

Understanding

Low-grade non-Hodgkin lymphoma

Caring for people with cancer

Understanding

Low-grade non-Hodgkin lymphoma

This booklet has information on:

- Treatment for low-grade non-Hodgkin lymphoma
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist nurse

Family doctor (GP)

Haematologist

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Main hospital number

Emergency department

Hospital records (medical) number (MRN)



Contents

About low-grade non-Hodgkin lymphoma	7
Subtypes of low-grade non-Hodgkin lymphoma	15
Diagnosis and tests	29
Treating low-grade non-Hodgkin lymphoma	41
Types of treatment	55
Managing side-effects and symptoms	75
After treatment	83
Coping and emotions	91
Advice for carers	99
Support resources	105
What does that word mean?	118
Questions to ask your doctor	120



Fast facts

Can my cancer be treated? Page 41

Yes. There are a number of treatments for low-grade non-Hodgkin lymphoma (NHL). Treatment aims to put the lymphoma into remission (a cancer-free period). Complete remission means there are no visible signs of the lymphoma after treatment. Partial remission means the lymphoma has been reduced by at least a half but is not completely gone. You may not need treatment straight away if your lymphoma isn't causing you any problems.

Will I be OK? Page 39

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

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

How might my cancer and treatment affect me? Page 13

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

Tell your doctor if you have any symptoms or side-effects.

What kind of treatment might I have? Page 55

Watch and wait: Monitoring your cancer with no active treatment

Chemotherapy: Drugs to control the lymphoma

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

Targeted therapies / immunotherapy: 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**

Clinical trials Page 73

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

Support Line Freephone 1800 200 700

We're here for you

Page 110

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 Support Line on 1800 200 700
- Drop into a Daffodil Centre.
Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 110 for more about our services.

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses - call our Support Line or visit a Daffodil Centre.

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care - they know your medical history and your individual circumstances.

About lymphoma

What is the lymphatic system?	9
What is lymphoma?	10
What are the types of lymphoma?	11
Low-grade non-Hodgkin lymphoma	12
What are the signs and symptoms of lymphoma?	13
How common is lymphoma?	13
What caused my cancer?	13

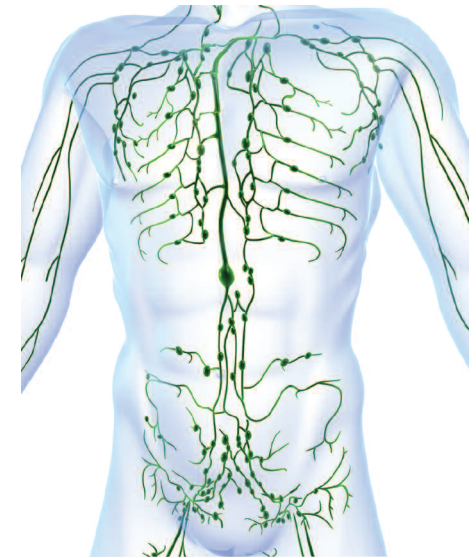
What is the lymphatic system?

The lymphatic system is part of the body's immune system, which helps to protect us from infection and disease. The lymphatic system is made up of thin tubes, known as lymph vessels, and lymph nodes (or lymph glands).

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.

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.

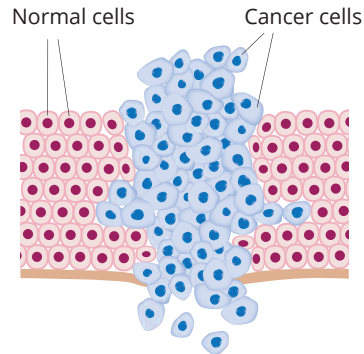
Your spleen is also an important part of the lymphatic system. The spleen helps to filter out damaged cells from the blood stream and also to fight infection.



What is lymphoma?

Lymphoma is cancer of the lymphatic system. The cancer develops from white blood cells in the lymphatic system. Lymphoma is a type of blood cancer.

In lymphoma, the cells that are affected are white blood cells called lymphocytes. They can be B or T lymphocytes. These lymphocytes become abnormal and cancerous. The lymphocytes grow out of control and do not die off as a normal cell would. They collect in the lymphatic system, particularly in your lymph nodes. This causes the lymph nodes to become swollen.



