

Understanding

High-Grade Non-Hodgkin Lymphoma

Caring for people with cancer

Understanding

High-Grade Non-Hodgkin Lymphoma

This booklet has been written to help you understand more about high-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 this lymphoma, its diagnosis and treatment and how it may affect you.

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



This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We especially thank the people who generously shared their personal experiences of cancer throughout this booklet. We also acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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- *Cancer in Ireland 2013*. National Cancer Registry Ireland, 2013.
- *Guidelines on Diagnosis and Treatment of Malignant Lymphomas*. Lymphoma Forum of Ireland, 2nd edn, 2010.
- *Clinical Practice Guidelines in Oncology: Non-Hodgkin's Lymphomas*. National Comprehensive Cancer Network, 2013.
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. R Govindan (ed), 9th edn. Lippincott Williams and Wilkins, 2011.
- *Cancer Nursing: Principles and Practice*. CH Yarbrow, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.

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Quick facts

Can my cancer be treated?

Page 33 ▶▶

Yes. There are a number of treatments for high-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 Remission means the lymphoma is no longer active and is under control. High-grade lymphomas often respond well to treatment, although the treatment can be intense. Treatment usually needs to start straight away.

Will I be OK?

Page 31 ▶▶

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.

Many people with high-grade NHL are cured or stay in remission for a long time, with a good quality of life.

What treatment will I have?

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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 55 ▶▶

Many people have no problems after their first treatment, but sometimes the lymphoma comes back and causes symptoms like fevers and sweating, loss of appetite, weight loss, extreme tiredness and skin irritations. You are likely to get temporary side-effects from intensive chemotherapy, such as a weaker immune system, fatigue and feeling or getting sick.

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

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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 82 for more about our services.

Introduction

This booklet has been written to help you learn more about the high-grade form of non-Hodgkin lymphoma (NHL) in adults.

We hope this booklet answers some of your questions. We encourage you to discuss them with your doctors and nurses.

Talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

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



Reading this booklet

Remember you do not need to know everything about high-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 speak to a cancer nurse by calling 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 82 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.



Cancer Nurseline Freephone 1800 200 700

My cancer story

🍷 I remember not feeling too well over a period of time and after a few tests I was called into the hospital where I was diagnosed with Non-Hodgkin Lymphoma. I was 19. It's a strange feeling being told that you have cancer.

I had Rituximab/CHOP treatment. It went on for 6 months, once every 3 weeks. I did feel tired at times but I felt the steroids caused the most issues as I put on a lot of weight and my sleep pattern altered at times. I have always been a positive person and I truly believe this helped me through my chemotherapy.

I also had fears. My biggest fear was not to be able to have children. After being told there was a high chance I would not be able to have children post chemotherapy I decided to have my sperm frozen before I started my treatment. I'm extremely proud to say that I am a father of two beautiful children. They were both conceived naturally and are healthy.

My relationships with people close to me were extremely important to how I got through my treatment. I was single at the time but my friends were amazing. I socialised when I could to maintain a positive mindset. It's true what they say that it's the little things that count.

My health now is great, I'm fully recovered. It took a bit of time to get physically fit again (apart from a bit of dad bod these days) but it's possible, just listen to your body.

Everyone has their own journey and has to do it their way.

What helped me was:

- Not letting my fears take over – trying to do something to counter them
- Doing things I enjoyed when I could
- Being honest in my relationships 🍷

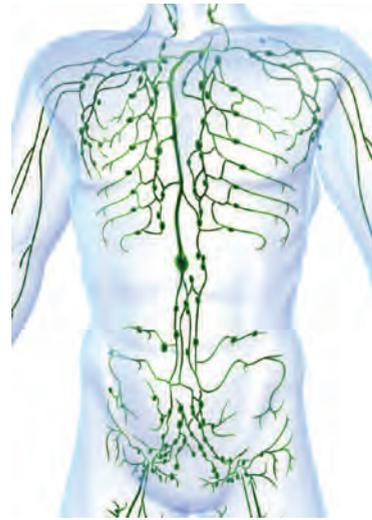


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What is the lymphatic system?

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.

