Irish Cancer Society

Understanding

High-grade non-Hodgkin lymphoma

Caring for people with cancer

Understanding

High-grade non-Hodgkin lymphoma

This booklet has information on:

- Treatment for high-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

Haematologist

Medical oncologist

Radiation oncologist

Family doctor (GP)

Medical social worker

Main hospital number

Emergency

Hospital records number (MRN)

Contents

Fast facts

Can my cancer be treated? Page 51

Yes. There are a number of treatments for high-grade non-Hodgkin lymphoma (NHL). Treatment aims to put the lymphoma into complete remission. Complete remission means there are no visible signs of the lymphoma after treatment. High-grade lymphomas usually respond very well to treatment. They can be cured in many cases. Sometimes only a partial remission happens. This means the lymphoma has been reduced by at least a half but is not completely gone. Patients who achieve a partial remission will often require further treatment, with many of these treatments aiming to cure the lymphoma.

How might my cancer and treatment affect me? Page 71

Lymphoma can cause symptoms like fevers and sweating, loss of appetite, weight loss, extreme tiredness and skin irritations. These should get better once you have had treatment. If you notice any symptoms after treatment, let your doctor know. All treatments, particularly intensive chemotherapy, can cause side-effects. Read about the treatments to learn more about their possible side-effects.

There are treatments to help with most side-effects, so tell your doctor or nurse. Don't suffer in silence!

What kind of treatment might I have? Page 71

Chemotherapy: Drugs to control the lymphoma.

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

Targeted therapies/immunotherapies: Drugs to boost your immune system and help your body to target and destroy cancer or to stop it spreading. Newer treatments for lymphomas include the immunotherapies CAR T-cell therapy and bispecific antibody therapy. Both of these treatments work by stimulating the immune system to kill lymphoma cells.

Radiotherapy: X-ray treatment to try to treat the cancer or relieve symptoms.

Some people may be suitable for a **stem cell transplant**.

Will I be OK? Page 49

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

Clinical trials Page 92

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.

We're here for you **Page 131**

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**

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.

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

We use gender-inclusive language. We sometimes use man/woman and male/female when they are needed to explain a person's treatment and care – for example, talking about hormones or body parts – and when needed to describe research or statistics.

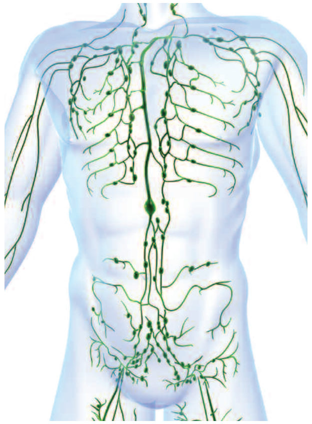
About lymphoma

What is a blood cancer?

- **Cancer is a disease of the body's cells**, which are the building blocks of the body's tissues and organs. Cancer cells are abnormal cells that grow without control and spread into surrounding tissues.
- **Blood cancers affect blood cells.** Our blood is made up of different types of blood cells, which are made in the bone marrow in the middle of our bones. There are 3 main types of blood cells: red blood cells (which carry oxygen), platelets (which help blood to clot) and white blood cells (which fight infection).
- **When a blood cancer occurs, normal blood cell development is affected by the uncontrolled growth of an abnormal kind of blood cell.** These cancerous cells stop your blood from performing the functions it's supposed to, like fighting infections or clotting your blood when you're cut.

There are 3 main types of blood cancers: lymphoma, leukaemia and myeloma. This booklet is about lymphoma. Lymphoma is a cancer of the lymphatic system.

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 lymph nodes, which are connected by tiny tubes called lymph vessels, and organs such as the spleen and bone marrow.

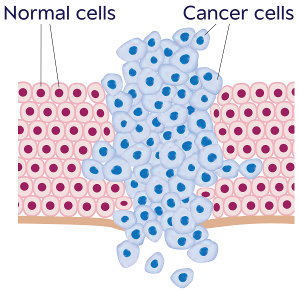
If cancer cells spread into lymph nodes or cancer starts in the lymph nodes, they can become swollen.

Parts of the lymphatic system

- **Lymph vessels:** Transport excess fluid and waste from body tissues and filter bacteria and viruses.
- **Lymph nodes (or lymph glands):** Contain infection-fighting white blood cells called lymphocytes. There are 3 main types of lymphocytes – B cells, T cells and natural killer (NK) cells. Lymph nodes often swell when they are fighting infection, which is a normal, healthy response. Lymph nodes are found mainly in the neck, armpit, groin, tummy and between the lungs.
- **The spleen:** Helps to filter out damaged cells from the blood and also to fight infection.
- **Other body organs:** Your tonsils, adenoids, thymus and bone marrow.

Sometimes cancer cells spread into lymph nodes or cancer can start in the lymph nodes themselves.

What is lymphoma?



Lymphoma is a type of blood cancer that affects the lymphatic system. Lymphoma happens when lymphocytes (a type of white blood cell) grow in an abnormal way. These abnormal cells start to collect in your lymphatic system, particularly in the lymph nodes. This causes swellings, known as lymphoma.

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. It also makes 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.

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, B-cell and natural killer (NK)-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.

Natural killer (NK)-cell lymphoma: Natural killer (NK) cells are affected. NK cells are mainly made in the bone marrow, but they mature in lymph nodes and other parts of the body. They release chemicals that can kill harmful cells in their early stage of development, such as viruses and cancer cells. This prevents these cells from spreading. NK-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 may cause you to become seriously unwell if not treated quickly. These types of lymphomas usually respond well to treatment. They can be B-cell lymphomas, T-cell lymphomas or NK-cell lymphomas.

This booklet is about high-grade non-Hodgkin lymphoma. For more information on low-grade non-Hodgkin lymphoma, you can get a copy of our booklet, ***Understanding low-grade non-Hodgkin lymphoma***. Call our Support Line or download it from **www.cancer.ie**

High-grade non-Hodgkin lymphoma

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

Subtypes

There are many subtypes of high-grade non-Hodgkin lymphoma. See page 17 for more details about some of these subtypes.

What are the signs and symptoms of lymphoma?

The most common early symptom of NHL is a painless swelling in the lymph nodes in one area of the body, for example, in your neck, armpit or groin. These lumps or painless swellings may come and go. Other symptoms, known as B symptoms, may happen over time. B symptoms include:

- Night sweats – these can be drenching. You may need to change your pyjamas or bed clothes.
- High temperatures or fevers
- Loss of appetite
- Unexplained weight loss (10% body weight loss over 6 months)
- 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, shortness of breath or difficulty swallowing.

