

Understanding

Chemotherapy

Caring for people with cancer

Understanding chemotherapy

This booklet has been written to help you understand more about chemotherapy. It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information here is an agreed view on chemotherapy, how it is given and how it may affect you.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you.



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The Irish Cancer Society is the national charity for cancer care, dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer. This booklet has been produced by Nursing Services of 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.

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First published by the Irish Cancer Society in 2004.
© Irish Cancer Society, 2004, revised 2006, revised 2008
Next revise: 2010



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ISBN 0-95323-690-1

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Introduction

This booklet has been written to help you understand more about chemotherapy. We hope it answers some questions you may have about this type of cancer treatment.

The information is divided into sections on how chemotherapy works, how it is given and how to manage some of the more common side-effects. You are likely to have questions and concerns about your own treatment which this booklet does not answer. This is because there are over 200 different types of cancer and many chemotherapy treatments. It is best to discuss details of your own treatment with your doctor.

At the end of the booklet, you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



Reading this booklet

You do not need to know everything about chemotherapy straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline 1800 200 700, if you wish. Or you can call Action Breast Cancer 1800 90 30 40 or the Prostate Cancer Information Service 1800 380 380. If reading this booklet helps you, why not pass it on to your family and friends who might find it helpful too.

What does that word mean?

Adjuvant chemotherapy	Treatment given soon after surgery and when a diagnosis of cancer is made.
Alopecia	Hair loss. No hair where you normally have hair.
Anaemia	When there are less red blood cells (haemoglobin) in your blood. This can make you feel tired, weak and breathless.
Anti-emetic	A tablet, injection or suppository given to stop you feeling sick or vomiting.
Benign	Not cancer.
Biological therapy	A treatment to help the immune system fight cancer, infections, and other diseases. It is also used to reduce certain side-effects that may be caused by some cancer treatments.
Bone marrow	Spongy material found in bones that make three types of blood cells: red blood cells, white blood cells and platelets.
Cannula	A small tube put into a vein in your arm or on the back of your hand to give chemotherapy drugs.
Central line	A long, thin flexible tube passed through your skin and into a large vein in your chest, neck or groin.
Chemotherapy	Treatment with anti-cancer drugs. Also known as chemo.
Cycle	A chemotherapy period.

Cytotoxic	A drug that can kill cancer cells and healthy cells.
Fatigue	Tiredness.
Haemoglobin	The protein in red blood cells that carries oxygen.
Implanted port	A small round metal or plastic disc that sits under the skin on your upper chest or arm. It is connected to a tube which leads to a large vein just above your heart. Also called a portocath.
Intravenous	Into a vein. Also called IV.
Malignant	Cancer.
Medical oncologist	A doctor who specialises in treating cancer patients with chemotherapy or other drugs.
Nausea	Feeling sick or wanting to be sick.
Neo-adjuvant	Treatment given before surgery to shrink the size of the cancer.
Neutropenia	When there are fewer neutrophils, a type of white blood cell. This can lead to infection.
Oncology	The study of cancer.
Palliative	Treatment given to improve symptoms of cancer, such as pain, pressure or bleeding, and improve quality of life.
PICC line	A peripherally inserted central catheter. This is a thin, flexible tube passed into a vein in your arm and tunnelled through until the end of the tube lies in a large vein near your heart.
Portocath	See implanted port.

About chemotherapy

What is chemotherapy?

Chemotherapy is a treatment using drugs that cure or control cancer. Not all forms of cancer are treated by chemotherapy, as other treatments may work better. Also, some cancers are not sensitive to chemotherapy drugs and so are not used.

The drugs mainly used are **cytotoxic**, which means they can kill both cancer cells and healthy cells in your body. Other drugs, like biological therapies, are aimed directly at specific cancer cells and do not harm normal cells. At present, there are about 70 types of chemotherapy drugs available. These can be given on their own or in combination.

How does chemotherapy work?

Chemotherapy drugs affect how a cancer cell divides and grows. In the centre of each living cell is the nucleus. This is the control centre of the cell. It contains chromosomes that are made up of genes. Each time a cell divides in two to make more cells, these genes must be copied exactly. Once chemotherapy drugs are in your bloodstream, they can reach cancer cells in your body. Chemotherapy damages the genes inside the cancer cell, preventing them from growing.

Some normal cells like those in the lining of your mouth, your bone marrow (which makes blood cells), hair roots and your digestive system also take up these drugs. Healthy cells usually repair the damage caused by chemotherapy but cancer cells cannot and so eventually die. However, damage to the normal cells is usually short term and most side-effects will disappear once the treatment is over.

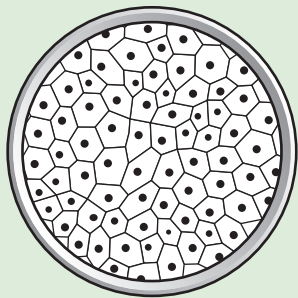
Cancer Helpline 1800 200 700



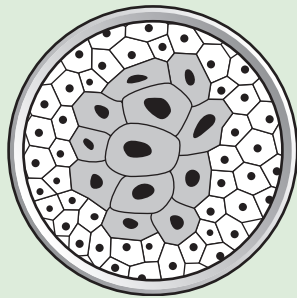
What is cancer?

Cancer is a word used to describe a group of diseases. Each one has its own name. For example: colon cancer, lung cancer and breast cancer. Each has its own type of treatment too.

All the tissues and organs in the body are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue, these cells repair or replace themselves when they get worn out or injured. When cancer occurs, the cells do not behave as normal and keep on growing even when there is no need.



Normal cells



Cancer cells growing

These abnormal cells can form a lump called a tumour. Tumours can be either benign or malignant. In general **benign** tumours do not spread to other parts of the body, so are not called cancer. **Malignant** tumours are sometimes called primary tumours. They are made up of cancer cells that can spread from where they first grew and harm other tissues and organs. This may happen when a cell or group of cells breaks away and enters the bloodstream or lymphatic system (which protects the body against infection) to form a new tumour somewhere else in the body. This is called a **metastasis** (meh-tas-teh-sis) or secondary tumour.

Why is chemotherapy given?

There are many reasons why chemotherapy is given. Sometimes it can be given for more than one reason.

Reducing the size of cancer

Chemotherapy can be given to shrink a cancer before surgery or radiotherapy. This can make it easier to remove during surgery or make radiotherapy work better. If curing the cancer is not possible, it can shrink cancers that are causing pain and pressure.

Curing cancer

Chemotherapy can destroy some cancers and cure the disease. The cancer cells will no longer be present in your body.

Preventing cancer coming back

Chemotherapy may be given after surgery or radiotherapy to destroy any remaining cancer cells. Sometimes cancer cells are so small that X-rays or scans cannot find them.

Controlling cancer

Chemotherapy can help cancer from spreading, slow its growth, or destroy cancer cells that have spread to other parts of the body.

Easing cancer symptoms

If a cure is not possible, chemotherapy may be given to shrink and control the cancer, or to reduce the number of cancer cells. This may then improve your quality of life. This is called palliative treatment.

When is chemotherapy used?

Sometimes chemotherapy is the only cancer treatment used. But usually you will get chemotherapy along with surgery, radiotherapy, hormone or biological therapy.

- **Before an operation or radiotherapy** – chemotherapy can be used before surgery to shrink the tumour and make it easier to remove. This is called neo-adjuvant chemotherapy. Chemotherapy can also be used to make a tumour smaller before radiotherapy so that treatment works better.

- **After an operation** – at times chemotherapy is given after surgery when the tumour has been removed but there is still a risk that some tiny cancer cells remain. In this case chemotherapy will try to destroy these cancer cells and improve your chances of a cure. This is known as adjuvant chemotherapy.
- **During radiotherapy** – chemotherapy can be given at the same time as radiotherapy to make treatment work better. This is called chemoradiotherapy.
- **With advanced cancer** – if cancer has spread to nearby tissues or other parts of your body, chemotherapy can be given to shrink and control the tumour. It can improve your quality of life and also prolong it. Chemotherapy used in this way can help to control symptoms caused by cancer.
- **Before a bone marrow or stem cell transplant** – with some types of cancer, for example, leukaemia, high-dose chemotherapy can be given. This will involve an infusion of stem cells or bone marrow cells afterwards. Normally this happens after the first chemotherapy treatment has destroyed the cancer cells but there is a greater risk of the cancer returning. More information is available in the booklet called *Understanding Bone Marrow and Stem Cell Transplants*. Call the National Cancer Helpline 1800 200 700 for a free copy.

How does my doctor decide which drugs to use?

Your doctor's choice of drug or drugs depends on:

- The type of cancer you have. Some kinds of chemotherapy drugs are used for many types of cancer. Other drugs are used for just one or two types of cancer.
- If you have had chemotherapy before.
- If you have other health problems, such as diabetes, heart disease, kidney disease.

For information on a particular drug, see the Irish Cancer Society website for details: www.cancer.ie

Your doctor may also ask you to take part in a research trial. This is where a new drug is being tested on patients, which has been proved to be safe. See page 26 for more details about research trials.

»»» For information on particular drugs, see the Irish Cancer Society website for more details: www.cancer.ie

Naming chemotherapy drugs

Chemotherapy drugs usually have two names: the generic name and the brand name. The generic name is the chemical name of the drug, for example, paracetamol. The brand name or trade name is the name given by the manufacturer of the drug, for example, Panadol. Sometimes drugs are known by their generic or brand names. Do ask your doctor or nurse if you would like more information about the name or names of the drugs you are taking.

The drug combinations used by your doctor are often known by a word made up from the first letters of the drug names (an acronym). For example, AC is adriamycin and cyclophosphamide.



To sum up

- Chemotherapy is a treatment using drugs that cure or control cancer.
- Chemotherapy damages the genes inside cancer cells, which prevents them from growing.
- Chemotherapy is given to shrink cancer, cure or control it or to prevent it coming back, or to ease symptoms like pain or bleeding.
- Chemotherapy can be given before or after surgery, before or with radiotherapy, with advanced cancer, or before a bone marrow/stem cell transplant.



How are the drugs given?

There are many ways to give chemotherapy drugs. The two most common ways are:

- **Intravenously** – injected into a vein or by drip infusion.
- **By mouth** (orally) – as capsules or tablets.

Less common ways are:

- **Intramuscularly** – injected into a muscle in your leg or buttock.
- **Subcutaneously** – injected under your skin.
- **Intra-arterially** – injected into an artery.
- **Intrathecally** – injected into the fluid around your spinal cord. In some conditions, such as leukaemia or lymphoma, cancer cells can pass into the fluid that surrounds the brain and the spinal cord.
- **Intracavity** – injected into a body cavity, e.g. your bladder. The drug is flushed in through a tube and may be drained out again some time later.
- **Intralesional** – injected directly into a tumour.
- **Topically** – as creams put on your skin. These creams are mainly used for some types of skin cancer and applied regularly for a few weeks. They are usually covered with a dressing.

Sometimes two or more ways may be used together. For example, your treatment may involve three different drugs; two of them could be given by injection and the third one as a tablet. Do ask your doctor or nurse if you would like more information about the ways of giving chemotherapy.

Intravenous therapy (IV)

Chemotherapy drugs are usually given by injection into a vein using a syringe or through an infusion.

- **By injection** – the drugs are injected into the rubber bung in a drip. It can last from a few minutes to 20 minutes.
- **By infusion (drip)** – drugs are diluted in a large bag of liquid and go in slowly over several hours.

- **Continuous infusion by drip or pump** – at home you may receive a very slow release of a drug given over 7 days. The amount of drug given is controlled by a pump which is small enough to sit in a pouch attached to your body.

Ways of injecting drugs

Chemotherapy drugs can be given directly into a vein using the following devices:

- 1 **Cannula** – a small tube is put into a vein in your arm.
- 2 **Central line** – a thin flexible tube is put in through the skin of your chest and into a vein near your heart.
- 3 **PICC line** (peripherally inserted central catheter) – a thin, flexible tube is put into a vein in your arm and then tunnelled through until the end of the tube lies in a vein near your heart.
- 4 **Implanted port** – sometimes called a portocath. This is an opening (port) that is attached to a thin, soft plastic tube which is put into a vein. It has an opening under the skin on your chest or arm. It can be felt but not seen.

