Irish Cancer Society

### Understanding

# Hodgkin lymphoma

Caring for people with cancer

Understanding

# Hodgkin lymphoma

This booklet has information on:

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

## Useful numbers

Specialist nurse

Family doctor (GP)

Haematologist

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Emergency

Hospital records number (MRN)

# Contents

# Fast facts

## Can my cancer be treated? Page 35

Yes. Hodgkin lymphoma can be treated with chemotherapy and other cancer drugs, radiotherapy and occasionally with a stem cell transplant.

## Will I be OK? Page 32

Many people have no further problems after their first treatment for Hodgkin lymphoma. Even if it comes back (recurs), it can still be treated successfully with chemotherapy.

## What kind of treatments might I have? Page 51

Chemotherapy, radiotherapy and high-dose chemotherapy with stem cell support are used to treat Hodgkin lymphoma. You may need one type of treatment or a combination of treatments.

## Are there any side-effects from treatment? Page 75

Some treatments can cause side-effects, but they usually go away after you finish treatment. You can read about the different treatments to learn more about possible side-effects.

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

## We're here for you Page 113

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 to speak to a nurse. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 113 for more about our services.

## Reading this booklet

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

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

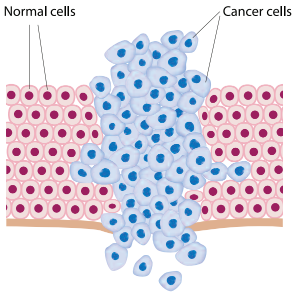
### About our information

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 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.

# About Hodgkin 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 of different types of blood cells, which are made in the bone marrow in the middle of our bones. There are three 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 do, like fighting infections or clotting your blood when you're cut.

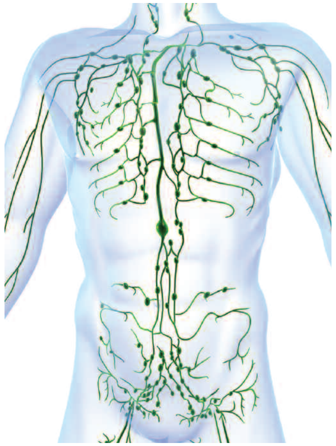
  There are three main types of blood cancers: lymphoma, leukaemia and myeloma. This booklet is about lymphoma. Lymphoma is cancer of the lymphatic system.

# What is the lymphatic system?

The lymphatic system is part of the body's immune system, which protects us from infection and disease. It is made up of lymph nodes connected by tiny tubes called lymph vessels.

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 two types of lymphocytes, B-cells and T-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 and tummy.
- **The spleen:** Helps to filter out damaged cells from the blood and also to fight infection.
- **Other body organs:** Your tonsils, adenoids, thymus, spleen 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 cancer of your lymphatic system. Lymphoma happens when lymphocytes (a type of white blood cell) grow in an abnormal way. The abnormal cells start to collect in your lymphatic system, particularly the lymph nodes. This causes swellings, known as lymphomas.

There are different types of lymphoma. They all start with a cancerous lymphocyte cell.

Knowing the type of lymphoma you have will help doctors decide which treatment will work best for you.

## What is Hodgkin lymphoma?

Lymphomas are described as either Hodgkin lymphoma or non-Hodgkin lymphoma. Most lymphomas are non-Hodgkin. About 1 in 5 is Hodgkin lymphoma.

Hodgkin lymphoma is identified by the way the lymphocyte cells look under the microscope. With Hodgkin lymphoma, lymphocytes are enlarged. These abnormal lymphocytes have two nuclei and are known as Reed-Sternberg cells. The cells are named after two scientists called Reed and Sternberg. Reed-Sternberg cells are found only with Hodgkin lymphoma.

This booklet is only about Hodgkin lymphoma. For a free booklet on non-Hodgkin lymphoma, call our Support Line on 1800 200 700 or download it from our website **www.cancer.ie**

# What are the types of Hodgkin lymphoma?

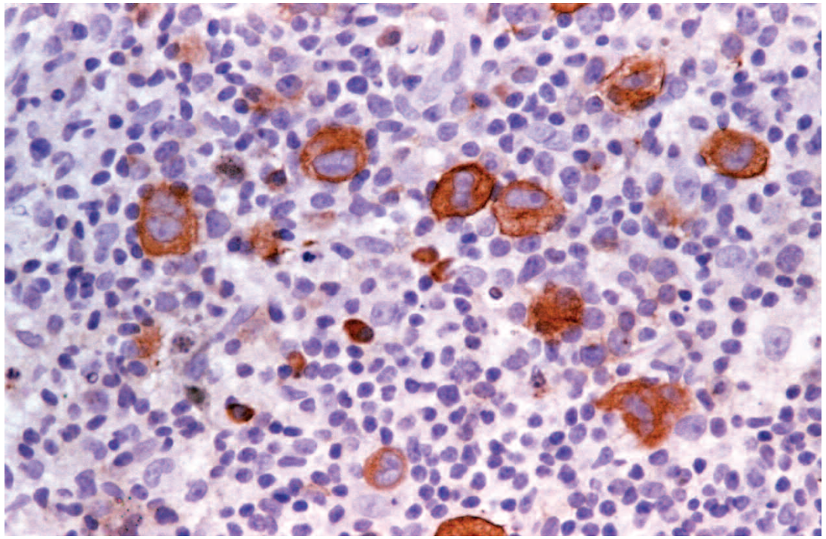
Hodgkin lymphoma is divided into two types:

- **Classical Hodgkin lymphoma**
- **Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)**

These types describe the disease in more detail, such as what the affected lymph nodes look like under the microscope and what other cells are present. In each type, Reed-Sternberg cells are present. The amount of Reed-Sternberg cells can vary between the types of lymphoma and can be mixed with many normal cells.

## Classical Hodgkin lymphoma

Most cases of Hodgkin lymphoma are of the classical type. Classical Hodgkin lymphoma is divided into four subtypes, the most common of which is called nodular sclerosis. It is usually found in the early stages when a lymph node becomes enlarged.