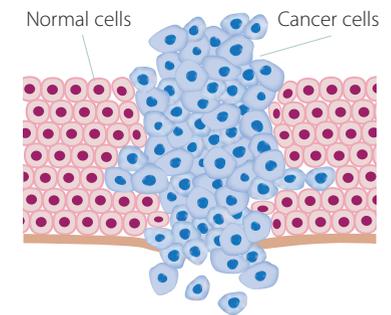


Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves; this is the most common place for this to happen but lymphoma can start in almost any part of the body, including the stomach, small bowel, skin, tonsils, thyroid or testicles. Lymphoma cells can also be found in the 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.



Lymphomas can be described, or 'classified' in different ways. The classification of your lymphoma 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

What are the types of lymphoma?

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 are rare and mainly affect 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.

High-grade non-Hodgkin lymphoma

High-grade non-Hodgkin lymphoma refers to a range of different fast-growing lymphomas. They usually cause symptoms and will need treatment straight away. It is possible to cure most of them.

Subtypes

There are many subtypes of high-grade non-Hodgkin lymphoma. See page 16 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. You can also contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse in confidence.

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.

Email: cancernurseline@irishcancer.ie

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 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 virus, and human T-cell leukaemia virus 1 (HTLV 1). Bacterial infections like *Helicobacter pylori* can also be responsible for certain types of lymphoma.
- **Age:** High-grade lymphoma can occur at any age but it is more common in older people.
- **Gender:** It's more common for men to get high-grade lymphoma – the reason for this is unknown.
- **Family:** High-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. Other symptoms, known as B symptoms, may include the following

- Night sweats – these can be drenching
- High temperatures or fevers
- Loss of appetite
- Unexplained weight loss
- Feeling tiredness 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. Your doctor will investigate them further, if necessary.



To sum up

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

Subtypes of high-grade non-Hodgkin lymphoma

Diffuse large B-cell lymphoma (DLBCL)	16
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What are the different subtypes?

There are many subtypes of high-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 14), 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.

Diffuse large B-cell lymphoma (DLBCL)

Why is it called diffuse large B-cell lymphoma? This lymphoma affects the B-cells. Here the cancer cells are much larger than in other lymphomas. Diffuse means the cancer cells are spread throughout the lymph nodes. This kind of lymphoma can occur in just the lymph nodes or outside your lymphatic system. For example, in your digestive tract, skin, brain, testicles, breast, lung, liver or bone. The cancer cells grow rapidly.

How common is it? It is the most common type of lymphoma. It occurs in about one-third of all non-Hodgkin lymphomas, and in 4 out of 5 high-grade types. It can occur between adolescence and old age but usually over the age of 60. Sometimes a low-grade lymphoma can change or transform into a DLBCL.

What other symptoms might I have? Depending on the part of your body affected by DLBCL, you might have other symptoms. For example, abdominal pain and diarrhoea if your bowel is involved.

How is it treated? Different types of chemotherapy drugs can be given together or combined with a monoclonal antibody. For example, R-CHOP. This stands for rituximab, cyclophosphamide, doxorubicin, vincristine and the steroid prednisolone.

Mantle cell lymphoma

Why is it called mantle cell lymphoma? In this lymphoma the cancer cells are found in the mantle zone of the lymph node. This is the outer ring of the cell. Even though the lymphoma is classed as a low-grade lymphoma, it often acts like a faster-growing one and is treated as such. Usually the cancer cells are found in one or more lymph nodes and can affect organs such as your bone marrow, bowel, stomach, liver, spleen or tonsils.

How common is it? This B-cell lymphoma is rare and occurs in about 5 in 100 cases of non-Hodgkin lymphoma. It usually affects men aged over 60.

What other symptoms might I have? An enlarged spleen. If the lymphoma affects other organs, you might have other symptoms. For example, abdominal pain, nausea and diarrhoea if your stomach or bowel is involved. Your doctors might do a gastroscopy or colonoscopy to take a closer look at your stomach or large bowel.

How is it treated? It is often diagnosed at a later stage, that is, when found in your stomach, bowel or bone marrow. This usually means stage 3 or 4. In general it is hard to treat and cure this type of lymphoma. Your doctor will consider your age, stage of disease and general health when deciding on treatment. Usually this lymphoma is treated with chemotherapy using a combination of drugs. Treatment options will depend on your age and general health.

You may also be suitable for a stem cell transplant (see page 51).