1 Cannula

The cannula is put into a vein in the back of your hand or your arm and secured with tape. It normally stays in for a few days. The chemotherapy drugs can be given through the cannula as an injection or injected into a bag to dilute them. Nowadays chemotherapy is often given through a pump so that your nurse can control how much of the drug you get over a set period of time.

While the drug is being given, sometimes people may experience some discomfort, pain, swelling or a change in sensation around the cannula area. This may be due to a small leakage of the drug into the tissues. Though this does not happen often, if it does, let your nurse or doctor know straight away.

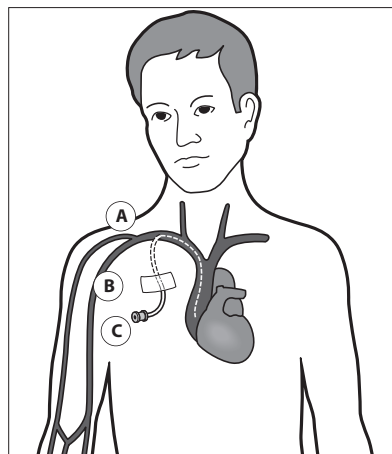
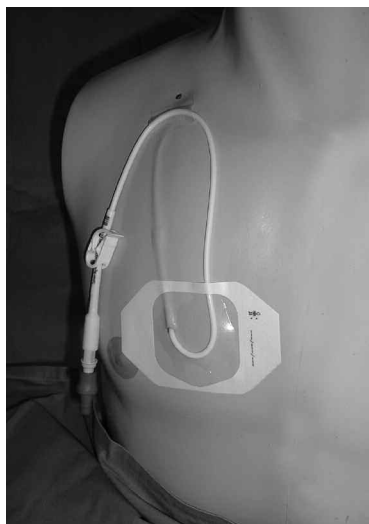
2 Central line

With this method, a long fine plastic tube is put into a vein in your

chest. It is called a central line. The line is tunnelled through the skin on your chest and a rubber bung is attached to the end of the line. In the centre of the tube is a space called the lumen. Sometimes the tube has two or three lumens, which are known as double or triple lumen. As a result, different treatments can be given at the same time. Each lumen has a special cap at the end of the line outside the body. A drip line or syringe can be attached to these lumens. The most common types of central line are Hickman, Cook or Quinton.

When putting the line in, the doctor and nurse will first explain what's involved. You will then be given a general or local anaesthetic. In most cases it only takes a few minutes to put in. Once in place, the central line is stitched and taped firmly to your chest to prevent it from being pulled out of your vein. Your doctor will arrange an X-ray afterwards to check the end of the tube is in the right place.

Your stitches will be removed 10–14 days later, depending on the hospital practice. The line can remain in your vein for many months. Removing it is very simple, sometimes needing a small local anaesthetic.



A The central line is placed in a large vein here
B The line is threaded under your skin
C The line reaches the surface of your skin here

You will be able to bathe or shower with the central line in place. However, you should prevent water from getting on the site where the tube enters your skin. A plastic dressing can be used for this purpose. Otherwise, there are very few restrictions to your everyday life. Before you go home, make sure that you are confident about looking after your central line. A family member or relative can also be trained to care for the site. This will involve how to dress the site, change the bung and flush it with heparin – a drug to prevent clotting. Depending on where you live, your doctor, public health nurse, or your relative will look after your site twice a week at home.

If you have any problems, contact the staff on the ward for advice. If you would like more information about caring for a central line, a video called *Learning Your Lines* is available from the Irish Cancer Society. It has two versions: one for females and one for males. Contact the National Cancer Helpline 1800 200 700 if you would like a free copy.



Problems with central lines

From time to time there may be some problems with the central line.

The main problems are:

- blockage
- infection
- the tube falling out.

Blockage: Blockage is caused by blood clotting where the line enters your vein, like in a wound. Depending on the type of line you have, it will need to be flushed with heparin once a week to prevent clotting.

Infection: If you notice any redness, darkening or soreness of the skin around the central line, or if you have a temperature over 38°C (100.5°F), contact your doctor or nurse immediately. You may have an infection in the line. If this happens, you will need antibiotics through the line to clear the infection.

Tube falling out: In general, it is hard for a line to fall out, as your skin will grow around it. If your line does fall out, however, do not panic. During the day, contact the day unit of the hospital straight away. If the line falls out at night, contact the inpatient ward. When you are first discharged from



hospital, you will be given instructions about who to contact if you have problems during the day or night. You will be asked to come to the ward or day unit so another line can be put in. Put a clean dressing over the site first. It is unlikely to bleed but if it does, put a dressing over the area and apply pressure. The wound generally heals quickly, but will need to be covered for a few days to prevent infection.

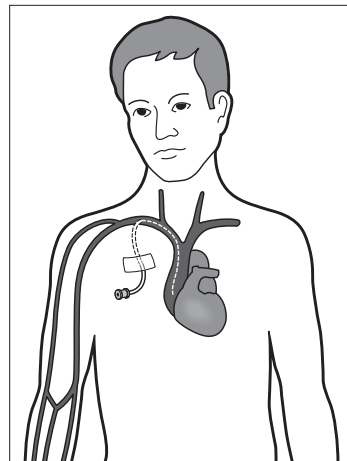
Do not throw the line away. Keep it so your doctor or nurse can check if it is complete and that no parts have been left inside your skin. Some lines can be repaired.

On very rare occasions, the line can snap or puncture (perforate). If this happens, contact the day unit immediately. Clamp the tube by tying it with a knot above the hole if necessary. Again, do not throw away the rest of the line, but bring it with you to the hospital.

3 PICC lines

Your doctor or specialist nurse may put a long fine line into a vein in your arm. This is then threaded all the way to a large vein above your heart. It is called a **peripherally inserted central catheter** (PICC). A common type is Groshong. The PICC can also have double or triple lumens.

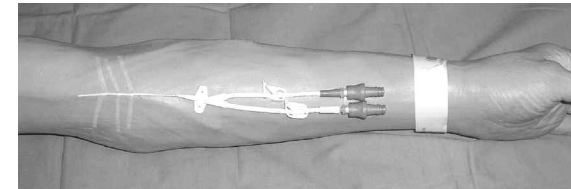
Your doctor or specialist nurse will first explain how it is put in. You will be given a local anaesthetic beforehand. Once in place, the PICC line may be stitched in and taped firmly to your arm. You will need an X-ray afterwards to check if the end of the tube is in the right place. The stitches will remain in as they prevent the line from being pulled out of your vein. It can also be held in place by a transparent dressing. The line can remain in your vein for up to 6 months or more.



The tube is tunneled through the vein until it is near to your heart

As with the central line, you will not need a cannula put in each time you have your chemotherapy. Blood can also be taken through the line for testing.

You will need to place a plastic dressing over the site before you take a bath or shower. However, there are very few restrictions to your everyday life.

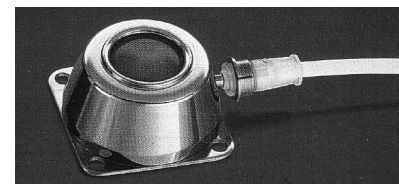


Before you go home, make sure you are confident about looking after your line. If you have any

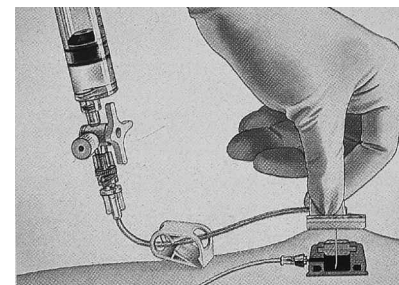
problems, contact the staff on the ward for advice. The possible problems are the same as for central lines – blockage, infection and the tube falling out. See page 15 for more information. In general, the public health nurse will flush the line with heparin once a week.

4 Implanted ports (portocaths)

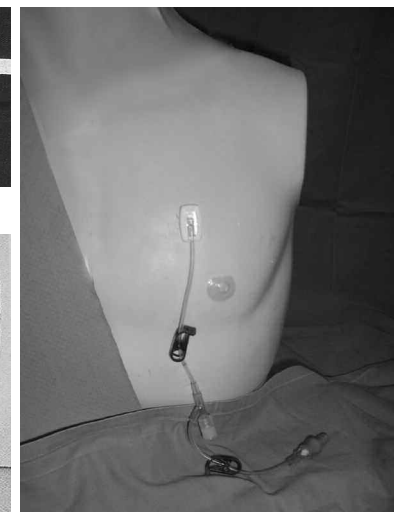
An implanted port or portocath is a device put under the skin on your chest or arm and linked to a tube put into one of your veins.



The port is placed under the skin on your chest



Giving drugs through the port



The port is a small round metal or plastic disc about 2.5 to 4 cm in diameter. The tube, known as a catheter, is long, thin and hollow and made of soft plastic. The tip of the catheter lies in a large vein just above your heart, while the other end connects with the port that sits under the skin on your upper chest or arm. You will not be able to see the port as it is underneath your skin, but you will be able to feel it like a small bump.

Drugs are given in through the port and into your vein through a fine needle securely attached. Blood can also be taken from the vein through the port. The portocath can be used for as long as is needed.

>>> Tips & Hints – caring for central and PICC lines

- Keep the site clean and dry.
- Be careful when removing your clothes, so the line does not get caught.
- When showering or bathing, place a plastic dressing or clingfilm over the site.
- Avoid swimming, as it may cause infection.
- Do not lift heavy objects with the arm your PICC line is in.
- Wear loose-fitting tops or shirts for easy access.
- Do not pull or tug on the tubing.
- If you are worried that your site is showing signs of infection or clotting, contact the day unit immediately.
- If your line falls out, place a clean dressing over the site.
- If the wound bleeds, apply pressure with a clean dressing.
- If the line falls out at home, do not throw it away but bring it to the hospital.



Talk to your doctor or nurse about the different ways of getting intravenous chemotherapy. They will explain the different options to you.

Continuous infusion

Continuous infusion is when you receive a controlled amount of chemotherapy through a special pump. Pumps are often attached to catheters or ports. They can control how much and how quickly chemotherapy goes into a catheter or port. An external pump remains outside your body and you can carry it around with you. Usually it is small enough to fit in a pocket.

Over a period of time the pump slowly releases the drug into your bloodstream, usually a week. The pump can be linked to either a central line or a PICC line.

The hospital usually prepares the drugs and you, or a family member or friend, will be taught how to use and look after the pump. Pumps work in different ways. Some are battery operated and must not get wet, while others are pressure controlled, such as I-Flow pumps. Your nurse will give you full instructions on how to care for them. If you need advice when at home, contact the day unit at the hospital.

>>> If you notice any leakage of the drug from the pump or the tube, let the nurse at the hospital know immediately.

Chemotherapy tablets or capsules

Taking tablets or capsules at home may also be part of your treatment. They may be all the treatment you need or you may have intravenous drugs as well. Your doctor or nurse will explain:

- When to take the tablets or capsules
- How often to take them
- Whether to take them with food or not
- How to handle the tablets – with gloves or not
- How to store them, for example, in a fridge or cool place
- What to do if you forget to take your tablets

When taking chemotherapy tablets, they should never be touched with bare hands as they may cause dermatitis. Place them in a spoon or small cup instead. Wash your hands afterwards. If someone is

helping you, make sure they wear gloves. Store the tablets in a safe place and keep them away from children.

If you cannot take your tablets for any reason or if you are sick soon afterwards, contact your doctor or nurse immediately for advice. If you forget to take your tablets, don't take a double dose the next day.

The drugs given to you by the hospital are a full course of treatment. For this reason, you must take them exactly as prescribed. If you need more supplies, talk to your hospital doctor, who can contact your local pharmacy.



To sum up

Chemotherapy can be given in different ways.

- The most common ways are by injection into a vein (intravenously) or by mouth.
- The less common ways are by injection into muscles or under the skin, by injection into an artery, or the fluid around the spine, directly into a cavity such as the abdomen or bladder or directly into a tumour, or as a cream put on the skin.

Where do I go for chemotherapy?