How common is non-Hodgkin lymphoma?

About 800 people are diagnosed with non-Hodgkin lymphoma each year in Ireland. Lymphoma can occur at any age, but it is more common in older people.

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 lymphoma, see our website **www.cancer.ie** or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

Subtypes of high-grade non-Hodgkin lymphoma

There are many subtypes of high-grade non-Hodgkin lymphoma. Some are listed in this section. 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.

As well as general lymphoma symptoms like swollen lymph nodes, and B symptoms, like drenching night sweats (see page 14), any specific symptoms are listed with each subtype.

Diffuse large B-cell lymphoma (DLBCL)

Why is it called diffuse large B-cell lymphoma?

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

How common is it?

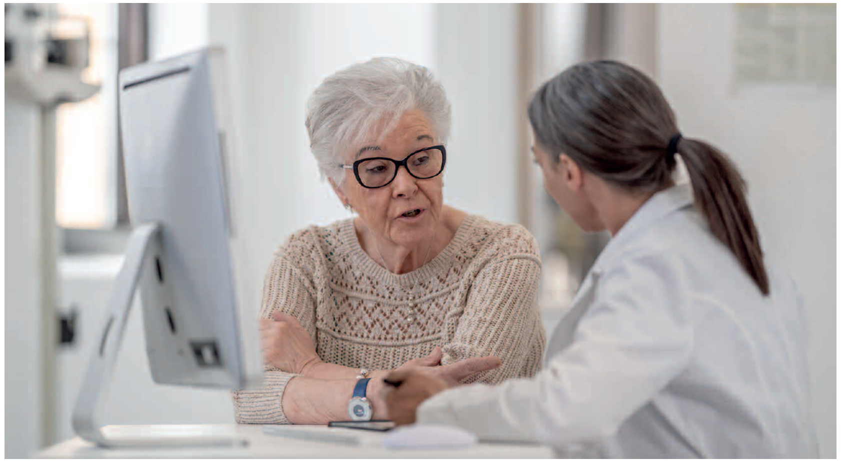
It is the most common type of lymphoma. It occurs in about one-third of all non-Hodgkin lymphomas, and in 4 out of 5 high-grade types. It can occur between adolescence and old age, but usually occurs over the age of 60. Sometimes a low-grade lymphoma can change or transform into a DLBCL.

What other symptoms might I have?

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

How is it treated?

Different types of chemotherapy drugs can be given together or combined with a monoclonal antibody. For example, Pola-R-CHP. This stands for polatuzumab, rituximab, cyclophosphamide, doxorubicin and the steroid prednisolone. You may be admitted for the first cycle of chemotherapy, although it is usually given as an outpatient in the chemotherapy day ward. Your specialist nurse will talk to you about this.



Mantle cell lymphoma

Why is it called mantle cell lymphoma?

In this lymphoma, the cancer cells are found in the mantle zone of the lymph node. This is the outer ring of the lymph node. Even though the lymphoma is classed as a low-grade lymphoma, it often acts like a faster-growing one and is treated as such. However, like other low-grade lymphomas, it commonly recurs (comes back) after initial treatment has been completed. Usually, the cancer cells are found in one or more lymph nodes and can affect organs such as your bone marrow, bowel, stomach, liver, spleen or tonsils.

How common is it?

This B-cell lymphoma is rare and occurs in about 5 in 100 cases of non-Hodgkin lymphoma. It more commonly affects men aged over 60.

What other symptoms might I have?

You may have an enlarged spleen. If the lymphoma affects other organs, you might have other symptoms. For example, abdominal pain, nausea and diarrhoea if your stomach or bowel is involved.

Your doctors might do an endoscopy to take a closer look at your stomach or large bowel. This is a test which uses a long, thin tube with a camera on one end. The tube is inserted into your body and the images and video taken by the camera can be viewed by your doctor on a screen.

How is it treated?

It is often diagnosed at a later stage when found in your stomach, bowel or bone marrow. Your doctor will consider your age, stage of disease and general health when deciding on treatment. Usually, this lymphoma is treated with chemotherapy using a combination of drugs. You may also be suitable for a stem cell transplant (see page 90) and/or maintenance treatment after chemotherapy. Maintenance treatment aims to delay the time that your lymphoma may recur (come back).

Burkitt’s lymphoma

Why is it called Burkitt’s lymphoma?

This lymphoma is named after the Irish doctor, Denis Parsons Burkitt, who first described it in Africa. It is a form of NHL in which cancer starts in the immune cells called B cells.

Burkitt’s lymphoma is linked to the Epstein–Barr virus. It usually affects your body in many places. For example, your chest, tonsils, back of nose and throat. It can be found in other organs such as your liver and bone marrow. It can occasionally affect the brain.

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

How common is it?

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

What other symptoms might I have?

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

How is it treated?

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

Peripheral T-cell lymphomas (PTCLs)

Why are they called peripheral T-cell lymphomas?

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

The 3 most common are:

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

How common are they?

They are rare. Together they account for about 10 in 100 of all non-Hodgkin lymphomas. They are all considered separate diseases and treated in that way (see pages 25-28).

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

What does the name mean?

It refers to a group of diseases that do not fit into any of the other subtypes of PTCL.

How common is it?

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

What other symptoms might I have?

Body organs other than lymph nodes can also be affected. For example, your liver, spleen, bone marrow, stomach, bowel and skin. This can give rise to other symptoms, such as unintentional weight loss and itchy skin.

How is it treated?

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

Anaplastic large cell lymphoma (ALCL)

Why is it called anaplastic large cell lymphoma?

This lymphoma affects T cells. The name refers to how the affected T cells look under a microscope. Anaplastic means they no longer look or act like normal cells. These abnormal cells also appear larger than normal cells.

ALCL either affects the whole body (systemic) or the skin (cutaneous). Patients with systemic ALCL are divided into 2 groups, depending on whether or not the surface of their cells have an abnormal form of a protein called ALK (anaplastic lymphoma kinase). Your doctors might say the lymphoma is ALK positive or negative.

How common is it?

This type of lymphoma is rare, accounting for about 1 in 100 of all NHLs. Being ALK-positive is more common in young adults and children, particularly men and boys. ALK-negative ALCL occurs more often in older adults, aged 60 and over.

What other symptoms might I have?

