

Understanding

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, oncologists (cancer doctors), nurses and patients. The information is an agreed view on lymphoma, its treatment and how it may affect you.

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.



| Name | Telephone |
|-------------------------------|-----------|
| Specialist nurse | |
| Family doctor (GP) | |
| Haematologist | |
| Medical oncologist | |
| Radiation oncologist | |
| Radiation therapist | |
| Medical social worker | |
| Emergency | |
| Hospital records number (MRN) | |

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LYMPHOMA ADVISERS

Dr Brian Bird, Consultant Medical Oncologist
Karena Maher, Haematology Clinical Nurse Specialist

CONTRIBUTOR

Anna Drynan-Gale, Daffodil Centre Nurse

EDITOR

Sarah Lane

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Quick facts

Can my cancer be treated?

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Yes, there are a number of treatments for low-grade non-Hodgkin lymphoma (NHL). Treatment aims to put the lymphoma into remission. Remission means the lymphoma is no longer active and is under control. Even if the disease isn't cured, it can usually be kept under control. You may not need any treatment straight away, if your lymphoma isn't causing you any problems.

Will I be OK?

Page 30 ▶▶

What is likely to happen to you (your prognosis) can be hard to predict. The best thing to do is to ask your consultant about your own situation.

Treatments for low-grade NHL are often effective at controlling the disease for a long time.

What treatment will I have?

Page 39 ▶▶

Watch and wait: Monitoring your cancer with no active treatment

Chemotherapy: Drugs to control the lymphoma

Steroids: Drugs given along with chemotherapy to help to kill lymphoma cells and improve symptoms

Biological therapies: Drugs to boost your immune system and help your body to target and destroy cancer or to stop it spreading

Radiotherapy: X-ray treatment to try to control the cancer (not often used)

Some people may be suitable for a stem cell transplant.

How will my cancer and treatment affect me?

Page 53 ▶▶

Most people's lymphoma is advanced when they are diagnosed. Advanced NHL can be hard to get rid of completely. It may 'flare up' at times and cause symptoms like fevers and sweating, loss of appetite, extreme tiredness and skin irritations. You will need more treatment if this happens.

Clinical trials

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Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

We're here for you

Page 80 ▶▶

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Cancer Nurseline on 1800 200 700
- Drop into a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

See page 80 for more about our services.

Introduction

This booklet has been written to help you learn more about the low-grade form of non-Hodgkin lymphoma.

We hope this booklet answers some of your questions. We encourage you to talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

If you have high-grade NHL, call our Cancer Nurseline on 1800 200 700 for a copy of the booklet, *Understanding High-Grade Non-Hodgkin Lymphoma*. You can also get one from a Daffodil Centre or download a copy from www.cancer.ie



Reading this booklet

Remember you do not need to know everything about low-grade lymphomas. Read a section that you are interested in. Then read another section when you want to know more. If you do not understand something that has been written, ask your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 80 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

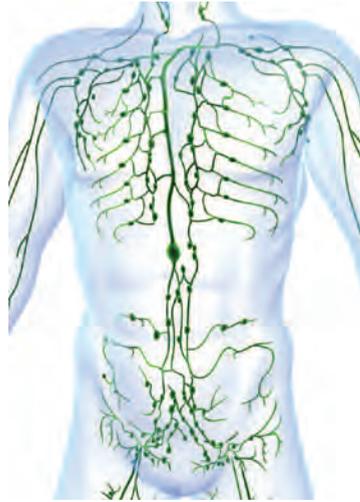


About lymphoma

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What is the lymphatic system?

The lymphatic system is a system of thin tubes, known as lymph vessels, and lymph nodes (or 'lymph glands') that run throughout the body. It is part of the body's immune system, which helps to protect us from infection and disease. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels transport extra fluid and waste from body tissues; they filter out bacteria and viruses. The lymph nodes contain infection-fighting white blood cells called lymphocytes. Lymph nodes often swell when they are fighting infection, which is a normal, healthy response. You may only become aware of your lymph nodes if they become swollen or enlarged. Your spleen is also an important part of the lymphatic system. The spleen helps to filter out damaged cells from the blood stream and also to fight infection.