Where you get your chemotherapy depends on the drugs you are prescribed and the way they are given. Most intravenous chemotherapy is given during visits to a day hospital or clinic, without needing to stay overnight. Usually it can take anything from half an hour to a few hours. Sometimes an overnight stay is needed for a couple of days. Some people may be able to have their chemotherapy at home.

Some chemotherapy treatments are given slowly over a number of days using an infusion pump. Occasionally, chemotherapy treatments, like high-dose chemotherapy, will mean you need to stay in hospital for longer, perhaps a few weeks.

➤➤➤ Usually chemotherapy is given in a day unit at the hospital. But for some treatments you may need to stay in hospital overnight or for longer.

Before your treatment starts, your doctor or nurse will explain exactly what it will involve. Do ask as many questions about your treatment as possible. Write down new questions as they think of them. Use the fill-in form at the back of this booklet to help you. You can also call the National Cancer Helpline 1800 200 700 for information and advice.



Hints & Tips – having chemotherapy at home

- Avoid direct contact with the chemotherapy drugs.
- Wash skin with soap and water if chemotherapy spills on your skin. Contact the hospital if any redness or irritation caused by the spillage does not clear within the hour.
- If you notice any leakage of the drug from the pump or the tube, let your doctor or nurse at the hospital know straight away.
- For 48 hours after receiving chemotherapy, flush the toilet twice after using it.
- Wear gloves when handling clothing or bedsheets soiled with vomit or diarrhoea.
- Check with your pharmacist or nurse on how the chemotherapy tablets, capsules or injections should be stored.
- Store all drugs out of reach of children to prevent serious harm if taken by accident.
- If you feel sick or unwell at any time, phone the nurse or doctor at the hospital for advice.



Cancer Helpline 1800 200 700



Treatment and side-effects

How does the doctor plan my treatment?

When planning your treatment, there are some things your doctor will take into account:

- The type of cancer you have
- Where it is in your body
- If it has spread or not
- Where it has spread to (if at all)
- Your age
- Your general health and fitness

Some drugs affect your body more than others. As a result, your doctor must judge if you are well enough to cope with any side-effects of the treatment before it starts. How often you have treatment and how long it lasts can depend on:

- The type of cancer
- The chemotherapy drugs used
- How the cancer cells respond to the drugs
- Any side-effects from the drugs

Your doctor or specialist nurse will explain your treatment plan beforehand. Do ask as many questions as you like. Don't be afraid to repeat a question if you do not understand the answer. You can use the fill-in form at the back of this booklet for your questions. It can also help to bring a close relative or friend with you to remind you of the questions you want to ask.

You may notice that other patients are having different treatments to you, even though they have the same type of cancer as you. Don't let this worry you, it only means that everyone's treatment is individual.

How long will I need chemotherapy?

How often and how long you get chemotherapy will depend on the type of cancer and the drugs used. You will have to visit the hospital regularly for at least 3 to 6 months. Depending on the drugs used, each treatment can last from a few hours to a few days.

Each chemotherapy period is called a **cycle**. Each cycle is followed by a rest period. The rest period helps your body to recover from the effects of the chemotherapy. Sometimes your treatment may be delayed if your body needs more time to recover. Again, the number of cycles you have will depend on the stage of your cancer and how well you respond to treatment. It may take several months to complete your chemotherapy.

Deciding on treatment

When faced with a life-threatening illness, it can sometimes be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. Often you might want more time to think things through. But remember there is always time for you to consider what sort of treatment you want.

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your reasons and concerns first. They will tell you what can happen if you do not accept treatment. It may help to talk to your GP as well.

>>> The important thing is that you are fully informed of the benefits and risks of treatment.

Benefits and risks

It is important to know why your treatment is being given. Treatment can be given for different reasons and the benefits will vary depending on your situation. It may be a question of curing, preventing or controlling cancer or improving your quality of life. Some people will choose to be treated, even when there is only a small benefit. Others want to make sure the benefits of treatment outweigh any side-effects, and others will choose the option that offers the best quality of life. It can help to discuss with your cancer specialist how much difference the chemotherapy may make in your own situation.

Talking with doctors and family/friends

Talking it over can help you to decide the right course of action for you.

- Talk to your doctor a few times before deciding on treatment.

- Don't worry if you ask the same questions over and over again.
- Write down your questions before seeing your doctor.
- Bring a family member or friend to take part in the conversation or just listen.
- Take notes during the visit.
- Talk to people who you think might help: your family or friends, nursing staff, GP, medical social worker, chaplain, religious leader or adviser.
- Contact the helpline nurses at the Irish Cancer Society: 1800 200 700.
- Get a second opinion if you prefer.

A second opinion

You may like to get a second opinion from another cancer specialist. Many patients feel uncomfortable doing this but it happens more and more often now. In fact, most doctors welcome another doctor's views. Your doctor or GP may be able to recommend a specialist for this consultation.

Afterwards, you may feel more confident about your choices or the treatment advised by your specialist. You can ask for a second opinion, even if treatment has started or you still want to be treated by your first doctor.

Giving consent for treatment

You may be asked to sign a consent form saying that you give permission for chemotherapy to be given. In some cases you may give verbal permission. No medical treatment can be given without your consent. Before treatment, you should know:

- The type and amount of treatment you are advised to have
- The benefits and risks of the treatment
- Any other treatments that may be available
- Any major risks or side-effects of the treatment.

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 cancer treatments are hard to understand and may need to be explained more than once. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.



Research – what is a clinical trial?

Research into new ways of treating cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. Many cancer patients take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.



Phases of research

There are many stages or **phases** when research is done. If a drug or treatment looks as if might be useful in treating cancer, it is given to patients in research studies called **clinical trials**. These aim to find a safe dose, see what side-effects may occur and identify which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be followed closely during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called **informed consent**. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

If you would like more information, a booklet called *Understanding Cancer Research Trials (Clinical Trials)* is available. Call the National Cancer Helpline **1800 200 700** for a free copy.

How will I know if the chemotherapy is working?

After a few cycles of treatment, your doctor will arrange some tests and exams. These tests will show if the cancer has shrunk or disappeared. They include blood tests, X-rays, scans. If chemotherapy is being given as a palliative treatment, the relief of symptoms may tell you if the treatment has worked. If chemotherapy is used to prevent a recurrence, it may not be possible to say if this treatment has worked. Do ask your doctor about your test results and what they show about your progress.

Your doctor will also ask you about how well you feel. Tests and exams can tell a lot about how chemotherapy is working, whereas side-effects tell very little. You cannot tell if chemotherapy is working based on its side-effects. Sometimes people think that if they have no side-effects, the drugs are not working. Or if they do have side-effects, the drugs are working well. But side-effects can vary so much between people and between drugs that they are not a reliable sign of the treatment working or not.

Changes in your treatment plan

Sometimes, depending on the results of the tests, your treatment plan may need to be changed. It may be because the drugs are starting to cause damage to particular parts of your body, such as your bone marrow, kidneys, liver or the nerves in your hands and feet. In other cases, it can be because the drugs are not shrinking the cancer enough. Changing the drugs you are getting may be needed. Your doctor will discuss this with you.

What tests will I need before and during treatment?

Some of the following tests may be done before or during treatment:

- **Weight and height:** Your weight and height will be checked before the first cycle of treatment. This is done so the doctor can work out the right dose for you.

- **Blood or urine tests:** Before each cycle of treatment, you will have blood tests done. This is check if you are fit for treatment and see how your body is responding to the drugs. Sometimes urine tests will be done to see the effect of chemotherapy on your body. A close eye will be kept on your liver and kidneys too.
- **Physical exam:** This will be done before each cycle of treatment.
- **X-rays and scans:** Sometimes you may need X-rays and scans. These are to check that you are fit for treatment and to see how the tumour is responding to treatment. For example, a chest X-ray.
- **Heart monitoring:** Some drugs can affect your heart so you may need a recording of your heartbeat (ECG) or heart ultrasound (ECHO).
- **Lung function tests:** Some chemotherapy drugs can affect your lungs, so they will be checked regularly.

You may have to wait for the results of the blood tests before treatment can begin. To help pass the time in hospital, either waiting for tests or treatment, it can be helpful to bring a book, newspaper, crosswords or perhaps some letters to write.

What are the side-effects of chemotherapy?

Side-effects are problems caused by cancer treatment. Some common problems are fatigue, nausea, vomiting, lowered blood cell counts, hair loss and mouth sores. Your doctors and nurses will let you know which drugs you are taking and their side-effects.

1 Will I get side-effects from chemotherapy?

Every patient is different, so you may get many side-effects, some, or none at all. It all depends on the type and amount of drugs you get and how your body reacts to them.

2 Where do I get side-effects?

Chemotherapy affects all cells that grow quickly in your body. This includes both cancer cells and healthy cells. Healthy cells that grow quickly are found in your mouth and digestive system, in your bone

marrow where blood cells are made, and in your hair and skin. Chemotherapy causes side-effects when it damages these healthy cells. Your doctor and nurse will explain to you beforehand which side-effects to expect.

3 How long do side-effects last?

Side-effects, if they happen, can be either short term or long term. Most side-effects are short term and gradually go away once treatment is over. But sometimes it can take months or even years for them to clear up. Chemotherapy can also cause long-term side-effects that do not go away. These may include damage to your heart, lungs, nerves, kidneys, or reproductive organs. Do ask your doctor or nurse if you are likely to get any long-term side-effects.

4 What can be done about side-effects?

Nowadays, there are ways to prevent or control some side-effects. Always tell your doctor and nurse about any changes you notice or anything that is making you unwell. He or she may be able to give you medication to help or else make changes to your treatment to ease any side-effects.

5 What possible side-effects can I expect?

There are a number of possible side-effects of chemotherapy. These are listed below in order of severity. Again you may experience only some or none of them.



Possible side-effects include:

Infection	Constipation	Eye changes
Anaemia	Mouth and throat changes	Mental confusion and memory problems
Bleeding and bruising	Hair loss	Anxiety and depression
Kidney and bladder problems	Fatigue	Infertility
Nausea and vomiting	Skin and nail changes	Sexual changes
Loss of appetite	Nerve changes	
Diarrhoea	Hearing changes	

Infection

Chemotherapy drugs make you more likely to get infections. This happens because most of the drugs affect the bone marrow where white blood cells are made. These cells help the body fight infection. If you do not have enough white cells (neutropenia), even a small infection like a cold or a sore throat could make you ill. During each treatment cycle you will have blood tests to make sure you have enough white blood cells. Seven to 14 days after your chemotherapy treatment, your white blood cells are usually at their lowest. But this can vary with the type of drug given.

>>> If you feel shivery or unwell or have a high temperature of 38°C or higher, contact the hospital straight away.

You will be asked to watch out for signs of infection at all times, especially if your white cell count is low. These signs could include feeling shivery and unwell or running a high temperature of 38°C or higher. If this happens, contact the hospital straight away, even at night-time. Some hospitals prefer you to ring the ward directly. Check this with your nurse or doctor before you start treatment. If you have a high temperature or feel unwell, you will need to have a blood test to see if your white cells are low. You may also need medication in hospital to treat the infection.

You will be more at risk of picking up infections. Try to avoid crowds or close contact (such as hugging or kissing) with people who have colds or flu and other infections, such as 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. Infection is a serious complication of chemotherapy. It needs to be treated as soon as possible. Talk to your doctor or nurse, who will give you more advice.

Your doctor may also give you drugs called **growth factors**, sometimes called G-CSF or GM-CSF. These will help your bone marrow to make more white blood cells quickly. As a result, they reduce the risk of infection.

Anaemia

Chemotherapy can also cause the bone marrow to make less red blood cells (less haemoglobin). Fewer red blood cells is called anaemia. Red blood cells are needed to carry oxygen around your body. With anaemia, your heart must work harder to get enough oxygen. Anaemia can make you feel tired and weak, short of breath, dizzy, faint or light-headed and your muscles and joints can ache. Regular blood tests to measure your red cell count will be done during treatment. You may be given a blood transfusion to help your breathlessness and give you more energy. Once the chemotherapy is over, the tiredness will ease off gradually. However, some people still feel tired for a year or more after treatment.