Classical Hodgkin lymphoma with Reed-Sternberg cells (in brown)

## Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

This type of lymphoma is very rare, accounting for only 1 in 20 of all Hodgkin lymphomas. It is usually diagnosed at an early stage and is usually slow growing. It tends to occur more in men and is often diagnosed in older people but can also occur in young adults. When seen under the microscope, there are some abnormal cells that look like popcorn, but few Reed-Sternberg cells. Although slow growing, over time NLPHL can transform into a form of aggressive non-Hodgkin lymphoma known as diffuse large B-cell lymphoma (DLBCL).

For more information about the types of Hodgkin lymphoma, call our Support Line on 1800 200 70 or visit a Daffodil Centre.

# How common is Hodgkin lymphoma?

Hodgkin lymphoma is a rare cancer that can occur at any age, but most often occurs in young people between the ages of 15 and 30 and in people aged 65 and over. About 155 people are diagnosed with it in Ireland each year.

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

# 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 okay 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 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

## 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

### Note: If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.

## Questions to ask your doctor

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

What exactly is Hodgkin lymphoma?

What is the stage of my disease?

What type of treatment do I need?

How successful is this treatment for my cancer?

Are there other treatment options? Why is this one best for me?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

What side-effects or after-effects will I get?

Should I expect any late or long-term side-effects?

Do I need to use contraception during my treatment?

What will happen if I, or my partner, get pregnant?

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

Should I eat special foods?

Will treatment affect my normal life and activities?

How will I know if my illness has come back?

# Diagnosis and further tests

## Being diagnosed with Hodgkin lymphoma

Hearing that you have cancer 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

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

- Ask to speak to the cancer (oncology) liaison nurse, haematology nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society 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.
- Talk to other people affected by cancer. Join our online community at **www.cancer.ie/community**
- Go to your local cancer support centre. For more information, see page 120.

> “However you feel, you are not alone.”

## 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. See also, page 120 for information about support centres in your area.

# Tests after diagnosis

- Tests you may have include blood tests, scans and bone marrow tests.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

You might need more tests after you have been diagnosed with Hodgkin lymphoma.

The tests give doctors more information about your cancer. Some tests may also be used to see how well you are responding to treatment.

**Tests you may have include:**

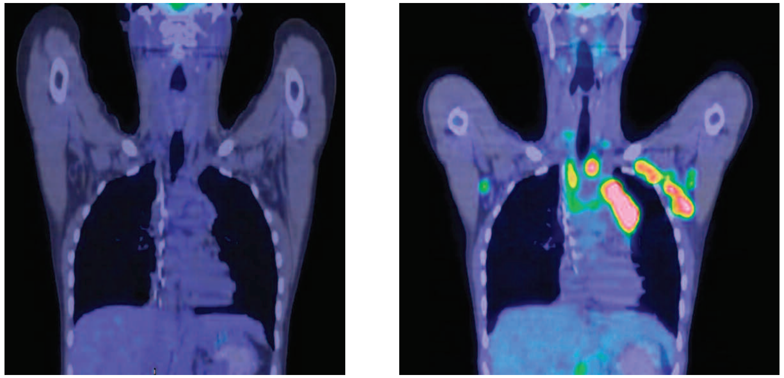
## Blood tests

Your blood will be tested to see how many red blood cells, white blood cells and platelets are in your blood. Your blood will also be checked regularly for a protein called lactate dehydrogenase (LDH). If the level of this protein is high, it can help identify cell damage sometimes caused by cancer.

Other blood tests can check how well your kidneys and liver are working. These tests will also be done regularly if you are having chemotherapy, to check the effects of the treatment on your body.

## PET scan

A PET scan can show if the cancer is in other tissues and organs. A low dose of radiotracer (radioactive sugar) is injected into your arm. An hour or so later you will have a scan. The PET scan uses the radiotracer to 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. Before the scan, you may have to fast (not eat) and drink only plain unflavoured water for a few hours.



Left: A PET scan with no lymphoma cells.
Right: PET scan showing lymphoma cells (in pink) in left armpit and upper chest

You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

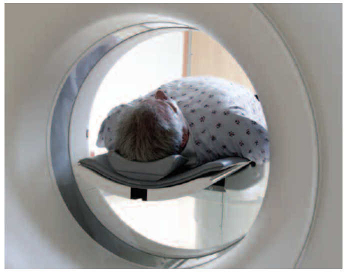
PET scans are important for managing Hodgkin lymphoma. They can show how well the cancer is responding to treatment.

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

Drink plenty of fluids and empty your bladder regularly after the scan; this can help flush the radiotracer from your body.

## CT scan (CAT scan)

This is a special type of X-ray that gives 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.

## MRI scan

This is a scan that uses magnetic energy and radio waves to build up a picture of the tissues inside your body. MRI scans can produce images from different angles all around the body. You will need to complete a form before the test to ensure that it is safe for you to have a MRI scan.

During the test you will lie inside a tunnel-like machine. The length of time the test takes depends on the number of images that are needed and the area of the body being scanned. It can take between 15 and 90 minutes.

Some people are worried 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/headphones to help block out the sound. You might get an injection before the scan to show up certain parts of your body. It is important that you keep as still as possible during the scan.

During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home after the scan.

For most scans you will be alone in the treatment room, but the medical staff can still see you and hear you. If you need anything, just speak or raise your hand.

## Ultrasound scan

This is a scan which uses sound waves to create a picture of the inside of your body. It is done in the X-ray department of the hospital. The scan is painless and only takes a few minutes.

Some gel is put on your abdomen (tummy) and then a small hand-held device is passed over the gel – this can check if your liver is affected by the cancer.

## Other tests

Some chemotherapy drugs might weaken your heart muscle. In this case, you might need an echocardiogram (echo) scan before treatment to check how well your heart is working. An echo is a type of ultrasound scan used to look at the heart and nearby blood vessels.

Sometimes chemotherapy drugs may affect your lungs and cause a cough, chest pain or shortness of breath. You may have breathing tests (pulmonary function tests) to measure how well your lungs are working before you start treatment. These usually involve you breathing into a measuring device. Your doctor will give you more advice.