ALCL can affect organs in your body other than your lymph nodes. For example, your skin, bones, soft tissues, lungs, liver and bone marrow. Depending on the location, you might get other symptoms. For example, you might have red, itchy skin patches if your skin is affected.

When is it treated?

Most patients have stage 3 or 4 disease when diagnosed and need treatment straightaway. But if only your skin is affected, you may not need treatment immediately. It often depends on the number of skin areas affected.

How is it treated?

Chemotherapy is the main treatment. A combination of drugs is usually given, which may include an antibody treatment to target lymphoma cells. Chemotherapy works well for ALK-positive disease but less so for ALK-negative. You may need high-dose chemotherapy and a stem cell transplant to improve the treatment outcomes. If your lymph nodes are significantly enlarged, you may benefit from radiotherapy, especially in the early stages. If you have cutaneous ALCL, radiotherapy to the skin patches can often work well.

How might it be treated if it recurs (comes back)?

You are more likely to experience recurrence if you have ALK-negative disease. You may be given more chemotherapy or a monoclonal antibody drug, along with a stem cell transplant after remission. Also, you have a higher risk of recurrence if you have cutaneous ALCL and many areas of skin are affected. In this case, the recurrence may be treated with mild chemotherapy or radiotherapy.

Angioimmunoblastic T-cell lymphoma

Why is it called angioimmunoblastic T-cell lymphoma?

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

How common is it?

It is a rare lymphoma, found in about 2 in 100 of all non-Hodgkin lymphomas. It occurs in older people, usually aged 50 and over.

What other symptoms might I have?

- Enlarged liver and spleen
- Fluid retention
- Inflamed joints

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

How is it treated?

It can be quite difficult to treat. Most patients have stage 3 or 4 disease at the time of diagnosis. The first treatment is usually chemotherapy using a combination of drugs. Sometimes it responds to milder therapies such as steroids and other medications. These will also improve any symptoms you have. You may need high-dose chemotherapy and a stem cell transplant to improve your treatment outcomes.

Lymphoblastic lymphoma

Why is it called lymphoblastic lymphoma?

This lymphoma affects immature cells called lymphoblasts. These cells, when healthy, grow into the white blood cells called lymphocytes, which help your body fight disease and infection. This type of lymphoma usually develops from T-cells. This is known as T-LBL. It can also develop from B-cells, but this is less common. This is known as B-LBL. Lymphoblastic lymphoma looks very like acute lymphoblastic leukaemia (ALL) and the treatments are similar.

How common is it?

Lymphoblastic lymphoma is a rare type of non-Hodgkin lymphoma. It mainly affects people under the age of 35 and tends to be more prevalent in children and teenagers than in adults.

What other symptoms might I have?

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

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

How is it treated?

It is treated like an acute lymphoblastic leukaemia (ALL). This involves chemotherapy and other drugs given over a long period of time. Radiotherapy is sometimes given to the brain and spine if the lymphoma is advanced. If needed, chemotherapy can be given directly into the fluid that surrounds your brain and spinal cord. You might also receive a stem cell transplant. For a free copy of the booklet, ***Understanding acute lymphoblastic leukaemia***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also download a copy from **www.cancer.ie**

More information

If you would like more information on your subtype, talk to your doctor or nurse. For more about the different treatments, see page 71.

Preparing for your hospital appointments

Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.

Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you aren't fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is OK to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one
- Your private health insurance details, if you have insurance
- The appointment letter from the hospital, if you got one
- A referral letter or GP letter, if you got one
- Your GP's name and contact details
- Your medical history – remember, your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medications. Hand-written lists can be hard to read or inaccurate
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed
- Medications and any medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time. (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure)
- Your phone and your phone number
- Contact details of the person to call in an emergency
- Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Ensure you are booked in for your follow-up appointment before you leave, if required

After the appointment

- Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

It's important to go to your appointments

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. Contact your GP if you have any trouble getting an appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask. Never be shy about asking questions. It is always better to ask than to worry.

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

What subtype do I have?

What does high grade mean?

What type of treatment do I need?

How successful is this treatment for my lymphoma?

Are there other treatment options?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

What side-effects will I get?

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

Would I be suitable for a clinical trial?

Should I eat special foods?

What if the lymphoma comes back?

Diagnosis and tests

Being diagnosed with high-grade NHL

Hearing that you have high-grade 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 is happening 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 (haematology/oncology) liaison nurse, the medical social worker at the hospital or the psycho-oncology team. 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 Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our cancer nurses can put you in touch with a volunteer.
- Go to your local cancer support centre. For more information, see page 138.

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 or need a little time to adjust. 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 will tell your medical team more about your cancer and help them to decide on the best treatment for you.

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 (tummy area).
- 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 aspirate and 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. Other tests may be used to measure your response to treatment.

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 only takes 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.

PET CT scan

This scan is used in the staging of lymphomas. Staging means finding out how much of your body is affected by the disease (see page 47). The scan may also be used to see 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 scan, so you should avoid 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.

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

Bone marrow aspiration and biopsy

Aspiration means removing some bone marrow fluid. Biopsy means removing a small piece of the central spongy part of the 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.

You do not usually need to fast (not eat) before the procedure, but your doctor or nurse specialist will confirm this with you. Tell your doctor if you are taking any anticoagulation (blood thinner) medications.

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 20-30 minutes and you may feel a little discomfort for a short while. Usually, you don't need to stay in hospital after this test.

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

It is often recommended that you have someone accompany you for a bone marrow test, to drive you home afterwards.

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 you will be 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 and perform specialised tests to see if any lymphoma cells are present. This test should not be 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. If you experience headaches 12 hours or later after your procedure, let your doctor or nurse know as you may need additional fluids.

Repeated lumbar punctures and injections of chemotherapy may be needed as part of your treatment. The chemotherapy is injected into the spinal fluid after the sample has been removed. This is known as intrathecal chemotherapy (see page 74).

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. This injection can give you a very warm feeling in your groin area. It may feel like you are passing urine – this is very normal.

During the scan you cannot wear metal jewellery. Tell the staff if you have any metal in your body such as dental braces, metal pins, a pacemaker 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 couple of weeks for all the test results to come back, be discussed and for a treatment plan to be developed that is right for you. 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.

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. It helps your doctor to decide the best treatment for you. With high-grade lymphoma, the stage of the disease has a different meaning compared to solid organ cancers. Many people are diagnosed when the lymphoma is already at an advanced stage, but treatment is still given with the goal of curing it.

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 in a single organ.