Your doctor may give you a drug called **erythropoietin** to help the bone marrow make more red blood cells quickly. It is given as an injection in your thigh or abdomen, once or three times a week. Sometimes your doctor and dietician may give you advice about taking iron or vitamins.

Bleeding and bruising

Chemotherapy can affect the number of platelets made in your bone marrow. Platelets are needed to help make your blood clot and stop any bleeding if you hurt yourself. With fewer platelets, you may bleed or bruise very easily, get nosebleeds or bleed more heavily than usual from small cuts or grazes or during your periods. A low platelet count is called **thrombocytopenia**.

Let your doctor or nurse know straight away if you are bruising easily, have unexplained bleeding or notice tiny red spots under your skin, which can look like a rash. You may need a platelet transfusion.

During treatment, you will have regular blood tests to count the number of platelets in your blood. While on treatment, avoid any injury. For example, use an electric razor when shaving, or when gardening wear thick rubber gloves to protect yourself from cuts and grazes. Check with your doctor or nurse before taking any vitamins, herbs, minerals, dietary supplements, aspirin, or other over-the-counter medicines.

Kidney and bladder problems

Some chemotherapy drugs can damage the cells in your kidneys and bladder. As a result, you may have burning or pain when you empty your bladder, urgency or frequency, be unable to pass urine, incontinence, or blood in your urine. Some drugs can change the colour of urine as well.

Blood and urine tests will be done regularly to check your kidneys. Fluids can help to flush out the chemotherapy from your kidneys and bladder. Before each treatment, fluids may be given by drip into your vein for several hours. Drink as much as you can – about 1½ litres per day. Avoid, where possible, drinks that contain caffeine, e.g. tea, coffee, coca cola.

Nausea and vomiting

Some chemotherapy drugs can cause nausea and vomiting or both. Nausea is when you feel sick but do not vomit. For some people, the drugs cause no sickness at all. At what stage you feel sick usually depends on the drug given. Nausea and vomiting can happen while you are getting chemotherapy, straight after, or many hours or days later. It may last for a few hours or, in rare cases, for several days.

Nowadays, there are better treatments to prevent nausea and vomiting. Your doctor can prescribe anti-sickness drugs called **anti-emetics**. You may need to take these 1 hour before each chemotherapy treatment and for a few days after. They may be given by injection and as tablets to take home afterwards. Do take the tablets, even if you do not feel sick. How long you take them will depend on your type of chemotherapy and how you react to it. If one kind of anti-emetic does not work for you, your doctor can always prescribe another one. Also, you may need more than one type of drug to help with nausea. Talk with your doctor or nurse for more advice about this side-effect.

Low doses of steroids can help to reduce nausea and vomiting too. Given in this way, the steroids will not do any lasting harm. They can make you feel better overall and help with any loss of appetite too.

Research studies have found that acupuncture can help improve nausea and vomiting as well. If you would like more information,

contact the National Cancer Helpline 1800 200 700 for a copy of the booklet, *Understanding Cancer and Complementary Therapies*.



Loss of appetite

Some chemotherapy drugs can affect your appetite. This may happen for a short time while on treatment. It is best to get advice from a dietician if this happens. A booklet with useful tips called *Diet and the Cancer Patient* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



Tips & Hints – nausea and loss of appetite

- Tell your doctor if you have any nausea or vomiting.
- Tell your doctor if the anti-sickness tablets are not working well.
- Eat bland, easy-to-digest foods and drinks, like cream crackers, toast or plain biscuits.
- Eat about 5 or 6 small meals or snacks each day.
- Do not fill your stomach with fluids before eating.
- Take fluids slowly, with small sips. Ice cubes can help too.
- Do not eat or prepare food if you feel sick.
- Avoid food and drinks with a strong smell, like garlic, onions, fried foods, etc.
- Eat warm or cool foods if you cannot tolerate the smell of hot food.
- Find out when is best for you to eat and drink before treatment. Some people need a light snack, while others need an empty stomach.
- Some complementary therapies, like acupuncture, may help.



Cancer Helpline 1800 200 700

>>> Should I eat a special diet?

Low-sugar diet

There are many myths about cancer and one of them is that 'sugar feeds cancer'. For this reason, some people greatly reduce the amount of sugar in their diet. There is no good reason to do this. It is best to eat a well-balanced diet while on chemotherapy.

If you have diabetes or are taking steroids while on chemotherapy, your blood sugars will be checked regularly. Again you should eat a well-balanced diet, as advised by your dietician. If there are any changes to your blood sugars, your dietician will advise you on your diet.

Special diets

It is best not to experiment with special diets while on chemotherapy. Many of these diets are restrictive, which means that certain food items must be avoided. Restrictive diets can lead to poor appetite and weight loss, fatigue, and other nutritional deficiencies and may be harmful. If you take large doses of vitamins or minerals, it may affect how the chemotherapy works.

Do get advice from your dietician or call the National Cancer Helpline for a copy of *Understanding Cancer and Complementary Therapies*.

Diarrhoea

Some drugs can harm the cells that line your bowels and cause diarrhoea. Diarrhoea is basically passing bowel motions that are soft, loose or watery more than twice a day. You may also get some cramping or abdominal pain. Diarrhoea can also be caused by infections or drugs used to treat constipation.

If you have diarrhoea, drink lots of clear fluids to replace the fluid you are losing. Do tell your doctor or nurse if you have diarrhoea for more than 24 hours. There are medicines called **anti-diarrhoeals** that can stop this side-effect of treatment. Again it might be useful to talk to a dietician who can offer advice at this time.

Constipation

Chemotherapy may slow down the movement of your bowels. As a result, your regular bowel habit may change. You may find it painful or hard to pass a bowel motion. Or you may feel bloated or have nausea. This is known as constipation.

If this happens, let your doctor or nurse know as soon as possible. You may need to drink more clear fluids and/or take a laxative. In some cases, your doctor may have to adjust your treatment. Getting some exercise can help to move your bowels too.

>>> Tips & Hints – diarrhoea and constipation

- Eat small snacks or meals instead of three large meals a day.
- Have a low-fibre diet. Eat less raw fruit, cereals and vegetables, if you have diarrhoea.
- Avoid milk, alcohol or very hot or cold drinks, if you have diarrhoea.
- Avoid spicy or fried foods, if you have diarrhoea.
- Drink plenty of clear fluids (1½ to 2 litres a day), if you have diarrhoea.
- Keep a record of when your bowel opens.
- Eat more fibre, raw fruit, cereals and vegetables, if constipated.
- Drink plenty of fluids, if constipated. Prune juice and warm drinks can often help.
- Be as active as you can. Take gentle exercise, like walking or yoga, if possible.



Mouth, throat and taste problems

Mouth and throat problems due to chemotherapy can include a dry mouth, mouth sores and ulcers, or infections of gums, teeth or tongue. A sore mouth, if it happens, can occur about 5 to 10 days after the drugs are given. Your mouth may be more sensitive to hot or

cold food as well. There are many mouthwashes and medication to help, which your doctor can prescribe for you. It can help to clean your teeth often and gently with a soft toothbrush. Keep your mouth moist by sipping cool water during the day. If your mouth becomes very sore, there are gels, creams or pastes available to ease the soreness.

Changes in taste and smell can also happen. Food may not taste like it used to or taste more salty, bitter, or like chalk or metal. Normal taste will come back after your treatment has ended. Make sure to visit your dentist before your treatment starts or ask your doctor or nurse when is it safe to get dental work. The booklet, *Diet and the Cancer Patient*, has some helpful advice on how to manage taste changes. Phone 1800 200 700 for a copy.



Tips & Hints – mouth and throat changes

- Clean your teeth and gums or dentures after each meal and at bedtime.
- Brush your teeth with a soft-bristled or child's toothbrush.
- Use a mouthwash regularly if prescribed for you.
- Avoid mouthwashes that have alcohol or toothpaste that stings. Make your own mouthwash with one teaspoon of baking soda dissolved in warm water.
- Avoid toothpicks.
- Take crushed ice or pineapple to keep your mouth fresh and moist.
- Use a lip balm or Vaseline to keep your lips moist.
- Drink about 1½ litres (3 pints) of fluid a day. This can be water, weak tea, weak coffee, or soft drinks such as apple juice.
- Avoid citrus drinks like lemon, orange or grapefruit.
- Choose foods that are moist, soft and easy to chew or swallow.
- Add gravies and sauces to your food to make it moist and easy to swallow.



- Eat only the foods that you like.
- Avoid foods that can irritate your mouth: alcohol, spices, garlic, onion, vinegar, salty or very sugary foods.
- Use herbs and seasonings to add flavour to your food.
- Marinate your food if you have problems tasting food.
- Do not smoke as tobacco can irritate your mouth and throat.
- Ask your dietician for more advice about suitable food and drinks.

Hair loss

Some chemotherapy drugs can cause hair loss or alopecia. This is when all or some of your hair falls out. It can happen anywhere on your body: your head, face, eyelashes and eyebrows, arms, underarm, legs, and pubic area. How much hair falls out depends on the drug given, the amount and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss due to treatment.

- **When?** If you lose your hair, it usually starts within 2 or 3 weeks of treatment. You may get tingling or sensitivity of your scalp before your hair starts to fall out. This is normal and may last a day or so.
- **Will it come back?** Try not to worry as your hair will start to grow again once treatment stops. It may take a few months. When it regrows, it may not feel the same as before. It might have changed colour, texture or style. It might be darker or lighter in colour, thinner or become straight or curly.



You may get tingling or sensitivity of your scalp before your hair starts to fall out, which may last a day or so.

- **Any treatments?** In general you cannot prevent hair loss entirely. Depending on your chemotherapy, it may be possible to reduce or delay hair loss by using a 'cold cap'. This is also known as scalp cooling. The treatment reduces blood flowing to the scalp for a

short period so less of the drug reaches the scalp. While it can reduce the risk of hair loss, it does not always prevent it. The cold cap only blocks the action of certain drugs as well. It is also not suitable for all patients and not all hospitals offer this kind of treatment. Ask your doctor or nurse if it would be useful for you.

- **Ways to cope?** It is natural to feel upset at the thought of losing your hair. Don't be afraid to talk to your nurse or medical social worker about your feelings. They will help you find ways to cope with your hair loss. Also, talk to your family and friends as they can give you support too. If you have children, it is best that you prepare your children for your hair loss before it happens. Your medical social worker can give you advice on what to say.
- **Hairpieces?** If you like, you can get a wig or hairpiece when you lose your hair. Or you may prefer to wear a hat or bandana. If you decide to get a wig, it is better to organise it before your hair falls out. That way you will get a better match to your own hair colour. Your medical social worker or nurse may be able to advise you about getting a wig. If your hospital does not have a medical social worker, ask if they have the name of a wig fitter that you could visit. In some cases it is possible to get financial assistance towards the cost of a wig or hairpiece. If you have a medical card, you are entitled to a new wig every 6 months. If you have private health insurance, e.g. with the VHI, you are covered for the cost of a wig too.

>>> If you are likely to lose your hair, ask your doctor or nurse about wigs early on, so that the wig will be as close a match to your normal hair.

- **Other headwear?** You may like to wear a hat or scarf instead when you go out. There are also turbans which can be worn in the house. For more information and advice, call the National Cancer Helpline 1800 200 700 for a copy of the factsheet, *Hair Loss and Cancer Treatment*.



Tips & Hints – your hair

- Get your hair cut short before it falls out or shave your head. The weight of long hair can pull it out faster.
- Brush or comb your hair gently with a soft or baby brush.
- Use gentle hair products.
- Dry your hair by patting it with a soft towel.
- Avoid hairsprays, hair dryers, curling tongs, curlers.
- Use a gentle moisturiser on your scalp if it becomes dry or itchy.
- Avoid hair dyes but, if you must, use a very mild vegetable-based colour. Ask your nurse or hairdresser for more advice.
- Do not perm your hair during chemotherapy or for 3 months afterwards.
- Keep your head warm by wearing a hat, turban, scarf or wig.
- Protect your scalp by putting sunscreen on your head when outdoors



Tiredness and fatigue

Fatigue is a common problem with chemotherapy and radiotherapy. This is where you feel tired and weak and rest does not seem to help. It is quite normal and may be caused by the drugs themselves or by your body fighting the disease. Sometimes the tiredness can be mild or extreme. So do try to get plenty of rest and accept help when offered. The tiredness will ease off gradually once the chemotherapy is over. However, some people can still feel tired for a year or more afterwards.

