy will depend on the HSE area.

## Travel to hospital

You can 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, usually for patients with medical cards.

See page 72 for information on the Care to Drive and Travel2Care 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 – Information Service

Oisín House  
212–213 Pearse Street  
Dublin 2

Tel: 1850 662 244  
Leaflet line: 1890 202 325  
Email: [info@welfare.ie](mailto:info@welfare.ie)  
Website: [www.welfare.ie](http://www.welfare.ie)

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](mailto:info@hse.ie) **Website:** [www.hse.ie](http://www.hse.ie)

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

### Citizens Information

Tel: 0761 07 4000  
Email: [information@citizensinformation.ie](mailto:information@citizensinformation.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)



## 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 unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with 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 71 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurses 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 73 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 79 for more information.

## 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
- Haematology/oncology liaison nurses
- Cancer information booklets and factsheets
- 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 freefone 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. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **[www.cancer.ie](http://www.cancer.ie)** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **[helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)**
- **Message Board** is a discussion space on our website to share your stories and experiences with others.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

## Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

## Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See pages 74–77 for more details.

## Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance on the phone. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

## 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 National Cancer Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

## 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.

## Haematology/oncology liaison nurses

The Society funds some haematology or 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 and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. These booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from [www.cancer.ie](http://www.cancer.ie) or picked up at a Daffodil Centre.



## Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in great 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. If you are travelling over 30 km to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

**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](mailto:travel2care@irishcancer.ie)

**Financial Aid:** A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology liaison nurse or contact the Irish Cancer Society at (01) 231 6619.

### 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 chemotherapy 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.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. You can also visit the website [www.cancer.ie](http://www.cancer.ie) or a Daffodil Centre.

National Cancer Helpline Freefone 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](mailto:helpline@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

**The Carers Association**  
Market Square  
Tullamore  
Co Offaly  
Tel: 057 932 2920  
Freefone: 1800 240 724  
Email: [info@carersireland.com](mailto:info@carersireland.com)

**Citizens Information**  
Tel: 0761 07 4000  
Email: [information@citizensinformation.ie](mailto:information@citizensinformation.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

**HARI: The National Fertility Centre**  
Rotunda Hospital  
Parnell Square  
Dublin 1  
Tel: 01 807 2732  
Email: [info@hari.ie](mailto:info@hari.ie)  
Website: [www.hari.ie](http://www.hari.ie)

**Irish Oncology and Haematology Social Workers Group**  
Website: <http://socialworkandcancer.com>

**Irish Nutrition & Dietetic Institute**  
Ashgrove House  
Kill Avenue  
Dún Laoghaire  
Co Dublin  
Tel: 01 280 4839  
Email: [info@indi.ie](mailto:info@indi.ie)  
Website: [www.indi.ie](http://www.indi.ie)

**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](mailto: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](mailto:info@avivahealth.ie)  
Website: [www.avivahealth.ie](http://www.avivahealth.ie)

**GloHealth**  
PO Box 12218  
Dublin 18  
Tel: 1890 781 781  
Email: [findoutmore@glohealth.ie](mailto:findoutmore@glohealth.ie)  
Website: [www.glohealth.ie](http://www.glohealth.ie)

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

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

## Survivors Supporting Survivors

### ARC Cancer Support Centres

Dublin and Cork (see pages 75 and 76).

### Brain Tumour Support Group

Medical Social Work Department  
St Luke's Hospital  
Highfield Road  
Rathgar  
Dublin 6  
Tel: 01 406 5163

### CanTeen Ireland

Young Peoples' Cancer Support Group  
Carmichael Centre  
North Brunswick Street  
Dublin 7  
Tel: 01 872 2012  
Freefone: 1800 200 700  
Email: info@canteen.ie  
Website: www.canteen.net

### Lakelands Area Retreat & Cancer Centre

Multyfarnham  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
CallSave: 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

For more details, contact the Irish Cancer Society at 1800 200 700 or email: [support@irishcancer.ie](mailto:support@irishcancer.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: ballinasloecancer@yahoo.co.uk

### 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

### Gort Cancer Support Group

The Hawthorn  
Ennis Road  
Gort  
Co Galway  
Tel: 086 312 4220  
Email: gcsupport@eircom.net  
Website: 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

### 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: scsc@eircom.net  
Website: www.sligocancersupportcentre.ie

### Tuam Cancer Care Centre

Cricknet 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 Bella Rose Foundation

[Women with cancer]  
Merry Maid House  
West Park Campus  
Garner Lane  
Citywest  
Dublin 24  
Tel: 086 879 3242  
Email: thebellarosefoundation@gmail.com

### Bray Cancer Support & Information Centre

36B Main Street  
Bray  
Co Wicklow  
Tel: 01 286 6966  
Email: info@braycancersupport.ie  
Website: www.braycancersupport.ie