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

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

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

Early or late stage

Early stage: This includes stage 1 and possibly stage 2.

Advanced stage: This is usually stage 2, 3 or 4. It is possible to treat and cure advanced-stage lymphoma.

Letter codes

A: You have no symptoms other than swollen glands.

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

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

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

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

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 life expectancy. 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 your 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 or it may be incorrect. 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 or nurse again after you have thought about everything.

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 may help you.

Treating high-grade non-Hodgkin lymphoma

How is high-grade NHL treated?

- High-grade lymphomas are fast growing and usually need to be treated quickly.
- Treatments include chemotherapy, targeted therapy/immunotherapy drugs, radiotherapy and, in some cases, a stem cell transplant.
- High-grade lymphomas usually respond well to treatment.

High-grade lymphomas are fast growing and usually need to be treated without delay. Your type of treatment will depend on where the disease is, your subtype and other factors that affect prognosis. Your doctor will also take into account your age and general health.

Aims of treatment

High-grade lymphomas usually respond very well to treatment. In most cases, treatment is given with the aim of curing the lymphoma.

Doctors often say that the lymphoma is in remission rather than cured. Remission means that there are no signs of cancer in your body, but it could still return. Cure means a disease is permanently gone.

The longer you stay in remission, the less likely it is that the lymphoma will return. If it does come back after treatment, this is called recurrence or a relapse. If recurrence happens, there are still effective treatment options available. In many cases, these are again given with the hope of achieving a cure.

Remission

Remission means the lymphoma is no longer active and is under control. 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.

The target of treatment in high-grade lymphoma is usually to achieve complete remission.

Treatment of limited disease (stage 1A)

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

- **Radiotherapy:** You might be given radiotherapy to the affected nodes. For more information, see page 88.
- **Anti-cancer drug therapies:** Your doctor might decide to give you a short course of chemotherapy and a targeted therapy drug called a monoclonal antibody, as well as radiotherapy. This is done to increase the chances of curing the disease. See page 73 for more on chemotherapy and page 84 for more on targeted therapies.

Treatment of all other stages

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

Anti-cancer drug therapies: Intensive chemotherapy is often given to shrink high-grade lymphomas very quickly. You might get 3 or 4 different drugs with or without a monoclonal antibody. Steroids are often given as well to kill the lymphoma cells and to improve how the chemotherapy works. See pages 73-87 for more information on drug treatments.

Intrathecal chemotherapy: Sometimes lymphomas can affect your brain and spinal cord. Chemotherapy given into a vein may not reach these areas. So if the lymphoma is found in your brain or spinal fluid, or your doctor thinks you are at high risk of it developing, you will get chemotherapy into the spinal fluid. This is called intrathecal chemotherapy. This is given during a lumbar puncture. For more information on lumbar punctures, see page 45.

What happens if my lymphoma comes back?

Many people achieve complete remission after their first treatment. This means that cancer cells can no longer be detected in your body. But for some, the lymphoma does come back. This is called recurrence. Recurrence is more likely within the first 2 years after treatment. Even if the lymphoma recurs, it may be possible for you to have further treatment which aims to achieve complete remission. Usually, a different combination of chemotherapy drugs can be given. A stem cell transplant or CAR T-cell therapy may be considered for some people.

Refractory disease

If your lymphoma did not respond to the first course of treatment or came back very quickly afterwards, this is called refractory disease. This is harder to treat than recurrent lymphoma. Usually, chemotherapy with a monoclonal antibody may be used to treat it. Radiotherapy may also be an option. A stem cell transplant or CAR T-cell therapy may be considered for some people.

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, your MDT may include a haematologist, specialist nurse, radiologist, medical oncologist and radiation oncologist. The team will meet to discuss your test results and your suggested treatment plan.

Understanding treatment

Your doctor and nurse will explain your treatment options.

Ask as many questions as you need to. You could write down any questions you have in advance, so you don't forget anything. You could use the fill-in page at the back of this booklet for your questions and answers.

If you do forget something or need more explanation, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about your treatment if you are unsure when it is first explained to you. Some patients will require immediate treatment. Your doctor and specialist nurse will discuss this with you.

Second opinion

While you might find it reassuring to have another medical opinion to help you decide about your treatment, because high-grade non-Hodgkin lymphoma tends to grow quickly, it is important that treatment starts as soon as possible. Be assured, your medical team will use the latest scientific information and best practice to develop your treatment plan.

If there is time for a second opinion, your GP or treating doctor can refer you to another specialist 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 of the treatment and the impact that no treatment will have on your survival.

Time to think

As high-grade non-Hodgkin lymphoma can be a fast-growing cancer, treatment may start as soon as possible after diagnosis. This can be hard when you are coming to terms with your diagnosis. Talk to your consultant or specialist nurse if you're feeling overwhelmed or if you have any questions or worries.

Giving consent for treatment

Before you start any treatment, you will 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 will be given full information about:

- Your disease
- 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, including long-term risks
- Any other treatments that may be available

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

Individual treatment

You may notice that other people with non-Hodgkin lymphoma are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Treatment decisions can also depend on your general health. Everyone's treatment needs will be different. Ask your doctor about your treatment if you have any questions or worries.

If you have time before your treatment begins, ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects.

Who will be involved in my care?

Usually, a team of healthcare professionals will be involved in your treatment and care. These may include:

Haematologist: A doctor who specialises in treating blood and bone marrow diseases, including blood cancers.

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

Registrars/SHOs/interns: Qualified doctors who are continuing their training. They help look after you each day, managing your care under the supervision of your main consultant.

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.

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

Radiation oncologist: A doctor who specialises in treating cancer patients using radiotherapy.

Radiation therapist: A specially trained person who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.

Radiologist: A doctor who specialises in interpreting X-rays and scans such as ultrasound, CT, MRI and PET, and also undertakes biopsies under image-guidance.

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

Physiotherapist: A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

Occupational therapist: A therapist who specialises in helping people who are ill or have disabilities learn to manage their condition and their daily activities, such as washing, dressing, housework, parenting, work and leisure activities.

Medical social worker: A person trained to help you and your family with your social issues and emotional and practical needs. They can also give advice on social welfare benefits, financial matters and practical supports and services available to you.

Pharmacists: 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 how you can cope with your diagnosis.

Community health services: These include family doctors, public health nurses (who can visit you at home), community welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Palliative care team: This team is experienced in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you.

How can I help myself?