Burkitt lymphoma

Why is it called Burkitt lymphoma? This lymphoma is named after the doctor, Denis Parsons Burkitt, who first described it in Africa. It is a form of NHL in which cancer starts in the immune cells called B cells. Burkitt lymphoma is linked to the Epstein-Barr virus. Burkitt lymphoma usually affects your body in many places. For example, your chest, tonsils, back of nose and throat. It can be found in other organs such as your chest, liver and bone marrow. It can occasionally affect the brain.

Most people are very unwell at diagnosis and need urgent treatment, but it is usually highly curable. There are 3 types: endemic – seen mostly in African children, sporadic – occurring worldwide, usually originating in the bowel, or immunodeficiency associated. Those with HIV or AIDS also have a higher risk of developing this lymphoma.

How common is it? It is a rare lymphoma. It occurs in about 2 in 100 lymphomas, usually in young adults and children. It is more common in men than women.

What other symptoms might I have? Depending on the part of your body affected by Burkitt lymphoma, you might have other symptoms. For example, abdominal pain, nausea, vomiting and diarrhoea if your bowel is involved. If lymph nodes in your chest or throat are enlarged, you might have a sore throat or find it hard to breathe or swallow.

How is it treated? It is treated using intensive chemotherapy, if the person's system is strong enough. Intensive chemotherapy means the drugs are given in high doses over a number of months. This chemotherapy is given by intravenous form and also by the intrathecal route, (a small dose of chemotherapy given via a lumbar puncture needle into the back). Other treatments such as targeted therapies (ALK inhibitor tablets), steroids, radiotherapy and stem cell transplants may also be used.

Peripheral T-cell lymphomas (PTCLs)

Why are they called peripheral T-cell lymphomas? T-cell lymphomas affect immune cells called T- cells. They develop in lymphoid tissues outside of the bone marrow such as the lymph nodes, spleen, gastrointestinal tract, and skin. There are different subtypes of PTCLs, which all have their own features and treatments. The three most common are:

- Peripheral T-cell lymphoma not otherwise specified (PTCL-NOS)
- Anaplastic large cell lymphoma (ALCL)
- Angioimmunoblastic T-cell lymphoma (AITL)

How common are they? They are very rare. Together they account for about 10 in 100 of all non-Hodgkin lymphomas. They are all considered

separate diseases and treated in that way. See below for more about anaplastic large-cell lymphoma and page 20 for angioimmunoblastic T-cell lymphoma.

Peripheral T-cell lymphoma not otherwise specified (PTCL-NOS)

What does the name mean? It refers to a group of diseases that do not fit into any of the other subtypes of PTCL.

How common is it? It is the most common PTCL, affecting about a quarter of those diagnosed. It is also the most common T-cell lymphoma. It usually affects adults in their 50s and 60s.

What other symptoms might I have? Body organs other than lymph nodes can also be affected. For example, your liver, spleen, bone marrow, stomach, bowel and skin. This can give rise to other symptoms.

How is it treated? Most patients have stage 3 or 4 disease at diagnosis and need treatment straightaway. The main treatment is chemotherapy, often using a combination of drugs. This lymphoma can be hard to treat and has a high risk of relapse. Younger patients might benefit from high-dose chemotherapy and a stem cell transplant.

Anaplastic large cell lymphoma (ALCL)

Why is it called anaplastic large cell lymphoma? This lymphoma affects T-cells. ALCL either affects the whole body (systemic) or the skin (cutaneous). Patients with systemic ALCL are divided into two groups, depending on whether or not the surface of their cells have an abnormal form of a protein called ALK (anaplastic large-cell kinase) Your doctors might say the lymphoma is ALK positive or negative.

How common is it? This type of lymphoma is rare, accounting for about one percent of all NHLs. Being ALK-positive is more common in young adults and children, particularly men and boys. ALK-negative ALCL occurs more often in older adults, aged 60 onwards, and slightly more females are affected.

What other symptoms might I have? Anaplastic large cell lymphoma can affect organs in your body other than your lymph nodes. For example, your skin, bone, soft tissues, lung, liver and bone marrow.

Depending on the location, you might get other symptoms. For example, you might have red, itchy skin patches if your skin is affected.

When is it treated? Most patients have stage 3 or 4 disease when diagnosed and need treatment straightaway. But if only your skin is affected, treatment may be delayed. It often depends on the number of skin areas affected.