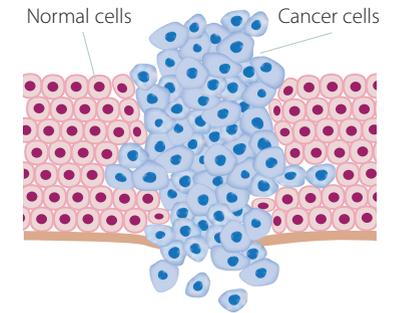


Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves; this is the most common place for this to happen but lymphoma can start in almost any part of the body, including the stomach, small bowel, skin, tonsils, thyroid or testicles. Lymphoma cells can also be found in the bone marrow – the soft tissue inside some bones where blood cells are made. Lymphoma that grows outside the lymph nodes is called extra-nodal lymphoma.

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.

In lymphoma, the cells that are affected are lymphocytes (these can be B or T lymphocytes). These white cells grow out of control and do not die off as a normal cell 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.



What are the types of lymphoma?

Lymphomas can be described, or 'classified' in different ways. The classification will give your doctor more information 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

T-cell and B-cell lymphomas

Lymphomas can be described by the type of lymphocyte white blood cells that are affected:

B-cell lymphoma: B-cell lymphocytes are affected. B-cells are made in your bone marrow and make antibodies to fight infection.

T-cell lymphoma: T-cell lymphocytes are affected. T-cells are made in your thymus gland behind your breastbone and help your immune system fight infection and disease in other ways. T-cell lymphomas happen more rarely, mainly in children and young adults.

Low-grade and high-grade lymphomas

Low grade and high grade describe how quickly the lymphoma is growing, based on how the cells look under the microscope

Low-grade lymphomas: Grow slowly and need little or no treatment for many years. These are also called indolent lymphomas.

High-grade lymphomas: Grow rapidly and may cause serious ill health if not treated quickly. These are also called aggressive lymphomas. They can be either B-cell lymphomas or T-cell lymphomas.

Low-grade non-Hodgkin lymphoma

Low-grade non-Hodgkin lymphoma refers to a range of different slow-growing lymphomas. They 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 of low-grade lymphoma can be completely controlled with treatment. If they do return, they can be treated again.

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. Transformation is more common in B-cell lymphomas. If any part of your lymphoma has transformed, you will be treated as having high-grade lymphoma.

Subtypes

There are many subtypes of low-grade non-Hodgkin lymphoma. See page 14 for more details about the most common ones.



Ask your doctor or nurse for more information about the grade or subtype of your non-Hodgkin lymphoma. Ideally ask them to write it down for you. If you have further questions you can also contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

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 330 women and 430

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 increases my risk of lymphoma?

The exact cause of lymphoma is unknown. But there are certain risk factors that can affect your chances of getting the disease. Having a risk factor doesn't mean you will definitely get cancer. Sometimes people without any known risk factors develop cancer. Some of the things that can possibly increase your risk of lymphoma are:

- **Reduced immunity:** Lymphomas are more likely to develop if your immunity is reduced due to an illness (like HIV) or if you're 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 (HTLV 1). Bacterial infections like *Helicobacter pylori* can also be responsible for certain types of lymphoma.
- **Age:** Low-grade lymphoma can occur at any age but it is more common in older people.
- **Gender:** It's more common for men to get low-grade lymphoma — the reason for this is unknown.
- **Family:** Low-grade lymphomas do not run in families, but if you're worried about this please discuss it with your doctor.

Like other cancers, lymphoma is not infectious and cannot be passed on to other people.

What are the signs and symptoms of lymphoma?

The most common early symptom of NHL is a painless swelling in the lymph nodes in one area of the body, for example, in your neck, armpit or groin. These lumps or painless swellings may come and go. However, often with low-grade lymphoma there may be few or no symptoms at all. Other symptoms, known as B symptoms, 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 abdominal pain, diarrhoea or indigestion. If it affects the chest area you may have a cough or experience difficulty swallowing.

Remember that all of these symptoms can be caused by conditions other than lymphoma. But it's important to tell your doctor and have these symptoms checked out.



To sum up

- The lymphatic system is an important part of your immune system that helps you to fight infection.
- Lymphoma is cancer of the lymphatic system.
- There are two types of lymphocyte blood cells that can be affected by lymphoma: B-cells and T-cells
- Non-Hodgkin lymphomas can be high grade or low grade.
- Low-grade types grow slowly and are also called indolent.
- High-grade types grow more quickly and are called aggressive.