Lymphoma most commonly affects the lymph nodes, but it can start in almost any part of the body, including the spleen, stomach, small bowel, skin, tonsils, thyroid or testicles. Lymphoma cells can also be found in the bone marrow. Bone marrow is the spongy material in the middle of bones. It makes all the different types of white blood cells, including lymphocytes, red blood cells, which carry oxygen from your lungs to other cells in your body and platelets, which help blood to clot and prevent bleeding and bruising. Lymphoma that grows outside the lymph nodes is called extra-nodal lymphoma. If you have extra-nodal lymphoma, your specialist doctor and nurse can explain this in more detail and what this may mean for your treatment.

Email: supportline@irishcancer.ie

What are the types of lymphoma?

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

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.

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 generally need little or no treatment for many years. These are also called indolent lymphomas.

High-grade lymphomas: Are fast growing and need treatment quickly. They may cause you to become seriously unwell if not treated quickly. They can be either B-cell lymphomas or T-cell lymphomas.

Low-grade non-Hodgkin lymphoma

Low-grade non-Hodgkin lymphoma (NHL) refers to a range of different slow-growing lymphomas. They may need little or no treatment for months or even years. The speed of their growth might change over time and there may be times when the disease is more active. After treatment, low-grade lymphomas usually get smaller or even disappear altogether. Some types of low-grade lymphoma can be completely controlled with treatment. If they do return, they can be treated again.



Transformation

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

Subtypes

There are many subtypes of low-grade non-Hodgkin lymphoma. See page 15 for more details about the most common ones.

What are the signs and symptoms of lymphoma?

People with low-grade lymphoma may have few or no symptoms. 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 happen over time. These include:

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

Sometimes you might have lymphoma in other areas of your body, for example, your stomach, bowel, skin or brain. In these cases the symptoms can be quite different. For example, with lymphoma in your bowel or stomach, you may experience abdominal (tummy) pain, diarrhoea or indigestion. If it affects the chest area you may have a cough or experience difficulty swallowing.

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 380 women and 480 men are diagnosed with it. It can occur at any age, but usually affects people over 60.

What caused my cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for non-Hodgkin lymphoma, see our website www.cancer.ie or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.



Subtypes of low-grade non-Hodgkin lymphoma

What are the different subtypes?	17
Follicular lymphoma	17
Chronic lymphocytic leukaemia (CLL) / small lymphocytic lymphoma (SLL)	19
Lymphoplasmacytic lymphoma (Waldenstrom macroglobulinemia)	21
Marginal zone lymphomas	22
MALT lymphoma	23
Splenic marginal zone lymphoma	25
Nodal marginal zone lymphoma	26
Cutaneous lymphoma (skin)	27

What are the different subtypes?

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

As well as general lymphoma symptoms like swollen lymph nodes and B symptoms like night sweats and fatigue (see page 13), any specific symptoms are listed with each subtype.

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

Follicular lymphoma

Why is it called follicular lymphoma?

The cells in the lymph nodes tend to grow in a cluster or circular pattern. They are irregular in size and shape and replace the normal cells there. It is a cancer of the B-cells. Usually the cancer cells have a protein called CD20 on their surface. Monoclonal antibody drugs can target this protein.

How common is it?

It is the most common type of low-grade lymphoma. In Ireland, it makes up about half of all low-grade and about one-fifth of all non-Hodgkin lymphomas. Most people are aged 60 and over when they're diagnosed. It rarely affects people under 20. It is slightly more common in women.

How quickly do the cancer cells grow?

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

Sometimes follicular lymphoma will be graded from 1 to 3. Higher grades tend to grow more quickly. The grade of your lymphoma may change and might become fast growing over time.

What other symptoms might I have?

It usually causes few symptoms in the early stages.

When is treatment given?

Doctors may decide to watch and wait at first. Many people live with follicular lymphoma for years without treatment and enjoy fairly good health. Treatment is started for follicular lymphoma if it progresses and causes significant symptoms.



How is it treated?

Very early-stage disease can be treated with radiotherapy alone. For those diagnosed with stage 1 and 2, the lymphoma might be cured completely. Advanced disease is often treated with chemotherapy along with a monoclonal antibody. Maintenance therapy is used to prolong remission after successful treatment of lymphoma. Immunotherapy is the most common type of maintenance therapy for people with lymphoma. See page 70 for more about radiotherapy, page 59 for chemotherapy and pages 68-69 for monoclonal antibodies and immunotherapy.

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

Other names: Small cell lymphocytic lymphoma.

Why is it called chronic lymphocytic leukaemia or small lymphocytic lymphoma?

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

How common is it?

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

How quickly do the cancer cells grow?