How is it treated? Chemotherapy is the main treatment. A combination of drugs is usually given, which may include ALK inhibitor tablets. Chemotherapy works well for ALK positive disease but less so for ALK negative. In this case, you may need high-dose chemotherapy and a stem cell transplant. If your lymph nodes are significantly enlarged, you may benefit from radiotherapy, especially in the early stages. If you have cutaneous ALCL, radiotherapy to the skin patches can often work well.

How may it be treated after relapse? You are more likely to relapse if you have ALK-negative disease. You may be given more chemotherapy or a monoclonal antibody along with a stem cell transplant after remission.

Also, you have a higher risk of relapse if you have cutaneous ALCL and many areas of skin are affected. In this case, the relapse may be treated with mild chemotherapy or radiotherapy.

Angioimmunoblastic T-cell lymphoma

Why is it called angioimmunoblastic lymphoma? In this T-cell lymphoma, there are abnormal blood vessels (angio) or lymph vessels. They make an abnormal protein which can affect your immune system. It is linked to a previous infection with the Epstein–Barr virus.

How common is it? It is a rare lymphoma found in about 2 in 100 of all non-Hodgkin lymphomas. It occurs in older people, usually aged 50 and over, and affects men and women equally.

What other symptoms might I have?

- Enlarged liver and spleen
- Fluid retention
- Inflamed joints

Immune disorders can occur with this lymphoma. For example, autoimmune haemolytic anaemia (AIHA) and immune thrombocytopenia (ITP). In these disorders your immune system does not recognise your own cells and tissues and tries to destroy them. For example, your red blood cells or platelets. The lymphoma can affect body organs such as your liver, spleen, skin and bone marrow.

How is it treated? It can be quite difficult to treat. Most patients have stage 3 or 4 disease at diagnosis. The first treatment is usually chemotherapy, using a combination of drugs. Sometimes it responds to milder therapies such as steroids and other medications. These will also improve any symptoms you have. Some patients may be suitable for an autologous stem cell transplant.

Lymphoblastic lymphoma

Other names: Precursor T-lymphoblastic lymphoma.

Why is it called lymphoblastic lymphoma? This lymphoma affects the immature cells called lymphoblasts. These cells, when healthy, grow into the white blood cells called lymphocytes. Normally the lymphoma develops from T-cells but sometimes from B-cells. It looks very like acute lymphoblastic leukaemia.

How common is it? It is very rare in adults. It usually affects young adults (under 35) and children, mostly teenage boys.

What other symptoms might I have?

- Difficulty breathing
- Fluid in lungs
- Swelling in chest (mediastinum)
- Enlarged liver or spleen

The lymphoma may affect other areas of your body, such as your liver, spleen, bone marrow, skin, testicles and brain. These can cause specific symptoms.

How is it treated? It is treated like an acute lymphoblastic leukaemia. This involves chemotherapy and other drugs given over a long period of time. Radiotherapy is sometimes given to the brain and spine if the lymphoma is advanced. If needed, chemotherapy can be given directly into the fluid that surrounds your brain and spinal cord.

You might also receive a stem cell transplant. For a free copy of the booklet, *Understanding Acute Leukaemia*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download a copy from www.cancer.ie

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 41–53.



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 the 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?: Talking about your Cancer*. 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 / CT with contrast (dye): This is a special type of X-ray that builds up a detailed picture of the tissues inside your body. During the scan you lie still 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 an injection or special drink to help show up certain parts of your body on the scan. Do let the radiographer know if you have asthma or are allergic to iodine before you take the drink or injection. The injection may make you feel hot all over for a few minutes.



Preparations for a CT scan can vary. Your doctor or nurse will tell you what to do. This test is usually done as an outpatient in the X-ray department, so you should not need to stay in hospital

Ultrasound scan: This is a scan that uses sound waves to build up a picture of the tissues inside your liver and upper abdomen. It is done in the X-ray department of the hospital. The scan is painless and only takes a few minutes. Some gel is first put on the area to be scanned and a small device moved around it.

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 (glucose) to measure activity in your cells.

A CT scan is usually done together with the PET scan. Once you are relaxed, the sugar is injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are located.