Remember that fatigue can be caused not only by chemotherapy but also anaemia, lack of sleep, having to make regular visits to the doctor or stress, anxiety and depression. If you normally have plenty of energy, you may find it hard and frustrating when feeling tired all the time. Do talk to your doctor if fatigue is a problem for you. A useful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

>>> Tips & Hints – fatigue

- Plan time to rest each day. Make sure to build short naps into your day.
- Try not to get overtired.
- Have a bedtime routine: quiet time or listening to relaxing music, taking a milky drink, going to bed at the same time each night.
- Ask for and accept help from others with housework, shopping, cooking, childcare or at work.
- Take light exercise, such as walking or yoga, to help you get a good night's sleep.
- Some relaxation therapies can help: visualisation, yoga, meditation.
- Keep your energy for the things you like most to do. Have a nap or short rest before you go out somewhere special.

Skin and nail changes

Because skin and nail cells grow quickly, some chemotherapy drugs can affect them. Your skin may become dry, flaky, red and itchy. They can also be sensitive to sun and sea or chlorine in swimming pools. With chemotherapy, nails grow more slowly. They may become dark, yellow or brittle and cracked. White lines can appear across them. Sometimes the nails can loosen and fall off. But don't worry about this, as new nails will grow back. Do tell your doctor or nurse if your skin or nails are affected.

It is best to stay out of the sun during the hottest part of the day. This is normally between 11am and 3pm.

>>> Tips & Hints – skin and nail changes

- Pat your skin dry with a soft towel after bathing.
- Avoid wet shaving. Use an electric razor.
- Moisturise your skin if it becomes dry or itchy.
- Use only creams and soaps recommended by your doctor and nurse.



- Avoid direct sunlight. Wear a wide-brimmed hat, long-sleeved loose cotton clothing and use a high factor suncream (SPF 15) to protect your skin.
- Do not use sunbeds.
- Wear nail varnish to disguise white lines.
- Wear gloves when doing the washing-up, cleaning or gardening.

Nervous system changes

Some drugs can cause damage to your nervous system. These can vary depending on the organ affected and can include:

- **Nerve changes:** Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as **peripheral neuropathy**. You may have trouble picking up objects or buttoning your clothes. This side-effect is usually temporary and goes away after treatment stops. But it may take several months for the numbness to go away completely. Do tell your doctor or nurse if this happens, as you may need medication or some changes to your treatment.
- **Hearing changes:** With some drugs you may be unable to hear high-pitched sounds. Or you may get a constant sound in your ears called tinnitus. As these buzzing or ringing sounds can be very upsetting, do tell your doctor if you develop them. Some new drugs are being developed to help this problem.
- **Balance and co-ordination problems:** You may have problems with your balance that can lead to falls. Or you may become clumsy. Sometimes you may feel dizzy, shake or tremble.
- **Eyesight problems:** You may get problems like dry or watery eyes, or blurry vision. Sometimes wearing contact lenses can make your eyes painful. Ask your doctor or nurse if you can wear contact lenses while getting chemotherapy. Do let him or her know if your vision is worse than usual.
- **Confusion and memory problems:** After a few treatment cycles, some patients may have mental confusion and memory loss. This is known as 'chemo brain' and can depend on the type of drug(s) given. It can also include a lack of focus and concentration and

being unable to organise daily activities. Do let your doctor know if you experience any of these problems. Sometimes it can be helped by relaxation, exercise, anti-inflammatory medicines or learning techniques to 'retrain' your brain. These activities focus on improving any memory loss and problems with attention, perception, learning and planning (cognitive rehabilitation). Research into new treatments is ongoing.

- **Anxiety and depression:** Some people can feel restless, anxious or develop insomnia and depression due to chemotherapy. Your doctor may prescribe medication to help or advise counselling and relaxation.

If you have any of these nervous system side-effects, let your doctor or nurse know as medication can often ease them. Many of these problems get better within a year of finishing chemotherapy, but some may last the rest of your life. You may find it helpful to talk to a close relative or friend about your feelings and concerns. If this is not possible, ask your doctor to refer you to a counsellor or a psychologist.



Tips & Hints – hands and feet problems

- Keep your hands and feet as warm as possible.
- Take gentle exercise if possible. Stress balls may help.
- Wear well-fitting shoes with rubber soles to prevent you falling.
- Be careful when handling knives, scissors and other sharp or dangerous objects.
- Be careful when cutting your nails.
- Be careful when using hot water.
- Check the temperature of the bath before stepping in.
- Wear gloves when cooking, cleaning or gardening.
- Keep your skin moisturised and soft.
- Prevent falls. Use a walking stick, walk slowly, use handrails when going upstairs, use non-slip bathmats.
- Wear cooling gloves. Ask your doctor and nurse for advice.



Other changes

Different drugs cause different side-effects. You may develop a side-effect or symptom not listed here. However, your doctor or nurse will give you information on the possible side-effects of your treatment. If you have any concerns, talk your doctor or nurse for advice.

Side-effect	Possible treatment
Anaemia	Blood transfusion, rest, erythropoietin, well-balanced diet, iron and vitamins
Bleeding and bruising	Platelet transfusion
Constipation	Fluids, laxatives, exercise, high fibre diet
Diarrhoea	Fluids, anti-diarrhoeal tablets, low fibre diet
Eye changes	Changes to chemotherapy treatment
Fatigue and tiredness	Rest, blood transfusion,
Hair loss	None or possibly 'cold cap'
Hearing changes	Medication, changes to chemotherapy treatment
Infection	Antibiotics, growth factors
Infertility	Sperm banking/egg freezing
Kidney and bladder problems	Fluids (by mouth and into a vein)
Loss of appetite	Low dose steroids
Confusion & memory problems ('chemo brain')	Changes to chemotherapy treatment, medication
Mouth and throat changes	Mouthwashes, gels, creams or pastes
Nausea and vomiting	Anti-sickness tablets, low dose steroids, acupuncture
Peripheral neuropathy	Changes to chemotherapy treatment, medication, painkillers, reflexology
Anxiety and depression	Medication, counselling, relaxation therapies
Sexual changes	Vaginal lubricants, HRT
Skin and nail changes	Moisturisers, suncreams when outdoors



To sum up

- When deciding on chemotherapy, your doctor will consider the type of cancer you have, where it is, if it has spread and where, your age, and your general health.
- How often you get chemotherapy will depend on the type of cancer, the drugs used, how the cancer is responding to the drugs and any side-effects you get.
- Each chemotherapy period is called a cycle.
- Your chemotherapy may last from 3 to 6 months.
- Your doctor will explain the benefits and risks of treatment beforehand. You are free to get a second opinion if you wish.
- After a few cycles, your doctor will arrange some tests and exams to see if the chemotherapy is working.
- Side-effects are problems caused by cancer treatment.
- Some common problems are fatigue, nausea, vomiting, lowered blood cell counts, hair loss and mouth sores.



Will chemotherapy affect my fertility?

Some cancer treatments and sometimes the disease itself can cause infertility. This means that sadly you cannot have children. This infertility may last a short while or for the rest of your life. Your chances of infertility depend on:

- Your age – how near you are to the menopause
- The type of cancer you have – ovarian, womb, prostate, testicular
- The type of chemotherapy given
- Any other treatments used – radiotherapy, hormone therapy
- If you have any other health problems.

Before treatment starts, talk to your cancer specialist about your chances of becoming infertile and your options. Bring your partner, so he or she can ask questions too. Many couples have had healthy

babies after one or the other has been treated for cancer. A booklet called *Fertility and Cancer* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy or more advice.

Will I be able to get pregnant?

Some drugs used to treat cancer can damage your ovaries. As a result, the number of healthy eggs and hormones can be affected. If this happens, you may be unable to get pregnant. If there is any chance you could be pregnant, your doctor may do a pregnancy test before treatment.

- **Short-term infertility:** Your periods may become irregular or stop during treatment or for a few months afterwards. This does not mean you are permanently infertile. You may get hot flushes, a dry vagina or other symptoms of the menopause. But after a few months your periods may return to normal. This happens in about a third of women. In general the younger you are, the more likely your periods will return to normal and you can get pregnant (fertile) if you wish.
- **Menopause:** The nearer you are to the menopause, the more likely your periods will stop permanently. This means you will not be able to have children. Usually it is not possible to stop this happening. But your doctor may prescribe hormone replacement therapy (HRT) to reduce the effects of the menopause, like hot flushes and a dry vagina. HRT replaces the hormones normally made in the ovaries. The treatment can be given as a tablet or through an implant under your skin, by creams or by a slow-release patch worn on your arm or leg.
- **Avoiding pregnancy:** You may not know if you are fertile or not, as periods usually stop during chemotherapy. But it is still possible for you to become pregnant during treatment. Side-effects of chemotherapy like vomiting and diarrhoea can make the contraceptive pill work less well. For this reason, you must use a reliable method of contraception throughout your treatment and for some time afterwards. Do not get pregnant as the drugs can harm

your baby, especially in the first 3 months of pregnancy. There can also be a risk of miscarriage.

- **Checking fertility after treatment:** Once treatment is over, there are blood tests that can check if you are fertile or not. Talk to your doctor or nurse who can organise them for you at a suitable time.
- **Getting pregnant after treatment:** Many doctors believe it is better not to get pregnant for at least 2 years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment. And by this time the likelihood of the disease coming back is much less.
- **Support:** It may help to talk to a family member or close friend about your fertility concerns. Ask your doctor or nurse for advice on what to do. You may need counselling if infertility is a problem for you, especially if you have no children.

>>> You may be able to freeze your eggs before treatment.

Freezing your eggs

If there is a risk that your chemotherapy will cause permanent infertility, you have the option of freezing your eggs (oocytes) before treatment begins. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital, Dublin provides a service where eggs can be frozen. If you still want to have children, discuss this as early as possible with your cancer specialist before treatment.

- **Who's suitable?** You must be over 18 years of age, be able to give informed consent and be referred to the HARI Unit by your cancer specialist (oncologist). Remember you may not be suitable for egg freezing. The type and location of your cancer, your age and medical history can affect your suitability. You will need to have a blood test to check for viruses, e.g. hepatitis B, hepatitis C, HIV and cytomegalovirus (CMV), which will be repeated 6 months later. You will also need to receive counselling as part of the service, as it will be a stressful time for you.
- **What's involved?** The procedure itself is not simple. It is still experimental and not without risk. The time factor too is important.

Your ovaries will need to be stimulated to make enough eggs before they can be stored. From the moment you are seen by a doctor at HARI and it is decided that you are suitable, your treatment will start with your first menstrual period. The eggs are then collected hopefully within 3 weeks. You should be aware that your own health will take priority over egg freezing. If this time period is not possible, due to the urgency of chemotherapy or radiotherapy, egg freezing cannot go ahead.

If the eggs are successfully collected (harvested), they are stored for a maximum of 10 years or until you are 45 years old. But you can write to the HARI Unit asking to extend this period. The eggs will only be stored while you are alive, so it is important you keep in touch with HARI every year. Let them know of any changes in your address or contact details.

- **Cost of egg freezing?** The service at HARI is free for all cancer patients living in Ireland.
 - **Trying to conceive?** When the time comes and you feel ready to become pregnant, you should talk to your oncologist. He or she can tell you if your body has recovered from the effects of chemotherapy. If you have frozen your eggs, you will need to contact HARI to discuss your options. HARI encourages women to use their frozen eggs by the age of 40. After that age, there is a high chance of complications and you are less likely to have a successful pregnancy.
- Your frozen eggs can be thawed followed by assisted reproduction techniques. This can involve IVF (in vitro fertilisation) and ICSI (intracytoplasmic sperm injection), which means your eggs will be fertilised in the laboratory. Before you start this treatment at HARI, you will need some fertility tests done first. You will be seen by a doctor and a counsellor. After signing content forms, therapy in the form of a tablet is given. If the eggs survive thawing and ICSI, the fertilised eggs will be put into your womb in the hope of a pregnancy.
- **Where?** You can decide to have this treatment at the HARI Unit. If you decide to be treated elsewhere, it is possible for the frozen eggs to be transferred to a clinic of your choice. However, your clinic must

agree to it beforehand and the transfer is done at your own risk. You will still need to have fertility tests done first.