### Cara Cancer Support Centre

Mullavalley  
Louth Village  
Dundalk  
Co Louth  
Tel: 042 937 4905  
Mobile: 087 395 5335  
Email: info@ccscdundalk.ie  
Website: http://ccscdundalk.ie

### Cois Nore: Cancer Support Services

**Kilkenny**  
8 Walkin Street  
Kilkenny  
Tel: 056 775 2222  
Email: coisnorekilkenny@gmail.com  
Website: www.kilkennycancersupport.ie

### Cuisle Centre

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

### Dóchas: Offaly Cancer Support

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

### 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  
Website: www.greystonescancersupport.com

**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 Weafer 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@larcc.ie  
Website: www.larcc.ie

**Newbridge Cancer Support Group**

144 Allenvue Heights  
Newbridge  
Co Kildare  
Tel: 083 360 9898  
Email: newbridgecancerhealinghelp@gmail.com

**Rathdrum Cancer Support Centre**

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

**Tallaght Cancer Support Group**

Millbrook Lawns  
Tallaght  
Dublin 24  
Tel: 087 217 6486  
Email: ctallaght@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

**Cork ARC Cancer Support House**

Cliffdale  
5 O'Donovan Rossa Road  
Cork  
Tel: 021 427 6688  
Email: info@corkcancersupport.ie  
Website: www.corkcancersupport.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

**Sláinte an Chláir: Clare Cancer Support**

Tír 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  
Earlscourt  
Waterford  
Tel: 051 876 629  
Email: infosecf@eircom.net  
Website: www.secf.ie

**Suimhneas 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

**Ulster support groups & centres****Cancer Support and Social Club**

Tiernaleague  
Carndonagh  
Co Donegal  
Tel: 086 602 8993 / 087 763 4596

**Coiste Scaoil Saor ó Ailse**

Knockastoller  
Gweedore  
Letterkenny  
Co Donegal  
Tel: 083 121 7857  
Email: coiste.scaoil.saor@icloud.com  
Website: www.scaoilsaor.ie

**Crocus: Monaghan Cancer Support Centre**

The Wellness Centre, 19 The Grange  
Plantation Walk  
Monaghan  
Tel: 087 368 0965

**Cuan Cancer Social Support and Wellness Group**

2nd Floor, Cootehill Credit Union  
22-24 Market Street  
Cootehill  
Co Cavan  
Tel: 086 455 6632

**The Forge Cancer Support Group**

The Forge Family Resource Centre  
Pettigo  
Co Donegal  
Tel: 071 986 1924

**Living Beyond Cancer**

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



## Support group & centres unaffiliated to Irish Cancer Society

### Cancer Care West

Inis Aoihbhinn  
University Hospital Galway  
Costello Road  
Galway  
Tel: 091 545 000  
Email: info@cancercareswest.ie  
Website: www.cancercareswest.ie

### Cúnamh: Bons Secours Cancer

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

### Dundalk Cancer Support Group

Philipstown  
Hackballscross  
Dundalk  
Co Louth  
Tel: 086 107 4257

### 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

Kille  
Kilcar  
Co Donegal  
Tel: 074 973 1292  
Email: riverbankdunne@eircom.net

### Solace: Donegal Cancer Support Centre

St Joseph's Avenue  
Donegal Town  
Tel: 074 974 0837  
Email: solacedonegal@eircom.net

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

## Useful contacts outside Republic of Ireland

### Action Cancer

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

### American Cancer Society

Website: www.cancer.org

### Cancer Focus Northern Ireland

40-44 Eglantine Avenue  
Belfast BT9 6DX  
Tel: 048 9066 3281  
Email: hello@cancerfocusni.org  
Website: www.cancerfocusni.org

### Cancer Network Buddies

Website: www.cancerbuddiesnetwork.org

### Cancer Research UK

Tel: 0044 20 7242 0200  
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  
[Live chat is available on their website for Irish patients too]

### Macmillan Cancer Support (UK)

Tel: 0044 20 7840 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

### National Cancer Institute (US)

Website: www.nci.nih.gov

## Helpful books

### Free booklets from the Irish Cancer Society:

- *Understanding High-Grade Non-Hodgkin Lymphoma*
- *Understanding Chronic Lymphocytic Leukaemia*
- *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*



### *Cancer Positive: The Role of the Mind in Tackling Cancers*

Dr James Colthurst  
Michael O'Mara Books, 2003  
ISBN 185479860X

### *Challenging Cancer: Fighting Back, Taking Control, Finding Options*

(2nd edn)  
Dr Maurice Slevin & Nira Kfir  
Class Publishing, 2002  
ISBN 1859590683

### *Low-Grade Non-Hodgkin Lymphoma*

Lymphoma Association, 2012  
ISBN 978-095704412

### *Lymphomas*

Lymphoma Association, 2012  
ISBN 978-0956475589

### *101+ Square Meals*

[Budget and nutrition]  
Norah Bourke et al  
MABS/HSE West/Paul  
Partnership/Limerick VEC/Safefood, 1998  
ISBN 187407514X  
[For more details, see www.mabs.ie]

## Helpful DVDs

### *A Guide to Chemotherapy*

HSE/Mid-Western Cancer Centre/ICS,  
2008  
Call 1800 200 700 for a copy.