Eat well

Eating as well as possible can help you to:

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

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet ***Understanding diet and cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it from our website **www.cancer.ie**
The Irish Cancer Society provides group online information sessions with an oncology dietitian on the important role nutrition has for people with cancer. To sign up for one of these webinars, call our Support Line on 1800 200 700.

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. We provide information and support on how you can make exercise part of your everyday life. We also offer free exercise classes, through ExWell Medical, to build strength and fitness in a supportive environment. Call our Support Line or visit a Daffodil Centre for details.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking.

However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment. For example, chest infections
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work
- Not smoking reduces your risk of further illness

If you would like advice or support on quitting, call the HSE Quit Team on Freephone 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

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. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE. Your doctor or nurse can also advise you on specific websites or support groups for patients diagnosed with NHL. You can also speak to a cancer nurse by calling our Support Line on 1800 200 700.

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

Activities like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups – online and in person – 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 (see page 115).

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.

Types of treatment

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- 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 cure or control lymphoma.

How often will I have chemotherapy?

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

How is chemotherapy given?

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

Central line: If your treatment involves a lot of injections or infusions, you may have a central line put into a large vein. This device can be left in place throughout your treatment. It will make it 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.

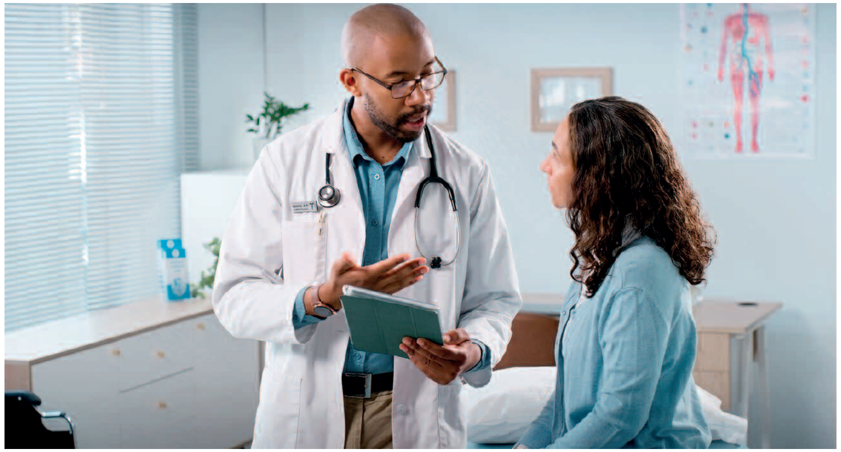
PICC line: A thin flexible tube put into a vein in your arm and then threaded through to the larger veins near your heart. This may be done on the ward or in the X-ray department, using an ultrasound or X-ray to guide the tube into the right place.

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.

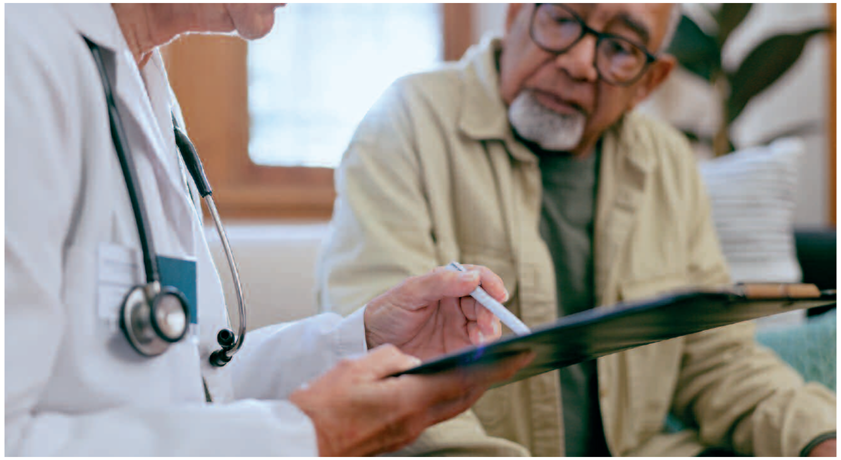
Intrathecal chemotherapy

If you have lymphoma cells in your brain and spinal fluid or your doctor thinks you may be at high risk of this, you will need extra treatment. You may be given chemotherapy injections into the spinal fluid. To do this, a specialist doctor will give you a series of lumbar punctures and the chemotherapy will be given at the same time. This is called intrathecal chemotherapy. For more on lumbar punctures, see page 45.



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. Chemotherapy drugs are often combined with steroids and antibody drugs to improve the effect of treatment for certain lymphoma subtypes.



Tumour lysis syndrome (TLS)

Tumour lysis syndrome (TLS) is a dangerous imbalance of chemicals in the blood that can damage organs like the heart and kidneys. The risk is highest at the time of the 1st cycle of treatment. When cancer cells are destroyed, they release chemicals into the blood. TLS can happen when chemotherapy drugs break down a lot of cancer cells very quickly and your body may not be able to cope with the amount of chemicals released. TLS is more common with high-grade lymphomas and acute leukaemias. You will probably be given medication to protect against TLS.

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 Products 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:

Risk of infection: Chemotherapy can reduce the number of white blood cells in your blood. This can make you more likely to get infections. Watch out for signs of infection. These signs include feeling shivery and unwell, having a high temperature, having a cough or sore throat, or pain passing urine. If this happens, tell your hospital doctor or nurse straight away. They will tell you what to do. You may be prescribed a medication or injection to take at home that reduces your risk of infection. Your doctor and specialist nurse will discuss this with you.

Hints and 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 the hospital immediately.** Make sure you have the hospital's emergency contact details easily available. Aoid 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 may 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 prepare food, 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.

Nurse specialist SOS Hotline

If you feel unwell or are concerned about symptoms before your next hospital appointment, you can call the nurse specialist SOS Hotline. This service offers advice and assessment to you if you become unwell:

- While receiving cancer treatment
- Up to 8 weeks after cancer treatment is completed
- Up to 1 year following immunotherapy treatment

You may be given advice over the phone which means that you avoid having to go to the emergency department. Or you may be asked to attend your nurse specialist, GP or emergency department.

This service runs from 8am to 4pm, Monday to Friday. You will be given the number of the SOS Hotline in your hospital, as well as an emergency contact number if you become unwell outside of these hours. Make sure these numbers are easily available to you and those around you.

Fatigue: Fatigue (extreme tiredness) is very common and can make you feel weak. For more information, see page 95.

Nausea and vomiting: Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects.