- **More information?** If you would like more information about egg freezing, talk to your doctor or nurse. You can also call the National Cancer Helpline 1800 200 700. Your GP can give you advice as well.

>>> Your own health will take priority over egg freezing.

Will I be able to father a child?

For some men, the cancer itself or some chemotherapy drugs may cause infertility. It can lower your sperm count or damage sperm cells making them less mobile. If your sperm are affected, it means you won't be able to father a child. Sperm tests done before treatment starts will show if it caused by the cancer. Do talk to your doctor beforehand if treatment is likely to affect your fertility, especially if you are a teenager. Infertility may be short term or last for the rest of your life.

- **Short-term infertility:** You may be on treatment for 2 to 3 months before your sperm count is reduced. But usually once treatment ends or soon afterwards your sperm will return to normal. In rare cases it may take a number of years. Don't worry that if you father a child it won't be healthy. Many men father healthy babies after treatment for chemotherapy. Your cancer will not be passed on to your children either.
- **Permanent infertility:** Some men may be infertile for the rest of their lives. Even though doctors know that some chemotherapy drugs may cause infertility, it is very hard to say if and when this will happen. Infertility due to chemotherapy does not mean that you cannot have an erection and orgasm.
- **Avoiding pregnancy:** Use a barrier method of contraception, like condoms, throughout your treatment and for some time afterwards. Do not get your partner pregnant in case the drugs damage your sperm and cause birth defects.

- **Support:** It may help to talk to a family member or close friend about your fertility concerns. Ask your doctor or nurse for advice on what to do. You may need counselling if infertility is a problem for you, especially if you have never fathered a child.

Sperm banking

If tests show that your sperm count is satisfactory, it may be possible to store your sperm (semen) before treatment begins. They can then be used at a later date. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital, Dublin provides a service where sperm can be frozen.

- **Who's suitable?** You will first need to be referred to HARI by your cancer specialist (oncologist). Also, you must be 16 years or over and be able to give informed consent. Your type of cancer or medical history can affect your suitability. You will need a blood test to check for viruses like hepatitis B, hepatitis C, HIV and cytomegalovirus (CMV), which will be repeated 6 months later.
- **What's involved?** You will be asked to give a number of sperm samples, normally at the HARI Unit. Usually three samples, collected at two-day intervals, are needed so that the best samples are got. Not all sperm are suitable for freezing, however. A sample will be analysed to see if the sperm can survive the freezing process. If they are suitable, the sperm will be frozen and stored until needed.

The sperm are normally stored for 10 years. But you can write to the HARI Unit asking to extend this period. Sperm will only be stored while you are alive. It is important that you keep in touch with the HARI Unit every year, and tell them of any changes in your address or contact details.

>>> It may be possible to store your sperm (semen) before treatment begins.

You may worry that organising the sperm banking may cause a delay in starting chemotherapy. This is seldom the case as it can be done while tests are being done and waiting for results. However, your own health

will take priority over sperm banking. Your oncologist will make this clear to you from the beginning and that your chemotherapy or radiotherapy will be the first priority.

- **Cost of sperm banking?** The service at HARI is free for all cancer patients living in Ireland.
- **Trying to conceive?** When the time comes and you and your partner feel ready to have a child, talk to your oncologist. He or she can tell you if your body has recovered from the effects of chemotherapy. If your sperm have been frozen, you will need to contact the HARI Unit to discuss your options. The first thing that needs to be checked is your fertility. It is possible that your chemotherapy may not have affected it at all. However, if it is affected, your frozen sperm can be thawed. More than likely, you and your partner will be advised to have assisted reproduction techniques. These can involve IVF (in vitro fertilisation) and ICSI (intracytoplasmic sperm injection), which means your sperm will fertilise your partner's eggs in the laboratory. But if you have many sperm samples, artificial insemination may be done instead.
- **Where?** You can decide to have this treatment at the HARI Unit. If you decide to be treated elsewhere, it is possible for the frozen sperm to be transferred to a clinic of your choice. However, your clinic must agree to it beforehand and the transfer is done at your own risk. You will need to have some fertility tests carried out first.
- **More information?** If you would like to find out more about sperm banking, talk to your doctor or nurse. You can also call the National Cancer Helpline 1800 200 700 for advice in confidence.

Coping with infertility

It is not easy to come to terms with infertility. You may be shocked and distressed if told you cannot have children. Having children may not have been a priority before treatment and now suddenly it is. The sense of loss can be painful no matter what your age.

>>> The sense of loss can be painful no matter what your age.

Your reaction to infertility can also vary. From acceptance to shock, sadness and silence to anger and depression. It is common to feel you have lost a part of yourself. You may also feel less of a man or less of a woman because you cannot have children. This is a normal reaction. There is also no set time to have these reactions. You may have them at any stage of your treatment. Indeed, the truth may only sink in when treatment is over.

Support

It can take a while to sort out your emotions and be able to talk about them. When you are ready, you may find it helpful to talk openly to your partner or a friend about these feelings. If they understand how you feel, it is often easier for them to offer help and support. It is important too to talk to your doctor or nurse. He or she may arrange for you to speak to a trained counsellor or a specialist, if you cannot deal with any strong emotions that you may have.



Pregnancy and cancer

Sometimes pregnant women learn that they have cancer. If you become pregnant before your cancer is diagnosed or before your chemotherapy starts, you should discuss all your options with your doctor. To give chemotherapy or not depends on:

- How far into your pregnancy you are
- The type of cancer you have
- If your cancer has spread
- The type of chemotherapy you will be having.



If you are in the first 3 months (trimester) of your pregnancy, giving drugs can harm your baby. Depending on your situation, it may be possible to delay starting chemotherapy until later in pregnancy or after your baby is born. In some cases, however, you will not have this choice. For this reason, you will need to talk to your doctor to make sure you know all the risks and options before making any decisions. You can also talk in confidence to the nurses on the National Cancer Helpline 1800 200 700. Remember in some cases it is possible to have chemotherapy and deliver a healthy baby too. However, great care must be taken during this time.

Will chemotherapy affect my sex life?

Chemotherapy may or may not bring changes to your sex life. A lot depends on:



- Your age
- If you have had these problems before
- The type of chemotherapy you are getting
- If you have any other illnesses



If you are worried that it will affect your sex life, discuss your concerns with your doctor before treatment. He or she can tell you about any likely side-effects. While it is usually safe to have sex during chemotherapy, do check with your doctor. If your platelet count is low and there is a risk of bleeding, your doctor may advise you not to have sex until your count is higher.

Do not worry that cancer can be passed on to your partner during sex. This will not happen. But most hospitals advise that males wear condoms to prevent any traces of the drugs passing into semen or vaginal fluids. While the chances of this happening are low, it is better to be safe.

Physical effects

Short-term effects: Tiredness, lack of energy or nausea can sometimes prevent you from having sex. Your desire for sex (libido) may be low too. If you are a man you might not be able to climax or have an erection. For women, sex may be more uncomfortable due to bladder or vaginal infections, a vaginal discharge or itching.

Long-term effects: For women, chemotherapy may damage the ovaries. This can bring on early menopause (see page 44 on infertility). As a result, you may have dryness of the vagina and less interest in sex. If this happens, your doctor may prescribe hormone replacement therapy (HRT) to help. If sex is painful, a cream or ointment can be prescribed. You can also get KY gel or other creams such as Replens from your local pharmacy to moisten your vagina.

For some men, chemotherapy can cause changes in hormone levels, reduce blood supply to the penis, or affect the nerves that control the penis. All of these can result in impotence.

Emotional effects

You may lose your desire for sex if you are feeling stressed, anxious or depressed. You may be worried about surviving cancer, or about your family or your finances. Your emotions may be turned upside down and you may find it hard to relax. This is a normal way to feel at this time.

If you have had surgery which has changed your body image, you may feel self-conscious or vulnerable being with your partner. You may be afraid that your partner – or a new one – will be put off by the changes to your body. You may not want anyone to see or touch your body. It can take some time to get used to your new image.

How long will it last?

Once you get back to your old routine and your energy level improves, your interest in sex should return. But there is no set time for you to be ready to have sex again. It varies from person to person. It may take a while and often depends on how long it takes you to come to terms with your illness. Your doctor will give you advice about any long-term effects.

Contraception

Do not presume that you are infertile while on chemotherapy. You must take good contraceptive precautions at this time. If you become pregnant, the chemotherapy drugs can harm your baby. To prevent this or any possible problems for your partner, your doctor may tell you to use a reliable method of contraception throughout your treatment. Barrier methods like condoms or the cap are usually best. You should continue this for a few months afterwards.

Cancer Helpline 1800 200 700

Talking about your worries

Talking about your feelings to your partner may help ease your anxieties. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Don't feel guilty or embarrassed to talk to your doctor or nurse about this matter either. Knowing how sensitive this issue can be, he or she will only be glad to help you. You can also be referred for specialist counselling, if you think that would be helpful.

A booklet called *Sexuality and Cancer* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy or for advice in confidence.

What follow-up do I need?

Follow-up visits to your specialist are very important. They will allow your doctor to check for signs of recurrence of the cancer, or follow up on any side-effects you still have. Your doctor will also be able to check for signs of new effects that may develop after you have finished treatment.

In rare cases, some types of chemotherapy may cause long-term damage to the heart and lungs. There is also a slight risk of developing a second cancer because of the treatment.

It is better to be aware of these as soon as possible so that effective treatment can be given. If you are between check-ups and you have a symptom or problem that worries you, let your doctor know. Make an appointment to see him or her as early as possible.

How can I get my life back to normal?

It is possible to have a fairly normal life during treatment. Often the drugs can make you feel better by easing any symptoms of the cancer. You may also get better quickly between the cycles of treatment. This can help you feel in control and do the things you normally like doing.

More than likely you will have a new routine while on chemotherapy. Once treatment finishes, it may take a while to get back to your old routine. You may even find that you miss the regular contact with the people who looked after you during your regular visits to hospital.

Depending on the effects of treatment – surgery, chemotherapy or radiotherapy – you may have to make some lasting changes to your life. Living a healthy lifestyle can help to reduce your chances of getting health problems in the future.

Fatigue

Fatigue or tiredness can be the biggest thing that affects your everyday life. In fact, it may be at least a year before your body gets over the effects of treatment and you regain your strength. See page 39 for more about fatigue. A useful booklet called *Coping with Fatigue* is also available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

»»» It may be at least a year before your body gets over the effects of treatment.

School or work

- **School or college:** Some students are able to continue with school or college during their treatment. But this can depend on where you are in your studies. If you are still in full-time education, consider putting your education on hold until your treatment is over. If you are preparing for important exams, it may be too much for you. You may find it hard to concentrate and focus. Instead, spend your time doing something that you enjoy until you are well enough for your studies.
- **Teenagers and school:** If your child is a teenager, usually they can manage to go to school. Sometimes they may not want to go back because they are embarrassed about hair loss or other side-effects of treatment. But mixing with school friends can help to make things normal for your child. Gentle reassurance and counselling can help

if it is a problem. Also, discuss your child's illness with the teachers. You will need to know when there are any infections like chickenpox or measles in your child's class. It is best if your child avoids games and PE while on treatment as they may get overtired.

- **Work:** Depending on how you feel and the type of work you do, you may be able to work during treatment. In general, most people do not work while receiving chemotherapy. Discuss the issue with your doctor and employer before treatment. But don't be in a rush to get back to your normal routine with work. Just do as much as you feel comfortable with. If you do work, you may need to take rests during the day or shorten your working day. When you decide to return to work, begin with reduced hours, e.g. mornings or afternoons only. Gradually build up your hours until you feel comfortable working a full day.
- **Finances:** If you are worried about your finances and costs of treatment, see page 69 for more about benefits and allowances that you may be entitled to.