The behaviour of CLL/SLL can vary from person to person. It generally flares up from time to time. In between those times nothing much happens. Some people have very slow-growing disease that needs no treatment. On the other hand, some might have a more aggressive form of the disease.

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

What other symptoms might I have?

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

When is treatment given?

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



How is it treated?

Treatment may involve chemotherapy, targeted therapy or immunotherapy. You may also be offered a combination of these treatments. Often, treatment involves targeted treatment in the form of tablets for a long duration of time. In some circumstances, younger patients with CLL may be offered treatment with a bone marrow or stem cell transplant. For more about CLL, see our booklet *Understanding Chronic Lymphocytic Leukaemia*. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it from www.cancer.ie

Lymphoplasmacytic lymphoma

Other names: Waldenström macroglobulinaemia.

Why is it called lymphoplasmacytic lymphoma?

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

How common is it?

It is a very rare form of lymphoma. It is most commonly diagnosed in people over 60 years of age.

How quickly do the cancer cells grow?

These lymphoma cells can be found in the bloodstream, the bone marrow and often the spleen too. They can interfere with the normal growth of healthy blood cells. As a result, you may develop anaemia (low red blood cells) and thrombocytopenia (low platelets). The globulins that are made can enter your bloodstream, causing your blood to thicken. This is called hyperviscosity, and you may need treatment for this. Sometimes the cells transform, where they start to grow larger and divide faster. In this case, the lymphoma behaves more like a high-grade lymphoma and is treated along those lines.

What other symptoms might I have?

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

Nosebleeds, confusion, blurred or loss of vision are caused by the thickened blood (hyperviscosity). This can raise the pressure in your smaller blood vessels as the blood tries to flow through. Your protein levels will also be checked regularly by your doctor. Sometimes a

different type of globulin or no abnormal proteins are made, so the symptoms are milder.

When is treatment given?

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

How is it treated?

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

Marginal zone lymphomas

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

MALT lymphoma

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

Why is it called MALT lymphoma?

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



How common is it?

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

How quickly do the cancer cells grow?

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

What other symptoms might I have?

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

When is treatment given?

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

How is it treated?

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

Splenic marginal zone lymphoma

Other names: Splenic lymphoma with villous lymphocytes.

Why is it called splenic marginal zone lymphoma?

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

How common is it?

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



How quickly do the cancer cells grow?

The lymphoma is usually slow growing. It may be found only in your spleen or in other tissues, like your bone marrow or bloodstream.

What other symptoms might I have?

If your spleen enlarges, you may develop anaemia and low platelets. These symptoms include:

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

An enlarged spleen is known as splenomegaly.

When is treatment given?

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

How is it treated?

Surgery may be an option if your enlarged spleen is causing you symptoms. This is called a splenectomy. You may be more likely to get infections afterwards and will be prescribed a small dose of protective antibiotics. If surgery is not suitable or the lymphoma is found in your bone marrow, other treatments may be discussed with you. These include targeted/immunotherapy drugs like rituximab, which can be given on its own or with chemotherapy. Radiotherapy to the spleen is another option. Blood transfusions may help to ease the symptoms of anaemia.

Nodal marginal zone lymphoma

Why is it called nodal marginal zone lymphoma?

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

How common is it?

It is a very rare type of lymphoma.

How quickly do the cancer cells grow?

The lymphoma normally develops very slowly. In some people, it may change into a high-grade non-Hodgkin lymphoma. This means it will need more intensive treatment.

What other symptoms might I have?

None specific.

When is treatment given?

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

How is it treated?

If treatment is needed, it can be done in the same way as follicular lymphoma. This usually involves chemotherapy alone or with monoclonal antibodies.

Cutaneous (skin) lymphoma

Other names: Cutaneous T-cell lymphoma, cutaneous B-cell lymphoma, mycosis fungoides, Sézary syndrome.

Why is it called cutaneous lymphoma?

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

How common is it?

Skin lymphomas are rare. They are more common in men than women.

How quickly do the cancer cells grow?

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

What other symptoms might I have?

With mycosis fungoides, you may have red skin patches or plaques:

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

When is treatment given?

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

How is it treated?

There are various ways of treating cutaneous lymphoma. Treatments may be applied directly to your skin. For example, steroid creams, chemotherapy lotions, ultraviolet light and radiotherapy. Other treatments like chemotherapy drugs, steroids and monoclonal antibodies may also be used.

More information

If you would like more information on your subtype, talk to your doctor or nurse. For more about the different treatments, see page 55.