Anaemia: Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment. You may need a blood transfusion to treat anaemia.

Bleeding and bruising: Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums, or if you notice tiny red spots under your skin that can look like a rash. You may need a platelet transfusion.

Mouth and throat problems: Chemotherapy can cause mouth and throat problems including a dry mouth, taste changes, 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. Sipping cold water, chewing sugar-free gum or sucking sugar-free boiled sweets/mints can be helpful in managing dry mouth.

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 grow back after you stop chemotherapy.

Constipation and diarrhoea: Chemotherapy can cause constipation (not having a bowel movement/poo often enough) and diarrhoea (frequent loose or watery bowel movements). Tell your medical team if you have constipation or diarrhoea. They can advise you on what to do and give you medications to help, if needed.

Skin and nail changes: Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle. These changes can be a normal response to the treatment you receive but always tell your medical team if they occur.

Numbness or pins and needles in your hands and feet (peripheral neuropathy): Some drugs can affect your nerve endings. Tell your doctor or nurse if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

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

Heart muscle damage: Chemotherapy drugs called anthracyclines (for example, doxorubicin) can damage your heart muscle. Ask your doctor about this and ways to look after your heart health. You should have a yearly blood pressure and cholesterol check after having this type of drug.

Blood clots: Chemotherapy and having cancer can both increase your risk of developing blood clots. A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually, they are treated with medication to thin your blood.

Other side-effects

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.

For more information on chemotherapy and possible side-effects, see our booklet ***Understanding chemotherapy and other cancer drugs.*** Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it at **www.cancer.ie**

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 prevent nausea associated with chemotherapy
- 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.

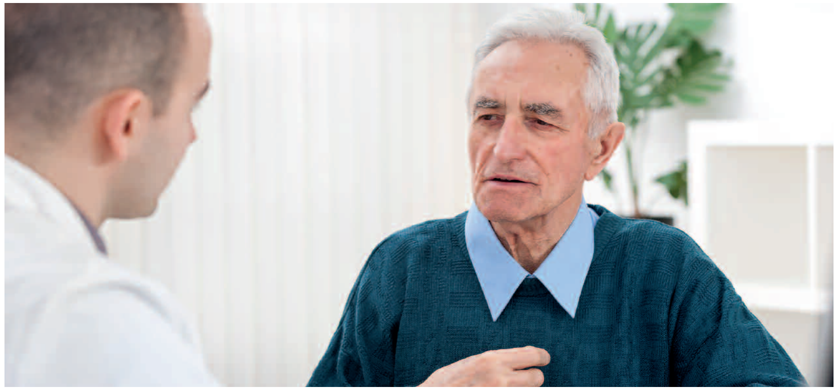
Other side-effects: If you have to take steroids for some time, you may have some other temporary side-effects. These may include:

- 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 have diabetes, you may find it more difficult to control your blood sugar level while taking steroids. 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. It may also increase your risk of osteoporosis and you may 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 77 for more information on infections.

Your doctor will likely prescribe medication to help protect your stomach and prevent infections while you are on steroids.

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. They will explain your steroid medication to you in more detail.

Targeted and immunotherapy drugs

- Targeted therapies target certain parts of cancer cells that make them different from other cells.
- Immunotherapy helps your body's immune system to work better to fight cancer cells.

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/immunotherapy drugs 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 recurs. For example, rituximab.

Other drugs used for lymphoma include: antibody-drug conjugates such as brentuximab or polatuzumab; BCL-2 inhibitors such as venetoclax; proteasome inhibitors such as bortezomib; histone deacetylase (HDAC) inhibitors such as vorinostat; Bruton's tyrosine kinase (BTK) inhibitors such as ibrutinib; PI3K inhibitors such as idelalisib; the immunomodulatory and targeted therapy drug lenalidomide; immunotherapy drugs like nivolumumab.

How are the drugs given?

Targeted and immunotherapy drugs 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 cancer drugs 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. You can also download it from **www.cancer.ie**

Ask your doctor if there are any targeted or immunotherapy drugs available to treat your cancer or if there are any clinical trials that are suitable for you.

Immunotherapy developments

In recent years, there have been major developments in immunotherapy treatments. These include:

CAR T-cell therapy

T cells are a type of white blood cell called lymphocytes, which help to fight infections and diseases. It can be difficult for T cells to tell the difference between cancer cells and normal cells. This means that T cells sometimes cannot recognise or attack cancer cells properly. Chimeric antigen receptor (CAR) T-cell therapy is a type of immunotherapy that works by changing your T cells so that they are better able to recognise and attack cancer cells.

During this treatment, T cells are removed from your body. They are sent to a special laboratory where they are modified (changed) to help them recognise and target the cancer cells. These modified cells are called CAR T cells. They are returned to your body through a drip. They then hopefully find and destroy the cancer cells.

Bispecific antibody therapy

This is a type of targeted immunotherapy that also involves T cells. Bispecific antibodies are specially designed antibodies that act like a ‘bridge’ to connect your T-cells directly to the lymphoma cancer cells. Once they are attached, the T-cell releases substances to kill the lymphoma cells.

If you would like more information on these therapies, speak to your doctor or specialist nurse. You can also speak to a cancer nurse by visiting a Daffodil Centre or calling our Support Line on 1800 200 700.

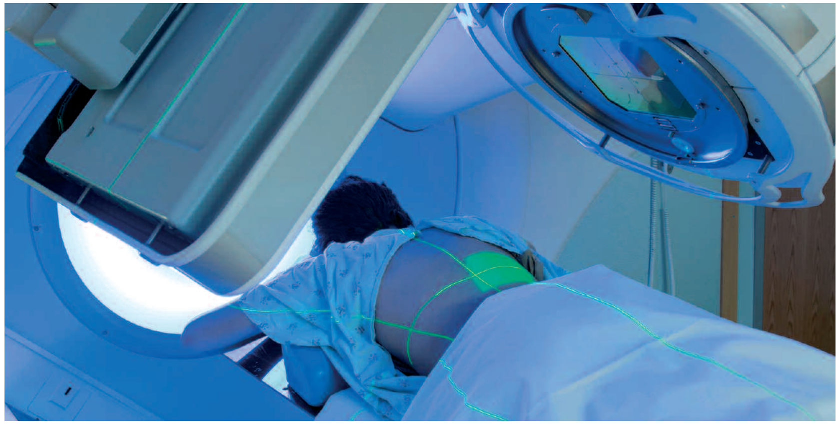
Radiotherapy

- 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 can be used for high-grade lymphomas. It is a treatment where high-energy X-rays are aimed at a cancer to cure, shrink or prevent it from coming back. The X-rays are only aimed at the lymphoma.