### Waiting for test results

It usually takes up to 2 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

# Staging Hodgkin lymphoma

- Staging describes the extent of the cancer and where in your body is affected.
- Staging helps your doctor to decide the best treatment for you.
- Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis are usually done to help the doctor to stage your cancer. To stage your illness, the doctors will take account of any symptoms you have as well as how many places in your body are affected.

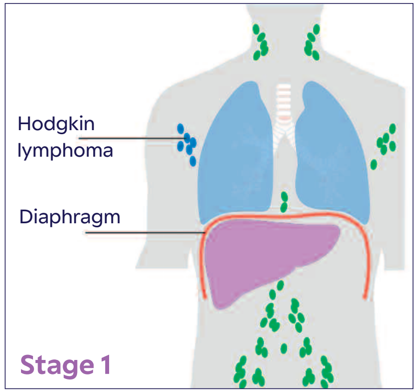
Hodgkin lymphoma usually starts in the lymph nodes in the upper part of the body, such as in the neck, armpits or chest. The diaphragm is a thin layer of muscle that separates the chest area from the abdomen. When staging Hodgkin lymphoma, it is important to see if the lymphoma is above or below the diaphragm. Staging is also based on whether the cancer is within the lymphatic system, or is outside the lymphatic system (extranodal) in an organ, blood or bone marrow. Staging is very important, as it helps your doctor to decide the best treatment for you.

# How is Hodgkin lymphoma staged?

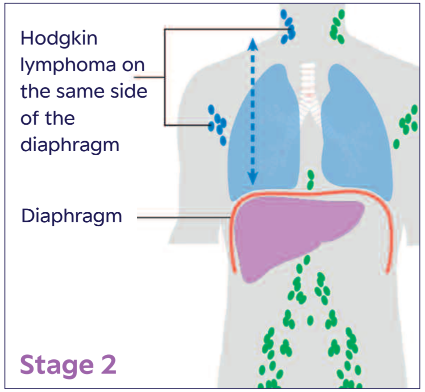
Hodgkin lymphoma is defined as stages 1 to 4, depending on how many lymph nodes or organs are involved. Your disease will also be given a letter code: A, B, E or S (see next page). The full staging will include a number and a letter. For example, early-stage Hodgkin lymphoma may be staged at 1A, meaning you have one group of lymph nodes affected and you have no symptoms. See below for further explanations of each number and letter.

## Number stages

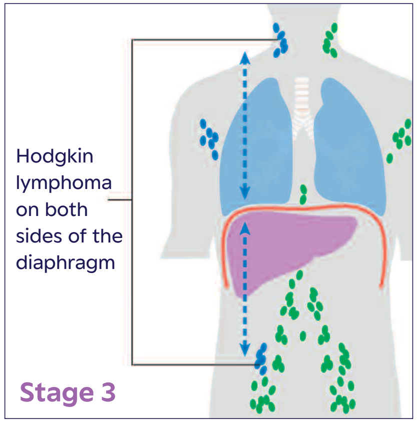
- **Stage 1:** One group of lymph nodes is affected on one side of your diaphragm (either above or below your diaphragm)



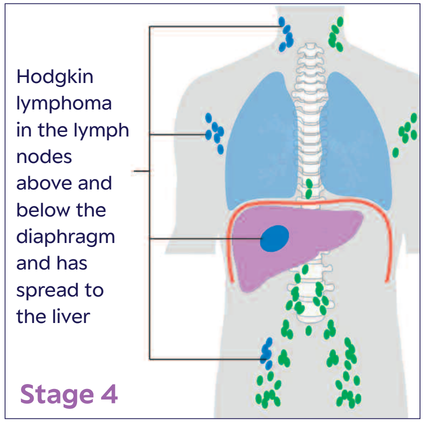
- **Stage 2:** Two or more groups of lymph nodes are affected either above or below your diaphragm



- **Stage 3:** Lymph nodes are affected above and below your diaphragm



- **Stage 4:** Lymphoma can be found in organs outside your lymphatic system or in your bone marrow



Images courtesy of Cancer Research UK / Wikimedia Commons

In general, the lower the number, the less advanced the cancer.

### Letter codes

- **A:** No symptoms
- **B:** You have 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)
- **S:** The lymphoma is in your spleen

## Early- and advanced-stage lymphoma

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

> 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:

- **Get the information 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 even 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 again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

# Treatment overview

## How is Hodgkin lymphoma treated?

- Chemotherapy, radiotherapy and high-dose chemotherapy with stem cell support are used to treat Hodgkin lymphoma.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you receive will depend on:

- The stage of the disease
- Your age and general health
- Your symptoms, if any, such as weight loss or fever

In many cases the lymphoma is curable and tests will show no signs of disease after treatment. This is called remission.

## Types of treatment

Some people only need one type of treatment, while others need a combination of treatments. Most treatments are outpatient treatments, so you will not need to stay in hospital overnight. The types of treatments usually recommended include:

**Chemotherapy:** Chemotherapy is the use of drugs to kill cancer cells. It can be given on its own or with other treatments, for example, steroids. See page 53 for more details.

**Radiotherapy:** Radiotherapy uses X-rays to destroy cancer cells. See page 61 for more details.

**Targeted therapies:** These drugs work with your body to fight cancer. Targeted therapies can be given to people with Hodgkin lymphoma, but usually only if it proves difficult to treat or if it comes back after treatment. See page 65 for more details.

**Immunotherapy:** Immunotherapy drugs help your immune system to work better to fight cancer cells. Immunotherapy is mostly used if the lymphoma hasn't responded to previous treatment or it comes back after treatment. See page 67 for more details.

**High-dose chemotherapy treatment with stem cell support:** This treatment might be given if Hodgkin lymphoma comes back after your first treatment or if the cancer has not responded to the treatment. It allows high doses of chemotherapy to be given to kill the lymphoma cells. See page 68 for more details.

## Stage of disease and treatment

Your treatment can also vary depending on the stage of the disease:

**Early-stage lymphoma:** In some rare cases you may not need to start treatment straight away, as the lymphoma may be slow growing. In these cases, your consultant will monitor your symptoms and may wait a while until treatment is required.