Diagnosis and tests

Being diagnosed with NHL	31
What tests will I have?	33
Staging non-Hodgkin lymphoma	38
Asking about your prognosis	39

Being diagnosed with NHL

Hearing that you have NHL 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
- **Angry** that this has happened to you

However you feel, you are not alone.

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

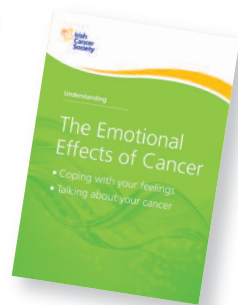
- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Survivor Support volunteer** who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer
- **Talk to other people affected by cancer.** Join our online community at www.cancer.ie/community
- **Go to your local cancer support centre.** For more information, see page 116.

Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the Emotional Effects of Cancer***. It 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?

- Tests you may have after diagnosis include scans, bone marrow biopsy and lumbar puncture.
- These tests help your doctor to 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).

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.

Tests you may have include:

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

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.

Support Line Freephone 1800 200 700

CT scan / CT with contrast (dye)

This is a special type of X-ray that builds up a detailed, 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan.

The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.



Ultrasound scan

This is a scan that uses sound waves to build up a picture of the tissues inside the body. It may be used to look at the organs inside the abdomen such as the liver or spleen. It may also be used to look at lymph nodes in your neck, armpit or groin. The scan is painless and takes only a few minutes. Some gel is first put on the area to be scanned and then a small hand-held device is passed over the gel.

For most scans you will be alone in the treatment room, but you can still talk to the medical team. Just speak or raise your hand if you need anything.

PET / CT scan

This scan is used in the staging of lymphomas. It is also a useful way of seeing how you are responding to treatment. A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body. During the scan, you will lie on a table, which moves through a scanning ring. The scan can last up to an hour. The PET / CT team will tell you about preparing for your scan. For example, not eating or drinking (except for water) for 6 hours before the scan and avoiding vigorous physical activity for 24 hours.

You will be slightly radioactive after the PET scan, so it's best not to have close contact with pregnant women, babies or young children for a few hours after the scan.

You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners. You will probably be at the hospital for 2-3 hours if you're having this test.

Bone marrow aspiration and biopsy

Aspiration means removing some bone marrow fluid, whereas biopsy means removing a small piece of bone with marrow cells in it. Both samples are sent to a laboratory, where they 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.

Usually the sample is taken from your hip bone. Before the test you will be given a local anaesthetic to numb the area. A needle is then passed gently through your skin into the bone marrow and the samples taken. This usually takes 10-20 minutes, and you may feel a little discomfort for a short while. Usually you don't need to stay in hospital for this test.

The area may feel tender and sore for a few days afterwards, but you will be given advice about suitable painkillers to take, if you need them.

Lumbar puncture

You might have a lumbar puncture done before you start treatment. This looks at the fluid around your brain and within your spinal cord (cerebrospinal fluid, or CSF) to see if there are any lymphoma cells in it.

Usually you will be lying 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. 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. The chemotherapy is injected in the spinal fluid after the sample has been removed. See page 60.

MRI scan

This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. It can take from 15-90 minutes, depending on the area being scanned and the number of images being taken. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs or headphones to wear. You might get an injection before the scan to show up certain parts of your body.

During the scan you cannot wear metal jewellery. Tell the staff if you have any metal in your body such as dental fillings, bridges and braces, surgical clips, pins or plates or cochlear implants.

Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

Waiting for test results



It usually takes a week or two 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 Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Support Line Freephone 1800 200 700

Staging 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.

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. Treatment for advanced-stage low-grade lymphoma aims to control it for as long as possible rather than cure it.

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

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).

Sometimes your doctor may describe your lymphoma as 'bulky' disease, if the area of lymphoma is above a certain size. Your nurse or doctor will explain what this means for your treatment.

Asking about your prognosis



Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about your prognosis. Everyone is different, so 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.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand, incorrect or the information may not be from a trusted source. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **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 Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treating low-grade non-Hodgkin lymphoma

How is low-grade non-Hodgkin lymphoma treated?	43
Deciding on treatment	47
Giving consent for treatment	48
Who will be involved in my care?	49
How can I help myself?	51

How is low-grade non-Hodgkin lymphoma treated?

- The aim of treatment is to put the lymphoma into remission. This means it is under control or has gone.
- Treatments for early-stage disease include watch and wait, radiotherapy and anti-cancer drugs.
- Treatments for advanced-stage disease include chemotherapy, targeted therapy drugs, radiotherapy and stem-cell transplants.