### *Understanding Radiation Therapy: A Patient Pathway*

Call 1800 200 800 for a copy.  
Website: www.cancer.ie

## What does that word mean?

|                           |   |
|---------------------------|---|
| <b>Abdomen</b>            | The part of your body that lies between your chest and hips. Also known as your belly or tummy.                             |
| <b>Alopecia</b>           | Loss of hair. No hair where you normally have hair.   |
| <b>Allogeneic</b>         | The use of someone else's tissue for a transplant. For example, your brother or sister.                                     |
| <b>Anaemia</b>            | When there are less red blood cells in your blood. This can cause tiredness, weakness and shortness of breath.              |
| <b>Antibody</b>           | A protein that attacks and kills organisms, such as bacteria and viruses, or cells that cause disease.                      |
| <b>Autologous</b>         | The use of a person's own tissue. For example, when cells are taken from your bone marrow or blood.                         |
| <b>Biopsy</b>             | Removing a small amount of tissue from your body and looking at it under a microscope to see if lymphoma cells are present. |
| <b>Cells</b>              | The building blocks that make up your body. They are tiny and can only be seen under a microscope.                          |
| <b>Chemotherapy</b>       | Treatment that uses drugs to cure or control cancer.  |
| <b>Complete remission</b> | There are no visible signs of the lymphoma after treatment.   |
| <b>Diaphragm</b>          | The thin muscle under your heart and lungs that separates your chest from your abdomen.                                     |
| <b>Fatigue</b>            | Ongoing tiredness often not helped by rest.   |
| <b>Intravenous</b>        | Into a vein.  |
| <b>Lymph</b>              | A clear watery fluid that carries material through your lymphatic system.   |

|                             |   |
|-----------------------------|---|
| <b>Lymphatic vessels</b>    | Tubes carrying lymph that connect to lymph nodes.   |
| <b>Lymph node</b>           | A small oval or round gland found along lymphatic vessels that removes bacteria and foreign particles from your body. |
| <b>Medical oncologist</b>   | A doctor who treats cancer with chemotherapy and other drugs.   |
| <b>Monoclonal antibody</b>  | Treatment using a manmade antibody to fight disease. Also called biological therapy or antibody therapy.              |
| <b>Nausea</b>               | Feeling sick or wanting to be sick.   |
| <b>Neutropenia</b>          | When there are less white blood cells called neutrophils in your body. As a result, you develop infections easily.    |
| <b>Oncology</b>             | The study of cancer.  |
| <b>Partial remission</b>    | After treatment, the lymphoma has been reduced by at least a half but not fully.                                      |
| <b>Radiation oncologist</b> | A doctor who specialises in treating cancer patients using radiotherapy.  |
| <b>Radiotherapy</b>         | The treatment of cancer using high-energy X-rays.   |
| <b>Refractory disease</b>   | When the lymphoma does not respond to the first course of treatment or comes back very quickly afterwards.            |
| <b>Relapse</b>              | When the lymphoma becomes active again after treatment.   |
| <b>Remission</b>            | When the lymphoma is no longer active and is under control. See also complete remission and partial remission.        |
| <b>Staging</b>              | A series of tests that measure the size and extent of cancer.   |
| <b>Thrombocytopenia</b>     | When there are less 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 your doctor. 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 non-Hodgkin lymphoma? Where exactly is it?
- What subtype do I have?
- What does low grade mean?
- What type of treatment do I need?
- How successful is this treatment for my lymphoma?
- Are there other treatment options?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects will I get?
- Is there anything I can do to help myself during treatment?
- Would I be suitable for a clinical trial?
- Should I eat special foods?
- What if the lymphoma comes back?

## Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

## Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or its previous version,

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Loreto Kissane, Oncology Liaison Nurse

Nicky Martin, Medical Social Worker

## 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 or visit a Daffodil Centre.

## 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. Please fill in the postcard in the pocket inside the back cover, and post it back to us for free.

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](mailto: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](mailto:fundraising@irishcancer.ie)

**Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.**

**Tel:** 01 231 0500 **Email:** [info@irishcancer.ie](mailto:info@irishcancer.ie) **Website:** [www.cancer.ie](http://www.cancer.ie)

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E: [info@irishcancer.ie](mailto:info@irishcancer.ie)

W: [www.cancer.ie](http://www.cancer.ie)

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

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