Radiotherapy may be used on its own when the lymphoma is found in 1 or 2 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, if it is has recurred or if treatment has failed.
- The treatment destroys all the blood cells in your bone marrow and provides you with stem cells. These stem cells are blood cells at their earliest stage of development that will grow into new healthy blood cells.

How do transplants work?

There are 2 types of transplants performed in patients with high-grade lymphomas:

- Autologous (using your own stem cells)
- Allogeneic (using stem cells from a donor)

Autologous transplants are more commonly used in lymphomas.

An autologous transplant works by giving high doses of chemotherapy to destroy any remaining lymphoma cells. However, as a side-effect of this chemotherapy, the blood cells in your bone marrow are also destroyed. Stem cells that have previously been collected from you are returned to you. This allows the blood cells of the bone marrow to recover after high-dose chemotherapy.

An allogeneic 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. These stem cells are usually taken from a donor's blood – often a brother or sister whose tissue type is a match to yours – but they may also be taken from their bone marrow.

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 to treatment (refractory)
- If the lymphoma has returned (recurred)
- 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 our booklets ***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, you may be given a different dose of a drug or you may be given 2 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**

Managing side-effects and symptoms

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common with cancer. Usually fatigue starts to improve 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.

Hints and tips: Fatigue

- **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 ***Understanding 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 may help too (see page 114).
- **If you are not sleeping well, have 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 to have naps in the earlier part of the day.
- **Try complementary therapies** like meditation, acupuncture or aromatherapy, 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 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. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again. You can also get a copy of our booklet, ***Understanding sex, sexuality and cancer***, from our Support Line, Daffodil Centres or on **www.cancer.ie**

There is no set time for you to be ready to have sex again. It varies from person to person.

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 a minimum of 6 months or 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 try not 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. Our booklet, ***Understanding sex, sexuality and cancer***, can be viewed or downloaded on **www.cancer.ie**

Will treatment affect my fertility?

Your fertility may be affected by some cancer 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. They 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, acupuncture, reflexology 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. Tell them also if you're using or considering using over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

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.

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.

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?

After your cancer treatment has ended, you will have regular check-ups at the hospital. This is called follow-up. It includes clinic visits, for a physical exam, blood tests and occasionally scans.

The type of follow-up you have and how often you have it will depend on your treatment plan. Usually, follow-up continues for up to 5 years after completing your treatment. 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 anything.

It's important to understand your follow-up and go to all your follow-up appointments so your doctor can check for signs of the cancer coming back (recurrence). They can also check for signs of new side-effects that may develop after you have finished treatment. These are called late side-effects. For example, thyroid, bone or heart problems and fertility issues. 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.

Life after treatment

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 115 for other ways to get emotional support.

Be involved in your healthcare

- 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.

Look after your health

- After treatment you may feel tired and fatigued for a number of months. This is normal. Allow yourself time to fully recover and gradually return to your usual activities or to work.
- Avoid infections. See page 77 for advice. It is important to be up to date on vaccinations after completing your cancer treatment. Ask your doctor for advice on all vaccinations available to you.

- Cancer treatment may sometimes cause problems later in life, for example weaker bones (osteoporosis) or heart issues. It is important to have a routine visit with your doctor annually to check your blood pressure and cholesterol levels. If you have had a lot of steroids as part of your cancer treatment, you may be recommended to have a DEXA scan to check your bone health.
- Always tell doctors, dentists and other healthcare professionals about your history of lymphoma. Even if your lymphoma is in complete remission, healthcare professionals may wish to take extra precautions when treating you.
- A history of lymphoma increases the risk that you could develop other cancers. If you notice any new or unusual symptoms, you should go to your doctor to have them checked out.

After-treatment workshops

You might like to join our free **Life and Cancer - Enhancing Survivorship (LACES)** workshops when you have completed treatment or have started maintenance therapy. Developed in partnership with the National Cancer Control Programme, LACES covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on supports and services to help you. Call our Support Line or visit a Daffodil Centre for details.

Living a healthy lifestyle

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and 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

It's also important to have any vaccines recommended for you. For example, flu and pneumonia. Some vaccinations may not be suitable if you've had cancer treatment, so check with your doctor which you should have and make sure you get them.

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.

Planning ahead

Many people find it puts their mind at rest to have medical plans in place and to sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead enables people to concentrate on their illness and its treatment knowing that their wishes and desires are clearly documented should a need arise.

Planning ahead might include:

- Thinking about how you feel about different types of medical treatment, including if you want to stop treatment at any stage or carry on for as long as possible.
- Writing an advance care directive. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- Picking someone to make medical decisions for you if you are not well enough.
- Making a will.
- Talking about what you want to your family, friends, carers and healthcare providers.
- Sorting financial affairs.

Who can help me plan?

Think Ahead is a planning pack with different sections and easy-to-read forms. You can fill in your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at **www.hospicefoundation.ie**

Coping and emotions

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.

The Irish Cancer Society funds professional one-to-one counselling remotely or in person at many local cancer support centres. To find out more about counselling, call our Support Line on 1800 200 700, email supportline@irishcancer.ie or visit a Daffodil Centre.

> "Counselling has helped me with every part of my life. I feel I have a future now."

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 138 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 and facing similar challenges. 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 doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services if they are available at your hospital.

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.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

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

Positive feelings

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 you to find ways to talk about your cancer and to ask for the help and support you need.

Changing relationships

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.

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet ***Talking to children about cancer***, which has practical advice about how to talk to children of different ages.

Supporting someone with cancer

How you can help

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 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. The Irish Cancer Society funds professional one-to-one counselling for friends and family members remotely and through many local cancer support centres. See page 114.

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.