Your type of treatment will depend on where the lymphoma is, the subtype you have and the stage. Your doctor will also take into account your age and general health. Your test results will help your doctors to plan the best treatment for you.

Aims of treatment

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



Remission

Remission means the lymphoma is no longer active and is under control. It has been reduced or got rid of completely. Remission can be either partial or complete.

- **Complete remission:** There are no visible signs of the lymphoma after treatment.
- **Partial remission:** The lymphoma has been reduced by at least a half but is not completely gone.

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

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



Treatment for early stage lymphoma

In early-stage disease, usually one or two groups of lymph nodes in just one part of your body are affected. After the first course of treatment, there is a good chance of getting a complete remission, so the lymphoma won't come back. It's more usual for patients to be diagnosed at a later stage.

- **Watch and wait:** No treatment may be given if you have no symptoms. See page 57 for more details.
- **Radiotherapy:** Radiotherapy can be given to the small area of affected lymph nodes and nearby nodes. See page 70 for more details.
- **Anti-cancer drug therapies:** There is a risk that some lymphoma cells may be left behind after radiotherapy, increasing the risk of the disease relapsing. In this case, your doctor may advise a short course of chemotherapy or targeted/immunotherapy drugs, given either before or after radiotherapy. Steroids may also be given as well. See pages 59-69 for more about these treatments.

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

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

Treatment for advanced stage lymphoma

Most people will have advanced stage disease when diagnosed. This means that lymph nodes are affected in several places in your body.

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

- **Chemotherapy:** A number of chemotherapy drugs may be given to bring about a remission. Over the years, you may receive several courses of treatment, sometimes a repeat of the same treatment or a different drug (see page 59). Steroids may also be given as well (see page 66).
- **Targeted therapies / immunotherapy:** These drugs use your immune system to target the lymphoma cells. See page 68 for more details.
- **Radiotherapy:** Radiotherapy might be given to the small area of affected lymph nodes and nearby nodes. See page 70 for more details.
- **Stem cell transplant:** Only some patients will be suitable for a stem cell transplant. It depends on things such as your age and general health. Transplants are not common and are only used if the lymphoma has come back. Your consultant and specialist nurse will discuss this in more detail. See page 71 for more details.

Specialist cancer centres

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

Your doctor will discuss your treatment options with you.

Deciding on treatment

Multidisciplinary team: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, 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. 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.

Time to think: You may feel under pressure to make a decision. It may feel as if everything is happening too fast. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you make a decision about your treatment. Your treating doctor or GP can 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 a particular 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, 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
- Possible side-effects from 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.

Email: supportline@irishcancer.ie

Who will be involved in my care?

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



Haematologist-oncologist A doctor who specialises in treating cancers of the blood, bone marrow and lymphatic system with chemotherapy and other drugs.

Medical oncologist A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Haematology / oncology nurse specialist A specially trained nurse who gives information and reassurance to you and your family from diagnosis, throughout treatment and during follow-up after treatment.

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.

Medical social worker A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on social welfare benefits, financial matters and practical supports and services available to you from the time of your diagnosis, right through to returning to work.

Dietitian An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms.

GP (family doctor) 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.

Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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.

How can I help myself?

Eat well

Eating as well as possible can help you during your treatment. It can help you to:

- Maintain a healthy weight
- Cope better with the side-effects of treatment
- Recover better



Avoid alcohol or stay within the low-risk guidelines. Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet *Diet and Cancer*. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website www.cancer.ie

Be active

Being active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning, but build up gradually.

Quit smoking and avoid alcohol

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers have fewer or less severe side-effects during cancer treatment, for example, chest infections
- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking reduces the risk of other illnesses



If you would like advice or support on quitting, go to www.quit.ie, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you.

Alcohol can interact with some drugs and may make some side-effects worse. Ask your consultant about alcohol – they may advise you to cut down or to avoid alcohol, particularly around treatment times.

Other ways to help yourself

Get 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. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

Don't keep any worries or 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. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

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.



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.

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.

Treatment types

Watch and wait	57
Chemotherapy	59
Steroids	66
Targeted and immunotherapy drugs	68
Radiotherapy	70
Stem cell transplants	71
Clinical trials	73

Watch and wait

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

Check-ups

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



Worrying about your condition

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

Looking after yourself

During this time it can help to take good care of yourself. See page 51 for healthy lifestyle tips.

What should I look out for?