Social activities

Just because you are getting chemotherapy doesn't mean your social life must come to a standstill. But, you may have to cut back on activities and nights out. You may also need to rest before you do go out. Do tell your doctor or nurse if you have a special occasion coming up, like a wedding or holiday. It may be possible to change the time of your treatment to suit you, so you feel as well as possible and enjoy the occasion. Having the odd alcohol drink from time to time will not affect your treatment either but do check with your doctor.

Travelling abroad

Do tell your cancer specialist if you plan to go on holidays abroad. Also, you should get a letter from him or her giving details of your illness and treatment, in case you get sick abroad. For some holiday destinations you may need vaccines but they can be harmful if you are receiving chemotherapy. These include live vaccines for polio, chickenpox, rubella (German measles), MMR (measles, mumps and rubella), BCG

(tuberculosis), yellow fever and typhoid. There are however vaccines which you can have, if needed. Do ask your doctor which vaccines are safe for you. Again, if you go on a sun holiday, you must protect your skin. See page 40 for more about skin care in the sun. If you would like more information or a copy of the booklet *Travel and Cancer*, call the National Cancer Helpline 1800 200 700.

Insurance

- **Travel insurance:** It is common for people who have or had cancer to have problems getting travel insurance. Sometimes it is hard to get travel insurance while you are having chemotherapy, but once it is over, it is usually less of a problem. Discuss this with your doctor, who can advise you. The Irish Cancer Society also has advice on travel companies that can help you. Call the National Cancer Helpline for the factsheet, *Travel Insurance and Cancer*.
- **Life insurance:** You may want to provide some finances for your family in the future or have a loan or mortgage paid off. Getting life insurance can be hard, if you have or had cancer. But it is not impossible. Call the National Cancer Helpline for advice and for the factsheet, *Life Insurance and Cancer*.

Quit smoking


Tobacco smoke may be more damaging for your lungs if you have had chemotherapy. If you smoke, you should consider stopping. The National Smokers' Quitline offers support and assistance for smokers. You can talk to a specially trained counsellor who will help you to prepare a plan and support you during this time. Call the Quitline 1850 201 203, Monday–Friday, 9am–5pm for more information. Some hospitals also have stop-smoking clinics. Ask your doctor or nurse if there is one in your hospital.

Feelings and emotions

You may have a variety of emotions and feelings during your treatment and afterwards. One of them may be anxiety about the cancer coming back. For more information see page 61.



What can I do to feel well?

- **Medication:** Ask your doctor what side-effects you can expect. Take medication as ordered by your doctor, especially for pain, backache or nausea and vomiting.
- **Rest:** Do not fight the tiredness. Get plenty of rest. If you are working, reduce your hours at work while having treatment. 
- **Sleep:** Have a bedtime routine. If you find it hard to sleep at night, tell your doctor or nurse. Your doctor may be able to prescribe some mild sleeping tablets for you.
- **Exercise:** If you are able for physical exercise, do some regularly. Take it easy at first, increasing the amount as you feel stronger.
- **Eating:** Eat small meals and a well-balanced diet, especially fruit and vegetables. Ask for help in preparing your meals. Take plenty of clear fluids such as water or juices. Exercise and cutting out sweets and cakes may help to bring your weight back to normal, if you put on weight during treatment. Do not diet while on treatment unless advised by your dietician and doctor.
- **Quit smoking:** Seek advice about quitting smoking, if you are a smoker.
- **Protect your skin:** Keep your skin covered up. Protect it by wearing a high factor sunscreen (SPF 15). Do not sunbathe for long periods.
- **Talking:** If you are feeling worried and anxious, talk to your close friends or family about your concerns. Ask to see a medical social worker, counsellor or specialist nurse if you prefer. They can help you find ways to cope.
- **Ask for help:** Cut down on unnecessary tasks. Get others to help you around the house, with shopping, cooking and childcare or with travelling to hospital.
- **Complementary therapies:** Some complementary therapies, like relaxation and medication, can boost your morale and give you a sense of well-being. Do ask your doctor or nurse if they can recommend therapies that are safe for you.

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them helpful and beneficial during their illness. In many countries the way cancer is treated depends on the culture and environment in which you live. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments which doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone treatments and biotherapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- | | | |
|------------------|--------------------------------|-----------------|
| ■ Meditation | ■ Reflexology | ■ Yoga |
| ■ Relaxation | ■ Music, art and dance therapy | ■ Acupuncture |
| ■ Visualisation | ■ Nutrition therapy | ■ Hypnotherapy. |
| ■ Gentle massage | ■ Shiatsu | |
| ■ Aromatherapy | | |

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some therapies like acupuncture can help with nausea and vomiting while stress management can help with side-effects such as pain, fatigue, anxiety and depression.

Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include:

- Diet therapy
- Megavitamin therapy
- Herbalism.

Most doctors do not believe that such treatments can cure or control cancer.

Interactions with chemotherapy

Some herbs, minerals or vitamins can make some chemotherapy drugs work less well. For example, St John's Wort, too much vitamin C and essiac can reduce the effect of chemotherapy drugs. Do talk to your doctor and nurse before taking any complementary therapy.



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



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, it is important to talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present, this area is not fully regulated in Ireland. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Cancer and Complementary Therapies*. If you would like a copy or more advice, call the National Cancer Helpline 1800 200 700.

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have lung cancer. Reactions can differ from person to person too. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until you recover from your illness that your emotions hit hard.

It is normal to be upset when told you have cancer.



Common reactions include:

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



Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. It may take a long time to come to terms with your emotions. Not only do you have to cope with the knowledge that you have cancer, but also the physical effects of chemotherapy.

If you would like more information or would like to talk in confidence, call the National Cancer Helpline 1800 200 700.

You can also ask for copies of our booklets, *Understanding the Emotional Effects of Cancer* and *Who Can ever Understand? Talking about your Cancer*.



How can my family and friends help?

Families and friends can support people through their cancer journey in different ways. Some family members and friends can offer a listening ear and give advice if needed. Some may gather up-to-date information on cancer to know what their loved one can expect and what they are going through. Others may prefer to help in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your friend or relative best.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with own your feelings too.

>>> Don't withdraw because you're afraid of what might happen to your relative or friend in the future.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may not think you are doing much by just listening. In fact, it is one of the best ways to help.

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let

them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

Lost for Words – How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



>>> Your friend or relative may sometimes get cross or irritable. These feelings are completely normal.

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as much as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to changes in their lives.

Every family deals with cancer in a different way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or that you're letting the children down. These are all natural feelings to have at this time.

Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more. Talk to children in language they will understand and without going into the details of your illness.

It is best to prepare children for what to expect from the side-effects of treatments and to answer their questions simply and honestly. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt, anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a copy, call the National Cancer Helpline 1800 200 700. Another helpful book for children is *The Secret C: Straight Talking about Cancer*. See page 83 for more details.



What else can I do?

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** 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.
- **Live well:** Try to eat as well as you can. Eat little and often, including lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do, as you feel stronger.
- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while to adjust to your new routine but keep an open mind. Change may bring new opportunities and blessings.
- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you

forget and are not sure what to do, ask your doctor. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones.

- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.
- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.
- **Seek professional help:** If you have any low moods or strong emotions talk to your close friends and family – or someone who is a good listener. If they are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.
- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. Sometimes spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation can help you focus on what has value and meaning in your life. Even if you don't consider yourself a religious or spiritual person, it is still possible to get support from any belief system that has importance for you. Some complementary medicines that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art may help too.

Support resources

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.



- Medical social worker
- Oncology liaison nurses
- Cancer nurse co-ordinators
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups
- Helpline nurses.



Medical social worker

The medical social worker in your hospital can help in many ways. He or she provides support and counselling to patients and their families and can provide advice on benefits, entitlements and services available when you go home.

Specialist nurses

Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses provide support to patients and their families from the time of diagnosis and throughout treatment. They along with other members of your medical team work together to meet your needs.

Psycho-oncology services

In some larger hospitals there are special units that provide psycho-oncology services. This means that psychological care and support is given to cancer patients during diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

Community health services

When you go home there are various community health services available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live in an area which is remote or far from the hospital where you have been treated, your community welfare officer can also help with practical issues such as financial worries, transport, etc. All these people in community health services can provide advice and support.

You can get more information on the services available either from the social worker in the hospital before you go home or at your local health centre.

Support groups

Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. Sometimes you may find it easier to share your thoughts and feelings with someone who has a similar experience than with anyone else. There are now a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. A list of support groups is given at the back of this booklet.

Helpline nurses

Often you might need practical advice about your financial matters, e.g. getting a mortgage or travel insurance. The Irish Cancer Society Helpline nurses will be happy to discuss any concerns you or your family may have, at any stage of your illness. They can give you more information about any of the services outlined above and can also let you know about support services in your area.

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given:



- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances



At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €66 a night charge up to a limit of €660 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €66. There is no charge if you have a medical card or are admitted to hospital as a result of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services, and outpatient services and medical appliances. Every person aged 70 or over has a right to a medical card and no means test is needed. It covers the applicant only and not their dependants.

To qualify for a medical card depends on a means test for most people. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office, i.e. the former

health board. If your means are above but close to the guidelines, you should apply for a card anyway as a card is granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

GP visit card

If you do not qualify for a full medical card, you may be eligible for another type of medical card. The 'GP visit card' was introduced in 2005. It covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependant children pay a limit of €90 each month to cover the cost of prescribed drugs, medicines and appliances. If you have not already received a DPS card for yourself and your family, you can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland this is available through the VHI, Quinn Healthcare, VIVAS Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

Benefits and Allowances

Information on the following is given in this section:



- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Appliances
- Travel to hospital



Illness Benefit

This is a benefit for insured people. Eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social and Family Affairs, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with a disability who are aged between 16 and 66. For this allowance you must satisfy a means test, normally live in Ireland and be medically suitable. To be medically suitable you should have an illness that has continued or may continue for at least 1 year. This means that you are unlikely to be able to work for at least 1 year due to your illness. You are allowed a free travel companion pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions and you must normally live in Ireland. You are allowed a free travel pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 704 3314, Ext. 48728.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, normally live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are allowed a free travel pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social and Family Affairs. You **cannot** get this allowance if you are receiving another Social Welfare payment.

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or Dublin (01) 704 3000.

Carer's Benefit

Under carer's leave legislation, you may be entitled to unpaid temporary leave from your employment. Or if you are employed but

wish to care for a sick relative full time, you may qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, normally live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 / Dublin (01) 704 3000.

Appliances

For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every 6 months.

Travel to hospital

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, e.g. hardship.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements which may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries contact:

Information Service Tel: 1850 662 244
Dept of Social and Family Affairs Leaflet line: 1890 202 325
Oisín House Email: info@welfare.ie
 212–213 Pearse Street Website: www.welfare.ie
 Dublin 2

If you have queries about health and social services, contact the HSE office in your area. In 2005 the health boards became the Health Service Executive based in four regions: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

HSE infoline: 1850 241 850; **Email:** info@hse.ie; **Website:** www.hse.ie

HSE East Coast Area
 [Co Wicklow, South East Dublin]
 Southern Cross House
 Southern Cross Business Park
 Boghall Road
 Bray
 Co Wicklow
 Tel: 01 201 4200

Tullamore
 Co Offaly
 Tel: 057 932 1868

HSE Northern Area
 [North Dublin]
 Swords Business Campus
 Balheary Road
 Swords
 Co Dublin
 Tel: 01 813 1800

HSE Mid-Western Area
 [Counties Clare, Limerick, Tipperary
 North]
 Head Office
 31/33 Catherine Street
 Limerick
 Tel: 061 483 286

HSE South Western Area
 [Co Kildare, West Wicklow, South Dublin]
 Oak House
 Millennium Park
 Naas
 Co Kildare
 Tel: 045 880 400

HSE North Eastern Area
 [Counties Cavan, Monaghan, Louth and
 Meath]
 Head Office
 Navan Road
 Kells
 Co Meath
 Tel: 046 928 0500

HSE Midland Area
 [Counties Laois, Offaly, Longford,
 Westmeath]
 Head Office
 Arden Road

HSE North Western Area
 [Counties Donegal, Sligo, Leitrim and
 West Cavan]
 Head Office
 Manorhamilton
 Co Leitrim
 Tel: 071 982 0400 / 1850 636 313

HSE South Eastern Area
 [Counties Carlow, Kilkenny, Wexford,
 Waterford, South Tipperary]
 Head Office
 Lacken
 Dublin Road
 Kilkenny
 Tel: 056 778 4100

HSE Western Area
 [Counties Galway, Mayo and Roscommon]
 Head Office
 Merlin Park Regional Hospital
 Galway
 Tel: 091 751 131

HSE Southern Area
 [Counties Cork and Kerry]
 Head Office
 Wilton Road
 Cork
 Tel: 021 454 5011

Information is also available from your local Citizens Advice Centre. A list of these centres is available from:

Citizens Information Board (formerly Comhairle)
 7th Floor, Hume House, Ballsbridge, Dublin 4
 Tel: 01 605 9000
 Citizen Information Service: 1890 777 121
 Email: information@ciboard.ie
 Website: www.citizensinformationboard.ie

There are also some booklets available that may help you. These include:

Information Guide to Health Services published by the Dept of Health and Children. Copies available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers or see page 74.