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

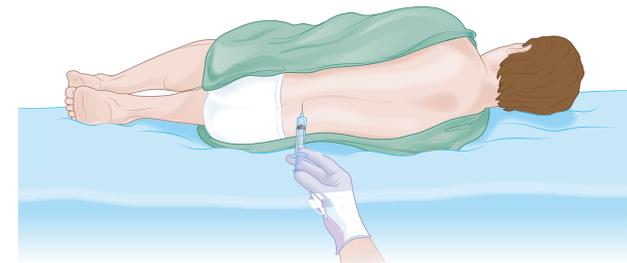
Bone marrow biopsy: You might have a bone marrow aspiration and biopsy as part of the staging. Aspiration means removing some bone marrow fluid, whereas biopsy means removing a small piece of bone with marrow cells in it. Both samples are examined under a microscope to see if there are any lymphoma cells 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, 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 a couch on your 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. It is possible to give chemotherapy in 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 type of scan uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic during the MRI scan. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. An MRI can also be noisy, but you will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

Waiting for test results

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



Staging high-grade non-Hodgkin lymphoma

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

How is lymphoma staged?

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.

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

What are the stages of non-Hodgkin lymphoma?

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. It is possible to treat and cure advanced stage lymphoma.

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).



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).
- It is possible to treat and cure advanced stage lymphoma.



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 high-grade non-Hodgkin lymphoma

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How is high-grade non-Hodgkin lymphoma treated?

High-grade lymphomas are fast growing and usually need to be treated fairly quickly. Your type of treatment will depend on where the disease is, your subtype and stage. Your doctor will also take into account your age and general health.

Aims of treatment

High-grade lymphomas usually respond very well to treatment. They can be cured in many cases. The aim of treatment is to get a long-term remission.

The longer you are in remission, the less likely the lymphoma will come back. It is more usual to say your disease is in remission rather than cured, as high-grade lymphomas can come back again after treatment. This is called a relapse. If a relapse happens, it can be treated again.

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.

Treatment of limited disease (stage 1A)

Stage 1A is where only one group of lymph nodes is affected by the lymphoma and you have no B symptoms (see page 14). In this case, you might receive one or more of the following treatments:

- **Radiotherapy:** You might be given radiotherapy to the affected nodes. For more information, see page 50.

- **Anti-cancer drug therapies:** Your doctor might decide to give you a short course of chemotherapy and a biological therapy called a monoclonal antibody as well as radiotherapy. This is done to increase the chances of curing the disease. See page 42 for more on chemotherapy and page 48 for biological therapies.

It is more usual for patients to be diagnosed at a later stage.

Treatment of all other stages

Most high-grade lymphomas are treated like they were at an advanced stage.

- **Anti-cancer drug therapies:** Intensive chemotherapy is often given to shrink high-grade lymphomas very quickly. You might get three or four different drugs with or without a monoclonal antibody. Steroids are often given as well to kill the lymphoma cells and to improve how the chemotherapy works. See pages 42 and 46 for more information.
- **Intrathecal chemotherapy:** Sometimes lymphomas can affect your brain and spinal cord. Chemotherapy given into a vein generally cannot reach these areas. So if the lymphoma is found in your brain or spinal fluid or your doctor thinks you are at high risk of it developing, you will get chemotherapy into the spinal fluid. This is called intrathecal chemotherapy. This is given during a lumbar puncture. For more information, see page 27.

Relapse

If a relapse happens or there is a high risk of relapse, other treatments may be used. These can include high-dose chemotherapy with a stem cell transplant. A relapse can happen several months or years after treatment.

Refractory disease

If the lymphoma did not respond to the first course of treatment or came back very quickly afterwards, this is called refractory disease. This is harder to treat than a relapse. Chemotherapy or a monoclonal antibody may be used to treat it.

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.

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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Chemotherapy

Chemotherapy is a treatment using drugs that can cure or control lymphoma.

How often will I have chemotherapy?

Chemotherapy is often given in cycles, with a rest period between treatments to allow your body time to recover. 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 for fast-growing lymphomas is usually given directly into a vein as an injection and/or through an intravenous infusion (drip). You may have a combination of drugs. You may have to spend some time in hospital, but usually your treatment will be given in the chemotherapy day care unit.