Watch for any B symptoms like high temperatures or fevers, night sweats, weight loss or poor appetite, and an itchy rash (see page 13). These might mean the lymphoma is becoming active. Tell your medical team if you have symptoms.



When does treatment begin?

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

Chemotherapy

- Chemotherapy is a treatment using drugs to treat and 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.

Chemotherapy is a treatment using drugs that can treat 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 can be given directly into a vein as an injection under the skin and/or through an intravenous infusion (drip), or as tablets. Tablets are just as effective as intravenous chemotherapy. You may take your tablets at home or you may go to an oral therapy clinic. Your specialist nurse or hospital pharmacist will explain how to take the tablets. Infusions and injections are usually given in the day hospital.

If you're taking chemotherapy tablets at home, it's important to follow the instructions about how to take them. Your doctors and nurses will tell you when to take the tablets, how to handle and store them safely and what to do if you have any side-effects. If you're not sure, ask them to explain again.

Intrathecal chemotherapy



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 (see page 36) and the chemotherapy given at the same time. 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 tube (a catheter) put into a main vein and brought out through your chest or arm. In most cases, it takes about 10–15 minutes to put in. You will be given a local anaesthetic beforehand. Removing the line is very simple, sometimes needing a small local anaesthetic.

PICC line

A thin flexible tube put into a vein in your arm and then threaded through to the larger veins near your heart. This may be done on the ward or in the X-ray department, using an ultrasound or X-ray to guide the tube into the right place.

Portacath

There are other ways to have easy access to your veins for taking blood samples and giving treatment. Sometimes the tube is attached to a port called a portacath. This is a small round plastic or metal disc placed under your skin. The port can be used for as long as is needed. Your doctor or nurse will explain the different options to you.

What kinds of drugs are used?

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



Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you know the name of your chemotherapy drug, visit the Health Product Regulatory Authority's website at www.hpra.ie for more information about the drug and possible side-effects.

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

Will I get side-effects?

The side-effects of chemotherapy vary from person to person. Some people have few side-effects. It mainly depends on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells. Ask your doctor or nurse if you're worried about side-effects or have any questions.

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

Infection: Chemotherapy drugs can reduce the amount of white blood cells in your body. This can make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough, or pain passing urine. Your nurse will advise you on what to do if you have any signs of infection.



Fatigue: Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 77.

Nausea and vomiting: Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

Hints & Tips – infections



- 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. Avoid taking medicines with paracetamol, as these can mask the signs of 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. Wash your hands for at least 20 seconds using soap and warm water or use an alcohol hand gel. Rub your hands together to form a lather and rub the backs of your hands between your fingers and under your nails, Rinse well and dry with a paper towel.
- Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.
- 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.

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. You may receive a blood transfusion to relieve symptoms of anaemia. 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. A low platelet count is called thrombocytopenia. 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.

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. A soft toothbrush is kinder to your teeth and gums. It's important to keep an eye on your mouth health during treatment and tell your doctor or nurse if you notice any problems or have any new symptoms.

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. Hair will usually grow back after you stop chemotherapy.

Constipation and diarrhoea: Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medicines to help.

Skin and nail changes: Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

Peripheral neuropathy: Some drugs can affect nerve endings in your hands and / or feet. It's important to tell your doctor if you have numbness, pain or a tingling or burning sensation in your hands or feet. This is known as peripheral neuropathy.



Changes in kidney function: Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. You will be given details of who to contact before you start your treatment.

Contact the hospital immediately if you have a temperature of 37.5°C (99.5°F) or higher, shortness of breath or bleeding that cannot be stopped.

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, www.cancer.ie for tips on coping with different side-effects.

Steroids

Your doctor may prescribe a short course of steroids with your chemotherapy. Steroids are hormones naturally made in your body. 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

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.

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. If you are diabetic you may find it more difficult to control your blood sugar level while taking steroids and you may need to change your diabetes treatment to help with this.

When you stop taking steroids you may feel down or even angry. Talk to your doctor or nurse if this happens to you.

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. See page 63 for advice on preventing infection.

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.

Targeted and immunotherapy drugs

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

Different drugs work in different ways. For example,

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

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 alongside another type of treatment, such as chemotherapy.

Targeted 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 such as bortezomib, Histone deacetylase (HDAC) inhibitors such as vorinostat, Bruton's tyrosine kinase (BTK) inhibitors such as Ibrutinib and PI3K inhibitors such as idelalisib.

How are the drugs given?

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

What are the side-effects?

Side-effects depend on the drugs being used and vary from person to person.