Guide to Social Welfare Services published by the Dept of Social and Family Affairs. Tel: 1850 662 244. Email: info@welfare.ie; Website: www.welfare.ie

Entitlements for People with Disabilities published by the Citizens Information Board. Tel: 1890 777 121 / 01 605 9000. Email: information@ciboard.ie; Website: www.citizensinformationboard.ie

Irish Cancer Society Services

The Irish Cancer Society funds a range of cancer support services that provide care and support for people with cancer at home and in hospital.



- Homecare nurses
- Night nursing
- Oncology liaison nurses
- Cancer Information Service (CIS)
- Action Breast Cancer
- Counselling
- Cancer support groups
- Cancer information booklets
- Patient grants



Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly night hours) to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer Information Service (CIS)

The Society also provides a Cancer Information Service with a wide range of services: the **National Cancer Helpline** is a freefone service

that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues such as prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put patients in contact with the various support groups that are available. The helpline **1800 200 700** operates Monday to Thursday from 9 am to 7 pm, and every Friday from 9 am to 5pm. A **Prostate Cancer Information Service 1800 380 380** also operates at the same time.

All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**. The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private. **CancerForum** is a bulletin board on our website (**www.irishcancer.ie**) that gives the public the chance to post their comments. The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

Action Breast Cancer

Action Breast Cancer (ABC) is a project of the ICS that provides breast cancer information and support and also funds breast cancer research. Its services are free and confidential. They include a national helpline, publications, one-to-one support, breast awareness talks and advocacy. The ABC helpline **1800 90 30 40** runs weekdays from 9am to 5pm.

Counselling

Coping with a cancer diagnosis can be very stressful at times. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the Cancer Helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.



Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards.

Patient grants

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial assistance to patients in need. If you would like to request this kind of help, contact your oncology or medical social worker at the hospital where you have been treated. He/she should then make the request in writing to the Irish Cancer Society.



If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.



Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
Fax: 01 231 0555
National Cancer Helpline
1800 200 700
Action Breast Cancer: 180 30 90 40
Action Prostate Cancer: 1800 380 380
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Citizens Information Board (formerly

Comhairle)
7th Floor, Hume House
Ballsbridge
Dublin 4
Citizen Information Service:
1890 777 121
Tel: 01 605 9000
Email: information@ciboard.ie
Website:
www.citizensinformationboard.ie

The Carers' Association

Bulger House
Patrick Street
Tullamore
Co Offaly
Tel: 057 932 2933
Freefone: 1800 240 724
Email: info@carersireland.com
Website: www.carersireland.com

Dept of Social and Family Affairs – Information Service

Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1850 662 244
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted

Reproduction Ireland)
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion HSE

Website: www.healthpromotion.ie

Irish Patients Association

Unit 1
21 Church Road
Ballybrack
Co Dublin
Tel: 01 272 2552
Out-of-hours emergency no. 087 6529448
Email: info@irishpatients.ie
Website: www.irishpatients.ie

Health insurers

Quinn Healthcare (formerly BUPA)

Mill Island
Fermoy
Co Cork
Local: 1890 700 890
Fax: 025 42122

Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

VIVAS Health

Paramount Court
Corrig Road
Sandyford
Dublin 18
Tel: 1850 717 717
Email: support@vivashealth.ie
Website: www.vivashealth.ie

Voluntary Health Insurance (VHI)

VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
Email: info@vhi.ie
Website: www.vhi.ie

Support groups & support centres

ARC Cancer Support Centre

ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Beacon Cancer Support Centre

Suite 15
Beacon Court
Sandyford
Dublin 18
Tel: 01 213 5654

BMT Support

Bone Marrow Transplant Support Group
c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Email: info@bmtsupport.ie
Website: www.bmtsupport.ie

Brain Tumour Cancer Support Group

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Tel: 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 482 615
Website: www.mwhb.ie/cancercentre

Cancer Plus [support group for parents of children with cancer]

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Email: support@irishcancer.ie

CanTeen Ireland

Young Peoples' Cancer Support Group
c/o Carmichael Centre
Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: canteen@oceanfree.net

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: Karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Chronic Myeloid Leukaemia Support Group

c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Fax: 01 231 0555
Email: support@irishcancer.ie
Website: www.cancer.ie

Colostomy & Ileostomy Care Group

c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

The Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net

Dóchas – Offaly Cancer Support

Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: dochasoffaly@hotmail.com

Donegal Cancer Support Group

Clar
Co Donegal
Tel: 074 974 0837

The Gary Kelly Support Centre

Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Fax: 041 980 5101
Email: info@garykellycentre.org
Website: www.garykellycentre.org

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: kk@kathleenkelleher.com

HOPE

Enniscorthy Cancer Support & Information Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555

The LARCC Retreat Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 71971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Lios Aoibhinn Cancer Support Centre

85 Nutley Lane
Donnybrook
Dublin 4
Tel: 01 260 5756

Lymphoedema Support Association

c/o Patricia Hannigan
St Micheal's
Mount Anville Park
Dublin 14
Tel: 01 288 6683

Lymphoma Support Ireland

c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Fax: 01 231 0555
Email: support@irishcancer.ie
Website: www.lymphoma.ie

Men Against Cancer (MAC)

c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Macmillan Support & Information Centre

Belfast City Hospital Trust
79–83 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Fax: 028 9069 9203
Email: belfast@macmillan.org.uk

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407

Reach to Recovery

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 30 90 40
Email: support@irishcancer.ie

Sligo Cancer Support Centre

2A Wine Street
Sligo
Tel: 071 967 0399
Email: scsg@tinet.ie

South East Cancer Foundation

7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Fax: 051 876 718
Email: infosecf@eircom.net

The Tuam Cancer Care Centre
30 Temple Jarlath Court
High Street
Tuam
Co Galway
Tel: 093 28522
Email: info@tuamcancercare.ie
Website: www.tuamcancercare.ie

Turning Point – Positive Health Centre
23 Crofton Road
Dún Laoghaire
Co Dublin
Tel: 01 280 7888
Email: turningpoint@eircom.net
Website: www.turningpoint.ie

Useful contacts outside Republic of Ireland

Action Cancer
Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Fax: 028 9080 3356
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society
1599 Clifton Road NE
Atlanta, GA 30329-4251
Website: www.cancer.org

Cancerbackup
3 Bath Place
Rivington Street
London EC2A 3JR
Tel: +44 207 696 9003
Helpline: +44 207 7392280
Website: www.cancerbackup.org.uk

Cancer Research UK
Website: www.cancerhelp.org.uk

Macmillan CancerLine
Macmillan Cancer Relief
89 Albert Embankment
London SE1 7UQ
Tel: +44 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Memorial Sloan-Kettering Cancer Center (US)
Website: www.mskcc.org

National Cancer Institute (US)
Website: www.nci.nih.gov

Royal Marsden Hospital Foundation NHS Trust
Website: www.royalmarsden.org

The Ulster Cancer Foundation
40/42 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 906 63281
Website: www.ulstercancer.co.uk

University of Pennsylvania Cancer Center
Website: www.oncolink.com

Wessex Cancer Trust (UK)
Website: www.wessexcancer.org

Helpful books



Free booklets from the Irish Cancer Society

- **Understanding Chemotherapy**
- **Understanding Radiotherapy**
- **Radiation Therapy: A Patient Pathway (DVD)**
- **Coping with Fatigue**
- **Understanding the Emotional Effects of Cancer**
- **Lost for Words: How to Talk to Someone with Cancer**
- **Who Can Ever Understand? Taking About Your Cancer**
- **Talking to Children about Cancer. A Guide for Parents**



Cancer at Your Fingertips

Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1-85959-036-5

Cancer Positive: The Role of the Mind in Tackling Cancers

Dr James Colthurst (with Patrick Scrivenor)
Michael O'Mara Books Ltd, 2003
ISBN 1-85479-860-X

Cancer: What Every Patient Needs to Know

Jeffrey Tobias
Bloomsbury, 2001
ISBN 0-74755-410-2

Challenging Cancer: Fighting Back, Taking Control, Finding Options

(2nd edn) Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1-85959-068-3

Taking Control of Cancer

Beverley van der Molen
Class Publishing, 2003
ISBN 1-85959-091-8

The Bristol Approach to Living with Cancer

Helen Cooke
Robinson, 2003
ISBN 1-84119-680-0

The Key Model—A New Strategy for Cancer Recovery

Dr Seán Collins & Rhoda Draper
Ardagh Clinic, 2004
ISBN 0-95214-445-X

The Secret C: Straight Talking About Cancer

[explaining cancer to children]
Julie A Stokes
Winston's Wish, 2000
ISBN 0-95391-230-2

Understanding Cancer

Gareth Rees
Family Doctor Publications, 2002
ISBN 1-89820-551-5

What You Really Need to Know about Cancer

Dr Robert Buckman
Pan, 1997
ISBN 0-33033-628-2

For more details on helpful and up-to-date books and their availability, call the National Cancer Helpline 1800 200 700.

Questions to ask your doctor

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

- Will chemotherapy cure or control my cancer? Will it stop it returning?
- How successful is this treatment for my cancer? What are the benefits and risks?
- Are there other treatment options? Why is this one best for me?
- What will happen if I have no treatment?
- Where can I have my treatment? Do I have to stay in hospital or can it be given at home?
- How will the chemotherapy be given?
- How long will my treatment take?
- How often will I have to come to the hospital or clinic? Will the arrangements change next time I come to the hospital or clinic?
- What drugs am I receiving?
- What tests will I have before treatment each time?
- How will I know if the treatment is working?
- What side-effects will I have? Can I take something to control the side-effects?
- How long will the side-effects last?
- Do I need to use contraception during my treatment? What will happen if I or my partner becomes pregnant while I am on treatment?
- Will treatment affect my fertility?
- Should I eat special foods?
- Is there anything I can do to help myself during treatment? Is there anything I should avoid?
- Can I use complementary therapies?
- Can my treatment be timed to let me go on holiday or attend a special event?
- What happens when treatment is finished?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer

Your chemotherapy diary

Drug name	Form (injection, liquid, tablet)	Dose	How often	Any side-effects

Tell your doctor or nurse, if the following occur (e.g. high temperature, bleeding)

Emergency tel: _____

Number of courses planned: _____ Dates: _____

Treatment will be reviewed on: _____

Notes



Notes



Large green rectangular area for taking notes.

Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

The Human Assisted Reproduction Ireland (HARI) Unit

Michelle Quinn, Oncology Liaison Nurse

Catherine O'Brien, Clinical Nurse Manager

Susan Rowan, Patient Education Editor

Eileen O'Donovan, Cancer Information Nurse

Aoife McNamara, Cancer Information Nurse

Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you would like more information or someone to talk to, please phone our National Cancer Helpline 1800 200 700.

Would you like to be a patient reviewer?

If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome.

Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers. If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes our patient booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us.

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.

Tel: **01 231 0500**; Email: **info@irishcancer.ie**; Website: **www.cancer.ie**

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life with three programme areas to achieve them: advocacy, cancer services and research.