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

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

Portacath: There are other ways to have easy access to your veins for taking blood samples and giving treatment. Sometimes the tube

is attached to a port called a portacath. This is a small round plastic or metal disc placed under your skin. The port can be used for as long as is needed. Talk to your doctor or nurse, who will explain the different options to you.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat high-grade non-Hodgkin lymphoma. Your doctor or nurse will discuss your treatment with you. You may be given one drug or more likely a combination of chemotherapy drugs. Often you will take steroids with your chemotherapy medication.

If you have B-cell lymphoma, you may have chemotherapy drugs in combination with monoclonal antibodies (see page 48).

Tumour lysis syndrome (TLS)

Tumour lysis syndrome is a dangerous imbalance of chemicals in the blood that can damage organs like the heart and kidneys. When cancer cells are destroyed they release chemicals into the blood. TLS can happen when chemotherapy drugs break down a lot of cancer cells very quickly and your body may not be able to cope with amount of chemicals released. TLS is more common with high-grade lymphomas and acute leukaemias. You will probably be given a medication to protect against TLS.

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.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Cancer Nurseline on 1800 200 700.

What happens if my lymphoma comes back?

Many people have no further problems after their first treatment but for some the lymphoma does come back. This is called a relapse. A relapse is more likely within the first 2 years after treatment. Even if the lymphoma relapses it may be possible for you to have further treatment. Usually a different combination of chemotherapy drugs can be given. A stem cell transplant may be possible for some people.

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 include:

- **Fatigue:** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 56.
- **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.
- **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. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.
- **Infection:** Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection. These signs include feeling shivery and unwell, having a high temperature (above 37.5°C (99.5°F)) 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.
 - Ask your doctor about getting vaccinations to protect you from infection before and after treatment.
 - Ask your doctor about seeing a dentist before treatment starts.
-
- **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.
 - **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.

- **Heart muscle damage:** Drugs called anthracyclines (e.g. doxorubicin) can damage your heart muscle. Ask your doctor about this side-effect and ways to look after your heart health. You should have a yearly blood pressure and cholesterol check after having this type of drug.

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.

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.

>>> **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.**

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

There are a number of side-effects to steroids. 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. Don't take them after 4 in the afternoon if your sleep is disturbed.

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. This can have an effect on your body. You will notice that you put on weight, especially on your face, waist and shoulders.

You may also have a lowered resistance to infection. Try to avoid close contact with people who have colds, flu or any kind of infection while you are taking steroids. Do remember that all these side-effects are temporary and will gradually disappear once you are no longer taking steroids.

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



To sum up

- Chemotherapy is a treatment using drugs to cure or control lymphoma.
- The drugs are usually given 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.

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 53). 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.

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

Radiotherapy

Radiotherapy is rarely used for high-grade lymphomas. It is a treatment where high-energy X-rays are aimed at a cancer to cure or shrink it.

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

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

For more information about the side-effects of radiotherapy, contact 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 is given directly to the lymphoma site and nearby lymph nodes.
- It only affects the lymphoma in the area being treated.

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 treatment 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.
- To extend your remission period after standard chemotherapy (for example, for younger patients with some types of mantle cell lymphoma).

- 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 are not suitable for everyone. It depends on things like your age and general health, if a donor is available, the type of lymphoma you have and your other treatment options.

For more information on stem cell transplants, call our 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.

“ After the high-dose chemotherapy, I felt bloated and nauseous and I had diarrhoea ... but with every day, I felt a little bit better. ”

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. You may still feel tired even after resting.

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

Fatigue is a very common symptom of cancer which can affect your day-to-day life, but there are things that can help. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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



Tips & Hints – fatigue

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



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

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.

Email: cancernurseline@irishcancer.ie

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



Cancer Nurseline Freephone 1800 200 700



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?

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

Email: cancernurseline@irishcancer.ie

Living with high-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 45 for advice.
Contact your doctor straight away if you have signs of infection, symptoms of lymphoma (see page 14), 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

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 88.
- 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 59 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 68 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 69 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 84 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 59 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. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.

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 high-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.

Get informed: Learn more about high-grade NHL, its treatment, any possible side-effects, and the emotional effects it can cause. Ask the specialist nurse at the hospital for advice or talk to one of our cancer nurses by calling 1800 200 700 or by visiting a Daffodil Centre. 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: 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. 🙏

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

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.

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



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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 83 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 84 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.
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 high 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



Notes



Notes



Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

- Share your cancer story
- Tell people about our services
- Describe what it'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.

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