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

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, as these could be signs of an allergic reaction to the drug. You may be given a medication before treatment to make side-effects less likely.

For more information on targeted therapies and their side-effects, or a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



New treatments



New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 73). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Radiotherapy

- 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.

Radiotherapy is not often used for low-grade lymphomas. It is a treatment where high-energy X-rays are aimed at a cancer to cure or shrink it. The X-rays are only aimed at the lymphoma.

Radiotherapy may be used on its own when the lymphoma is found in one or two groups of lymph nodes in the same part of your body. It may also be given after a course of chemotherapy.

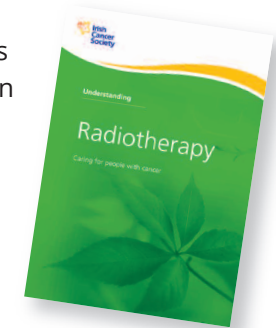
Radiotherapy can also be used if the lymphoma is found in the fluid around your brain or if there is a high risk that it may develop there. Treatment planning is a very important part of radiotherapy so it may take a few visits before your treatment can go ahead.

What are the side-effects of radiotherapy?

Radiotherapy is given directly to the site of the lymphoma and nearby lymph nodes, so any side-effects that occur affect 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 are:

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

For more information about the side-effects of radiotherapy, contact our Support Line 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



Stem cell transplants

- 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.

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 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 non-Hodgkin 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 Support Line 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

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects.

Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of, or as well as, the standard treatment you may 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.

Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

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 your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For 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 Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

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

Support Line Freephone 1800 200 700



Managing side-effects and symptoms

How can I cope with fatigue?	77
Will treatment affect my sex life?	79
Will treatment affect my fertility?	81
Cancer and complementary therapies	81

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common with cancer. 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.

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

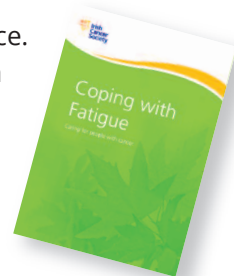
Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.



Hints & Tips – Fatigue

- Balance rest and activity. Ask your doctor about exercising. Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- Plan your days: Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- Ask for help at work or at home with any jobs that you find tiring.
- Try to eat a well-balanced diet. Eat little and often if your appetite is poor. Our booklet *Diet and Cancer* has tips to help.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 94) may help too.
- If you are not sleeping well, try to get a good bedtime routine and try relaxation techniques. Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- Short naps (less than an hour) and rest periods can be helpful, as long as they don't stop you from sleeping at night.
- Try complementary therapies like meditation, acupuncture or massage, if your doctor says they're safe for you.

Our booklet *Coping with Fatigue* has more advice. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. It's also on our website www.cancer.ie



Will treatment affect my sex life?

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



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

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. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy.

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. Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

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 Support Line 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 supportline@irishcancer.ie

Email: supportline@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. 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. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility 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 professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and aromatherapy.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Integrative care



Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website www.cancer.ie



After treatment

What follow-up will I need? 85

Living with low-grade non-Hodgkin lymphoma 86

What follow-up will I need?

After your cancer treatment has ended you will still need to have regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans. Normally you will see your consultant every 3–6 months.

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. It can help to write down what you want to say before you see the doctor, so you don't forget what you wanted to say.



It's important to attend your follow-up appointments so your doctor can check for signs of the cancer coming back (recurrence) and help with any 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, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

Living with low-grade NHL

- **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 63 for advice. Contact your doctor straight away if you have signs of infection, symptoms of lymphoma (see page 13), or any other health problems. Some people may experience pneumonia or other lung problems.
- **If you develop any issues 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 healthy lifestyle

A healthy lifestyle can help you to:

- Recover faster
- Cope better with any side-effects
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun
- Taking part in cancer screening programmes, such as bowel or breast screening

Vaccines

It's important to have any vaccines recommended for you. For example, Covid-19, flu and pneumonia. Some vaccinations may not be suitable if you've had cancer treatment, so it's important to check with your doctor first.

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



Be involved in your healthcare

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

- Don't be afraid to ask questions.
- 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 81 for more about complementary therapies.

Your feelings after treatment

It can take some time to adjust to life after cancer treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

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

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

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 95 for other ways to get emotional support. Ask the nurses for a copy of our booklet *Life after Cancer*, which has advice on living well – physically and emotionally.