Some people with early-stage Hodgkin lymphoma will have chemotherapy alone. Or, your course of chemotherapy may be followed by radiotherapy. Alternatively, you may have radiotherapy on its own. How long your radiotherapy treatment lasts depends on where the cancer is.

**Advanced-stage lymphoma:** If you have advanced Hodgkin lymphoma, you will be treated with chemotherapy over 4-6 months. In some cases, the course of chemotherapy is followed by radiotherapy.

**Refractory/recurrence:** For a small number of people, the Hodgkin lymphoma may not respond well enough to treatment (refractory) or it may return (recur). In this case, targeted therapies, immunotherapy, more chemotherapy and possibly radiotherapy may be suggested. Sometimes high-dose chemotherapy with stem cell support may be an option.

## What is remission?

Remission means the lymphoma is no longer active and is under control. It has been reduced or is gone completely. A long-term remission can be either partial or complete.

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

**Complete remission:** There are no visible signs of the lymphoma after treatment. The longer you are in complete remission, the less likely it is that the lymphoma will come back.

## Specialist cancer centres

Hodgkin lymphoma is treated in specialist cancer centres in Ireland. The staff at these centres are experienced in managing patients with Hodgkin lymphoma. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan.

### Multidisciplinary team

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

### Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. 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 explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on Freephone 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 the treatment if you are unsure when it's first explained to you.

### Second opinion

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

### Accepting treatment

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

## Who will be involved in my care?

Some of the following health professionals may be involved in your care.

**Haematologist:** A doctor who specialises in disorders of the blood and lymphatic system.

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

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

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

**Pathologist:** A doctor who examines any tissue samples taken and helps to reach a diagnosis.

**Oncology or haematology liaison nurse/clinical nurse specialist:** A specially trained nurse who works in a cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout treatment.

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

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

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

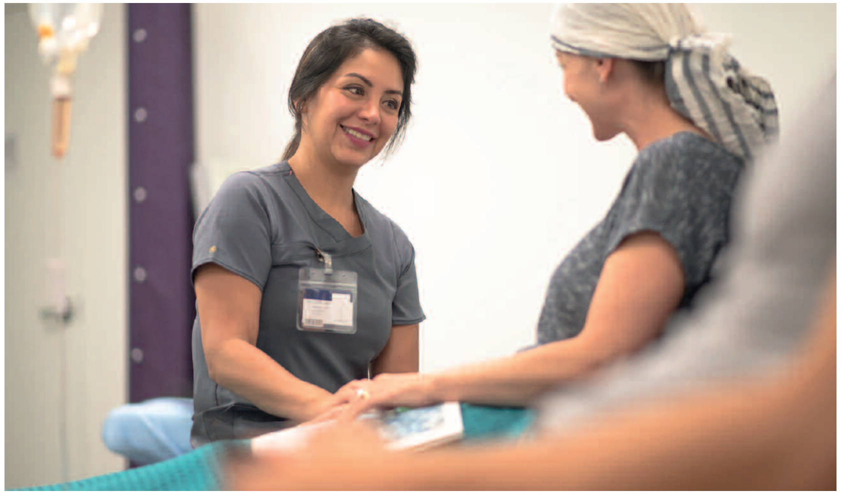
**GP (family doctor):** While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

**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 emotional and personal matters and can help you to make decisions.

**Counsellor:** A person trained to give you emotional support and advice when you find it difficult to come to terms with your illness.



**Community health services:** This includes 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.

## Giving consent for treatment

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

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

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

### Individual treatment

**You may notice that other people with 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 any previous treatments you have had and your general health. Everyone's treatment needs will be different. Don't be afraid to ask your doctor about your treatment.**

## Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

If you are worried, talk to your doctor. You can also call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

You might like to focus on your health and wellbeing while you're waiting for treatment. For example, eating well and staying active (see page 46).

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on cancer treatments, including what to expect and how to manage side-effects.

# How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

## Eat well

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

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better, so you can finish your course of treatment
- Cope better with side-effects of treatment
- Reduce your risk of infection and other complications
- Recover faster

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**

## Keep active

If you are able, it can really help to stay active before, during and after your treatment. Keeping up or increasing your activity levels 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 – build up gradually.

## 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, such as chest infections
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work
- Not smoking can help you to heal better after surgery
- Not smoking reduces your chance of further illness

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

You will have a better quality of life if you give up smoking.

## Other ways to help yourself

### Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

### Involve your family and close friends

Don't keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed.

Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

### Use your support network

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

### Try relaxation and stress management techniques

Therapies like meditation or yoga can help you cope with stress. Some cancer support centres have groups to teach 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.

### Be aware that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

### Try to cope day by day

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

# Types of treatment

# Chemotherapy

- Chemotherapy uses drugs to kill or control cancer cells.
- Chemotherapy can cause a range of side-effects.
- Side-effects normally go after treatment ends.

Chemotherapy is a treatment that uses drugs to kill cancer cells. Medical oncologists and haematologists are doctors who specialise in chemotherapy.

## How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments to give your body time to recover. You will have blood tests before each chemotherapy treatment to check you are well enough to have your planned treatment. Your consultant will discuss your treatment plan with you before treatment starts and your clinical nurse specialist will give you any extra information you need.

The number of cycles of chemotherapy can vary, depending on the stage of your cancer and how well it is responding to treatment. It usually continues for between 3 and 6 months.

## How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump). It may also be given in tablet form.

You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports, Hickman lines and PICC lines. Usually your treatment will be given in the chemotherapy day unit.

## What kinds of drugs are used?

There are several chemotherapy drugs used to treat Hodgkin lymphoma. Your chemotherapy treatment will depend on the type and stage of your Hodgkin lymphoma. Your doctor may advise a combination of chemotherapy drugs, depending on the stage of the disease. Occasionally you will be given steroids as well (see page 59).

Your doctor or nurse will discuss your treatment with you.

### 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 drug, you can visit the Health Products Regulatory Authority's website at **www.hpra.ie** for 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 Freephone 1800 200 700.