How to talk to someone with cancer

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

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

Support for you

Our cancer nurses are there to support you. 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**

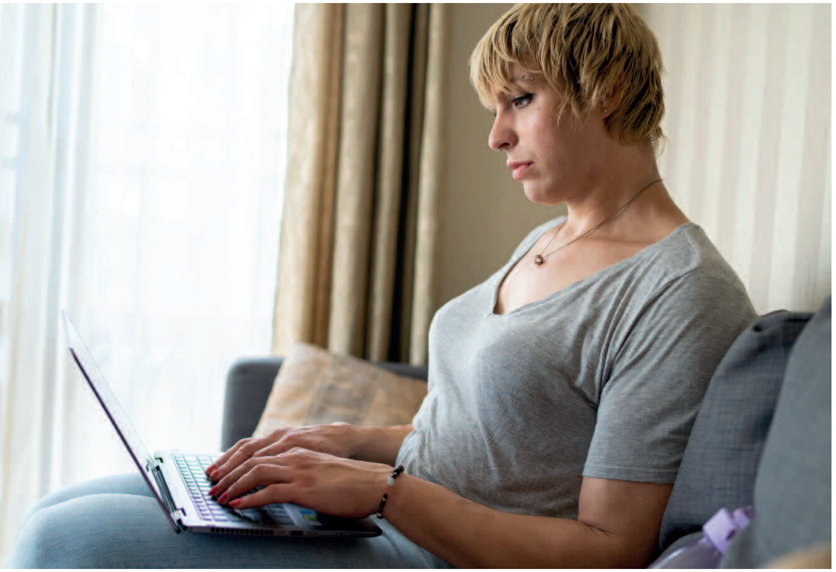
Free copies are available from our Daffodil Centres or the Support Line, or download it from our website **www.cancer.ie**

Support resources

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.



Irish Cancer Society Welfare and Supports Team

We provide appropriate supports and advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis/returning to work**
- **Housing and homelessness issues**

We can tell you about the public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having an Irish Cancer Society Welfare Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. Our nurses will chat with you and confirm if a discussion with one of our Welfare Officers or other supports might be of help.

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: (01) 704 3000 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 keep a copy of completed forms, so take a photo or photocopy them 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 072 000 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 135 for more details of our Transport 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.

Money and finances

Go to **www.cancer.ie** and see our **Welfare and support** 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 website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Team may also be able to help (see page 128).

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Welfare and Supports Team (see page 128)

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am-5pm.

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of this service, please go to **https://www.cancer.ie/Support-Line-Video-Form**

You can also email us at any time on supportline@irishcancer.ie

Daffodil Centres

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

This is a walk-in service; you do not need an appointment. For opening hours and contact details for each of the Daffodil Centres, go to **www.cancer.ie** and search 'Daffodil Centres'.

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

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our telephone interpreting service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on 1800 200 700, Monday to Friday 9am-5pm, or contact your nearest Daffodil Centre.

Tell us in English the language you would like. You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.

We will connect you to an interpreter.

The interpreter will help you to speak to us in your own language.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

For more information on Peer Support, search 'peer support' at **www.cancer.ie**

Patient Education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person in one of our 13 Daffodil Centres nationwide or online. To register for a place at one of our patient education workshops, call our Support Line on 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie. You can also learn about different treatments by watching our patient education videos at **www.cancer.ie/our-services/patient-education**

Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support 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.

For more information about what's available near you, visit **www.cancer.ie/local-support**, contact your nearest Daffodil Centre or call our Support Line on 1800 200 700.

Transport Service

We provide patient travel and financial grants for patients in need who are in cancer treatment.

- Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for radiotherapy patients attending University Hospital Cork and the Bons Secours Hospital, Cork for treatment.
- **Travel2Care** is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for the fund if they are travelling over 50km one way to a national designated cancer centre or approved satellite centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these services please contact your hospital healthcare professional, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

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 night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

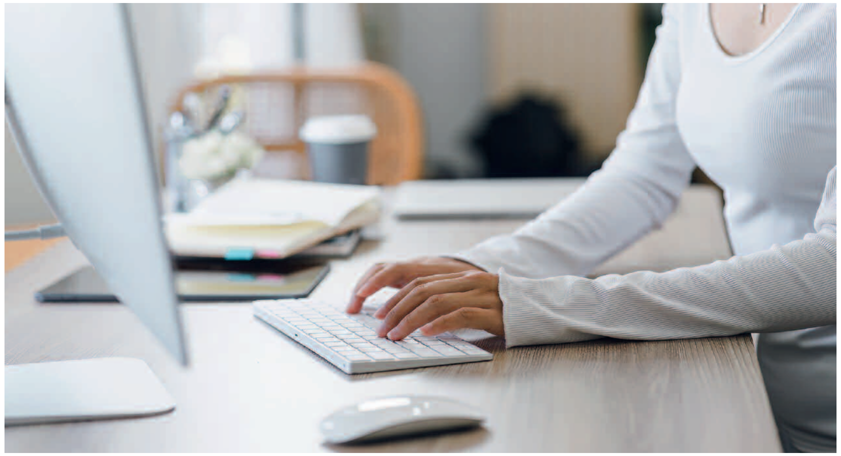
For more information, please contact the healthcare professional who is looking after your loved one.

> “We were really lost when we brought Mammy home from the hospital and the night nurse’s support was invaluable. She provided such practical and emotional support.”

> “Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.”

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also Freephone our Support Line or call into your nearest Daffodil Centre for a free copy of any of our publications.



To find out more about the Irish Cancer Society’s services and programmes:

- **Visit us at www.cancer.ie**
- **Call our Support Line on Freephone 1800 200 700**
- **Email our Support Line at supportline@irishcancer.ie**
- **Contact your nearest Daffodil Centre**
- **Follow us on:**
  - **Facebook**
  - **X**
  - **Instagram**
  - **LinkedIn**

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, their partners, families and carers, during and after treatment, many of which are free. For example:

- Professional counselling (the Irish Cancer Society funds free one-to-one counselling through many local support services)
- 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 aromatherapy, reflexology and acupuncture
- Specialist services such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- Mind and body sessions such as 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'.

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.

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's.

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 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.

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.

Monoclonal antibody: Treatment using a laboratory-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.

Refractory disease: When the lymphoma does not respond to the first course of treatment or comes back very quickly afterwards.

Recurrence/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: Tests that measure the size of your cancer and to see if it has spread.

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

Notes/Questions

Notes/Questions

Acknowledgments

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

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The following sources were used in the publication of this booklet:

- *National Cancer Strategy 2017-2026,* National Cancer Control Programme (published 2017, updated 2024)
- *Cancer in Ireland 1994-2022,* National Cancer Registry Ireland (2024)
- *Cancer Nursing: Principles and Practice,* CH Yarbro, D Wujcik, B Holmes Gobel. Jones & Bartlett Learning, 8th Ed (2018)

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The Irish Cancer Society is a registered charity, number CHY5863.

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit **www.cancer.ie** if you want to get involved.

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 Peer 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

Did you like this booklet?

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

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie