Irish Cancer Society

Understanding

Cancer of unknown primary

Caring for people with cancer

Understanding

Cancer of unknown primary (CUP)

This booklet has information on:

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

Useful numbers

Specialist nurse

Medical oncologist

Family doctor (GP)

Radiation oncologist

Radiation therapist

Surgeon

Medical social worker

Emergency:

Hospital medical records number (MRN):

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Can my cancer be treated? Page 29

When CUP is diagnosed, it is already a secondary cancer, which means that it may already be at an advanced stage. As a result, your treatment may focus on controlling symptoms and improving your quality of life. Symptoms can be controlled for a long time. For some people, your medical team will actively treat your cancer while also managing your symptoms.

Will I be OK? Page 27

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things and everyone's prognosis is different. The best thing to do is ask your medical team about your situation.

What kind of treatment might I have? Page 45

The most common treatment for CUP is chemotherapy. You might also have radiotherapy, targeted therapy, hormone therapy or surgery. You might have one type of treatment or a combination.

Are there side-effects from treatment? Page 67

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

Clinical trials Page 65

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

We're here for you Page 113

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

Ways to get in touch

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

See page 113 for more about our services.

Reading this booklet

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

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

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

About our information

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

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

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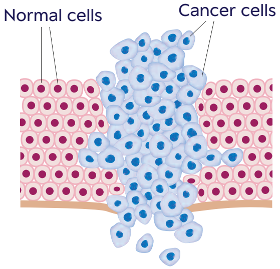
What is cancer?

- **Cancer is a disease of the body's cells**
  All the cells in our body are constantly growing, dividing, dying and being replaced in a controlled way. Cancer occurs when normal cells grow and change in an abnormal and uncontrolled way.

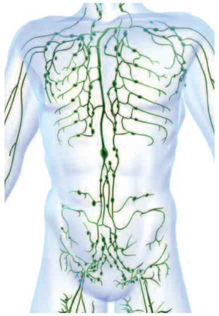
  

  When groups of these cancer cells continue to grow, they can form a lump called a tumour.

  Not all cancers cause a tumour. In blood cancers, such as leukaemia, abnormal blood cells grow out of control, affecting how normal blood cells work.

- **Cancers are named after the organ or cell where the cancer starts**
  For example, prostate cancer starts in cells in the prostate gland, breast cancer starts in cells in the breast. This is known as the primary cancer.

- **Cancers sometimes spread**
  If a tumour does develop and it is cancerous (malignant), it can spread to other parts of the body through the blood stream or the lymphatic system. The lymphatic system is part of our immune system. It protects us from infection and disease and removes extra fluid and waste from the body's tissues.

  If the primary tumour spreads to other parts of the body and forms a new tumour, this is known as secondary cancer or metastasis. Secondary cancers are made up of the same type of cancer cells found in the primary cancer. For example, if bowel cancer spreads (metastasises) to the lungs, it is still treated as bowel cancer, not lung cancer. It may be called metastatic bowel cancer.

What is cancer of unknown primary (CUP)?

CUP means that your doctors have found a secondary cancer but they cannot find the primary cancer. In other words, they have found where your cancer has spread to, but they cannot find the place in your body where the cancer began.

When cancer is diagnosed, you will undergo tests to find out if it is a primary or secondary cancer. If a secondary cancer is suspected, you will have tests to try to find the primary cancer. If this cannot be found, you will be diagnosed with CUP.

When CUP is diagnosed, it is already a secondary cancer, which means that it may already be at an advanced stage. As a result, your treatment may focus on controlling symptoms and improving your quality of life.

If further tests find the primary cancer, your cancer will no longer be classed as CUP.

Why can the primary cancer not be found?

There are a number of reasons why a primary cancer may not be found. These include:

- It may be too small to be seen on scans
- It may be hidden by a larger secondary cancer
- The body's immune system may have already got rid of the primary cancer, but not the secondary cancer

Why is it important that the primary cancer is found?

Different types of cancer need different types of treatment. Finding the primary cancer allows doctors to come up with the best plan for your care because it helps them decide what specific treatment will benefit you the most. It also gives them a better idea of how well your body is likely to respond to treatment.

While treatment can still be given if you have CUP, it may not be as specific or targeted as it would be if the primary cancer was known.

How can doctors tell if it is a secondary cancer?

During your diagnosis, a small amount of tissue would have been taken from your body and examined under a microscope to find out if cancer cells were present. This is a biopsy. During a biopsy, a specialist known as a pathologist can tell if the sampled tissue does not belong to the surrounding tissue. This can then be confirmed by further tests.

How common is CUP?

An average of 577 people are diagnosed with CUP every year in Ireland. This is 2-3% of all cancers diagnosed each year. CUP can affect people of all ages but is most common in older people.

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Preparing for your hospital appointments

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

Before your appointment

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

What to take to your appointment

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

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

Before leaving the appointment

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

After the appointment

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

If you have to cancel your appointment...

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

Questions to ask your doctor

Is there any sign of where my cancer may have started?

What tests do I need?

Will I have to stay in hospital for the tests?

How long will I have to wait for the test results?

What type of treatment do I need?

Are there other treatment options?

How long will treatment last?

If tests shows where my primary cancer is, will my treatment change?

What are the risks and possible side-effects of treatment?

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

Am I suitable for any clinical trials?

Who do I contact if I have a problem when I go home?

What support services are available to help me cope with my cancer?

Diagnosis and further tests

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Being diagnosed with CUP

Hearing that you have cancer will be a huge shock.
You may be feeling:

- **Upset and overwhelmed** by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Angry** that this is happening to you

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

- Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital. They can help you and you and your family to cope with your feelings and advise you about practical matters.
- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people affected by cancer. Join our online community at **www.cancer.ie/community**. Or contact the Sarah Jennifer Knott Foundation, an Irish organisation that promotes awareness, education and research into CUP. Email info@sjkfoundation.org
- Go to your local cancer support centre. For more information, see page 119.

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

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straightaway. You may be unsure how to break the news or need time to adjust, or you may be unsure how to explain that your primary cancer cannot be found. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding The emotional effects of cancer.*** It can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have after diagnosis?

- Tests you may have include an ultrasound, CT scan and MRI scan.
- There is no staging system for CUP.
- Your prognosis is what your doctor expects to happen with your cancer. This can be difficult to predict with CUP.

After you have been diagnosed with cancer, it is normal to have additional tests. These tests give doctors more information about your cancer and some are used to see how well you are responding to treatment.

With CUP, doctors may also continue to carry out tests to try to find the primary cancer (where the cancer started). These additional tests can be tiring and you may get frustrated if the primary cancer still cannot be found.

At some point, your doctors may suggest that you should not have any more tests aimed at finding the primary cancer and that focus should switch entirely to treatment. This may be difficult for you to accept, especially if loved ones are encouraging you to continue with tests.

Blood tests

Blood tests can help to check your general health. They will be done regularly during your treatment. Blood tests can also check the level of substances called tumour markers or biomarkers. Checking biomarker levels may help doctors to see how well you are responding to treatment.

Ultrasound

This is a scan that uses sound waves to look at different parts of your body. It only takes a few minutes. Some gel is put on your skin over the area the doctors are checking. Then a small hand-held device is passed over the area being scanned.

You may have to have a rectal or vaginal ultrasound. The technician will use a different type of probe that can be inserted into your body.

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. It gives doctors an accurate picture of the location and size of any tumours you may have.

For some CT scans you may be asked to fast (not eat) beforehand. For others you may be given a special drink or injection which helps show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes.

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

MRI scan

This is a scan that uses magnetic energy and radio waves to create a picture of the tissues inside your body. MRI scans are sometimes used to clarify any irregularity seen on a CT scan.

You will need to complete a form before the test to ensure that it is safe for you to have an MRI scan. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. You cannot wear jewellery during the scan.

During the test you will lie inside a tunnel-like machine for around 40-60 minutes. The length of time depends on the number of images that are needed and the area of the body being scanned.

Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiographer if you are feeling anxious.

An MRI can be noisy, but you will be given earplugs/headphones to wear. You might get an injection before the scan to show up certain parts of your body. It is important that you keep as still as possible during the scan.

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

PET scan

A PET scan can give your doctors more information about your cancer by measuring the activity of cells in different parts of your body. A low dose of radiotracer (radioactive sugar) is injected into your arm and you have the scan about an hour later. The PET scan uses the radiotracer to highlight cancer cells in the body.

Before the scan, you may have to fast (not eat) and drink only plain, unflavoured water for a few hours. You may also be asked to avoid strenuous exercise the day before and the morning of the scan.

During the scan you will lie on a table that moves through a scanning ring. The scan usually lasts between 20 and 60 minutes. You will be asked to stay still during the scan.

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

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

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

Other tests

You may have other tests as well. These will all be explained to you by your medical team. You may have to wait a few weeks for test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Why isn't CUP staged?

Staging refers to the size of your cancer and how much it has spread. Staging helps doctors to decide the best treatment for patients. Patients are given a number stage – from 1 to 4. The higher the number, the more advanced the cancer is. For example, stage 4 means the cancer has spread to other parts of the body.

However, there is no staging system for CUP because the cancer has already spread and doctors don't know where the primary cancer started.

You will usually still have tests to find out where the secondary cancer is. Your medical team will use those results and all the other information they have gathered to decide on the best treatment options for you.

Asking about your prognosis

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

It's not always easy for doctors to answer a question about life expectancy, especially if the primary cancer is unknown. Everyone is different so what happens to you might be quite different from what the doctor expects.

While it is not usually possible to cure most cancers of unknown primary, some forms can be controlled with treatment for months or years. Some people who have CUP in only one small area, such as a lymph node in the neck or groin, may be able to achieve long-term control, or even a cure, with certain treatments.

Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

If you decide you want information on your prognosis:

Get the information from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information you are being given. Even though there may be uncertainty around your illness, doctors will do their best to answer any questions you have.

Ask a friend or family member to go with you if you would like some support.

Be careful with online information. It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation. Ask your doctor or nurse specialist for recommended websites.

Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.

If you feel upset or anxious about your prognosis, you can get support from family, friends or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment overview

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How is CUP treated?

- There are many different treatment options for CUP.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

You may be disappointed that the primary cancer cannot be found, however there are still treatment options open to you. Your treatment will depend on a number of things including:

- Where in the body your secondary cancer is located
- Where in the body your primary cancer is suspected of starting
- Test results
- Your general health

The most common treatment for CUP is chemotherapy. However, you may have other treatments such as radiotherapy, hormone therapy and surgery. You may have more than one type of treatment.

Types of treatment

Chemotherapy

Chemotherapy is the use of drugs to kill or control the growth of cancer cells. It can be used alone or with radiotherapy. See page 47 for more about chemotherapy.

Radiotherapy

Radiotherapy is the use of high-energy rays to kill the cancer cells. External radiotherapy is where the radiation comes from machines called linear accelerators, which aim rays directly at your tumour.

Internal radiotherapy (brachytherapy) is when the radiation source is placed inside your body for a very short time to kill the cancer cells. See page 54 for more about radiotherapy.

Hormone therapy

Hormones are chemical substances made by glands in the body. They have a huge role to play in how the body works, affecting things like growth, metabolism, sexual function, reproduction and mood.

Some cancers are what is known as hormone sensitive or hormone dependent. This means they use hormones to grow or develop. Hormone therapy works by blocking or lowering the amount of certain hormones in the body, with the aim of stopping or slowing down the growth of cancer. See page 57 for more about hormone therapy.

Immunotherapy

Immunotherapy treatment helps your immune system to work better to fight cancer cells. Your immune system protects you against disease and infection. Sometimes, cancer cells find a way of hiding from the immune system. This allows cancer to develop or spread. Different immunotherapy treatments work in different ways. Some help the immune system to attack the cancer directly. Others boost the immune system in a more general way. See page 61 for more about immunotherapy.

Targeted therapies

Targeted drug therapies target certain parts of cancer cells that make them different from normal cells. They can help stop cancer from spreading, slow its growth or destroy cancer cells that have spread to other parts of the body. They can also treat cancer that has spread or come back after treatment. See page 58 for more about targeted therapies.

Surgery

Surgery involves making a cut in your body to remove tissue. For example, to remove a tumour. Surgery is more often used to treat cancer found at an early stage. Because CUP has already spread, surgery may not be the best treatment. However, it may be used in some cases. For example, if the secondary tumour can be easily removed. It can also be used sometimes to help with symptoms such as pain. See page 60 for more on surgery.

Deciding on treatment

Multidisciplinary team

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

Understanding your treatment

Your doctor and nurse will explain your treatment options. Because your cancer has already spread, it may be at an advanced stage. This means treatment is unlikely to cure it. However, treatment may be able to control your cancer, improving your symptoms and overall quality of life.

Because your primary cancer has not been found, you may have lots of questions about why your medical team has chosen a particular treatment. You could use the fill-in page at the back of this booklet to write down your questions. Ask as many questions as you like.

If you forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses. Call our Support Line on 1800 200 700.

Time to think

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

Second opinion

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

Accepting treatment

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

Who will be involved in my care?

Some of the following professionals may be involved in your care:

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

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

Radiation therapist A healthcare professional who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

Advanced nurse practitioner (ANP) A specialist nurse who has extra experience and skills looking after patients in a speciality area.

Oncology liaison nurse/clinical nurse specialist (CNS) A specialist nurse who works in a cancer care unit. They give information and reassurance to you and your family throughout your treatment.

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

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

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

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

Psycho-oncology team These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

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

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

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

Giving consent for treatment

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

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

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You may also be finding it difficult to understand how treatment can go ahead when your primary cancer is still unknown.

Talk to your doctor or nurse if you have any worries about your treatment plan. You can still change your mind after you have started treatment.

Waiting for treatment to start

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

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

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

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.

How can I help myself?

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

Eat well

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

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

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

Keep active

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

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

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

Quit smoking

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

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

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

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

Other ways to help yourself

Get information about your cancer and treatment

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

Involve your family and close friends

Don’t keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too so try to talk openly and find ways to support each other.

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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

Be aware that there will be ups and downs

Sometimes people feel that 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.

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Chemotherapy

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

Chemotherapy is a treatment that uses drugs to kill cancer cells. It is one of the most commonly used treatments for CUP. The doctor who specialises in chemotherapy is called a medical oncologist.

Chemotherapy may be given:

- **As a treatment on its own.**
- **Before surgery or radiotherapy** to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- **At the same time as radiotherapy** to make the treatment work better (chemoradiotherapy).
- **In combination with immunotherapy** to make the treatment work better.
- **In combination with targeted therapies** to make the treatment work better.
- **After surgery** to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- **When a cure is not possible,** chemotherapy can be given to improve quality of life, reduce or control the side-effects of cancer and help a person to live longer. This is known as palliative chemotherapy.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and cycles can vary, depending on things like how well you are responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump). It may also be given in tablet form. You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports, Hickman lines and PICC lines. Usually, your treatment will be given in the oncology day ward.

What kinds of drugs are used?

There are several types of chemotherapy drugs that may be used to treat CUP. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or in combination with each other.

Understanding your drug treatment

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

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

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

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person. Some people have fewer side-effects than others. The type of side-effects you might get and how severe they are mainly depends on the amount of chemotherapy you have and the drugs used. Ask your doctor or nurse if you're worried about side-effects or if you have any questions.

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

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. It is very common. For more information, see page 71.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Tell your doctor or nurse if they are not working well for you. Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects. For more on nausea, see page 73.

Risk of infection

Chemotherapy drugs make you more likely to get infections. You will be given a number to call for advice if you have signs of infection. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine.

If you have a high temperature, or feel unwell (even with a normal temperature), it is very important to call the hospital straight away – never delay. Check with your hospital about the temperature advice to follow.

Anaemia

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

Bleeding and bruising

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

Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you. You will also be told how to look after your mouth during treatment to try to prevent mouth problems.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair usually grows back 3-6 months after you stop chemotherapy.

Constipation and diarrhoea

Chemotherapy can cause constipation. This is when you don't have a bowel movement (poo) often enough. It can also cause diarrhoea. This is when you have frequent loose or watery bowel movements. Your doctor can give you medication to help, if needed.

Skin and nail changes

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

Peripheral neuropathy

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

Changes in kidney or liver function

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

Allergy

On rare occasions people can have a reaction to certain chemotherapy drugs. Reactions can include a rash, itching, low blood pressure and shortness of breath. Tell your medical team if you have these symptoms.

Blood clots

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

Loss of appetite

It is often hard to eat well due to cancer and the effects of treatment. But try to eat as well as you can to keep your strength up. Eat smaller amounts more often. Getting some fresh air and exercise may help to boost your appetite. For more tips on coping with a poor appetite, see page 78.

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

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

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- Radiotherapy is painless and only takes a few minutes.
- The treatment is usually just a few short sessions.

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

Radiotherapy may be given:

- **Before surgery to shrink the cancer.** This makes it easier to remove. This is called neo-adjuvant treatment.
- **After surgery to destroy small amounts of the cancer** that may be left. This is called adjuvant therapy.
- **In combination with chemotherapy** (chemoradiotherapy).
- **To control and relieve symptoms,** such as pain, bleeding and shortness of breath. This is called palliative radiotherapy. This is the most common reason why people with CUP have radiotherapy.

Radiotherapy can be given externally (outside of the body) or internally (inside the body). External radiotherapy is where the radiation comes from machines called linear accelerators, which aim rays directly at your tumour.

Internal radiotherapy (brachytherapy) is when the radiation source is placed inside your body for a very short time to kill the cancer cells.

People with CUP are most likely to have external radiotherapy treatment.

Planning your external radiotherapy treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby areas.

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

Getting your treatment

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

The treatment normally takes a few minutes and is painless.

How much radiotherapy do I need?

You may only need one treatment or you may be given radiotherapy Monday to Friday for several weeks. You will get a break at the weekend.

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

Radiotherapy is normally given in special cancer treatment centres, so you may have to attend a different department or hospital from where you had chemotherapy or other treatment.

For more information on radiotherapy, or to order a copy of our booklet ***Understanding Radiotherapy***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Side-effects of treatment

Side-effects will depend on the area of the body that is being treated and the dose of radiation you are given. Common side-effects can include:

- Nausea (feeling sick)
- Fatigue (extreme tiredness)
- Skin problems. The skin around the treatment area may become red, dry or itchy and it may be sensitive to touch
- Eating-related issues. Radiotherapy to the head or neck area can cause problems such as swallowing difficulties, sore mouth and changes to your sense of taste
- Hair loss. Radiotherapy causes hair loss only in the area that is being treated. If you need radiotherapy to the brain, the hair on your head will fall out

How severe side-effects are varies from person to person. Most side-effects develop during or shortly after your treatment and can usually be managed with simple medications. Most side-effects improve or go away in the weeks after you have finished treatment.

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

Hormone therapy

- **Hormone therapy works by blocking or lowering the amount of certain hormones in the body, with the aim of stopping or slowing down the growth of cancer.**
- **It is given as tablets, injections or implants.**
- **There are many different types of hormone therapies. Your doctor will explain the best type for you.**

Hormones are chemical substances made by glands in the body. They control how normal cells grow and work.

Some cancers are known as hormone sensitive or hormone dependent. This means they use hormones to grow or develop. Hormone therapy works by blocking or lowering the amount of certain hormones in the body, to stop or slow down the growth of cancer.

If tests show that your secondary cancer is hormone dependent, or if doctors suspect that your primary cancer may be hormone dependent, you may be given hormone therapy.

Side-effects

The side-effects of hormone therapy will depend on the specific drug given. However, common side-effects include:

- Fatigue (extreme tiredness)
- Nausea (feeling sick)
- Muscle/joint pain
- Weight gain
- Mood changes

If you have these or any other side-effects, during or at any time after treatment, tell your doctor or nurse.

Targeted therapies

- Targeted therapies target certain parts of cancer cells that make them different from normal cells.
- Side-effects depend on the drugs being used and vary from person to person.

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

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

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

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

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy as part of a clinical trial (see page 65). 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.

Side-effects

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

- Fatigue (extreme tiredness)
- Nausea (feeling sick)
- Vomiting (getting sick)
- Rash
- Dizziness
- Diarrhoea

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

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

Surgery

- Surgery aims to remove cancer from the body.
- Surgery can also be used to relieve symptoms.

Surgery to remove a tumour is often used if a cancer is in the early stages and hasn't spread. Surgery is not often used to treat CUP as the cancer has already spread. However, there are some situations where surgery may still be used. These include:

- If there is a single tumour that can be removed easily
- If the cancer is located in lymph nodes that are close together in a single area, such as in the neck or armpit
- To relieve symptoms of cancer. For example, by removing some or all of a tumour that is causing pain by pressing on an organ

After surgery

How long you have to stay in hospital after your surgery will depend on:

- What type of surgery you had. For example, keyhole surgery vs open surgery
- Where in the body the surgery was
- If you have any side-effects from surgery that need to be managed in hospital. For example, if you have eating difficulties
- Your general health

You may experience some pain after surgery, but this is usually temporary. Painkillers should help. Always tell your doctor or nurse if you are in pain.

You will be observed to make sure an infection doesn't develop. Let your doctor or nurse know immediately if you start to feel hot or unwell.

If lymph nodes have been removed during surgery, you may develop lymphoedema. This is a swelling caused by a build-up of lymph fluid when the lymphatic system isn't working properly to remove the fluid. Tell your doctor or nurse immediately if you have any unexplained swelling, as lymphoedema is easier to manage when it is treated early. You can also call our Support Line for information and advice on 1800 200 700.

Immunotherapy

Immunotherapy treatment helps your immune system to work better to fight cancer cells. Your immune system protects you against disease and infection. Sometimes cancer cells find a way to hide from the immune system. This allows cancer to develop or spread.

Immunotherapy treatments are used for particular cancer types which have been shown to respond to them. However, because the primary cancer is unknown in CUP, this makes it difficult to plan effective treatment. As a result, immunotherapy is not often used to treat CUP. However, some patients will go on to receive it.

Side-effects

Common side-effects of immunotherapy can include:

- Fatigue
- Rash or itch
- Inflammation of organs or tissues, such as the colon or lungs
- Diarrhoea
- Nausea or vomiting

Palliative care

Palliative care aims to control your symptoms and improve your quality of life, rather than cure your illness. It is used to treat people whose cancer has spread, so many people with CUP will receive palliative care.

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

Palliative care can include things like:

- Treatments such as chemotherapy or radiotherapy to improve symptoms like breathlessness or fatigue
- Help with keeping active and managing day-to-day life
- Physiotherapy
- Counselling
- Family support
- Spiritual support
- Complementary therapies such as yoga or aromatherapy
- Advice about practical matters like financial entitlements
- End-of-life care

Who is palliative care for?

Palliative care is for anyone with a life-limiting condition. This means a condition, illness or disease which is progressive and cannot be cured.

When is palliative care given?

Some people think that palliative care is only given when you have finished all other treatment and need end-of-life care. But while palliative care includes end-of-life care, the palliative care team are experts in managing pain and controlling symptoms, so you may be given palliative care at any stage during your illness to manage symptoms and complications.

Having the palliative care team involved early may mean symptoms will be better controlled and potential problems kept in check. It also means you will have emotional support earlier on in your illness.

Where is palliative care given?

Depending on what kind of palliative care you are having, you may be given palliative care:

In hospital, by the specialist palliative care team

At home, by specialist palliative nurses who work with your family doctor, the specialist palliative care team, the public health nurse and your family

In a community hospital or nursing home, by specialist palliative nurses who work with your family doctor and/or a specialist palliative care team

In a hospice

How is palliative care arranged and do I need to pay?

Palliative care can be arranged by your family doctor (GP) or by the hospital. Ask your doctor or nurse about palliative care. If you don't feel well enough, your family can do so.

Palliative care is free for all patients. You don't need a medical card.

For more information on palliative care, visit the Palliative Hub at **www.adultpalliativehub.com**, talk to your doctor or nurse or call our Support Line on 1800 200 700.

Clinical trials

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

Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of, or as well as, the standard treatment, you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together.

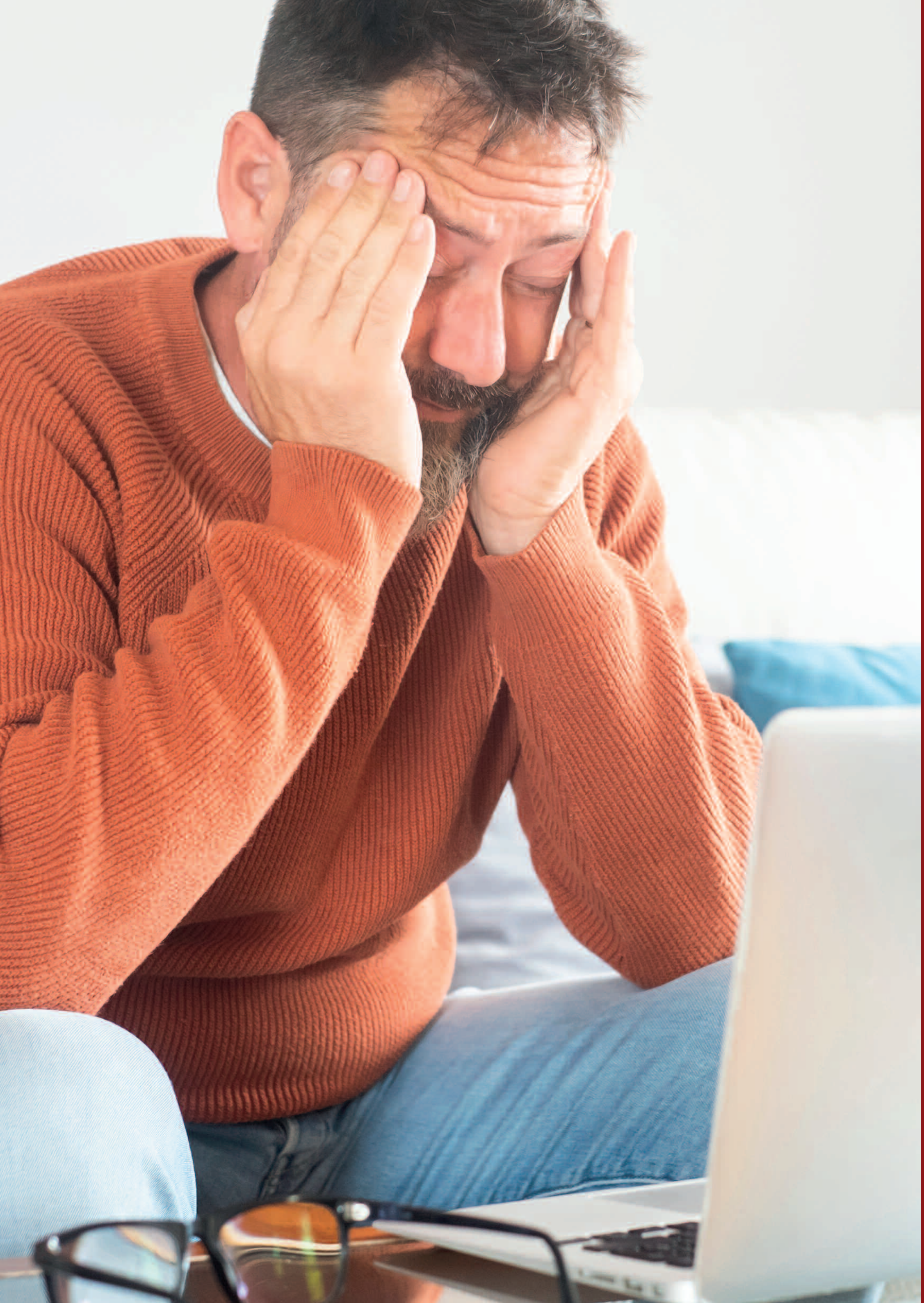
Because the drugs are still in trial, you'll be closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment. 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**



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Symptoms and side-effects can vary from person to person. Most can be treated and some can even be prevented. You should always tell your medical team about any symptoms or side-effects you are experiencing.

The most common symptoms and side-effects of CUP are pain, fatigue (extreme tiredness), nausea (feeling sick), breathlessness and eating problems.

Pain

This is a common worry among people with CUP. However not everyone will experience pain and if you do, there are many ways that it can be relieved.

What causes pain?

Pain can be caused by:

- The cancer itself
- Cancer treatment. For example, some cancer drugs can cause muscle or joint pain
- Nerve damage caused by a tumour or cancer treatment
- Other medical conditions that have nothing to do with your cancer

How is pain treated?

There are lots of effective painkillers available. For example:

- Over-the-counter drugs like paracetamol
- Strong prescription painkillers such as opioids
- Other drugs, such as antidepressants (good for nerve pain) and steroids
- Nerve blocks. This is when a local anaesthetic is injected into or near your nerves
- Epidural injections. This is an injection into your spinal cord
- Anti-inflammatory drugs or bone-strengthening drugs

Some people worry that if they have a lot of pain, this means their cancer is growing. However, the amount of pain you have doesn't always relate to the size of your cancer. For example, a very small tumour can cause a lot of pain if it's pressing on a nerve.

Fatigue

Fatigue means feeling extremely tired all or most of the time. Often it is not relieved by rest. Fatigue is very common with cancer. Usually, fatigue starts to improve once treatment is over but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you so that they can help you.

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

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

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

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days.** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Understanding Diet and Cancer*** has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 96).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night. Try to have naps in the earlier part of the day.
- **Try complementary therapies** like meditation or acupuncture, if your doctor says they are safe for you.

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

Nausea

Nausea (feeling sick) can be caused by the cancer itself or cancer treatments, such as chemotherapy. Other causes can include infections, constipation and anxiety.

What are the symptoms?

- Feeling like you are going to vomit (be sick)
- Increased saliva (spit)
- Dizziness or light-headedness
- Trouble swallowing
- Skin temperature changes
- Fast heart rate

How is nausea treated?

- Anti-sickness drugs (anti-emetics). There are various anti-sickness drugs to help with nausea and vomiting.
- If your chemotherapy or other drug treatment is likely to make you feel sick, your doctor will give you medicine to prevent it before your treatment. You will also be given tablets to take at home after treatment.
- Tell your doctor if the medicine isn't helping. They can prescribe a different one. You may need more than one medication.
- Low doses of steroids can help to reduce nausea and vomiting too. Given in this way, steroids will not do any lasting harm. They can make you feel better overall and help with any loss of appetite too.

Hints and tips: Nausea and vomiting

- **Take any anti-sickness drugs as prescribed.** Anti-sickness drugs work better when you take them regularly or before you start to feel sick.
- **If chemotherapy is causing your symptoms, try to find out when is best for you to eat and drink before treatment.** Some people need a light snack while others feel better with an empty stomach.
- **If nausea or vomiting are stopping you from eating enough, tell your medical team.** They can give you advice to help and refer you to a dietitian, if necessary.
- **Eat before you get hungry,** as hunger can make nausea worse.
- **Eating little and often may help rather than having 3 bigger meals.** Eat slowly and chew food well.
- **If you are sensitive to the smell of cooking, try using ready meals or avoid being in the kitchen while food cooks.** Ask a family member or friend for help with cooking if possible.

- **Sip on clear liquids** to avoid getting dehydrated between meals.
- **Take plenty of nourishing fluids** if you miss a meal or two.
- **Rest after eating.**
- **Try the following foods and drinks,** as they might help:
  - Cold, bland foods like yoghurt, desserts, boiled potatoes, rice, noodles, breakfast cereal or cheese
  - Dry food like toast, scones, crackers or breakfast cereal
  - Herbal teas like mint
  - Foods containing ginger, such as ginger nut biscuits, ginger cake or fresh ginger in hot water
- **Some people find the following foods make nausea worse:**
  - Fatty, greasy or fried foods
  - Spicy foods
  - Very sugary foods
  - Foods with a strong smell, like onions and garlic
- **Eat foods that you are able to tolerate.** When your nausea subsides, try other foods for variety (if you can tolerate them).
- **Some people find relaxation exercises, aromatherapy or meditation help with their nausea.** Check with your medical team first to make sure the therapy you're thinking about is safe.

If you are vomiting, you should contact your medical team if:

- You can't keep fluids down.
- You can't take the medicines you need.
- You're vomiting for 24 hours or longer.

Breathlessness

Breathlessness is when you feel you can't breathe normally or that your breathing is tiring or difficult. You will feel aware of a change to your normal breathing. Breathlessness can range from mild to severe.

Shortness of breath (dyspnoea) can be very uncomfortable and distressing. Tell your doctor if you feel breathless so they can find out the cause and treat it. Some hospitals have special clinics to help with breathlessness.

What causes breathlessness?

There are many possible causes of breathlessness, including:

- Respiratory infections
- Lung diseases, such as COPD
- Damaged lungs due to treatments such as chemotherapy or radiotherapy
- Fluid around your lungs (pleural effusion)
- Fluid in your abdomen (ascites)
- Blood clots in your lungs
- Panic or anxiety
- Lack of physical fitness
- Smoking

If you feel a change in your normal breathing, tell your doctor or nurse immediately. They can carry out tests, such as blood tests and chest X-rays, to try to find the cause.

How is breathlessness treated?

Treatment depends on what is causing the problem. For example, if your breathlessness is due to a low red blood cell count (anaemia), a blood transfusion may help. If you are breathless due to a chest infection, antibiotics may help.

Simple breathing exercises may also help. Your doctor may refer you to a physiotherapist who can teach you these exercises. They will help to control your breathing, no matter how fast or shallow you breathe.

If a tumour is causing your breathlessness, chemotherapy or radiotherapy may be used to shrink the tumour and improve your breathing.

Hints and tips: Breathlessness

- **Ask the hospital physiotherapist or nurse to show you some breathing exercises** that will help to strengthen your muscles used in breathing. Follow any exercise plan they recommend.
- **The physiotherapist can also show you ways to sit** that will increase the amount of air in your body.
- **You may find that you sleep better in a comfortable chair rather than in a bed.**
- **Avoid doing things that increase your shortness of breath, such as climbing flights of stairs.** Take your time getting dressed and wear clothes and shoes that are easy to put on and take off.
- **Anxiety can make a breathing problem seem much worse, so a quiet setting can really help.** Listening to relaxing music can help too.
- **If you are anxious or upset, speaking to a counsellor may help.** We offer free counselling to cancer patients. For more information, call our Support Line on 1800 200 700 or call into a Daffodil Centre.

Eating problems

Eating well during and after cancer treatment is very important as it will help you to:

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

Many people with CUP experience eating-related issues, including:

- Poor appetite
- Difficulty swallowing
- Smell and taste changes
- Nausea
- Constipation or diarrhoea
- Weight loss or too much weight gain

How are eating problems treated?

If you have any eating problems, tell your medical team immediately. They can give you advice on how to solve the problem. They can also refer you to a dietitian or speech and language therapist, if necessary.

Treatment will depend on the problem. For example, if you feel sick (nausea), the doctor can give you medication to help with this. (For more on nausea, see page 73.)

If you are not eating enough and/or are losing weight, the hospital dietitian can advise you on how to get more nutrition. You might be given supplements or a special diet. For example, you may be advised to eat lots of high-energy and high-protein foods.

Always tell your medical team if you are losing weight.

For more on how to cope with eating problems, call our Support Line on 1800 200 700 to order a free copy of the booklet ***Understanding Diet and cancer***. It can also be downloaded from our website **www.cancer.ie**

Always tell your medical team if you are experiencing these or any other side-effects or symptoms.

Will treatment affect my sex life?

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

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

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Contraception

If you are having sex and are fertile, you should use a reliable method of contraception during and for some time after treatment. Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

Ask your doctor's advice about contraception or if you are thinking about having children in the future.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor or nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by chemotherapy, targeted therapies or radiotherapy. You may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, in some cases, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. The Society funds free one-to-one counselling. Call our Support Line on 1800 200 700 for more information or to speak to a cancer nurse in confidence.

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, yoga, acupuncture and aromatherapy.

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

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

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 treating cancer. 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**

Palliative care

Palliative care helps to manage your symptoms and improve your quality of life. It also offers emotional support and comfort to patients and their families. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness.

For more information on palliative care, see page 62, or visit the Palliative Hub at **www.adultpalliativehub.com**.

After treatment

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What follow-up will I need?

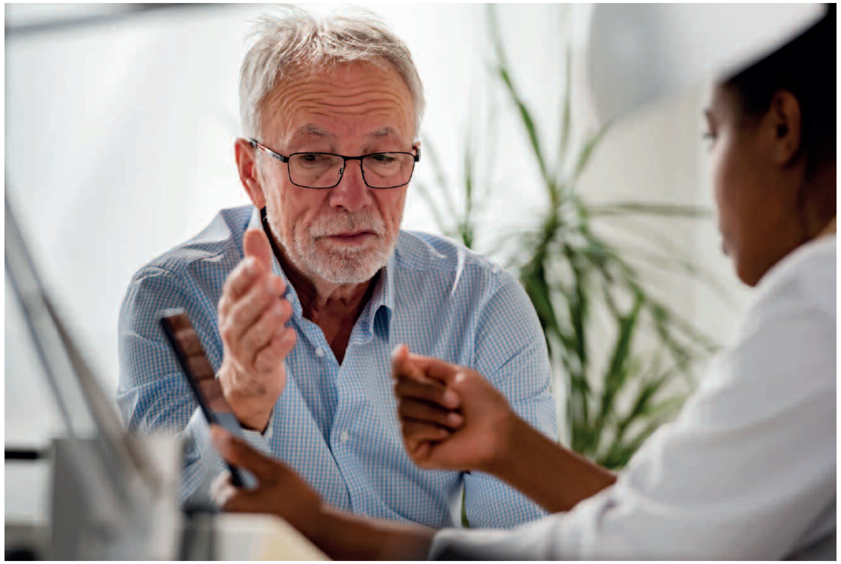
After your cancer treatment has ended, you will still need to go back to the hospital for regular check-ups. This is called follow-up. Your medical team will discuss your follow-up with you. How often and the type of follow-up you have will depend on your treatment plan.

The follow-up is often shared between the teams that have treated your cancer. The purpose of follow-up is to:

- Help with any side-effects that you may have
- Check for signs of new side-effects that may develop after you have finished treatment
- Check for signs of the cancer coming back (recurrence)

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 may help to write down what you want to say before you see the doctor, so you don't forget anything.



For some patients, follow-up may involve consultations over the phone. For others, they may need to go to the hospital for clinical assessment. Follow-up tests can include blood tests and imaging tests such as X-rays or CT scans. There may be a combination of phone consultations and outpatient visits.

If you're between check-ups and have a symptoms or problem that's worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary. Go to your GP if you're unwell and you can't contact the hospital team or attend the hospital's emergency department, if necessary.

Life after treatment

It can take some time to adjust to life after 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 the cancer coming back or spreading further. 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
- Depression or sadness
- Relief that treatment is over and a new phase in your life can begin

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

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 97 for more ways to get emotional support.

After-treatment workshops

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

Living a healthy lifestyle

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

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Cope better with side-effects of treatment
- Reduce your risk of further illness

A healthy lifestyle includes:

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

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

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

What if the cancer comes back?

If cancer does come back (recurs), it may come back in the same place or in other parts of the body. Tests will be carried out to find out as much as possible about the cancer. You and your medical team will then discuss the treatment options open to you.

Chemotherapy is often recommended for recurrent CUP. If you previously had chemotherapy, you may be given the same drugs as before or different ones. Your doctor may also suggest a clinical trial if one is available. Whatever treatment you have, you will also have palliative care to help with symptoms and side-effects.

It is possible that you will develop a new cancer that is unrelated to CUP. Again, tests will be carried out and all treatment options will be discussed with your medical team.

Planning ahead

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

Planning ahead might include:

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

Who can help me plan?

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

Coping and emotions

How can I cope with my feelings? 95

Ways to get emotional support 97

You and your family 99

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.

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

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

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

Anxiety and depression

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

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

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

Counselling

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

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

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

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that their diagnosis brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

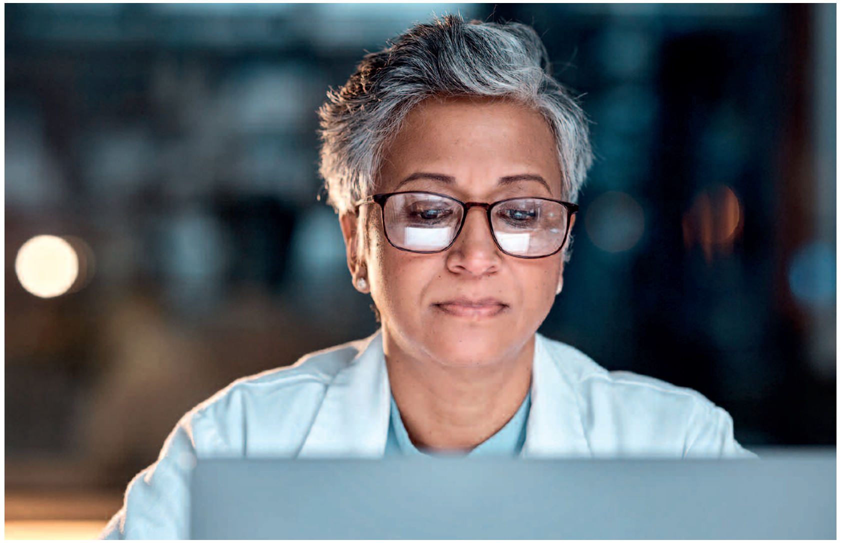
> “I am very happy and content … even though I have to live with this.”

Ways to get emotional support

Find out about support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 119 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer. Peer Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has had a similar cancer experience. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

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



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

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

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

You and your family

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

Changing relationships

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

Further information and support

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

Supporting someone with cancer

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How you can help

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

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

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds one-to-one counselling for friends and family members at many local cancer support centres. For more information, see page 96.

Find out about support for carers

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

Support for you

Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information. Our booklet, ***Caring for someone with cancer***, has lots of information on:

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

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

How to talk to someone with cancer

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

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

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

Support resources

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Irish Cancer Society services 113

Local cancer support services 119

Money matters

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

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

Practical and financial solutions from the Irish Cancer Society

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

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

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

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Benefits and allowances

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

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

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

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

If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 117 for more details of our Transport Service and the Travel2Care fund.

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

Money and finances

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

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

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

Irish Cancer Society services

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

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Transport Service
- Night Nursing
- Publications and website information
- Support in your area
- Practical and financial solutions (see page 110)

Support Line Freephone 1800 200 700

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

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

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

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

Daffodil Centres

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

This is a walk-in service; you do not need an appointment. For opening hours and contact details of your nearest Daffodil Centre, go to **www.cancer.ie** and search ‘Daffodil Centres’.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – just call in if you want to talk or need information on any aspect of cancer including:

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

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

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

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

We will connect you to an interpreter.

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

Peer Support

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

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre. For more information on Peer Support search 'peer support' at **www.cancer.ie**

Patient Education

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

The workshops take place in person, in one of our 13 Daffodil Centres nationwide, or online. To register for a place at one of our Patient Education Workshops, call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie

Counselling

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

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

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

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality, confidential support in a location that's convenient to them.

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

Transport Service

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

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

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

Night Nursing

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

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

Publications and website information

We provide information on a range of topics, including cancer types, treatments and side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.

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

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

Local cancer support services

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

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

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

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

What does that word mean?

Anaemia When there are fewer than normal red blood cells in your blood. This can cause tiredness, weakness and shortness of breath.

Benign Not cancer. A tumour that does not spread.

Biopsy The removal of a small amount of tissue from your body to find out if abnormal cells are present.

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

Chemotherapy Treatment that uses drugs to cure or control cancer.

Fatigue Feeling extremely tired most or all of the time.

Hormones Chemicals made by the body which control many functions in the body, such as metabolism, growth and reproduction.

Hormone therapy Treatment that works by blocking or lowering the amount of certain hormones in the body, with the aim of stopping or slowing down the growth of cancer.

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

Intravenous Into a vein.

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

Malignant Cancer. A tumour that can spread.

Metastasis The spread of cancer from one part of your body to other tissues and organs. Metastatic cancer is also known as advanced or secondary cancer.

Nausea Feeling sick or wanting to be sick

Oncology The study of cancer.

Palliative care This aims to control your symptoms and improve your quality of life, rather than cure your illness.

Palliative care team A team of doctors and nurses who are trained in managing pain and other physical symptoms caused by cancer. They will also help you to cope with any emotional distress.

Pathology The study of tissues/cells to determine their exact nature.

Primary cancer The area/site in the body where the cancer first started.

Prognosis The expected outcome of a disease.

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

Secondary cancer If cells break away from the primary cancer and spread to another part of the body, they may form a new tumour. This is a secondary cancer. It is the same type of cancer as the primary tumour. For example, colon cancer cells that have spread to the lungs are still colon cancer cells (not lung cancer cells).

Targeted therapies Drugs that target specific genes and proteins that are involved in the growth and survival of cancer cells.

Tumour A mass formed by the overgrowth of abnormal cells.

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.

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- *Cancer in Ireland 1994-2021: Annual statistical report of the National Cancer Registry*. National Cancer Registry Ireland (2023)
- *Understanding Cancer of Unknown Primary.* Cancer Council Australia (2020)
- *Cancer Trends – Cancer of unknown primary.* National Cancer Registry Ireland (2019)
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Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

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

Did you like this booklet?

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

Our cancer nurses are here for you:

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

Irish Cancer Society

www.cancer.ie