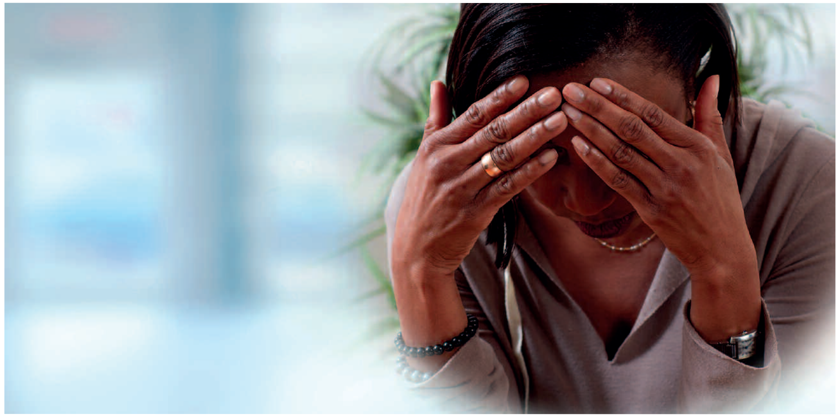
## What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

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

### Fatigue

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



### Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. There are medications that work well to prevent nausea and vomiting.

### Increased risk of infection

Chemotherapy drugs can make you more prone to infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or pain passing urine.

## Hints and tips: Avoiding infections

- **If you have a high temperature, or feel unwell (even with a normal temperature), it is very important to call the hospital straight away – never delay.** Check with your hospital about the temperature advice you should follow.
- **Avoid crowds and close contact,** such as hugging or kissing, with people who have colds, flu or other infections. This includes chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections.
- **Wash your hands often during the day,** especially before you eat and after going to the toilet.
- **Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry,** and the skin of raw vegetables and fresh fruit.
- **Ask your doctor about getting recommended vaccinations** to protect you from infection before and after treatment.
- **Ask your doctor about seeing a dentist** before treatment starts.

### Anaemia

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

### Bleeding and bruising

Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

### Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

### Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. 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).

### Skin and nail changes

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

### Peripheral neuropathy

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

### Changes in kidney or liver function

Some drugs can irritate or damage kidney and liver cells. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.

### Infertility and birth defects

Some of the drugs used to treat Hodgkin lymphoma may cause infertility. It may be temporary or permanent. If you are younger and fertile, chemotherapy can cause birth defects so contraception should be used. See page 82 for more information.

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

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

## Steroids

- Steroids can help some cancer drugs to work better.
- They can also help with side-effects.
- Usually you will be given steroids for short periods with chemotherapy.

Steroids are hormones that are made naturally in your body. Some treatments are more successful when steroids are given too. They can also help with some of the side-effects you might experience. They often help you to feel better quickly.

In most cases, if steroids are given for Hodgkin lymphoma, they are given for short periods with chemotherapy. They can be administered into a vein (intravenously) or given as tablets. There are a number of side-effects to steroids in the short-term. These include:

- Increased appetite
- Feeling more energetic
- Stomach upsets
- Finding it hard to get to sleep

If you are taking steroid tablets, it is better to take them as early in the day as possible. Take them no later than 4pm if you find it hard to sleep at night. And take them with food, if possible.

### Other side-effects

If you are taking steroids for some time, there may be other temporary side-effects. For example:

- Puffy eyelids, hands, fingers and feet
- Raised blood pressure
- Increased sugar in your blood
- Mood or personality changes, such as feeling very happy, excited or angry.

If you develop high blood glucose levels (blood sugar), your doctor will prescribe treatment. This will need to be taken daily to bring your blood glucose levels back to normal. For this and other side-effects, the dose of steroids you are taking may need to be reduced.

Sometimes your treatment might involve taking steroids for a longer time. This can lead to weight gain and low resistance to infection. These side-effects are temporary and will gradually disappear as the steroid dose is reduced.

Usually you come off steroids gradually to allow your body to slowly get used to being without them. Ask your doctor or nurse for more information about steroids. You should always carry a card with you stating that you are taking steroids. This information would be very important if you suddenly became ill.

## Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- Radiotherapy is most useful when the Hodgkin lymphoma is only in one part of the body.
- Any side-effects normally go once your treatment is over, but some can last a long time or develop later on.

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

Radiotherapy may be given
- On its own to try to destroy the cancer cells
- With chemotherapy to make the treatment work better

Radiotherapy can also be used to control and relieve symptoms. This is called palliative radiotherapy.

## External beam radiotherapy

The radiation comes from machines which aim rays directly at the cancer site. The machines are called linear accelerators.

### Planning your external radiotherapy treatment

Radiotherapy must be carefully planned so that the highest dose is given to the area affected by cancer and as little as possible to the nearby cells.

You will have a CT scan to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Lymphoma often affects the lymph glands around your head, neck and upper chest. If you are having radiotherapy to your head or neck region, you will need to wear a mask to keep your head completely still during treatment. The mask is moulded from plastic to the shape of your face.

### Making your mask

You will need a plastic mould or mask fitted before treatment is given. Marks are put on the mask to show where treatment will be given. The mask keeps your head still. It can be made from clear plastic (Perspex) or thermoplastic.

## Getting your treatment

Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. As a result, the centre may be some distance from the hospital where you received surgery or chemotherapy.

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day.

External radiotherapy does not make you radioactive. It's completely safe for you to mix with family and friends afterwards, including pregnant women and children.

## How much radiotherapy do I need?

Treatment for Hodgkin lymphoma generally involves between 10 and 20 treatments and lasts between 2 and 4 weeks.

## Side-effects of treatment

Any side-effects tend to affect the area of the body being treated. Lymphoma often affects the lymph glands around your head, neck and upper chest, so the most common side-effects affect these areas.

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

How severe these side-effects are will vary from person to person, depending on the amount of treatment you receive. Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment. Some side-effects are long-term or may even be permanent.

If you feel unwell or have any other side-effects or symptom – during or at any time after treatment – tell your doctor, nurse or radiation therapist.

For more information on radiotherapy and side-effects or a copy of our booklet ***Understanding Radiotherapy***, call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre.

## Targeted therapies

Targeted therapies are drugs that target certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells.

Different targeted therapies work in different ways. Targeted therapies can work to:

- Block or turn off chemical signals that tell the cancer cell to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill them

Targeted therapies may be used as part of your treatment. They are also sometimes used for Hodgkin lymphoma that has come back after treatment or when other treatments haven't worked. You may be given a targeted therapy together with chemotherapy.

Monoclonal antibodies are a type of targeted therapy usually used to treat Hodgkin lymphoma. Monoclonal antibodies trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance. An example is brentuximab, which is used to treat disease that is difficult to treat or that has come back (recurred).

Some drugs are given in tablet form. Others are given into a vein through a drip.

## Side-effects

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include:

- Flu-like symptoms (fever, chills)
- Headaches
- Changes in blood pressure
- Fatigue
- Tummy pain
- Feeling sick
- Diarrhoea

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.

## New targeted therapies

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 71). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

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

# Immunotherapy

Immunotherapy treatment helps your immune system to work better to fight cancer cells. Our immune system is often not good at recognising or clearing cancer cells from our body. Sometimes cancer cells find a way to hide from the immune system, allowing cancer to develop or spread.

Immunotherapy treatments can change special immune cells to help them attack the cancer directly. They can also change other parts of the immune system to make it more difficult for cancer cells to grow or spread.

Immunotherapy tends to be used in cases where your lymphoma hasn't responded to previous treatment or comes back after treatment (recurs).

## Checkpoint inhibitors

The newest class of systemic therapy (cancer treatment that targets the entire body) is a type of immunotherapy called immune checkpoint inhibitors.

A T-cell is a type of lymphocyte (white blood cell) that can be distinguished from other lymphocytes by the presence of a T-cell receptor on the surface of the cell.

The receptor, or protein complex, can turn on an immune response and other proteins turn it off. These are called checkpoints. Cancer cells sometimes find ways to use these checkpoints to hide from the immune system. They do this by making high levels of proteins to switch off T-cells, when the T-cells should really be attacking the cancer cells.

Checkpoint inhibitors work by blocking the proteins that stop the immune system from killing cancer cells. When checkpoint inhibitors block these proteins, this turns the immune system back on and the T-cells are able to find and destroy the cancer cells.

## Side-effects

The side-effects of immunotherapies depend on the drugs being used and vary from person to person. Because immunotherapy acts on the immune system, it can cause inflammation in any part of your body.

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 straight away if you don't feel well or if you are having any symptoms that are troubling you.

# High-dose treatment with stem cell support

For a small number of patients there is a risk of the cancer coming back despite treatment. Others may need more treatment if the first treatment has failed. In this case, high-dose chemotherapy may be given to kill off the lymphoma cells completely. However, giving high-dose chemotherapy will also destroy all your healthy blood cells in your bone marrow.

By collecting stem cells from your blood or bone marrow before the treatment and returning them to you after treatment, they can grow into new healthy blood cells to replace the ones that were destroyed.

## Peripheral blood stem cell transplant (PBSCT)

With this method, the stem cells are usually taken from your bloodstream. Stem cells are normally found in your bone marrow and are the most basic cells from which all other blood cells grow. For example, red blood cells, white blood cells and platelets. Before these stem cells can be collected from your bloodstream they must be moved out of your bone marrow. Drugs are usually given to make your bone marrow produce a lot of these stem cells. For example, chemotherapy and a special drug called a growth factor. As your bone marrow gets overcrowded, the extra stem cells spill into your bloodstream. They are then collected from your bloodstream using a special machine.

This procedure is called a peripheral blood stem cell harvest (PBSCH).

## Moving stem cells into your bloodstream

Chemotherapy is usually given for a day or so to move the stem cells into your bloodstream.

The growth factor is injected under your skin until there are enough stem cells to be collected. You can give the injections yourself or your doctor or nurse will do it for you. Growth factor injections can have side-effects, such as bone pain. It's important to let your nurse or doctor know if you are experiencing this as they can suggest medication that may help.

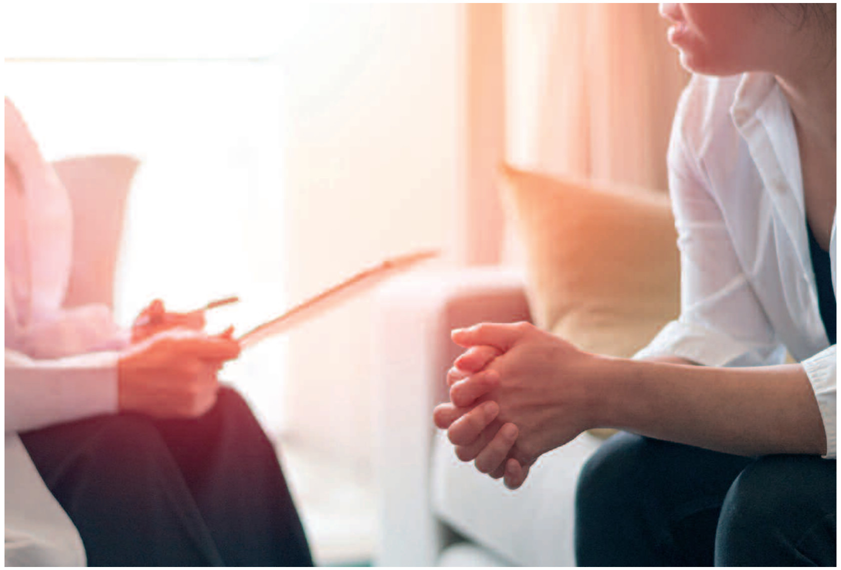
## Collecting the stem cells

When your blood is ready, the stem cells can be collected. This takes about 4–5 hours. Usually it takes one day to collect all the stem cells but sometimes a second day is needed. The stem cells are collected using a central line or a drip placed in large veins in your arms. Blood is taken out through the drip into a machine that separates the stem cells from the rest of your blood. This is called a leukapheresis machine. This procedure is usually carried out in a specialist cancer centre.

The stem cells are collected into a bag and the rest of the blood is returned to you. The stem cells are then frozen and stored until you have had the high-dose chemotherapy.

## Returning the stem cells

After the high-dose chemotherapy, the stem cells are thawed out and returned to you through a drip or central line. These stem cells will help your bone marrow recover from the effects of treatment. This normally takes about 2 weeks. However, it may take 3-12 months before you are fully recovered. You may need to stay in hospital for 2-3 weeks, due to infection or other effects of treatment.



Ask your nurse for more information about this treatment or speak to a cancer nurse on our Support Line 1800 200 700 or at a Daffodil Centre. They can send you a copy of our booklet ***Understanding Autologous Stem Cell Transplants*** or you can download it from our website **www.cancer.ie**

# Clinical trials

Clinical trials are research studies that try to find new or better ways of diagnosing or treating diseases, or reducing side-effects. They can also help to improve a person's quality of life when living with a diagnosis.

Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of the standard treatment, you get a new trial drug. Or you may be given existing treatments used in different ways. For example, 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 Freephone 1800 200 700 or by dropping into a Daffodil Centre.

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

## What if the lymphoma comes back?

Most people have no further problems after their first treatment for Hodgkin lymphoma. Even if it does come back (recurs), it can still be treated with chemotherapy and usually cured.

Sometimes treatment may only be able to control the Hodgkin lymphoma. In this case, it can improve your symptoms and give you a better quality of life. When deciding on treatment, your doctor will consider your general health and where the lymphoma is located. They will also take into account the kind of treatment you have had in the past.

Your doctor may advise different chemotherapy drugs, immunotherapy or targeted therapies that may help. There may also be treatments that you can have as part of a clinical trial (see page 71). Your doctor will tell you if there are any clinical trials that might be helpful for you.

In many cases, treatment can help you to live longer with better control of your symptoms. Your doctor will discuss the best treatment options for you with the healthcare team.

Thanks to recent advances in research and treatments, many people are living longer with cancer and with a better quality of life.

You can also have treatment to help with any symptoms. You may be referred to the palliative care team, who are experts in managing the symptoms of cancer.

### Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness. The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is free for all patients. You don't need a medical card or health insurance.

# Managing side-effects and symptoms

## How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common with cancer. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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

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

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

## Hints 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 96).
- **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 complementary therapies** like meditation, acupuncture or massage, if your doctor says they're safe for you.

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

# 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, aromatherapy and meditation.

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

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

## What's the difference between complementary and alternative therapies?

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

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

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.

## 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.

## More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on Freephone 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**

## Will treatment affect my sex life?

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

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

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can also 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.

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. But you may find it will be some time before you will feel well enough to have sex again after treatment.

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

Many specialists recommend that you wait for up 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. They are well used to taking 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

# Will treatment affect my fertility?

Many people go on to have healthy babies following treatment for Hodgkin lymphoma. However, some treatments for lymphoma and sometimes the disease itself can cause infertility. This infertility may be temporary or permanent.

If you are planning to start a family or have more children in the future, talk to your doctor as soon as possible. If you have a partner, you can visit the doctor together, so that you both understand any options open to you and have a chance to discuss any fears or worries.

Your doctor will tell you if your treatment is likely to cause infertility and if there is anything that can be done so that you can try to have children later on. 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 you think this is an option for you.

Sometimes there may not be time to freeze eggs before treatment starts, as the process can take a few weeks. Many lymphomas can be cured if treatment starts early enough and so the doctors will be keen to start your treatment as soon as possible. Sperm banking (freezing sperm samples) takes less time than freezing and storing eggs.

## Coping with infertility

Coping with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your worries with someone who is a good listener or with a professional counsellor. You can also call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

# After treatment

## What follow-up will I need?

After your cancer treatment has ended you will still need regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and scans.

At first you will see your consultant every 3 months, but these check-ups will become less frequent over time.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. 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 attend your follow-up appointments as they will allow your doctor to check for signs of the cancer coming back (recurrence) and to help with any side-effects that you may have. They can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

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

## Life after treatment

It can take some time to adjust to life after cancer treatment. You may 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 or college and family or friendship 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 97 for other ways to get emotional support.

### After-treatment workshops

You might like to join our **Life and Cancer – Enhancing Survivorship (LACES)** programme when you have completed treatment or have commenced 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 support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

## Living a healthy lifestyle

This may be a good time to focus on your wellbeing and recovery, and concentrate on a healthy lifestyle. Having a healthy lifestyle can help you to:

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of other illnesses

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.

## What if the cancer comes back?

If cancer does come back, it can often be treated again. Your cancer doctor will advise you on what your treatment options are.

## 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 decision about you if you are now 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?

There are many different reactions to getting a cancer diagnosis. There is no right or wrong way to feel and there is no set time to have any particular emotion.

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.

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

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.

> Being diagnosed with cancer 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.

## Hodgkin lymphoma and young adults

While most cancers tend to affect older people, a big proportion of Hodgkin lymphoma cases affect young people between the ages of 15 and 30.

If you're younger, a cancer diagnosis can really turn your life upside down, at a time when you're facing the challenges of establishing your own identity, your social and financial independence and coping with education and work worries.

As you try to get on with the practical business of having treatment and getting well, you might find yourself struggling emotionally as you deal with issues such as:

**Physical changes** – these might include hair loss and weight gain or loss

**Concerns about friendships and relationships** – will your friends understand your diagnosis and support you or will they start avoiding you?

**Feelings such as anger and resentment** – anger at what has happened and resenting having cancer when others do not

**Worries** about what to tell other people

**Fears** that the cancer will come back

It's normal to have some anxiety or strong emotions during and after treatment, but if you are feeling very depressed or angry, it can affect many aspects of your life. Dealing with cancer is probably one of the most stressful situations you will ever be in. It's easy to forget about your emotional health, but it's important to talk to someone about your feelings and get help if you need it.

### It helps to talk

You may feel most comfortable talking to friends and family and people who care about you. On the other hand, you may find it hard to deal with their reactions and prefer to talk to someone less involved in your situation.