Subtypes of low-grade non-Hodgkin lymphoma

| | |
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| Follicular lymphoma | 14 |
| Chronic lymphocytic leukaemia (CLL) / small lymphocytic lymphoma (SLL) | 15 |
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| Splenic marginal zone lymphoma | 20 |
| Nodal marginal zone lymphoma | 21 |
| Cutaneous lymphoma (skin) | 21 |

What are the different subtypes?

There are many subtypes of low-grade non-Hodgkin lymphoma. Some of the most common ones are listed in this section,

As well as general lymphoma symptoms like swollen lymph nodes and B symptoms like night sweats and fatigue (see page 12), any specific symptoms are listed with each subtype.

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.

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. Monoclonal antibodies can target this protein.

How common is it? It is the most common type of low-grade lymphoma. In Ireland, it makes up about half of all low-grade and about one-fifth of all non-Hodgkin lymphomas. Most people are aged 60 and over when they're diagnosed. 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. 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. Higher grades tend to grow more quickly. The grade of your lymphoma may change and might become fast growing over time. Grade 3a is a low-grade NHL but grade 3b is usually treated as a high-grade NHL.

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 a monoclonal antibody. Maintenance therapy is used to prolong remission after successful treatment of lymphoma. Immunotherapy is the most common type of maintenance therapy for people with lymphoma.

See page 48 for more about radiotherapy, page 41 for chemotherapy and pages 47-48 for monoclonal antibodies and immunotherapy.

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 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, along with monoclonal antibodies. The condition can also be treated with other types of chemotherapy alone, with just monoclonal antibodies, 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 our booklet *Understanding Chronic Lymphocytic Leukaemia*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it from www.cancer.ie

Lymphoplasmacytic lymphoma

Other names: Waldenström 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 biological therapies.

How is it treated? There are various ways to treat it, depending on your situation. It may include chemotherapy alone or with a monoclonal antibody 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 monoclonal antibodies 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 monoclonal antibodies.

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 targeted/immunotherapy drugs like rituximab, 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 monoclonal antibodies.

Cutaneous (skin) lymphoma

Other names: Cutaneous T-cell lymphoma, cutaneous B-cell lymphoma, 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? Treatment 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 monoclonal antibodies may also be used.

More information

If you would like more information on your subtype, talk to your doctor or nurse. For more about the different treatments, see pages 40–51.

Email: cancernurseline@irishcancer.ie

Diagnosis and tests

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Being diagnosed with lymphoma

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

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

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

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

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

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

Email: cancernurseline@irishcancer.ie

Telling people about your diagnosis

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

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

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



What tests will I have?

The following tests give doctors more information about your lymphoma and your general health. The 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.

Some tests – for example heart and lung tests – may also be used to see if you are well enough to have chemotherapy drugs. Others may be used to measure your response to treatment.

Tests you may have include:

- CT scan
- Ultrasound scan
- PET scan
- Bone marrow biopsy
- Lumbar puncture
- MRI scan

CT scan (CAT scan) / CT with contrast (dye): This is a special type of X-ray that gives a detailed picture of the tissues inside your body. During the scan you will lie on a table which passes through a doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You may be asked to fast (not eat) for a few hours before the test. You may also be given a special drink or injection to help show up certain parts of your body on the scan. Before you take the drink or injection let the radiographer know if you have asthma or are allergic to iodine.



The injection might make you feel hot all over for a few minutes. The preparation for a CT scan can vary, but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

Ultrasound scan: This is a scan that uses sound waves to look at your liver and upper abdomen. This test is painless and only takes a few minutes.

Some 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. It is done in the X-ray department of the hospital.

PET scan: This scan is 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 to measure activity in your cells. 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. During the scan, you will lie on a table which moves through a scanning ring.

Before the scan, you may have to fast (not eat) for a few hours.

A CT scan is usually done together with the PET scan.

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 your skin will be cleaned and 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 or pressure during it but it usually only takes a couple of minutes to take the samples. The whole procedure will take around 30 minutes.

The area may feel tender and sore for a few days afterwards. You may need to take a mild painkiller for a day or two.

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 or in a sitting position. The doctor doing the procedure will tell you which position they want you to be in.



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 is to prevent headaches.

You will also be advised to drink plenty of fluids to reduce the risk of headaches. Repeated lumbar punctures and injections of chemotherapy may be needed as part of your treatment.

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

Waiting for test results



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

Staging low-grade non-Hodgkin lymphoma

The tests you have after diagnosis are usually done to help the doctor to stage your cancer. Staging means finding how much of your body is affected by the disease. Staging helps your doctor to decide the best treatment for you.

Non-Hodgkin lymphoma is usually described using numbers 1-4 and letters A, B and E, depending on your symptoms and how many lymph nodes or organs are involved. In general, the lower the number, the less the cancer has spread.

Number stages

Stage 1 (I) One group of lymph nodes is affected on one side of your diaphragm or a single organ

Stage 2 (II) Two or more groups of lymph nodes are affected either above or below your diaphragm

Stage 3 (III) Lymph nodes are affected above and below your diaphragm

Stage 4 (IV) Lymphoma can be found in organs outside your lymphatic system or in your bone marrow

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

Letter codes

A You have no symptoms other than swollen glands

B You have other symptoms, such as weight loss, fever and night sweats

E The lymphoma is in unusual places outside your lymph nodes. For example, in your stomach. This is called extranodal lymphoma (the letter E stands for extranodal).

Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.



To sum up

- Tests you may have after diagnosis include:
 - Scans (CT, ultrasound, PET, MRI)
 - Bone marrow biopsy
 - Lumbar puncture
- These tests help your doctor to learn more about your cancer so that they can recommend the best treatment for you.
- Staging refers to how much of your body is affected by the disease. There are four stages of lymphoma (1 to 4)

Asking about your prognosis



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

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

Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

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

Treating low-grade non-Hodgkin lymphoma

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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.

Aims of treatment

The aim of treatment is to get a long-term remission.

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.

Complete remission: There are no visible signs of the lymphoma after treatment.

Partial remission: The lymphoma has been reduced by at least a half but is not completely gone.

It is more usual to say your disease is in remission rather than cured, as low-grade non-Hodgkin lymphoma can come back after treatment. This is called relapse. The longer you are in remission, the less likely the lymphoma will come back.

If a relapse happens, it can be treated again with chemotherapy, radiotherapy or immunotherapy/targeted therapy drugs.

Treatment for early stage lymphoma

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, so the lymphoma won't come back. It's more usual for patients to be diagnosed at a later stage.

- **Watch and wait:** No treatment may be given if you have no symptoms. See page 40 for more details.
- **Radiotherapy:** Radiotherapy can be given to the small area of affected lymph nodes and nearby nodes. See page 48 for more details.
- **Anti-cancer drug therapies:** There is a risk that some lymphoma cells may be left behind after radiotherapy, increasing the risk of the disease relapsing. In this case, your doctor may advise a short course of chemotherapy or targeted/immunotherapy drugs, given either before or after radiotherapy. Steroids may also be given as well. See pages 41-48 for more about these treatments.

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.

Treatment for advanced stage lymphoma

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 come back (relapse). In fact, it often behaves like a chronic condition. This means having lymphoma can be like having a long-term illness, which needs treatment from time to time when the condition flares up. The treatment will aim to get the disease under control and bring about another remission.

- **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 41 and 45 for more details.

- **Biological therapies:** These drugs use your immune system to target the lymphoma cells. See page 47 for more details.
- **Radiotherapy:** Radiotherapy might be given to the small area of affected lymph nodes and nearby nodes. See page 48 for more details.
- **Stem cell transplant:** Only some patients will be suitable for a stem cell transplant. Transplants are not common and are only used if the lymphoma has come back. Your consultant and specialist nurse will discuss this in more detail. See page 50 for more details.

Specialist cancer centres

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

Deciding on treatment

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

Treatment options: Your doctor and nurse will discuss your treatment options with you. Do ask as many questions as you like. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

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

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

Giving consent for treatment

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

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

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

🗨️ **If you are ever worried about anything just ask. Everyone is there to help you.** 🗨️

Cancer Nurseline Freephone 1800 200 700

Who will be involved in my care?

Usually a team of health professionals will be involved in your treatment and care.

| | |
|--|---|
| Haematologist-oncologist | A doctor who specialises in treating blood and bone marrow diseases. |
| Medical oncologist | A doctor who specialises in treating cancer patients using chemotherapy and other drugs. |
| Radiation oncologist | A doctor who specialises in treating cancer patients using radiotherapy. |
| Radiation therapist | A specially trained person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment. |
| Haematology/oncology liaison nurse or clinical nurse specialist | A specially trained nurse who works in a special cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment. |
| Medical social worker | A person trained to help you and your family with your social issues and practical needs. They can give counselling and emotional support. They can give advice on benefits and financial matters and on practical supports and services available to you when you go home. |
| GP (family doctor) | Your GP can be a great support to you. You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope. |

| | |
|----------------------------------|--|
| Palliative care team | This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals. |
| Physiotherapist | A therapist who treats injury or illness with exercises and other physical treatments related to the illness. |
| Dietitian | An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms. |
| Psycho-oncology team | These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses. |
| Psychologist | A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.. |
| Counsellor | A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness. |
| Community health services | These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services. |



Treatment types

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Watch and wait

Sometimes your doctors may prefer to hold off treatment and closely monitor your lymphoma instead. This approach is called watch and wait. There may be little or no benefit to treatment if the lymphoma is very slow growing and not causing any symptoms. It may be the best option for you as you will still be closely monitored but you won't have any of the side-effects that treatment can cause. 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. See page 61 for healthy lifestyle tips.

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 (see page 12). 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. 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.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on the type and stage of your lymphoma and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy can be given as an infusion (drip), injection or tablet. For low-grade lymphoma you may be given chemotherapy in tablet form. Tablets may be taken at home or you may attend an oral therapy clinic. Infusions and injections are usually given in the day hospital.

If you have lymphoma cells in your brain or spinal fluid or your doctor thinks you may be at high risk, you will need extra treatments. You may be given chemotherapy injections into your spinal fluid. A specialist doctor will give you a series of lumbar punctures and chemotherapy will be given at the same time (see page 27). This is called intrathecal chemotherapy.

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. Your doctor or nurse will explain the different options to you.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat lymphoma. You may be given one drug or – more likely – a combination of chemotherapy drugs. Often you will take steroids with your chemotherapy medication.

Understanding your drug treatment

It's important that you understand the medicine you have been given. Don't be afraid to ask your doctor or specialist nurse for more information about any drugs you are taking, what they are for and any possible side-effects. They may be able to give you a printed sheet to take home with you.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given.

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

- **Fatigue:** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 54.
- **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.
- **Infection:** Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature (above 37.5°) or a low temperature below 35°C (95°F), having a cough, or pain passing urine.



Tips & Hints – infection



- Avoid crowds and close contact, such as hugging or kissing, with people who have colds or flu and other infections. This includes chickenpox, shingles or measles.
- Let your doctor know if you are in contact with these or any other infections.
- Wash your hands often during the day, especially before you eat and after going to the toilet.
- Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.
- If your temperature goes above 37.5°C (99.5°F) or below 35°C (95°F) or if you suddenly feel shivery or unwell, even if your temperature is normal, contact your doctor or the hospital immediately.

The haematology units will have a direct phone number to call for advice if your temperature is too high or too low.

- **Anaemia:** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.
- **Bleeding and bruising:** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.
- **Mouth and throat problems:** Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.
- **Hair loss (alopecia):** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out

depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.

- **Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).
- **Skin and nail changes:** Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.
- **Peripheral neuropathy:** Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.
- **Changes in kidney function:** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.

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

»»» 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.

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



Steroid therapy

Your doctor may prescribe a short course of steroids with your chemotherapy. Steroids can be used:

- As part of your treatment to help destroy cancer cells and make chemotherapy more effective
- To help reduce an allergic reaction to certain drugs (particularly immunotherapy)
- To improve your appetite if you are feeling sick

Side-effects of steroid therapy

Short-term side-effects include:

- Increased appetite
- Stomach upset
- Feeling more energetic
- Mood changes / disturbance
- Difficulty in getting to sleep

It is better to take steroids as early in the day as possible, usually with or just after breakfast. Take them no later than 4 in the afternoon if getting to sleep is a problem for you.

When you stop taking steroids you may feel down or even angry. Talk to your doctor or nurse if this happens to 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 be more likely to get infections. 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 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 can be used as part of your treatment to help destroy cancer cells and make chemotherapy more effective

👉 I did feel tired at times but I felt my body was able to take the chemotherapy. 🍏

Biological therapies

Biological therapies work with your body. They can help your body to target and destroy cancer or stop it spreading.

There are different types of biological therapies. For example:

- **Immunotherapy** helps your body's immune system to fight cancer.
- **Targeted therapies** have specific effects on cancer cells or immune system cells to stop cancer growing or spreading.

Some treatments fit into more than one of these groups, so an immunotherapy drug can also be called a targeted therapy because of the way it works. These drugs are often used along with or after another type of treatment, such as chemotherapy.

»»» Doctors can now test tissue taken from your tumour to see if your cancer will respond to a particular biological therapy. This is called mutation testing.

Biological therapies for lymphoma

Monoclonal antibodies are targeted, immunotherapy drugs that can be used to treat lymphoma. They can be given as part of the first treatment or if the disease relapses, for example rituximab. Other targeted drugs used for lymphoma include proteasome inhibitors, Histone deacetylase (HDAC) inhibitors, Bruton's tyrosine kinase (BTK) inhibitors and PI3K inhibitors.

New biological therapies

New biological therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a biological therapy as part of a clinical trial (see page 51). Ask your doctor if there are any biological therapies available to treat your cancer or if there are any trials that are suitable for you.

How are the drugs given?

Biological therapies are often given as a drip (infusion) into a vein or as tablets, but you may also have an injection in your skin, depending on the drug.

What are the side-effects?

Biological therapies only target the cancer cells and leave normal cells alone. This means you usually get fewer side-effects than with chemotherapy. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects.

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include flu-like symptoms (fever, chills, aching) and low blood pressure. 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 or any other new symptoms. You may be given a medication before treatment to make side-effects less likely.



To sum up

- Biological therapies help your body's immune system to control or destroy cancer cells or target cells to stop cancer growing or spreading.
- Side-effects are usually mild and include flu-like symptoms (fever, chills, aching) and low blood pressure.

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. The X-rays are only aimed at the lymphoma.

Radiotherapy 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 radiotherapy?

Radiotherapy is given directly to the site of the lymphoma and nearby lymph nodes, so any side-effects 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. The most common side-effects 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 our Cancer Nurseline 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



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.

Email: cancernurseline@irishcancer.ie

Stem cell transplants

How do transplants work?

A transplant works by destroying all the blood cells in your bone marrow with high-dose chemotherapy (and sometimes radiotherapy to the whole body as well). The blood cells destroyed by chemotherapy are replaced with healthy stem cells, given to you through a drip. Stem cells are blood cells at their earliest stage of development that will grow into new healthy blood cells.

Stem cells are usually taken from a donor's blood – usually a brother or a sister whose tissue type is a match to yours – but they may also be taken from their bone marrow. This is called an allogeneic transplant.

You can also have a transplant using your own cells, but this is less common. This type of transplant is called an autologous transplant.

Your doctor may consider you for a stem cell transplant if:

- 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.

Stem cell transplants may not be suitable for everyone. It depends on a number of things such as:

- Your age and general health
- Whether a suitable donor is available
- The type of lymphoma you have and the risk of it coming back
- If there are other more appropriate treatments available

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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a booklet: *Understanding Allogeneic Stem Cell Transplants* or *Understanding Autologous Stem Cell Transplants*.

You can also download them from 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.
- The treatment destroys all the blood cells in your bone marrow and provides you with stem cells to make healthy new blood cells.

Clinical trials

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

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

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching lymphoma. Your doctor can advise you about this.

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. If you want more information, you can read our factsheet *Cancer and Clinical Trials*.

It's available to read or download on our website,

www.cancer.ie You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at www.cancertrials.ie





Managing side-effects and symptoms

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How can I cope with fatigue?

Fatigue means feeling extremely tired. With fatigue, you may still feel tired even after resting. It can affect your day-to-day life. Fatigue is a very common symptom of cancer, but there are things that can help.

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

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

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

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



Tips & Hints – fatigue

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



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



Will treatment affect my sex life?

Sex and sexuality

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

There is no right or wrong way to feel about your sexuality and sex life and there is no set time for you to be ready to have sex again. Everyone is different.

Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. You can also enjoy other forms of closeness, such as touching and holding each other.

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

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

Contraception

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

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

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

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so there's no need to feel embarrassed. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. For men, the lymphoma itself can sometimes cause infertility. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

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

Cancer and complementary therapies

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

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

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

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

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

Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects.

More information

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





After treatment

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What follow-up will I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. At first you will see your consultant every 3 months but these check-ups will become less frequent over time.

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

It's important to attend your follow-up appointments as they will allow your doctor to check for signs of relapse 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 and have a symptom or problem that is worrying you, tell your doctor or nurse. Make an appointment to see him or her as soon as possible.

What if the cancer comes back?

Relapsed NHL 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.

Email: cancernurseline@irishcancer.ie

Living with low-grade NHL

Take care of your health

- You may still feel tired and lacking in energy for months after treatment. 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.
- Avoid infections. See page 43 for advice.
- Contact your doctor straight away if you have signs of infection, symptoms of lymphoma (see page 12), or any other health problems. Some people may experience pneumonia or other lung problems.
- If you develop any problems such as bowel problems, you should contact your doctor as soon as possible.
- Have regular dental and eye check-ups. Take good care of your mouth, teeth or dentures, as they can be a source of infection. Check with your haematologist before having dental treatment.
- Always tell doctors, dentists and other healthcare professionals that you have lymphoma. If your white cell count or platelets are low it can increase your risk of bleeding or infection, so some procedures or treatments may not be suitable.
- Having lymphoma puts you at a higher risk of developing other cancers. For example: bladder, lung, stomach and myeloid leukaemias, so be aware of any unusual changes in your body. If you notice anything go to your doctor and get it checked out.

Living a healthier lifestyle

Many people want to make positive changes to their lives after a diagnosis of lymphoma. A healthy lifestyle can help you to:

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

A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun
- Avoid alcohol – drink no more than one standard drink a day

Vaccines

You will probably be advised to get the flu vaccine every year and the pneumonia vaccine every 5 years. Lymphoma can weaken your immune system, so some vaccinations may not be suitable for you. For example, live vaccines. Check with your doctor about which vaccinations are recommended for you and make sure you get them.

Be involved in your healthcare

Learn about your illness and treatment options so that you can make an informed decision and know what to expect.

- Don't be afraid to ask questions. There are some questions you might like to ask on page 86.
- Keep all your appointments and take all your medications – ask your doctor or pharmacist if you have any questions about your medication.
- Let your doctor know straight away if you have any new symptoms or any symptoms that are bothering you.
- Don't feel like you have to wait until your next appointment if you have any health problems or worries.

Mind your mental health

Living with cancer and coping with any symptoms can be stressful. The following may help:

- Try to avoid additional stress wherever possible. Spend time with your friends and family. Make time to relax and do the things that you enjoy.
- Use stress-management techniques if you do feel stressed. Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 57 for more about complementary therapies.

- Give yourself time to adjust. Once you feel better you may have financial or practical matters to sort out. Try not to let these overwhelm you and take one task at a time.
- Counselling or a short course of medication may also help you, if you are finding it hard to cope. See page 66 for more information.
- Having the support of loved ones, healthcare professionals and other people going through the same thing can also make a big difference. See page 67 for more about getting support.

Work and activities

It can take at least a year for you to get over the effects of treatment. If you feel well, there is no reason why you cannot return to work or study and carry on with your usual activities like socialising, sports and hobbies. If you stopped working during treatment, you might want to take your return to work slowly, by working part-time or reduced hours. If you are planning a holiday, ask your doctor about any special precautions you need to take or vaccinations you should have before you go. It's best to have travel insurance too. We have information on travel insurance on our website, www.cancer.ie You can also contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more details.

- 6 Physical and emotional after-effects can happen years after treatment. Don't be afraid to seek medical help or go back to counselling or support services if you need them. 9



Coping and emotions

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How can I cope with my feelings?

There are many reactions when you hear you have cancer. Reactions differ from person to person. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

Common reactions include:

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

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



Anxiety and depression

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

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

Counselling

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

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie



Ways to get emotional support

Find out about cancer support services in your area: There are lots of local cancer support services that provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 82 for more about cancer support services.

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

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

Get one-to-one support: The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support.

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

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

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

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

Learning to cope

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer, but in time most people are able to adjust.



