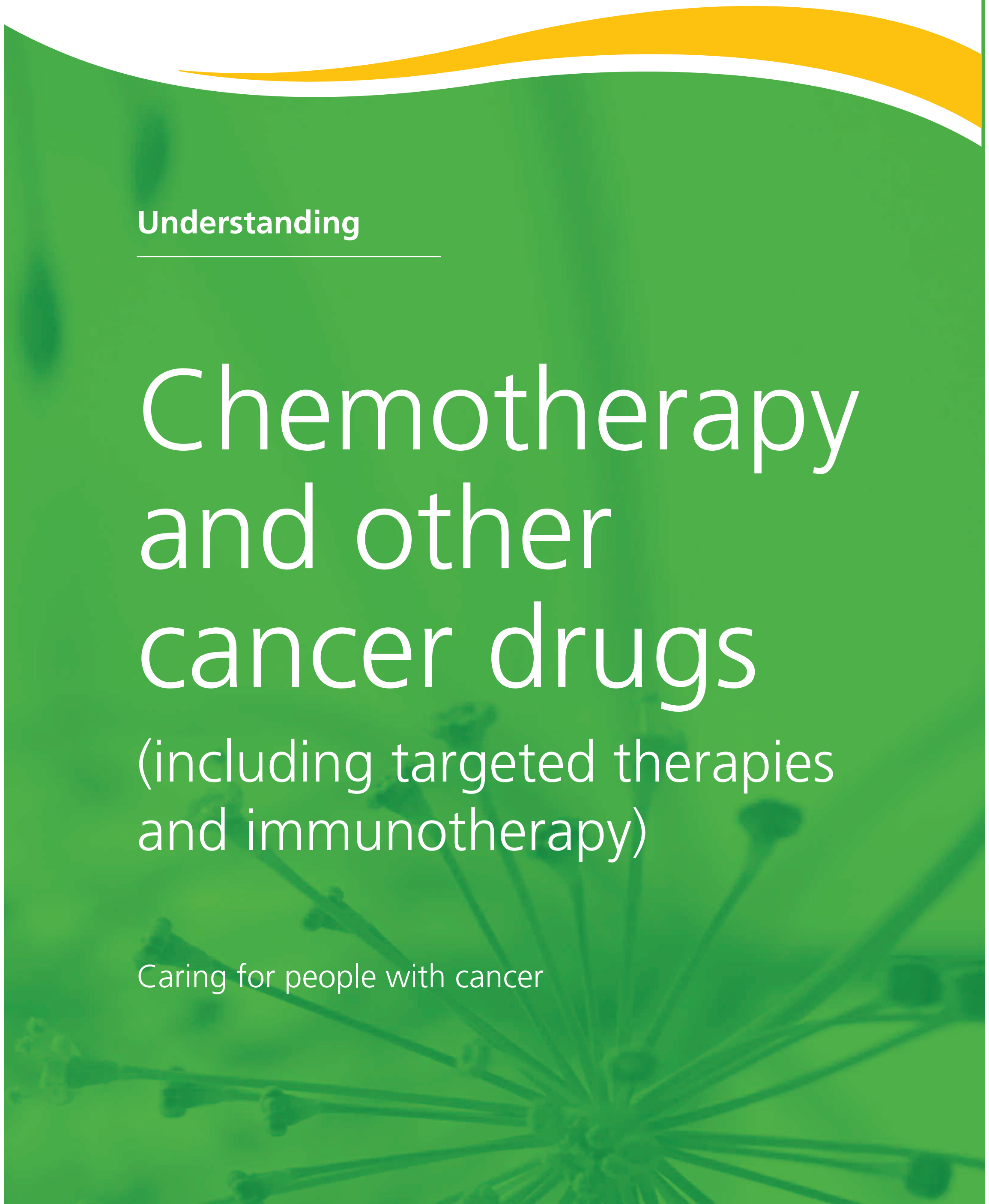
Irish
Cancer
Society



Understanding

Chemotherapy and other cancer drugs

(including targeted therapies and immunotherapy)

Caring for people with cancer

Understanding

Chemotherapy and other cancer drugs

(including targeted therapies and immunotherapy)

This booklet has information on:

- Chemotherapy, targeted therapies and immunotherapy
- Side-effects and how to manage them
- Life during and after treatment
- Financial and practical matters

Useful numbers

	TELEPHONE
Specialist nurse	
Hospital	
Family doctor (GP)	
Surgeon	
Medical oncologist / haematologist	
Radiation oncologist	
Medical social worker	
Main hospital number	
Emergency	
Pharmacist	
Hospital records number (MRN)	

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Cancer drugs can help cure cancer, prevent it from coming back or reduce the size of cancer before surgery or radiotherapy. They can also control cancer and ease cancer symptoms.

This booklet has information on:

- Chemotherapy (page 27)
- Targeted therapies (page 33)
- Immunotherapy (page 41)

How does my doctor decide which drug to use? Page 9

The type of drug and dose you need depends on many things, including the type of cancer you have and your general health. You might have a combination of drugs.

How are cancer drugs given? Page 51

The 2 most common ways to have cancer drugs are into a vein or tablets, taken by mouth. Most people have their treatment in a day hospital or clinic. Some people can have their treatment at home.

How long will I have treatment for? Page 17

Cancer drugs are usually given in a course of treatments. A treatment course can last weeks, months or years. For some types of cancers – for example, cancer that has spread – you can stay on treatment for as long as it is working for you.

Will I get side-effects? Page 69

Side-effects vary from person to person and depend on the cancer drugs you are having and the dose. Most side-effects ease in the weeks and months after treatment, although some may last longer. Ask your doctor or nurse to tick the side-effects on page 75 that may apply to you.

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

Clinical trials Page 20

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

We’re here for you Page 131

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

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

Reading this booklet

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

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

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

About our information

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

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

Helplines Partnership Member

Email: supportline@irishcancer.ie

About cancer drugs

There are many different types of cancer drugs. Some treat cancer and others help to relieve symptoms such as sickness and pain.

This booklet is about drugs that treat cancer. The drug treatments described in this booklet are:

- **Chemotherapy** (page 27)
- **Targeted therapies** (page 33)
- **Immunotherapy** (page 41)

This booklet does not have information on hormone therapies. For more information on hormone therapies, call our Support Line on Freephone 1800 200 700 or drop into a Daffodil Centre. You can also visit our website **www.cancer.ie.**

Why and when are cancer drugs given?

There are many reasons why chemotherapy, targeted therapy and immunotherapy drugs are given. Sometimes they can be given for more than one reason.

Curing cancer

Cancer drugs are sometimes given to cure cancer. This depends on the type of cancer and the stage of your disease.

Reducing the size of cancer

Some cancer drugs can be given to shrink a cancer before surgery or radiotherapy or in combination with radiotherapy prior to surgery. This can make a tumour easier to remove during surgery. Treatment given before surgery is called neo-adjuvant therapy.

If curing the cancer is not possible, some cancer drugs can help to improve symptoms, by shrinking cancers that are causing pain and pressure. For example, if the cancer is pressing on a nerve (causing pain), the drug can shrink the cancer and relieve the pain.

Preventing cancer coming back

Cancer drugs may be given after surgery or radiotherapy to destroy any remaining cancer cells, which may be so tiny they cannot be seen on routine X-rays or scans. This is to reduce the risk of the cancer coming back. Treatment given after another treatment is called adjuvant treatment. Doctors will decide if you need adjuvant treatment based on the stage of the cancer and the biology of the cancer cells that were taken during surgery. They will give adjuvant treatment as a preventative measure.

Controlling cancer

Cancer drugs can help stop cancer from spreading, slow its growth, or destroy cancer cells that have spread to other parts of your body. This can improve your quality of life and help you to live longer. This type of treatment can continue for years, if you are tolerating your treatment well and it continues to control your cancer.

Easing cancer symptoms

If a cure is not possible, cancer drugs 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.

Making radiotherapy and other cancer therapies more effective

Chemotherapy drugs can be given at the same time as radiotherapy to make it more effective. This is called chemoradiotherapy.

Systemic anti-cancer therapy (SACT)

The term systemic anti-cancer therapy describes all types of drugs used to treat cancer. Systemic means the drugs affect your whole body – they travel throughout your system.

How does my doctor decide which drugs to use?

The drug your doctor decides to give you is based on years of research. You may have a combination of cancer drugs. For example, chemotherapy and targeted therapies. The drug or drugs your doctor recommends for you depends on:

- **The type of cancer you have.** Some kinds of cancer drugs are used for many types of cancer. Other drugs are used for just one or two types of cancer
- **If the cancer has spread**
- **If you have had a cancer drug before**
- **If you have other health problems**, such as diabetes, heart disease or kidney disease
- **Your age and your fitness level.** This is also called your performance status
- **If you have a specific protein or gene that will respond well to a certain drug**
- **If you have specific genetic changes in your cancer**

Your doctor may also ask you to take part in a clinical trial. This is where a new drug treatment is being tested or an existing drug is used in different ways to see if it might benefit cancer patients. See page 20 for more details about clinical trials.

Before treatment – what you need to know

Before treatment – what you need to know

- It's important that you fully understand the drug or drugs you are being given, including the benefits and risks.
- Don't be afraid to ask your doctor or specialist nurse for more information about any drugs you are taking.
- Cancer drugs are usually given in a course of treatments. This course can last weeks, months or years.
- You will have tests before and during treatment to make sure that you are fit for treatment and to see how the cancer is responding to the drugs.

How does the doctor plan my treatment?

When planning your treatment, your doctor will take into account:

- The type of cancer you have
- Where it is in your body
- If it has spread
- 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, how long it lasts and the dose used can depend on:

- The cancer drugs used
- How the cancer cells respond to the drugs
- Any side-effects from the drugs
- Other cancer treatments you've had

Understanding your drug treatment

It's important that you understand your drug treatment. You will be given written information to take home with you, but don't be afraid to ask your doctor or specialist nurse for more information. For example, what the drugs are for, any possible side-effects and if you need to do anything to prepare for treatment. For example, getting dental work done or having any recommended vaccinations.

See page 140 for a list of questions people often want to ask. There is also space for you to write down your own questions. Don't be afraid to repeat a question if you don't understand the answer. You can also speak to our cancer nurses by calling our Support Line on 1800 200 700.

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

Deciding on treatment

Time to think

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

Second opinion

You might find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP will refer you to another specialist for a second opinion if you feel this would be helpful. Getting a second opinion will not affect the care you will receive.

Accepting treatment

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

Ask your doctor if there are any vaccinations you should have.

Giving consent for treatment

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

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects
- Any other treatments that may be available
- Any suitable clinical trial. For more information on clinical trials, see page 20

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

Cycles and courses of treatment

Your course of drug treatment can last weeks, months or years. A course is made up of cycles. A cycle is the day or days of your treatment. This may be followed by a rest period, when you have no treatment and your body is recovering. Some treatments are continuous. Your cancer doctor will explain the number of cycles you need to treat the cancer. It will depend on the type of cancer you have and the drug or drugs you are receiving.

What tests might I need before and during treatment?

Weight and height

Your weight and height may be checked before you start your treatment. This is so your doctor can work out the right dose for you. However, many targeted therapy and immunotherapy drugs are given as a set dose for everyone.

Blood or urine tests

Before treatment, you may have tests on your blood or urine to check if your cancer has a specific protein or gene. Before each cycle of treatment, you will have blood tests to check your red blood cell, white blood cell and platelet count, your kidney and liver function and possibly your hormone function. These blood tests can show if you are fit for treatment and see how your body is responding to the drugs. You may have to wait for the results of the blood tests before treatment can begin. Sometimes urine tests will be done to see the effect of a cancer drug on your body. Your urine may be collected for 24 hours. Women may also be asked for a urine sample for a pregnancy test, depending on your age and menopausal status.

Physical exam

This includes taking your blood pressure, heart rate, respiration (breathing) rate, temperature and oxygen levels. The nurse will do this for you. The oncology doctor might also do an examination, depending on the type of cancer you have and the treatment you are on. This could include listening to your chest, feeling your tummy, checking your glands. The doctor may also check your skin for rashes or other anticipated side-effects, depending on the drug you are on.

Top tip

To help pass the time in hospital, either waiting for tests or treatment, it can help to bring a book, newspaper, magazine, crosswords, music or a tablet device. Check with your nurses in advance if your unit has wifi. If not, it might be an idea to download what you want to watch or listen to in advance. You can also bring things to make you more comfortable such as lip balm, hard sweets to suck and comfortable clothes and slippers. Most units will have a tea and coffee trolley with cold foods but you should ask if you want to bring your own snacks into the unit.

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.

Heart monitoring

Some drugs can affect your heart, so you may need a recording of your heartbeat (ECG) or heart ultrasound (echo). Sometimes a multigated acquisition (MUGA) scan might be done to check if your heart is pumping blood properly.

Lung function tests

Some drugs can affect your lungs, so they will be checked before you start these drugs and at regular intervals afterwards, as recommended by your doctor.

Other tests

Some drugs may affect other parts of your body, so you may need other tests. For example, a hearing or sight test. Your cancer doctor or specialist nurse will talk to you about any tests, scans or check-ups you need before your treatment begins.

What are biological and biosimilar medicines?

Targeted therapies and immunotherapies are sometimes called biological medicines. This means that they have an active substance that is produced from a biological source, such as living cells.

A biosimilar medicine is a biological medicine that is very similar to an original biological medicine. If you are getting a biosimilar medicine, be assured that it is just as safe and effective as the original biological medicine. For more information, visit the website of the Health Products Regulatory Authority at www.hpra.ie and enter ‘Biosimilar medicines’ into the search box.

Clinical trials

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

Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of or as well as the standard treatment you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, using a known licensed drug at a different point in your treatment or using two treatments together. If there is a trial suitable for you, it can offer you the chance to receive the latest way of treating your disease.

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

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet ***Cancer and Clinical Trials***. It's available to read or download on our website, **www.cancer.ie**. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

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

> 'There are huge advances in treatment ... A new drug or a clinical trial may totally change things for you. I am alive because of one such drug.'

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time. Cancer treatment should start soon after diagnosis, but for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works. It's really important that your doctors know as much about your cancer as possible before you start treatment.

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

You might also like to focus on looking after yourself while you're waiting for treatment. For example, eating well and staying active. This can help you prepare for treatment and feel more in control. For more information see page 23.

How will I know if my drug treatment is working?

After a few cycles of treatment, your doctor may arrange some tests and exams. They may include blood tests, X-rays and scans. These tests will show if the cancer is stable or has reduced in size. If you are getting a cancer drug as a palliative treatment, your symptoms should improve if the drug is working.

Ask your doctor about your test results and what they show about your progress. Your doctor will also ask how well you feel.

Tests and exams can tell a lot about how cancer drugs are working, but side-effects tell very little. You cannot tell if a cancer drug is working based on its side-effects. Sometimes people think that if they have no side-effects, the drugs are not working and 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 way to tell if your treatment is working or not.

Changes in your treatment plan

Sometimes, depending on the side-effects or results of the tests, your doctor may need to change the drugs or the dose you are receiving. It may be because the drugs are not keeping the cancer stable or reducing it in size. In other cases, it can 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. Your doctor will discuss with you any changes in your treatment plan.

> ‘Always talk — if you are ever worried about anything just ask. Everyone is there to help you.’

How can I help myself?

- Taking care of yourself may help you to cope better with treatment.
- Getting support, talking about your diagnosis and learning how to manage your feelings can make things easier for you.

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

Eat well

Eating well when you have cancer can help you cope better with the side-effects of treatment, keep up your energy and strength and reduce the risk of infection and other complications. It can also help your recovery. Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet ***Diet and Cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website **www.cancer.ie**

Stay active

Being active has many benefits. It can help to reduce tiredness and some treatment side-effects. It can also improve your mood and quality of life and strengthen your muscles, joints and bones. Ask your doctor or nurse for advice before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that non-smokers have fewer or less severe side-effects during cancer treatment. For example, chest infections. Smoking can also reduce how well chemotherapy or radiotherapy works. If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit quit.ie or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you.

Alcohol

Cut down on the amount of alcohol you drink. Alcohol can interfere with the way some drugs work, so you may need to stop completely. Your doctors and nurses will give you specific advice.

Other ways to help yourself

Get information about your cancer and treatment

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

Involve your family and close friends

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

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need.

Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Accept change in your life

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs

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

Try to cope day by day

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

Chemotherapy

What is chemotherapy?

- Chemotherapy gets into cancer cells and either kills them or stops them growing.
- You can have chemotherapy as a drip (infusion) into the bloodstream, an injection or a tablet.
- Chemotherapy can also affect normal cells, causing side-effects.
- The side-effects of chemotherapy depend on the drugs being used and vary from person to person.

Chemotherapy is a treatment using drugs that cure or control cancer. Not all forms of cancer are treated with chemotherapy, as other treatments may work better. Also, some cancers are not sensitive to chemotherapy drugs. The drugs mainly used are cytotoxic. This means that they damage the way cancer cells grow and divide, but they also affect normal cells. Normal cells have the ability to recover, cancer cells do not.

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. The nucleus contains chromosomes that are made up of genes. Each time a cell divides to make more cells, these genes must be copied exactly.

Chemotherapy can damage the chromosomes and genes inside the cancer cell. It can also stop the chromosomes being put into a new cell, preventing them from growing.

Cancer cells are more sensitive to chemotherapy than healthy cells because they divide more frequently.

Some fast-growing, normal cells like those in the lining of your mouth, your bone marrow (which makes blood cells), hair roots, digestive system and your reproductive organs also take up these drugs. Healthy cells usually repair the damage caused by chemotherapy but cancer cells cannot and so eventually die.

Damage to the normal cells is usually short term. Most side-effects will disappear once the treatment is over. But chemotherapy can cause long-term side-effects that do not go away. For detailed information on side-effects, see page 69.

Naming chemotherapy drugs

Like all drugs, chemotherapy drugs usually have two names: the **generic name** and the **brand name**.

The generic name is the chemical name of a drug, for example, paracetamol.

The brand name or trade name is the name given by the manufacturer of the drug, for example, Panadol.

Your doctor or nurse specialist should give you an information leaflet with the name/names of the drugs you are getting, which will also show the list of expected side-effects for that drug.

Cancer is often treated with a combination of cancer drugs. These combinations used by your doctor are often known by the first letters of the drug names. For example, AC is adriamycin and cyclophosphamide.

Find out more

If you know the name of your chemotherapy drug, visit the Health Product Regulatory Authority's website at www.hpra.ie where you will find more information about:

- **What the drug is**
- **How it is given**
- **Possible side-effects**

How is chemotherapy given?

You can have chemotherapy as:

- **A drip into the bloodstream** through a vein (intravenous infusion). For more information see page 54
- **An injection into the bloodstream** (usually through a vein). For more information see page 54
- **Tablets or capsules.** For more information, see page 63
- **By injection into the fluid around the spine and brain** (intrathecal chemotherapy)
- **Directly into an organ**, such as the liver
- **As an injection under the skin** (subcutaneous)

Chemotherapy is usually given in a course of treatments that can last weeks or months. For more information, see page 17. For more information on where you will have your chemotherapy, see page 61.

What are the side-effects of chemotherapy?

Side-effects happen because chemotherapy affects healthy cells, as well as cancer cells. These side-effects depend on the drugs being used. Some people have fewer side-effects than others. For example, not all chemotherapy drugs cause hair loss.

Ask your doctor or nurse if you're worried about side-effects or have any questions. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects.

Chemotherapy affects some people more than others. Your doctor may need to adjust your dose to take this into account.

Always tell your doctor or nurse if you don’t feel well or if you are having any symptoms that are troubling you.

For more information on side-effects of cancer treatment, see our side-effects section on page 69. Common side-effects are listed on page 75 in alphabetical order. Ask your doctor or nurse to tick the side-effects that your treatment may cause.

Targeted therapies

Targeted therapies

- Targeted therapies can ‘target’ genes or proteins that help some cancers to grow or survive.
- Different targeted therapies work in different ways.
- You might have a targeted drug as your main treatment or you might have it with chemotherapy and/or radiotherapy.
- Targeted drugs can be given as a tablet, an injection under the skin or into a vein through a drip.
- The side-effects of targeted therapies depend on the drugs being used and vary from person to person.

What are targeted therapies?

Targeted drugs ‘target’ specific proteins or genes that help certain cancers to grow or survive. The drugs go directly to the cancer cell and block the protein or gene (also known as a biomarker), ‘turning off’ that cancer cell.

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

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

Unlike chemotherapy drugs, targeted therapies know the difference between a cancer cell and a healthy cell. Chemotherapy drugs affect both healthy cells and cancer cells, but with targeted therapies, healthy cells are not affected in the same way.

Am I suitable for targeted therapies?

Targeted therapies are not suitable for all types of cancers.
It depends on:

- **Your overall health**
- **The type of cancer you have and how far it has spread** (the stage)
- **Your treatment history**
- **Whether you have specific genetic changes or proteins** (also called biomarkers) in your cancer that the drug can target

For some cancers, targeted therapies are one of the main treatments. For example, melanoma. For other cancers, you might have a targeted drug with other treatments, such as chemotherapy and radiotherapy. This is called combination therapy.

Testing

Before you are considered for targeted therapy, you might need to have tests using some of your cancer cells or a blood sample to find out whether the treatment is likely to work. These tests look for changes in certain proteins or genes that the drug can target. Testing for these proteins or genes will give your doctor a better idea of whether the drug is likely to work for you. This is not the case for all targeted drugs and you don't always need these tests.

Personalised medicine

Personalised medicine is when your treatment is based on looking at the genes and molecules of your cancer. In most cases, doctors do not find any genes (oncogenes) or proteins connected to a cancer. But if there are particular genes or molecules, doctors can choose a specific treatment that has the best chance of working well, based on these. This can make treatment more effective and reduce side-effects. Ask your doctor or nurse about your treatment options and if you need a test in advance to see if a drug is likely to work for you.

Types of targeted therapies

There isn't a simple way of grouping targeted therapies. This can sometimes be confusing. Some drugs belong to more than one group because they work in more than one way. For ease, we have grouped them into:

Monoclonal antibodies

Cancer growth inhibitors, also known as small molecule therapies or small molecule medicines

Angiogenesis inhibitors

PARP inhibitors

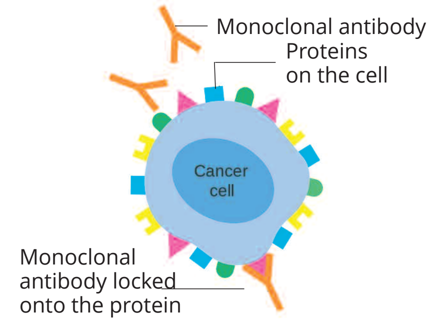
Monoclonal antibodies

Monoclonal antibodies are made in a laboratory. They find and attach to specific proteins on cancer cells, and 'lock' onto them like a key in a lock.

Once the monoclonal antibody has 'locked' into a protein it can:

- Block signals telling cancer cells to divide
- Carry a chemotherapy drug straight to a cancer cell

Some monoclonal antibodies trigger the immune system to attack and kill cancer cells. These monoclonal antibodies are also a type of immunotherapy. For more information on monoclonal antibodies that have an effect on the immune system, see page 46.



There are many different types of monoclonal antibodies and each one is made to attach to a different part of the cancer cell. Monoclonal antibodies are usually given as injections into a vein or under the skin.

Cancer growth inhibitors (small molecule drugs)

Cancer cells need to communicate with each other in order to grow and multiply. They do this through a series of chemical signals that tell the cancer cell to stay 'switched on' and continue to grow uncontrollably. Small molecule drugs can get inside the cell wall and block these communication pathways to stop the cancer cell from growing and dividing.

There are different types of cancer growth inhibitors and they each work in a different way. They can be grouped according to the types of chemical that they block. For example, tyrosine kinase inhibitors (TKIs) block chemicals called tyrosine kinases. Tyrosine kinases help cells to grow, so blocking them stops the cell growing and dividing.

Cancer growth inhibitors are usually given as tablets.

Angiogenesis inhibitors

Angiogenesis means the growth of new blood vessels. In a healthy person, angiogenesis is part of the normal healing process. For example, it helps to heal a wound. In cancer, angiogenesis provides a tumour with its own blood supply. A cancer needs a good blood supply to provide itself with nutrients and oxygen.

Angiogenesis inhibitors interfere with the growth of blood vessels. This means that the cancer is unable to receive the oxygen and nutrients it needs to survive. There are different types of angiogenesis inhibitors. They can work to:

- Block the chemical signals that tell blood vessels to grow
- Block the chemicals that cells use to tell each other to grow

Angiogenesis inhibitors are usually given as an injection into a vein.

PARP inhibitors

PARP is a protein in our cells. It helps damaged cells to repair themselves. PARP inhibitors work by stopping the PARP protein from repairing cancer cells. The cancer cells then die.

PARP inhibitors are usually given as tablets or capsules.

How are targeted therapies given?

- Some drugs are given as tablets. (See page 65.)
- Others are given as an injection under the skin or into a vein through a drip. (See page 54.)

How often you have treatment and how many treatments you need will depend on the drug and the type of cancer you have.

Targeted therapies are usually given in a course of treatments. This course can last weeks, months or years. For more information, see page 17.

For more information on where you will have your targeted therapy, see page 61.

Find out more

If you know the name of the targeted therapy you are looking for, visit the Health Product Regulatory Authority's website at www.hpra.ie where you will find more information about:

- **What the drug is**
- **How it is given**
- **Possible side-effects**

What are the side-effects of targeted therapies?

The side-effects of targeted therapies depend on the drugs being used and vary from person to person. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Doctors have ways to reduce most side-effects. This will not affect how well your treatment will work. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you.

For more information on common side-effects of targeted therapies, see our side-effects section on page 69. Ask your doctor or nurse to tick the side-effects that may affect you. Side-effects are listed on page 75.

New developments

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 20) or a compassionate access programme.

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

Immunotherapy

Immunotherapy

- Immunotherapy drugs change parts of your immune system to work better to fight cancer cells.
- Different immunotherapy drugs work in different ways.
- You can have immunotherapy into a vein through a drip or an injection under the skin or as a tablet.
- You might have immunotherapy on its own or with other cancer treatments, such as chemotherapy or targeted therapies.
- The side-effects of immunotherapy drugs depend on the drugs being used and vary from person to person.

What is immunotherapy?

Immunotherapy treatment helps your immune system to work better to fight cancer cells.

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

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

Am I suitable for immunotherapy?

A relatively small but growing number of patients are benefitting from immunotherapy drugs. Immunotherapy is not right for everyone, so talk to your doctor to find out whether you may benefit from this treatment. To work out if immunotherapy is suitable, your doctor will consider:

- Your overall health
- The type of cancer you have and how far it has spread (the stage)
- Your treatment history

Testing

Before you have immunotherapy you might need to have tests to find out whether the treatment is likely to work. These tests look for changes in certain proteins, genes or chromosomes. You may have tests on your blood, bone marrow or cancer tissue, depending on the cancer type. You don't always need these tests.

The immune system

Your immune system protects you against disease and infection caused by bacteria, viruses, fungi or parasites. It is made up of organs such as your spleen, your lymph system and special cells, all working together. It is a collection of reactions and responses that the body makes to damaged cells or infection. It is sometimes called the immune response.

To understand how immunotherapy works, we need to know about white blood cells called lymphocytes, which are part of the immune system. There are 2 types of lymphocytes:

B cells

B cells make proteins called antibodies. The job of antibodies is to lock onto the invading bacteria or virus. The body then knows the invader is dangerous and needs to be destroyed. B cells also remember these invaders. The next time the same germ tries to invade, the B cells are ready for it and fight it off quickly.

T cells

There are 2 different kinds of T cells – helper T cells and killer T cells:

- **Helper T cells** encourage B cells to make antibodies and help killer cells develop.
- **Killer T cells** kill the body's own cells that have been invaded by viruses or bacteria. This stops the germ from infecting other cells.

Types of immunotherapy

There isn't a simple way of grouping immunotherapy drugs. This is because some drugs work in more than one way and belong to more than one group. So you might hear the same drug or treatment called different things.

Checkpoint inhibitors

Checkpoints are proteins that act like the ‘brakes’ for T cells. When the brakes are off, T cells can attack cancer cells. But cancer cells can make high levels of proteins that trick the checkpoints to ‘turn on the brakes’, stopping the T cells from attacking the cancer cells. In this way, cancer cells can ‘hide’ from the immune system. Checkpoint inhibitor drugs release the brakes on the T cells, so that they can attack and kill the cancer cells again.

There are many different types of checkpoint inhibitors. Whether you have this treatment depends on what treatment you’ve had before and the type and stage of your cancer. You may also have this treatment as part of a clinical trial.

Monoclonal antibodies

The immune system makes large numbers of antibodies to fight off disease and infection. Antibodies are proteins that travel around the body to seek out other proteins called antigens. When both of these proteins join together, the body knows there is an invader that needs to be destroyed.

Scientists can design antibodies to target a certain antigen, such as one found on cancer cells. They can then make many copies of that antibody in the lab. These are known as monoclonal antibodies.

Monoclonal antibodies work in different ways and some are classed as targeted therapies. For more information, see page 37.

Cytokines

Cytokines are proteins or chemicals in our body that control the activity and growth of immune system cells. There are two main cytokines in the body:

- Interleukin works by stimulating anti-cancer T cells
- Interferon works by helping the immune system slow the growth of cancer

Scientists are now able to make these proteins in a lab.

Cancer vaccines

Most of us know about vaccines given to healthy people to help prevent infections, such as measles. They are made from weakened or harmless versions of the disease they are protecting us from.

When you have the vaccine, the immune system makes antibodies that can recognise and attack the harmless versions of the disease. Once the body has made these antibodies it can recognise the disease if you come into contact with it again. So you’re protected from it.

Research in the area of cancer vaccines is at an early stage. Scientists are trying to find out if cancer vaccines can help the immune system to recognise cancer cells as abnormal and destroy them.

Adoptive cell transfer

This type of immunotherapy is still in the early stages of development. One type of adoptive cell transfer is CAR T-cell therapy. The aim of adoptive cell transfer is to improve your immune system by:

- Removing immune system cells from your body
- Genetically modifying those cells in a lab so they can better fight cancer
- Reintroducing these cells back into the patient using a drip

How is immunotherapy given?

Most immunotherapy drugs are given intravenously (through a vein). For more information, see page 54. They can also be given as a tablet or an injection. Sometimes two immunotherapy drugs are given together. Immunotherapy can also be given with targeted therapies or chemotherapy.

Immunotherapy is usually given in a course of treatments. This course can last weeks, months or years. For more information, see page 17.

For more information on where you will have your immunotherapy, see page 61.

It's important to talk to your cancer doctor before taking steroids or antibiotics. They can interfere with the way immunotherapy works.

Find out more

If you know the name of the immunotherapy drug you are looking for, visit the Health Product Regulatory Authority's website at www.hpra.ie where you will find more information about:

- **What the drug is**
- **How it is given**
- **Possible side-effects**

New developments

New immunotherapy drugs are being developed all the time and existing therapies are being used in new ways. You may also be given an immunotherapy as part of a clinical trial (see page 20). Ask your doctor if there are any immunotherapy drugs available to treat your cancer or if there are any trials that are suitable for you.

What are the side-effects of immunotherapy drugs?

Side-effects depend on the drug being used and vary from person to person. Because immunotherapy acts on the immune system, it can cause the immune system to incorrectly attack normal organs and cells in your body and affect the way they work. This can lead to an inflammation to any organ in your body or inflammatory conditions. The letters 'itis' at the end of a word often mean inflammation. For example, colitis (inflammation of the colon), pneumonitis (inflammation of the lungs), dermatitis, (inflammation of the skin). This effect – where the immune system attacks your own body (called an 'auto-immune effect') – can happen in any organ in the body, but tends to be more common in the skin, bowel, lungs and hormone-producing glands. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects.

Always contact the hospital...

Side-effects from immunotherapy drugs can sometimes be serious. It is important to contact your treating hospital as soon as possible if you have any side-effects, especially loose watery poos, itchy skin and rashes. Do not self-medicate or seek advice from your pharmacist or GP if you are having side-effects. Your hospital team is more familiar with immunotherapy side-effects and how to treat them. They may need to give you a course of steroids to settle the immune system back down. Even vague symptoms like fatigue can be a warning sign for hormone problems. (See page 84 for more information.)

Longer term side-effects

Some immunotherapy drugs can stay active in your body for up to a year after they are given. This is a good thing, as the anti-cancer effect of the drug will continue to work long after the dose is given. On the other hand, you may also continue to have side-effects during this time – for up to 1 year after the drug is stopped. You will be able to go back to your oncology team during this period to report any side-effects that you need help with.

For more information on side-effects, see page 69. Ask your doctor or nurse to tick the side-effects listed on page 75 that may apply to you.

How are the drugs given?

How are the drugs given?

- Chemotherapy, targeted therapies and immunotherapy can be given in different ways.
- The 2 most common ways are directly into a vein or as a tablet to swallow.
- Some drugs can also be injected into a muscle or under your skin, injected into an artery or the fluid around your spine, injected into a cavity such as your bladder, or put as a cream on your skin.
- Most people have their treatment in a day hospital or clinic. Some people can have their treatment at home. Some may have to stay in hospital for their treatment.

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

Intravenously: Injected into a vein or by drip infusion. See page 54.

By mouth (orally): As capsules or tablets. See page 63.

Less common ways are:

Intramuscularly: Injected into a muscle in your thigh 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 your brain and spinal cord.

Intracavity: Injected into a body cavity, for example, 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. Ask your doctor or nurse if you would like more information about the ways of giving drugs.

Intravenous therapy (IV)

Cancer drugs are usually given into a vein using a syringe or through an infusion:

- **By injection** – the drugs are injected into 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 slowly into your blood. This can take minutes or several hours.
- **Continuous infusion by drip or pump** – at home you may receive a very slow release of a drug over 1–7 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

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

Cannula – a short, thin tube is put into a vein in your arm or the back of your hand.

Central line – a thin, flexible tube is put in through the skin of your chest or neck and into a vein in your chest.

PICC line (peripherally inserted central catheter) – a thin, flexible tube is put into a vein in your arm and then put in (threaded through) to a vein in your chest.

Implantable port (sometimes called a portacath) – a thin, soft, plastic tube is put into a vein. It has an opening (port) under the skin on your chest.

Cannula

The cannula is put into a vein in the back of your hand or arm and secured with a clear dressing. It is normally removed after your treatment. If you need to stay in hospital, it may be left in place for a few days.

The drugs can be given through the cannula as an injection or injected into a bag to dilute them.

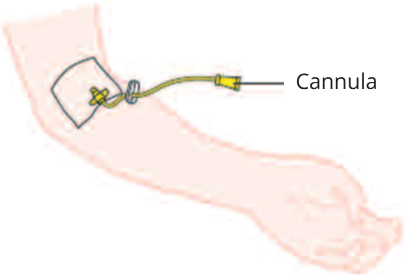


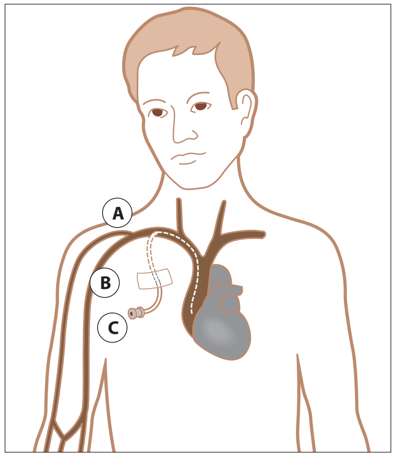
Image courtesy of
Cancer Research UK / Wikimedia Commons

Your treatment 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 experience some discomfort, pain, swelling, burning or a change in sensation around the cannula area. This may be due to a small leakage of the drug into your tissues. This does not happen often. If it does, let your nurse or doctor know straight away.

Central line

A central line is a long, thin, hollow tube that is inserted into a vein in your chest. It is sometimes called a skin-tunnelled central venous catheter. A central line may also be called by its brand name. For example, Hickman® or Groshong®.



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

Your central line will be put in at the hospital by a doctor. You will usually be given a local anaesthetic, but sometimes a general anaesthetic is used.

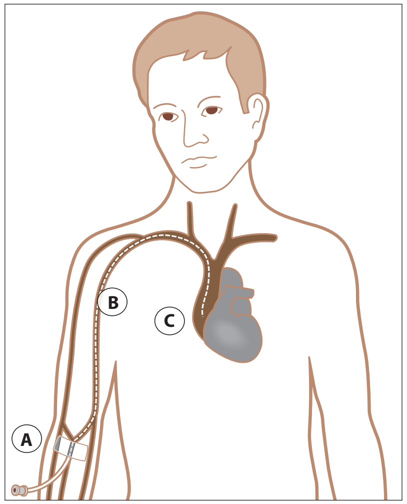
Before the procedure, your neck will be checked for a suitable vein using a small ultrasound machine. Your doctor will then make a small cut in the skin near your collarbone and gently put (thread) the tip of the line into a large vein just above your heart. The other end of the line is put in (tunnelled) under your skin to reach the exit site. This is where it comes out of your body. You will have a chest X-ray afterwards to make sure the line is in the right place.

Around the central line, you will feel a small 'cuff' just under the skin. The tissue under your skin will grow around this cuff in about three weeks and hold the line safely in place. Until this happens, you will have a stitch holding the line in place.

PICC line

A PICC (peripherally inserted central venous catheter) line is a long, thin, hollow tube that your doctor puts into a vein near the bend in your elbow. You will be given a local anaesthetic to numb the area before the line is put in.

The doctor or specialist nurse gently threads the line along the vein until the tip sits in a large vein in your chest. The end of the line comes out just below the crook of your elbow. Once it is in place, the PICC line is taped firmly to your arm to prevent it being pulled out of the vein.



A The PICC line is inserted in a vein here
B The line is threaded under your skin
C The tip of the line sits in a large vein in your chest here

Implantable ports (portacaths)

An implantable port is a thin, soft plastic tube with a rubber disc (port) at the end. It can be put in under a general or local anaesthetic. The tube is inserted into a vein until its tip sits just above your heart and the port lies under the skin on your upper chest. You cannot see the port as it is underneath your skin, but you will be able to feel it like a small bump.

A special needle called a huber needle is put into the port in the hospital to allow the drugs to be given through the port. Blood can also be taken from the vein through the port. The implantable port can be used for as long as is needed.

Caring for your line or implantable port

Generally, the nurses in the hospital will arrange for a nurse in the community or your local hospital to dress and flush your line. Sometimes a patient or relative may be shown how to care for the line.

Possible problems with your line or implantable port

Most people won't have any serious problems with their line or port. Possible problems can include blockage and infection. Your nurse will tell you what to look out for. Contact the hospital for advice straight away if you have:

- **Soreness, redness or darkening of the skin around the line or port**
- **Fluid leaking from the skin around the line or port**
- **Swelling of your arm, chest, neck or shoulder**
- **Pain in your chest, arm or neck**
- **A high temperature.** Most hospitals say that a temperature above 38°C (100.4°F) is high, but some use a lower or higher temperature. The cancer doctors and nurses at your hospital will advise you. You should also contact the hospital if you are feeling shivery or unwell after your line or port has been flushed.

The type of line you are given can depend on the drugs that are used, their doses and the length of time you are expected to be on treatment. A line might also be put in if your medical team feels that your veins will not tolerate the drug.

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

Hints and tips: Caring for your line or implantable port

- 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 shower sleeve or clingfilm over the site. Your nurse will discuss this with you.
- Avoid swimming, as it may cause infection.
- Do not lift heavy objects with the arm containing your PICC line.
- Wear loose-fitting tops or shirts for easy access.
- Avoid sports like tennis, badminton or hurling, as they might dislodge the line.
- 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.

Continuous infusion

Continuous infusion is when you receive a controlled amount of a drug through a special pump. Pumps are often attached to catheters or ports. They can control how much and how quickly the drug 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. The length of time you wear the pump will vary and your doctor or nurse will explain this to you. The pump can be attached to either a central line or a PICC line.

The hospital's pharmacy staff usually prepare the drugs. You or a family member or friend will be taught how to use and look after the pump. Pumps work in different ways. Your nurse will give you full instructions on how to care for your pump and and how to stop the pump in case of an emergency.

If you need advice when at home, contact the day unit at the hospital.

Allergic reactions

On rare occasions, people can have a reaction to certain anti-cancer drugs. Reactions can include rash, itching, low blood pressure, shortness of breath and chest pain. If your drug is known to cause a reaction, the nurse will keep medications beside you to stop the reaction immediately. The nurses are highly trained to expect these reactions and know how to treat them. There's no need to worry— just let your nurse know if you feel different, flushed or unwell in any way. The nurse will stop the drug immediately, treat the reaction and maybe restart the drug at a slower rate if it is safe to do so. If the drug you have been prescribed is likely to cause an allergic or hypersensitivity reaction, you may be asked to take medication the day before your treatment to prevent this. Your nurse or doctor will tell you if this applies to you.

Leakage of drugs (extravasation)

Extravasation is when drugs leak into the tissues around the vein when they are being given. It is uncommon, but it can happen if your cannula comes out of the vein. It rarely happens with a central line.

Tell your nurse if you notice any pain, swelling or redness at the cannula site during your treatment. Leakage can be successfully treated if noticed early.

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

Tablets or capsules

Taking tablets or capsules at home may also be part of your treatment. They may be the only treatment you need or you may have intravenous drugs as well. For more information on taking tablets at home, see page 67.

Where will I go for my drug treatment?

Where you go for treatment depends on the drugs you are prescribed and the way they are given. Some intravenous drugs are given during visits to a day hospital or clinic, without needing to stay overnight. It can take anything from half an hour to a few hours. Your hospital nurse will be able to give you an idea of the expected length of time that your treatment might take. Sometimes you may need to stay overnight or for a few days. Some people may be able to have their treatment at home.

Before your treatment starts, your doctor or nurse will explain exactly what it will involve. Ask as many questions about your treatment as possible. Write down new questions as you think of them. Use the fill-in pages at the back of this booklet to help you.

You can also call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre for information and advice.

Treatment by mouth (oral therapies)

Treatment by mouth (oral therapies)

- Some cancer drugs are taken by mouth as a tablet or capsule. These are known as oral therapies.
- Oral therapies are just as effective as intravenous drugs.
- It is very important to take your tablets exactly as prescribed. Taking less or more of the prescribed dose could be dangerous and will affect how well your treatment works.

What are oral therapies?

Some cancer drugs are taken by mouth as a tablet or capsule. These are known as oral therapies.

After you take the drug by mouth, it is absorbed into your bloodstream and carried around your body, just like intravenous drugs.

In general, you will get your drugs from your local pharmacy, but the drugs may also be prepared and dispensed in hospital. For example, if you are part of a clinical trial.

The following healthcare professionals can help you when you are taking your oral therapies:

- **Clinical nurse manager**
- **Advanced nurse practitioner (ANP)**
- **Oncology / haematology liaison nurse**
- **Pharmacist**
- **Oncologist / haematologist**
- **Our cancer nurses.** Call our Support Line 1800 200 700 or visit a Daffodil Centre

Oral therapies are just as effective as intravenous drugs.

Before you start oral therapies at home

Your oncologist / haematologist or a member of your medical team will prescribe the medication. You and a family member or carer will attend an oral therapy information session. You will also be provided with written information.

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
- How to store them. For example, in a fridge or cool place
- What to do if you forget to take your tablets

It's important to ask any questions if you have them, so that you feel confident about taking your medication when you go home.

You may find a patient diary useful to help you keep track of your medication. It also important to keep track of any side-effects. See page 73 for an example of how you can do this. This will also help you to remember what to tell the doctor or nurse when you are in the hospital.

When you are at home

Never touch your cancer drugs with bare hands as they may cause skin irritation. 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 drug prescription given to you by your doctor will be for 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.

Hints and tips: Taking cancer drugs at home

- **Avoid direct contact with the drugs.**
- **Wear gloves when handling clothing or bedsheets soiled with vomit or diarrhoea.**
- **Check with your pharmacist or nurse on how the tablets or capsules should be stored.**
- **Store all drugs out of reach of children to prevent serious harm if taken by accident.**
- **If another person or child takes your tablets by mistake, contact a doctor straight away.**
- **If you feel unwell or you're worried about anything, phone the nurse or doctor at the hospital for advice.**
- **Return any unused drugs in their original containers to the pharmacy where you got them. Do not flush them down the toilet or put them in the general waste bin.**

Side-effects

Side-effects of cancer drugs

Side-effects can be unpleasant or upsetting, but many of the side-effects are not harmful to your health and they may not be as bad as you expect.

- Discuss your side-effects with your doctor or nurse – often they can be prevented or treated if they do happen.
- Some side-effects can lead to very serious medical conditions that need to be treated.
- Phone the hospital and speak to your doctor or nurse urgently if you are worried about a side-effect.
- If you don't get side-effects, it doesn't mean that your treatment isn't working.

This section describes some common side-effects, and some ways you may be able to manage them. No one will have all these effects, but some people may have more than one. There may be some side-effects not mentioned here. This section is best read with information about the type of cancer you have.

Everyone’s experience of cancer and its treatment is different, and side-effects vary from person to person. Your doctor and specialist nurse will discuss with you in detail your treatment and its possible side-effects. Always tell your doctor or nurse about any side-effects you have. Your doctor can give you medicine to help control some side-effects. After your treatment is over, most side-effects start to improve.

> ‘Your team will give you medications to get you through the side-effects. Take them. Tell your doctor or nurse how you’re feeling and they will be able to help you.’

Serious and life-threatening side-effects

Some cancer treatments can cause severe side-effects. Rarely, these may be life-threatening. Your cancer doctor or nurse can explain these side-effects to you. They will also give you telephone numbers for the hospital. If you feel unwell or need advice, you should call them – at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

Top tip

The side-effects we describe in this section are listed on page 75 in alphabetical order. Ask your doctor or nurse to tick the side-effects that may apply to you.

Keeping a note of your side-effects

You may find it helpful to keep a record of your side-effects. This can help you talk to your doctors and nurses, and find the best way to manage them. Ask your doctor or nurse about ways to keep track of your symptoms, like a diary or phone app.

Here is an example of how you might describe a side-effect:

1. **Where is the side-effect? What does it feel like?**

   It's in my fingers and toes. They feel tingly and numb, like pins and needles. Sometimes I have a burning feeling.

2. **How long have you had it? How often do you notice it?**

   It started 4 days ago. It comes and goes but it is getting worse.

3. **How bad is it? (0 is very mild, 10 is severe)**

   3 most of the time. 7 when it gets bad.

4. **How is it making you feel?**

   Uncomfortable, irritated and frustrated.

5. **Is there anything that helps?**

   Keeping my hands and feet warm. Doing some gentle exercises.

Side-effects

Ask your nurse or doctor to tick the side-effects that may affect you.

Allergic reactions	☐
Anaemia	☐
Anxiety and depression	☐
Appetite loss	☐
Bleeding and bruising (thrombocytopenia)	☐
Blood clots	☐
Breathing problems	☐
Constipation	☐
Diarrhoea	☐
Endocrine (hormone) problems	☐
Fatigue	☐
Fertility issues	☐
Hair loss (alopecia)	☐
High blood pressure	☐
Infection	☐
Joint or muscle pains	☐
Kidney and bladder problems	☐
Liver function changes	☐
Memory problems and confusion	☐
Mouth, throat and taste problems	☐
Nausea and vomiting	☐
Nerve changes (peripheral neuropathy)	☐
Sexual side-effects	☐
Skin and nail changes	☐

Allergic reactions

On rare occasions people can have a reaction to certain anti-cancer drugs. Reactions can include rash, itching, low blood pressure, shortness of breath and chest pain. Contact the hospital if you have these side-effects.

Anaemia

Some cancer drugs can cause the bone marrow to make fewer 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 lightheaded
- Sore in your muscles and joints

Tell your doctor if you feel like this. You will have regular blood tests to measure your red cell count during treatment. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion. Your doctor may also adjust the dose of your drug to lower the risk of anaemia in some cases.

Your doctor might give you an injection of a drug called erythropoietin into your thigh or tummy (abdomen). This drug helps your bone marrow make more red blood cells quickly. Sometimes your doctor and dietitian may give you advice about taking iron or vitamins. Once your treatment is over, the tiredness (fatigue) will ease off gradually. However, some people still feel tired for a year or more after treatment, depending on the type of treatment you had and your general health. For more information on fatigue, see page 85.

Anxiety and depression

Some people can feel restless, anxious or develop insomnia and depression due to cancer drugs. Your doctor may prescribe medication to help or advise counselling and relaxation. For more information, see page 125.

Appetite loss

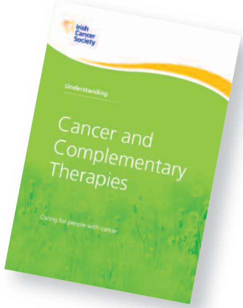
Cancer drugs can affect your appetite and cause changes to your taste. This may happen for a short time while on treatment. It is best to get advice from a dietitian or nurse if this happens. You can also call our Support Line on 1800 200 700 for a free copy of the booklet, ***Diet and Cancer.***

Hints and tips: Loss of appetite

- **Take any medication as prescribed.** Tell your doctor if the anti-sickness tablets are not working.
- **Make the most of your appetite when it's good.** Eat what you can whenever you feel like it.
- **Eat bland, easy-to-digest foods and drinks**, like cream crackers, toast or plain biscuits
- **Eat regularly, about 5 or 6 small meals or snacks each day,** about every 2-3 hours.
- **Take snacks high in calories and protein.**
- **Take only small sips while eating,** as drinking might make you full.
- **Choose drinks that can also provide nutrition** such as milk, juices and soup. You can freeze healthy smoothies, and have them like an ice lolly, which can soothe a sore mouth.
- **Try build-up drinks,** which have a balanced mix of nutrients for when it's hard for you to eat food. Talk to your dietitian about suitable ones for you. Your doctor can also give you a prescription for these drinks. These can also be frozen if that feels easier to tolerate and digest.
- **Take regular exercise,** if you can, as it may help your appetite. Fresh air can help too.
- **Use a smaller plate for your meals.** Large portions can be off-putting if your appetite is small.
- **Talk to your doctor about medications to help other problems,** like constipation, nausea, pain or other side-effects of treatment, if they affect your appetite.

Should I eat a special diet?

It is best not to experiment with special diets while on treatment. Many of these diets are restrictive, which means that certain foods 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 your treatment works. Get advice from your dietitian or nurse or call our Support Line on 1800 200 700 for a copy of ***Understanding Cancer and Complementary Therapies.***



Bleeding and bruising

Cancer drugs can affect the number of platelets made in your bone marrow. Platelets help to 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. During treatment, you will have regular blood tests to count the number of platelets in your blood. Your doctor may also adjust the dose of your drug to lower the risk of this side-effect in some cases.

You may need a drip to give you extra platelets. This is called a platelet transfusion.

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.

Blood clots

You have a higher risk of developing blood clots if you have cancer. Some cancer drugs can further increase this risk. You may need to take medicine to help prevent a blood clot.

Blood clots happen mainly in the legs or chest, but they can happen in different parts of your body, too. Symptoms include redness, swelling or pain in your leg or breathlessness, or chest pain if it happens in your chest. Let your doctor or nurse know if you have any of these symptoms, as blood clots can be very serious. Usually they are treated with medication to thin your blood.

Breathing problems

Some cancer drugs can cause inflammation of your lungs, so you may feel short of breath and cough. It is important to know what is normal for you – your baseline – if you already suffer with breathlessness. If you notice you're starting to feel more breathless than usual, especially if you have to stop when climbing the stairs, or you are becoming more breathless walking on a flat surface, talk to your team. They may need to check your lungs for a drug side-effect. A new or worsening cough is also important to report. If left untreated, it could lead to serious health conditions.

Constipation

Some cancer drugs 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 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. Treatments given by the back passage (rectum) such as enemas and suppositories are not recommended if you are having chemotherapy.

Hints and tips: Constipation

- **Keep a record of when your bowel opens.**
- **Eat more fibre, raw fruit, cereals and vegetables.**
- **Drink plenty of fluids. Prune juice and warm drinks can often help.**
- **Be as active as you can. Take gentle exercise, like walking or yoga, if possible.**

Diarrhoea

Some drugs can harm the cells that line your bowels and cause diarrhoea. Diarrhoea is passing bowel motions that are soft, loose or watery more than 3 times a day, over and above your normal bowel pattern. You could also get black, tarry, sticky stools or stools with blood or mucus. Other side-effects include cramping or abdominal (tummy) pain. Diarrhoea can also be caused by infections, long-term constipation or drugs used to treat constipation.

Tell your doctor or nurse immediately if you have loose or watery poos more than 3 times over and above your normal pattern over a 24-hour period. Your doctor or nurse will give you advice over the phone on how best to treat this diarrhoea. They may advise you to take medicine to help stop the diarrhoea or they may want you to have a blood test to see if you are dehydrated. They may need to give you special fluids to treat this. Your doctor may get a sample of your poo tested to check it isn't caused by an infection before they prescribe anti-diarrhoea medications.

Diarrhoea and immunotherapy

If you have diarrhoea when on immunotherapy, it's very important to let your treating hospital know. Diarrhoea could be a sign that your bowel (colon) is inflamed. Tell your doctor or nurse if you are passing bowel motions more often or if they are soft, loose, watery or blood stained. You may need to have tests, such as a scope (camera passed into your back passage), where a tissue sample can also be taken, or a CT scan of your tummy to give more information about any inflammation. These tests can help your doctor decide on the best treatment for you. You may need medication that can settle the immune system. Inflammation needs to be treated to avoid serious complications. Never treat yourself with anti-diarrhoea medicine at home, and always talk to your hospital team, rather than a pharmacist or GP.

Hints and tips: Diarrhoea

- **Your doctor may prescribe something to control the diarrhoea.** Take this as advised.
- **Drink plenty of clear fluids** (1½ to 2 litres a day) to replace the fluid you are losing.
- **Eat small snacks or meals** instead of three large meals a day.
- **Have a low-fibre diet.** Eat less raw fruit, cereals and vegetables.
- **Avoid alcohol and tobacco.** They can make diarrhoea worse.
- **Take care with the following, which may make diarrhoea worse: Fried, fatty or greasy foods, fizzy drinks, drinks with caffeine like coffee, tea, cola and hot chocolate, citrus fruits,** like orange and grapefruit and foods containing the artificial sweetener sorbitol such as chewing gum and diet or low-calorie products
- **Ask your doctor/dietitian about probiotics.** They may recommend trialling a probiotic product, but only when you have finished your treatment and your immune system has recovered.

Endocrine (hormone) problems

Immunotherapy drugs can make some hormone glands inflamed and affect the amount of hormones they produce. Glands that may be affected include the thyroid gland, pituitary gland, the pancreas and adrenal gland. Usually a blood test will find changes in your hormone levels before you start to have symptoms. Tell your doctor if you have any of the following:

- Headaches that don't go away
- Extreme tiredness or sleepiness
- Feeling cold
- Weight gain
- Feeling dizzy or faint
- Changes in behaviour or mood (like feeling anxious, angry, depressed)
- Infrequent or hard poos
- Muscle cramps
- A sick feeling in your tummy
- Trouble sleeping
- Tremors, trembling or sweating
- Type 1 diabetes, a condition that can lead to too much sugar in the blood, feeling thirstier than usual, frequency passing urine (especially at night) and unintentional weight loss can occur.

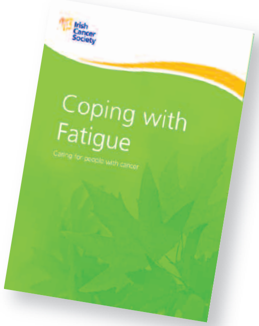
These side-effects may continue after you have finished treatment, especially in the first year after the drug stops.

Fatigue

Fatigue is a very common problem with cancer treatment. 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. The tiredness can be mild or extreme. Try to get plenty of rest and accept help when offered. The tiredness will ease off gradually once the treatment is over. Some people describe this heavy tiredness 'lifting' off them as their energy returns and they feel able to do their everyday things again. However, others can still feel tired for a year or more after treatment stops.

If you are receiving immunotherapy, fatigue may be a sign that there is a problem with your hormone levels. It's important to tell your doctor or nurse if you feel tired all the time. Remember that fatigue can be caused not only by your treatment 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 if you feel tired all the time.

Talk to your doctor if fatigue is a problem for you or if you have difficulty sleeping. We have a useful booklet called ***Coping with Fatigue***. Call our Support Line on 1800 200 700 for a free copy.



> 'You have to listen to your body. Nap if you need to and take things at your own pace. I find exercise great.'

Hints and tips: Fatigue

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

Fertility issues for women

Some cancer drugs can affect your fertility – for 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
- The type of cancer drug given
- Any other treatments used – for example, 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 they can ask questions too. These days, many cancer treatments are less likely to affect fertility. Many couples have healthy babies after treatment for cancer.

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 have difficulty getting pregnant after treatment and in some cases it may be impossible. If there is any chance you could be pregnant before starting treatment, let your doctor know.

- **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. The younger you are, the more likely your periods will return to normal and you can get pregnant naturally, but it varies from woman to woman, and also depends on the type of treatment you had.
- **Menopause:** The nearer you are to the menopause, the more likely your periods will stop permanently. This means that your chances of having a child in the future are significantly reduced.

  Usually it is not possible to stop this happening. But your doctor may prescribe hormone replacement therapy (HRT) to lessen the effects of the menopause, like mood changes, weight changes, hot flushes and a dry vagina. HRT replaces the hormones normally made in your ovaries.
- **Avoiding pregnancy:** You may not know if you are fertile or not, as your periods may stop during treatment. But it is still possible to become pregnant during treatment.

  Side-effects of treatment 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. Double-barrier methods of contraception are recommended for preventing pregnancy during and for a period after anti-cancer drugs stop. Double-barrier means using 2 methods of contraception – a barrier method, such as a male or female condom, and another method such as the contraceptive pill. Your specialist nurse can advise you about contraception.

  You should 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. The nurse may test a sample of your urine before treatment to make sure you're not pregnant. They will let you know when they need to do this.
- **Checking fertility after treatment:** Once treatment is over, there are tests that can check if you are fertile or not. For women, a blood test can tell how well your ovaries are working. Your doctor or nurse can organise this test for you. They may also refer you to a fertility specialist.
- **Getting pregnant after treatment:** Generally, doctors believe it is better not to get pregnant for at least 2 years after your treatment 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. But talk to your cancer specialist about your individual circumstances and what they recommend.
- **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.

> For most women, it is better not to get pregnant for at least 2 years after your treatment ends.

Freezing your eggs

If there is a risk that your treatment will cause permanent infertility, ask your doctor or nurse about the option of freezing your eggs (oocytes) before treatment begins. You can also call our Support Line on 1800 200 700. Your GP can give you advice as well.

Fertility issues for men

Many men father healthy babies after treatment for cancer. But some types of cancer and cancer drugs may affect your fertility by lowering your sperm count. Sometimes these effects are short-term and sperm production can recover. In other cases, the effects may be permanent.

In general, doctors recommend that you have a sperm test at least 6 months after treatment to check your fertility. But your cancer doctor will give you advice for your individual circumstances. It is important to talk to your doctor about sperm banking if you think you may want to have children in the future.

Avoiding pregnancy

Your cancer treatment can damage the sperm that you are currently producing and cause birth defects. It is important to use a barrier method of contraception, like condoms, throughout your treatment and for some time afterwards to avoid a pregnancy, as this could lead to foetal abnormalities. Some drugs may require using double-barrier contraception. This means using a condom and another method, such as your partner taking the contraceptive pill. Your team will discuss this with you. Ask your doctor or nurse how long you should continue using condoms.

Support

It may help to talk to a family member or close friend about any worries you have about fertility. Ask your doctor or nurse for advice on what to do.

Sperm banking

If you are producing sperm, even in low numbers, it may be possible for you to have a sample frozen and stored. If you would like to find out more about sperm banking, talk to your doctor or nurse. You can also call our Support Line on 1800 200 700 or email supportline@irishcancer.ie for advice in confidence.

Coping with infertility

It is not easy to hear that your fertility may be affected as a result of cancer. The sense of loss can be painful, no matter what age you are. Your reaction can vary from acceptance to shock, sadness and silence to anger and depression. There is also no set time to have these reactions.

Support

It can take a while to talk about your feelings and emotions. When you are ready, you may find it helpful to talk openly to your partner, your family or a friend about these feelings. If they understand how you feel, it is often easier for them to offer help and support. It's also important to talk to your doctor or nurse. They may arrange for you to speak to a trained counsellor or a specialist to help you deal with any strong emotions that you may have.

Hair loss

Chemotherapy and other cancer drugs can cause hair thinning or hair loss (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. If you lose your hair, it usually starts within 2 or 3 weeks of treatment. Before your hair starts to fall out, you may get tingling or your scalp may feel very sensitive. This is normal and may last a day or so.

How much hair falls out depends on the drug given, the amount and your reaction to it. Hair loss doesn't always happen with chemotherapy and is less likely with targeted therapies and immunotherapy. Your doctor and nurse will tell you if you are likely to have any hair loss due to treatment.

Can hair loss be prevented?

In general, you cannot prevent hair loss entirely. Depending on your cancer drug, 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 your scalp for a short period so less of the drug reaches the scalp. A cold cap is a hat you wear during chemotherapy to reduce blood flow to your scalp so less of the drug reaches your scalp.

While the cold cap 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 not suitable for all patients and not all hospitals offer this kind of treatment. Your doctor or nurse can tell you whether a cold cap is available in your hospital and if it might work for you.

WIll my hair grow back?

Fortunately, most of the time hair loss from chemotherapy is temporary. Your hair will start to grow back once your treatment has ended, usually within a few weeks. You should have a full head of hair within 6 months. Your hair may temporarily be a different shade or texture.

Coping with hair loss

Hair loss can be upsetting. It can affect your self-image and is also a visible sign that you have a cancer diagnosis. This can be hard if you would prefer not to share your diagnosis widely. You may like to wear a wig or hairpiece.

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's best to prepare them for your hair loss before it happens. Your medical social worker can give you advice on what to say.

Wigs and head coverings

If you like, you can get a wig or hairpiece when you lose your hair. 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 and style. Your specialist nurse or a medical social worker can advise you about getting a wig and give you the name of wig suppliers. They should also be able to tell you about schemes that will pay some or all of the cost of a wig.

If you have private health insurance you may be covered for the cost of a wig. Call and ask your insurer or check your policy.

You can also get advice about wigs and financial support by calling our cancer nurses on our Support Line or by visiting a Daffodil Centre.

You may prefer to wear a hat, bandana or scarf instead when you go out. There are also turbans, which can be worn in the house. Call our Support Line on 1800 200 700 or visit **www.cancer.ie** for more information on hair loss and cancer.

Hints and tips: Hair loss

- 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 and 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 advice.
- Do not perm your hair during treatment or for 3 months afterwards.
- Keep your head warm by wearing a hat, turban, scarf or wig.
- Protect your scalp by covering up or by putting suncream on your head when outdoors.
- If you lose your eyelashes, wear glasses or sunglasses to protect your eyes from sun and dust when you are outside.
- Look online for cancer beauty and make up tips and instructional videos. For example, there are products and techniques to help if you've lost your eyebrows or eyelashes.

High blood pressure

Some drug treatments can cause high blood pressure. You will have your blood pressure checked regularly. If you have headaches, nosebleeds or feel dizzy, let your doctor know. They can prescribe tablets to control high blood pressure if necessary. If you have high blood pressure before you start treatment, your doctor will monitor you closely during treatment.

Infection

Chemotherapy drugs make you more likely to get infections. This happens because the drugs can affect the bone marrow where white blood cells are made. These cells help the body to 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 have signs of infection, 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 include feeling shivery and unwell, having a high or low temperature, having a sore throat, cough, pain passing urine, diarrhoea, abdominal (tummy) pain, mouth ulcers, or redness at the drip site or the site of your port/PICC line. If this happens, contact the hospital straight away, even at night. Some hospitals prefer you to ring the ward directly.

Before you start treatment, your nurse will give you the list of contact numbers that you can call 24 hours a day, 7 days a week. Keep this number safe with you at all times. If you do get a high temperature, or feel unwell (even with a normal temperature), it is very important to call straight away – **never delay**. Most hospitals say that a temperature above 38°C (100.4°F) is high, but some use a lower or higher temperature. Check in your hospital about the temperature advice to follow.

If you do show signs of an infection, the doctors need to treat it early to prevent it from becoming a more serious infection, like sepsis. When you call the hospital you may be told to go to your nearest A&E for a blood test to see if your white cells are low. The doctor should see you fairly quickly and will probably start you on a course of antibiotics. These are generally given into a vein. You may need to stay in hospital for these antibiotics or other medications for a few days to treat the infection.

Chemotherapy is the main drug therapy that causes damage to your white cell count and so increases your risk of infection. It is rare for targeted therapies to cause this side-effect. It is very rare with immunotherapy.

Hints and tips: Infection

- **Have a small bag ready with a few items for an overnight hospital stay 'just in case'.** You may never use the bag, but If you do become unwell (especially during the night), at least you will feel ready.
- **You will be asked not to take paracetamol (or products containing paracetamol like Lemsip® or Solpadeine®) or other medicine like ibruprofen that will mask an infection while you are on treatment.** Talk to your team about alternate types of painkillers if you suffer from regular pain.
- **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 and ask about any vaccinations available to protect you.
- **Wash your hands often during the day,** especially before you eat and after going to the toilet. Infection is a serious complication of treatment. It needs to be treated as soon as possible. Talk to your doctor or nurse, who will give you more advice.

Your doctor might also give you drugs called growth factors, sometimes called G-CSF. These are given by injection under the skin (subcutaneously). They will help your bone marrow to make more white blood cells quickly. As a result, they reduce the risk of infection. Your white cell count can still dip after the G-CSF injection, so always report any signs of infection to your treating team without delay.

Joint or muscle pains

Some drug treatments can cause pain in your muscles, joints or bones. This can include back pain. You may also get weakness or spasms in your muscles. If this happens, tell your doctor so they can give you painkillers. Tell them if the pain does not get better. Having warm baths and regular rest may also help.

Kidney and bladder problems

Some cancer drugs can damage the cells in your kidneys and bladder. As a result, you may have burning or pain when you empty your bladder, have urgency or frequency, be unable to pass urine, leak urine, or have blood in your urine. Some drugs can change the colour of urine as well. Lower back pain may also be a sign of kidney trouble.

Blood and urine tests will be done regularly to check your kidneys. Fluids can help to flush out the cancer drugs 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 drinks that contain caffeine. For example, tea, coffee, cola.

Liver function changes

Some drugs can damage or irritate liver cells, affecting how well your liver works. Yellowing of the skin or eyes (jaundice) and itching may also be a signs of liver damage. The doctors and nurses will keep a close eye on your liver function by taking regular blood tests.

Memory problems and confusion

After a few treatment cycles, some patients may have some mental confusion and short-term memory loss. This is sometimes known as 'brain fog' or 'chemo brain'. The medical term is cognitive impairment or cognitive dysfunction. Symptoms include:

- Finding it hard to concentrate or focus
- Feeling confused
- Finding it hard to remember things that you've seen or heard, which you would usually remember
- Struggling to find the right word or to finish a sentence
- Being unusually disorganised
- Finding it hard to multi-task – doing more than one thing at a time
- Feeling like your brain is 'foggy' and unclear
- Finding it harder than usual to learn new things or to do your usual daily tasks

These symptoms can be upsetting and frustrating and can make it harder for you to carry on with your usual activities. These symptoms usually improve once treatment is completed, but for some people they can carry on for a longer time.

Let your doctor know if you experience any of these problems. They can advise on ways to cope and may prescribe a medication, such as steroids, that may improve things. Research into new treatments is ongoing. You might also try some of the following to see if they help.

Hints and tips: Brain fog

- **Getting organised:** Writing notes and having reminders on your phone can help you to remember things, such as important dates, appointments, things you need to do and phone numbers and addresses. Keeping a diary could help you to remember what has happened.
- **Rest and relaxation:** Being tired or stressed may make memory problems worse. Get enough rest and try stress-relief techniques such as meditation or massage. Some local cancer support centres have sessions where you can learn stress-relieving techniques such as mindfulness and meditation. Exercise can also help to reduce stress and help you to feel better in yourself.
- **Brain training:** Doing memory and thinking exercises and puzzles or trying to learn a new skill may help to keep your brain sharper.

Mouth, throat and taste problems

Mouth and throat problems due to chemotherapy and other cancer drugs can include a dry mouth, mouth sores and ulcers, or infections of gums, teeth or tongue. Your mouth may be more sensitive to hot or cold food as well. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

It helps to clean your teeth often and gently with a soft toothbrush and gentle flossing, especially after meals. You can also use a bland mouthwash of 1 level teaspoon of salt or baking soda (sodium bicarbonate) dissolved in half a litre of warm water. Keep your mouth moist by sipping water during the day. If your mouth becomes very sore, talk to your nurse or doctor – they can advise you about 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 it is safe to get dental work done. Our booklet, ***Diet and Cancer*** has some helpful advice on how to manage taste changes. Call 1800 200 700 for a copy or visit **www.cancer.ie**

Hints and tips: Mouth and throat changes

- **Clean your teeth or dentures and gums after meals and at bedtime** with a soft-bristled or child's toothbrush.
- **Ask your doctor about mouthwashes, gels and medications** to help with a sore mouth.
- **Try rinsing your mouth with a homemade mouthwash** made with 1 teaspoon of baking soda (sodium bicarbonate) and 1 teaspoon of salt to half a litre of warm water.
- **Eat soft, moist food.** You can moisten your food with sauces and gravies.
- **Take care with the following, as they can make a sore mouth or throat worse:**
  - Pickled, salty or spicy foods
  - Rough food, like crispy bread, dry toast or raw vegetables
  - Alcohol and tobacco
  - Citrus juices, like orange, lemon, lime, grapefruit or pineapple
- **Take sips of fluids like water or milk often.** Drink through a straw if your mouth is painful.
- **Avoid very hot food or very cold foods and drinks.** You may find it easier to have foods and drinks at room temperature.

Nausea and vomiting

Nausea (feeling sick) and vomiting (getting sick) can usually be very well controlled. Many people have no sickness at all. If sickness is a possible side-effect of your treatment, your hospital doctors will usually prescribe anti-sickness (anti-emetic) drugs or other drugs that can reduce this side-effect. It's important to take these drugs as they are prescribed. Anti-sickness drugs work better when you take them regularly, before you start to feel sick. Tell your doctor or nurse if the symptoms do not improve. If one kind of anti-sickness drug does not work for you, your doctor can prescribe another. Also, you may need more than one type of drug to help with nausea. Thinking or talking about treatment can also make you feel sick. This is called anticipatory nausea. Talk with your doctor or nurse for more advice if you're feeling sick or getting sick. It is especially important for you to talk to your doctor or nurse if your nausea is preventing you from eating or drinking enough. 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.

Nerve changes (peripheral neuropathy)

Some drugs can affect your nerve endings, which may cause numbness or a tingling or burning sensation in your hands and feet. You may have a feeling similar to pins and needles. This is known as peripheral neuropathy. You may have trouble picking up objects or buttoning your clothes. This side-effect is usually temporary. But it may take several months for the numbness to go away. Tell your doctor or nurse if you have this side-effect, as you may need medication or some changes to your treatment. For more information on peripheral neuropathy, call our Support Line on 1800 200 700 or visit **www.cancer.ie**

Immunotherapy drugs can cause inflammation of your nerves. which may cause pain, weakness or tingling in your hands and feet. This may worsen and spread to your legs, arms and upper body leading to weakness. Report these side-effects to your hospital team.

Hints and tips: Caring for hands & feet

- **Keep your hands and feet as warm as possible.**
- **Take gentle exercise if possible.** Stress balls that you squeeze 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.

Sexual side-effects

Chemotherapy and other cancer drugs 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 cancer drug you are getting
- If you have any other illnesses

If you are worried that your treatment will affect your sex life, discuss your concerns with your doctor before treatment. They can tell you about any likely side-effects. While it is usually safe to have sex during treatment, you should 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's 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: Some cancer drugs may damage the ovaries. This can bring on early menopause. As a result, you may have dryness of the vagina and less interest in sex. Depending on the type of cancer, 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 creams and vaginal lubricants from your local pharmacy to moisten your vagina. For some men, cancer drugs 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 difficulty in getting or keeping an erection (impotence).

Emotional effects

If you're feeling stressed, anxious or depressed you may lose your desire for sex. 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. It is normal to feel like this.

If you have also had surgery that 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?

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 adjust to your illness. Your doctor will give you advice about any long-term effects.

Contraception

Do not presume that you are infertile while on treatment. You must take good contraceptive precautions at this time. If you become pregnant, the 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 and for a time afterwards. Ask your nurse or doctor about how long you need to continue.

Barrier methods like condoms or the cap are usually recommended – your nurse or doctor can give you the best advice.

Talking about your worries

Talking about your feelings to your partner may help to ease any worries you have. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Try not to feel guilty or embarrassed to talk to your doctor or nurse about this. Knowing how sensitive this issue can be, they will be glad to help you.

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

Skin and nail changes

Cancer drugs can cause skin and nail problems. Your doctor or nurse will explain this before you start treatment and give you some advice.

Depending on your treatment and how you react to it, you may experience some of the following side-effects:

Dry or discoloured skin

Skin can become very dry with some drug treatments. Moisturise your skin if it's dry. Always ask your nurse or doctor about the best creams to use, as some may irritate your skin. Your skin may darken in patches or change colour. If you notice yellow eyes or skin, report this to your hospital doctor as soon as possible. They may need to do a blood test to check your liver function.

Rashes or itching

Rashes and itching can be mild or more severe. You may get bumps, pimples or an acne-like rash. Your skin may also feel sore. Ask your nurse or doctor for advice if you develop a rash or itchy skin – there are medicines and creams that can help.

In rare cases, a rash or itching may mean you're having a reaction to the drug, so it's important to always tell your medical team about any skin changes.

Increased sensitivity to sunlight

Some drugs make your skin very sensitive to sunlight, so it's more likely to burn. Ask your nurse or doctor about what precautions you should take and always protect your skin – cover up, wear a hat and use a suncream with a sun protection factor (SPF) of at least 30.

Sore skin on the palms of your hands or the soles of your feet

Some cancer treatments can cause redness, swelling and pain on the palms of the hands or soles of the feet. Sometimes you can get blisters. This is known as hand-foot syndrome.

Tell your doctor straight away if you get this side-effect. They may need to adjust your treatment.

Nail changes

Nails may become dark, yellow or brittle and cracked. White lines can also appear across them. Sometimes the nails can loosen and fall off. Try not to worry about this, as nails will grow back over time.

Inflammation of the skin

Immunotherapy drugs can cause inflammation of the skin. You may have peeling of the skin, itchiness, and/or skin redness. The skin inflammation (peeling, itching and redness) could also spread throughout your body. More severe skin reactions may involve the inside of your mouth, the surface of your eyes and genital areas. If needed, your team will involve skin care specialists (the dermatology team) in your care. Always report immunotherapy skin changes so that your doctors can treat you early.

Hints and tips: Skin and nail changes

- **Report any skin changes to your doctor and nurse.** Don't try to treat them yourself – get advice from your medical team.
- **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. Only use creams and soaps recommended by your doctor and nurse.
- **Avoid direct sunlight,** especially between 11am and 3pm. Wear a wide-brimmed hat, long-sleeved clothing and use a high factor suncream (SPF 30 or higher) to protect your skin.
- **Don't use sunbeds.**
- **Wear loose clothes** made of cotton or other natural fibres.
- **Wear nail varnish** to disguise discoloured nails.
- **Wear gloves when doing the washing-up, cleaning or gardening.**

Life during and after treatment

Adjusting to life during and after treatment

It is possible to have a fairly normal life during treatment. You may have symptoms and side-effects, but there are often medications that can help. You will get to know which parts of the treatment cycle tend to be good days and when you may need to rest. This can help you feel in control and do the things you normally like doing. Listen to your body, rest when you need to and do things you enjoy when you feel well.

Once treatment finishes, it may take a while to recover fully and get back to your old routine, so try not to feel upset if it doesn't happen straight away. Depending on the effects of treatment, 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. See page 121 for healthy lifestyle tips.

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 85 for more about fatigue.

> ‘So many kind and generous people asked me what I needed. Specific questions helped, like: “I’m at the supermarket, can I bring you dinner?” or “I'm off tomorrow, can I call in at 3?”’

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, you may need to 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 (see page 126) 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. 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, for example, 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 129 for advice about benefits and allowances and managing money.

Social activities

Just because you are having treatment for cancer doesn't mean your social life has to stop. But you may have to cut back on activities and nights out. You may also need to rest before you do go out. 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 for the occasion.

Travelling abroad

Tell your cancer specialist if you plan to go on holidays abroad. Also, you should get a letter from them giving details of any medicines you need to carry and your illness and treatment, in case you get sick abroad. You may need vaccines for some holiday destinations, but some vaccines can be harmful if you are receiving treatment. 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. Ask your doctor which vaccines are safe for you.

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 treatment, but once it is over, it is usually less of a problem. Discuss this with your doctor, who can advise you.

Life insurance: You may want to provide some finances for your family in the future or wish to have a loan or mortgage paid off. Getting life insurance can be hard, if you have or had cancer. But it is not impossible.

Visit **www.cancer.ie** for more information on insurance and cancer.

> 'It's OK to be gentle with yourself. It can be hard to sit back if you've been active all your life, but give yourself that time.'

Relaxation

It's important that you make time for activities that relax you. Stress uses up energy and might make you feel tired. The following suggestions may help:

- Talk to others about anything that is worrying you. If you find it difficult to talk to family and friends, ask your doctor to refer you to a counsellor. You can also make an appointment with an Irish Cancer Society-funded counsellor based in your local cancer support centre. See page 126 for more about counselling.
- Try to take your mind off your worries by reading, seeing friends and listening to music.
- Take light exercise such as walking.
- See if there are relaxation classes or groups in your local cancer support centre. For example, meditation or mindfulness. See page 137 for more.
- If you can, try to avoid situations that make you anxious.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and aromatherapy. Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

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

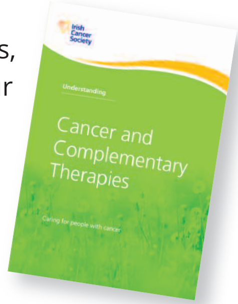
What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment. Alternative therapies are used **instead of** standard medical care.

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

More information

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



Life after cancer

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

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

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

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 125 for more about coping with your emotions.

What follow up will I need?

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

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope.

It's important to attend your follow-up appointments, so your doctor can check for signs of the cancer coming back (recurrence) and to help with any side-effects that you may have. They can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

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

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

Looking after yourself

Many people want to live a healthy lifestyle after their treatment has ended. Having a healthy lifestyle can help you to:

- Feel better
- Heal and recover faster
- Keep up your energy and strength

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun

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

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

After-treatment workshops

You might like to join our *Life and Cancer – Enhancing Survivorship (LACES)* programme when you have finished treatment. This workshop covers topics such as diet, exercise, wellbeing, finance and self management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

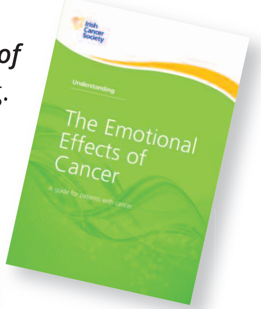
Coping and support

How can I cope with my feelings?

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

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed. Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

Our booklet ***Understanding the emotional effects of cancer*** discusses in detail how you may be feeling. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.



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

Anxiety and depression

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

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

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

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

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

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

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet ***Understanding the emotional effects of cancer*** can help to you find ways to talk about your cancer and to ask for the help and support you need.

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

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

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

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

Benefits and allowances

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

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

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

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

If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 134 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

Money and finances

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

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

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

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

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

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information.
The Support Line is open Monday–Friday, 9am to 5pm.
You can email us at any time on **supportline@irishcancer.ie** or visit our Online Community at **www.cancer.ie**

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

Daffodil Centres

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

Who can use the Daffodil Centres?

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

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

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

Peer Support

Speak to someone who has been through a diagnosis similar to yours. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

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

Patient travel and financial support services

We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

To access either of these services please contact your hospital healthcare professional.

Irish Cancer Society Night Nursing

We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

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

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website **www.cancer.ie** or call our Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free.
For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of one-to-one counselling through many local cancer support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage and reflexology
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions,** for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

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

What does that word mean?

Alopecia Hair loss. No hair where you normally have hair.

Anaemia Fewer 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.

Cannula A small tube put into a vein in your arm or on the back of your hand to give drugs. Some people also call this a ‘drip’.

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 The day or days of your treatment, followed by a possible rest period, when you have no treatment and your body is recovering.

Cytogenetics The study of chromosomes in cells.

Cytotoxic A drug that can kill cancer cells and healthy cells.

Endocrine To do with hormones.

Fatigue Ongoing tiredness, often not eased by rest.

Haematology The study of blood and blood disorders.

Implantable 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 portacath.

Immunotherapy Drugs that help your immune system to work better to fight cancer cells.

Intravenous Into a vein. Also called IV.

Malignant Cancer.

Medical oncologist A doctor who specialises in treating cancer patients with chemotherapy or other drugs.

Metastases Tumours that have spread from the first (primary) tumour into another part of the body. Also known as secondary tumours.

Nausea Feeling sick or wanting to be sick.

Neutropenia When there are fewer neutrophils, a type of white blood cell. This can lead to infection.

Oncology The study and treatment of cancer.

Oral To do with the mouth.

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.

Portacath See implantable port.

Progression The cancer has grown. There is more disease now than before treatment.

Remission There is no evidence of cancer.

Stable disease The cancer has not grown or shrunk since starting treatment. The amount of disease has not changed.

Targeted therapy Drugs that target certain parts of cancer cells that make them different from normal cells.

Questions to ask your doctor

Never be shy about asking questions. It's better to ask than to worry.

What type of treatment will I get?

Will the treatment cure the cancer?

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

Would I be suitable for a clinical trial?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

What side-effects will I get?

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

Are there any vaccines I should have?

Will treatment affect my fertility?

How often will I need check-ups?

What if the cancer comes back?

Notes/Questions

Notes / Questions

Acknowledgments

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

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

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- *Cancer in Ireland 1994-2016 with estimates for 2016-2018: Annual report of the National Cancer Registry* (2018)
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The Irish Cancer Society is a registered charity, number CHY5863

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

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

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