You could talk to one of our cancer nurses on our Support Line 1800 200 700 about support groups, or just to chat about how you feel. Or call in to your local Daffodil Centre to talk to a nurse.

Having a chat is a good first step. Our nurses can also tell you about online support groups for young people with cancer.

## 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 free 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 Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

> "Counselling has helped me with every part of my life."

## Ways to get emotional support

**Find out about 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 120 for more about cancer support services.

**Join a support or educational group:** You might find it reassuring to talk to other people who are 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 healthcare team can refer you to psycho-oncology services if they're available at your hospital.

**Get online support:** Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit **www.cancer.ie/community** to join the Irish Cancer Society online community.

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

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

## Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that their diagnosis 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 illness in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet ***Understanding The emotional effects of cancer*** can help to you find ways to talk about your illness 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 and find out how they 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 them, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

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

### Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website **www.cancer.ie** or call our Support Line for free copies of our 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 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 one-to-one counselling for friends and family members remotely or in person at many local cancer support centres. See page 96.

### Find out about support for carers

Find out about groups and organisations for carers. Many local cancer support centres have services for carers too.

## Support for you

Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, ***Caring for someone with cancer***, has lots of information on:

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

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

> "The emotional support I got made a huge difference to me."

## 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 illness. Or you may be afraid of saying the wrong thing. Often what people 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 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 car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

## Practical and financial solutions from the Irish Cancer Society

We provide individualised financial support and practical solutions for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**

We can tell you about 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 a Practical and Financial 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 Practical and Financial Officers might help.

## Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to 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 tests or treatment to check you're covered.

## Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

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

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting.

## If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential.
Call the MABS Helpline 0818 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 117 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 **Managing money** page for information on:

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

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

## Irish Cancer Society services

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
- Transport Service
- Children's Fund (for under-18s)
- Night Nursing
- Publications and website information
- Support in your area
- Practical and financial solutions (see page 110)

## 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. You can also email us any time on supportline@irishcancer.ie or visit our Online Community at **www.cancer.ie/community**

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 the service, please go to **https://www.cancer.ie/Support-Line-Video-Form.**

One of our nursing team will then email you with the time for your video call. The email will also have instructions on how to use Microsoft Teams on your phone, tablet or computer.

## 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 of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.

### Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – 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 Freephone 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

## 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 Freephone 1800 200 700.

## Transport Service

We provide transport 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 patients having radiotherapy treatment at University Hospital Cork and the Bons Secours Hospital, Cork.
- Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre. Travel2Care is made available by the National Cancer Control Programme.

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

## Children’s Fund (for under-18s)

The Irish Cancer Society’s Children’s Fund offers financial support to the parents of children (under 18) diagnosed with cancer. This is to help them with the unexpected expenses that a diagnosis brings, such as travel expenses to cancer treatment appointments, heating bills, childcare costs and home help.

This is a one-off grant of €3,000. It is not means tested. To qualify for the Children’s Fund, the child:

- Must be under the age of 18
- Must have been diagnosed with cancer and is currently receiving treatment
- Must live permanently in Ireland

For more information, contact the medical social worker in your child’s hospital or go to **www.cancer.ie**

## 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 health 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 call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies 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 remotely and 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 massage, 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,** for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

## What does that word mean?

**Abdomen** The part of your body that lies between your chest and hips. Sometimes called the belly or tummy.

**Alopecia** Loss of hair. No hair where you normally have hair.

**Anaemia** Fewer red blood cells in your blood. It can cause tiredness and shortness of breath.

**Antibody** A protein in your body that attacks and kills germs or cells that cause disease.

**Anti-emetic** A tablet, injection or suppository to stop you feeling sick or vomiting.

**Autologous** The use of a person's own tissue, for example, when cells are taken from your bone marrow or blood.

**Benign** Not cancer. A tumour or growth that does not spread.

**Biopsy** Removing a small amount of tissue from your body to find out if lymphoma cells are present.

**Cells** The building blocks that make up your body. They are tiny and can only be seen under a microscope.

**Chemotherapy** Treatment using drugs that cure or control cancer.

**Diaphragm** A 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.

**Lymph node** A small oval or round gland found along the lymph vessels that removes bacteria and foreign particles from your body.

**Lymphocytes** Small white blood cells that help to protect your body against infection and disease.

**Lymph vessels** Tubes carrying lymph that connect to lymph nodes.

**Malignant** Cancer. A tumour that can spread.

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

**Monoclonal antibody** Treatment using a man-made antibody to fight disease.

**Nausea** Feeling sick.

**Oncology** The study of cancer.

**Prognosis** The expected outcome of a disease.

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

**Radiation therapist** A radiographer who plans and delivers the radiotherapy treatment.

**Radiotherapy** The treatment of cancer using high-energy X-rays.

**Remission** When the lymphoma has been reduced or can no longer be found in your body.

**Targeted therapies** Drugs that stop the growth of particular types of cancer cells using your immune system. Also known as biological therapies.

**Staging** Tests that measure the size and extent of cancer.

**Thrombocytopaenia** Fewer platelets in your blood. This can cause you to bleed and bruise easily.

## Notes / questions

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# 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:

- *Hodgkin's lymphoma: ESMO clinical practice guidelines for diagnosis, treatment and follow-up.* European Society for Medical Oncology Guidelines Working Group, Annals of Oncology 29 (Supplement 4): iv19-iv29 (2018)
- *Clinical Practice Guidelines in Oncology: Hodgkin Lymphoma.* National Comprehensive Cancer Network, 2024.
- *National Cancer Strategy 2017-2026,* National Cancer Control Programme (2017)
- *Cancer in Ireland 1994–2021: Annual Statistical Report 2023.* National Cancer Registry Ireland (2023).
- *The Chemotherapy Source Book,* M Perry, D Doll and C Freter, 5th Ed (2012).
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology.* V DeVita, Jr; T Lawrence and S Rosenberg (eds). 12th edition. Wolters Kluwer (2023).
- *Blood.* Journal of the American Society of Hematology. ASH Publications.

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# Join the Irish Cancer Society team

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

## Support people affected by cancer

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

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our 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

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

## Did you like this booklet?

We would love to hear your comments or suggestions.
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