How can I help myself?

Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

Use your support network: Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don't be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

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

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

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

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

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

Try complementary therapies: Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help you to cope with the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 57 for more information on complementary therapies.

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

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

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

Try to cope day by day: Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Express yourself: Keeping a diary or journal can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

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

Positive emotions



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

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Who Can Ever Understand?* can help to you find ways to talk about your cancer and to ask for the help and support you need.

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre.

How can my family and friends help?

Don't feel you have to manage alone. Your family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friend best.

Further information and support

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

- 👉 **Family and friends just want to help ...**
 It's important to talk when you're feeling low and tired but it's also important to let family and friends know when you're feeling good. To be able to get out and do something normal – and your friends and family aren't worrying about you – is great for everyone. 🍷



Advice for carers

Caring for someone with cancer

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Caring for yourself

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Caring for someone with cancer

Caring for someone who has had a diagnosis of low-grade NHL can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

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

Learn about cancer: Learn more about low-grade NHL, its treatment, any possible side-effects and the emotional effects it can cause. There may also be workshops or information sessions in the hospital that you can go to. This will help you to understand how you can support your partner, relative or friend.

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

Healthcare: Support your loved one by making sure they take their medication every day and attend all appointments. Ask them about how they are feeling and encourage them to talk to their healthcare team if they have any symptoms or worries.

Emergencies: Find out who to call if you are particularly worried or in an emergency situation and make sure you know the phone number to call.

- 🍷 Don't be afraid to talk to your loved one about their illness. They will be reassured that you are trying to understand what they are going through. 🍷

Caring for yourself

It can be difficult to find time for yourself if you're busy caring for someone with cancer, but it's important to look after yourself, too, and get help if you need it.

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

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

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

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

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

How to talk to someone with cancer



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

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

Support for you



Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information. You could also ask for a copy of our booklet, *Caring for Someone with Cancer*, or download it from our website www.cancer.ie

Support resources

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Coping with the financial impact of cancer

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

If you do not have a medical card you will have to pay some of the cost of your care and medication. If you are over 70 years old, you can get a free GP visit card.

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

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness

Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

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

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 81 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

For more information go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

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

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



Irish Cancer Society services

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

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

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

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

- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area**. We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 82 for more information.

- **Patient travel and financial support services**. We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

- **Irish Cancer Society Night Nursing**. We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

- Our **publications and website information**. We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.



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

Local cancer support services

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

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

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

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

“ I find the centre so supporting and comforting... I was so afraid going in at the beginning but now it's my second home.”

Helpful books

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

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue



Coping and emotions

Understanding the Emotional Effects of Cancer

Lost for Words: How to Talk to Someone with Cancer

Who Can Ever Understand? Talking About Your Cancer

Caring for someone with cancer

Talking to Children about Cancer: A Guide for Parents

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



What does that word mean?

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

| | |
|-----------------------------|---|
| Lymph | A clear watery fluid that carries material through your lymphatic system. |
| Lymphatic vessels | Tubes carrying lymph that connect to lymph nodes. |
| Lymph node | A small oval or round gland found along lymphatic vessels that removes bacteria and foreign particles from your body. |
| Medical oncologist | A doctor who treats cancer with chemotherapy and other drugs. |
| Monoclonal antibody | Treatment using a manmade antibody to fight disease. Also called biological therapy or antibody therapy. |
| Nausea | Feeling sick or wanting to be sick. |
| Neutropenia | When there are less white blood cells called neutrophils in your body. As a result, you develop infections easily. |
| Oncology | The study of cancer. |
| Partial remission | After treatment, the lymphoma has been reduced by at least a half but not fully. |
| Radiation oncologist | A doctor who specialises in treating cancer patients using radiotherapy. |
| Radiotherapy | The treatment of cancer using high-energy X-rays. |
| Refractory disease | When the lymphoma does not respond to the first course of treatment or comes back very quickly afterwards. |
| Relapse | When the lymphoma becomes active again after treatment. |
| Remission | When the lymphoma is no longer active and is under control. See also complete remission and partial remission. |
| Staging | A series of tests that measure the size and extent of cancer. |
| Thrombocytopenia | 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

6

Answer

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

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

Did you like this booklet?

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

More information and support

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

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Email: cancernurseline@irishcancer.ie

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