Coping and emotions

How can I cope with my feelings?	93
Ways to get emotional support	95
You and your family	97

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

A cancer diagnosis can be hard on you - mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

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

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

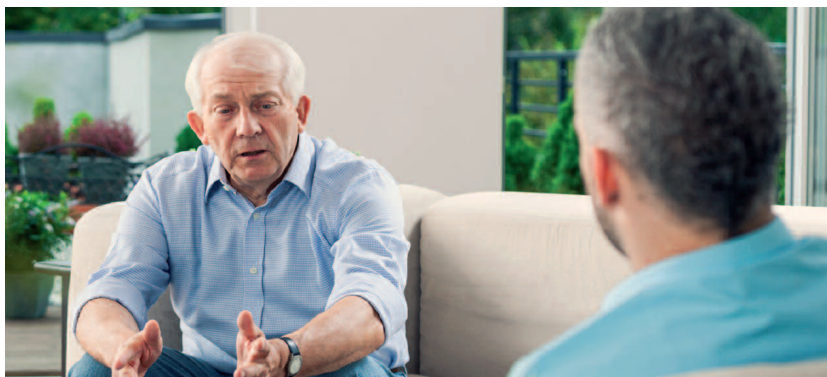
It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling

If you're feeling very distressed or finding it hard to cope, 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.

Free one-to-one counselling is available through many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

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



'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

Ways to get emotional support



Find out about cancer support services in your area: Most 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 116 for more about cancer support services.

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

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

Get online support: Special websites called online communities let you 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 worries. 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 Support Line on 1800 200 700 or drop into a Daffodil Centre.

Survivor Support



Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Positive emotions



In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

'I am very happy and content ... even though I have to live with this.'

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 *Understanding the emotional effects of cancer* can help to you find ways to talk about your cancer and to ask for the help and support you need.

People treating you differently



You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.



Talking to children and teenagers

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



How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer* is available free of charge from Daffodil Centres or by calling the Support Line. It's also available on our website www.cancer.ie.

If you or your family members need more support or advice, speak to your specialist nurse or 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. It also has information on supporting children and teenagers and helping them to deal with their emotions.

Advice for carers

Supporting someone with cancer	101
Support for you	102
How to talk to someone with cancer	103

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members through many local cancer support centres. Talk to your GP or see page 94.

Find out about support for carers

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. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, *Caring for Someone with Cancer*, has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website www.cancer.ie



Support Line Freephone 1800 200 700

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.

The booklet *Caring for Someone with Cancer* has a section on how to talk to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative.






Support resources

Money matters	107
Irish Cancer Society services	110
Local cancer support services	116

Money matters

- 
- If you have cancer you may not be able to work for a time. You may also have extra expenses.
 - You may have to pay for some of your cancer treatment.
 - You might be entitled to certain social welfare payments.
 - There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as 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 your illness if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

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 don't have a medical card you will have to pay some of the cost of your care and medication.

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

Benefits and allowances

There are benefits 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: 0818 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 0818 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 money problems

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 0818 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 113 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

Go to www.cancer.ie and see our **Managing money** page for information on:

- **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**

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.



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:

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

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information.

The Support Line is open Monday–Friday, 9am to 5pm. You can email us at any time on supportline@irishcancer.ie or visit our Online Community at www.cancer.ie

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



Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- End-of-life services
- Chemotherapy group education sessions
- Lifestyle and cancer prevention
- Emotional support
- Local cancer support groups and centres
- Practical entitlements and services
- Living with and beyond cancer

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.

Survivor Support



Speak to someone who has been through a diagnosis similar to yours. 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 and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to www.cancer.ie and search 'Find support'.

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 travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is mainly for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

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 a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

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 Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line 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 one-to-one counselling through many local cancer support centres)



- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage and reflexology
- **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 Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to www.cancer.ie and search 'Find support'.

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 fewer than normal 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 a transplant. 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 man-made antibody to fight disease. Also called targeted therapy or antibody therapy.

Nausea Feeling sick or wanting to be sick.

Neutropenia When there are fewer than normal 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.

Thrombocytopaenia When there are fewer platelets in your blood. This can cause you to bleed and bruise easily.

Questions to ask your doctor

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

What is non-Hodgkin lymphoma? Where exactly is it?

What subtype do I have?

What does low grade mean?

What type of treatment do I need?

How successful is this treatment for my lymphoma?

Are there other treatment options?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

What side-effects will I get?

Is there anything I can do to help myself during treatment?

Would I be suitable for a clinical trial?

Should I eat special foods?

What if the lymphoma comes back?

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 Support Line 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.
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