



# UNDERSTANDING CANCER OF UNKNOWN PRIMARY (CUP)

A guide for people with cancer of unknown primary, their families and friends

First edition February 2018.  
Understanding Cancer of Unknown Primary  
is reviewed approximately every two years.  
Check the publication date above to ensure this copy is up to date.  
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#### Acknowledgments

We would like to express our sincere gratitude to  
Dr. Miriam O'Connor MB FRCPI (Medical Oncologist)  
for her continuous support to the SJK Foundation  
and for her contribution in reviewing this booklet.

We would like to thank our sources including:

CUP Foundation UK- Jo's Friends  
Cancer Council Australia  
Macmillan Cancer Support  
Irish Cancer Society  
Cancer Trials Ireland

#### Note to reader

Always consult your doctor about matters that affect your health.  
This booklet is intended as a general introduction to the topic and  
should not be seen as a substitute for medical, legal or financial advice.  
You should obtain independent advice relevant to your specific situation  
from appropriate professionals, and you may wish to discuss issues  
raised in this book with them.

All care is taken to ensure that the information in this booklet is  
accurate at the time of publication. Please note that information on  
cancer, including the diagnosis, treatment and prevention of cancer, is  
constantly being updated and revised by medical professionals and the  
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## INTRODUCTION

This booklet has been published to provide information and help you understand more about Cancer of Unknown Primary (CUP). When first diagnosed with any form of cancer it is normal to feel shocked and upset.

Many people also go into denial for a short period of time. When diagnosed with CUP it can be especially difficult as it has often spread to many different areas of the body. In addition, doctors and medical staff are unable to locate where the cancer originated. This can be hard to accept especially given all the advances in modern medicine today.

Our aim is that this booklet helps you to understand more about CUP and how it is commonly diagnosed and treated.

It may not be able to answer all your questions, these may need to be reserved for your doctors. It also aims to provide information on where you can get further assistance and support, should you want to.

This booklet can be read by anyone wishing to know more about CUP. Some patients like to give copies to their friends and family so feel free to share it.

## HOW THIS BOOKLET WAS DEVELOPED

We have designed this booklet after gathering information from health professionals, cancer specialists, patients, friends and family of those who have been diagnosed with CUP. We have also consulted the latest clinical practice guidelines that are used internationally.

# WHAT IS CANCER?

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When thinking about CUP it is often helpful to first understand what cancer is. Everyday billions of new cells, or the body's building blocks are formed. These cells help us grow, heal and replace injured or old cells. Old cells typically die and are replaced without us noticing. Sometimes when new cells are being formed they grow and divide too rapidly. This can cause a lump or a tumour to form. Typically there are two forms of tumour, a benign and a malignant tumour.

Benign tumours, or lumps remain in one area and do not spread to other parts of the body. Malignant tumours can spread through the blood stream and through our immune system (lymphatic system). The body is unable to control where they spread and grow. Where a cancer begins is called the primary cancer.

Primary cancers are often called after the organ or tissue it has originated in for example lung cancer, breast cancer or bowel cancer.

A malignant tumour that remains in one area is called a localised cancer. It may get bigger and grow into tissues, blood vessels and lymphatic ducts or vessels. If a malignant tumour grows and spreads into a new site, it is called a secondary cancer or a metastasis (which is from the Latin word for "transition").

When a secondary cancer spreads to a new site it is still called after the primary cancer. For example, if lung cancer spreads to the liver it is called metastatic lung cancer. This is because the cells in the tumour contain cells from the lung, or the original tumour.

# CANCER OF UNKNOWN PRIMARY

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Cancer of Unknown Primary is where people get symptoms from a secondary or metastatic cancer and the original or primary cancer site is not known.

In most cases when people are diagnosed with a secondary cancer, the primary cancer can be found through tests such as scans and biopsies. However in some cases where the cancer began, or the primary cancer, cannot be detected.

This is known as Cancer of Unknown Primary (CUP). Sometimes CUP is referred to as Tumour of Unknown Origin (TUO), occult primary cancer or metastatic malignancy of unknown primary.

When CUP is first diagnosed it is a secondary cancer, this means it has spread and is classified as an advanced cancer. This means that for some people, treatment is aimed at controlling symptoms. In some patients, the medical team will actively treat the cancer while also making sure symptoms are well managed.

For more information on all aspects of CUP please visit [www.cupfoundjo.org](http://www.cupfoundjo.org)

# COMMON QUESTIONS

## Q Why can't the primary cancer be found?

There are many possible explanations why medical staff are unable to find the primary cancer.

- The original cancer may be too small to be seen on scans and have spread very rapidly.
- The body's own immune or defence system may have found and destroyed the primary cancer but have been unable to identify the secondary cancer. The primary cancer may be hidden by a secondary cancer growing close to it on scans and x-rays.
- There may not be a primary cancer tumour or lump. The cells may have been very small and moved in the blood or lymph system before being detected.
- A tumour may have been removed during previous surgery without doctors or patients knowing it was there.

## Q How can we tell it is a secondary cancer?

When a biopsy or sample of the tumour is taken, a doctor looks at it closely under a microscope to try and identify where it originated. It can be seen if the tumour is different and does not belong to the surrounding tissue, this can be confirmed by additional tests such as staining tests. However sometimes the origin of the tumour cannot be identified.

## Q Why is it important what the primary cancer is?

Different treatments are used for specific types of primary cancers. If the primary cancer is known treatment can be targeted at a specific type of cell. If the primary is not known treatment can still be given but it is not as specific. Doctors will often try and find as much information as possible regarding medical history, family history and symptoms.



## Q Are lots of tests necessary?

When trying to identify a primary cancer, several tests may be required. This can be difficult and frustrating, especially if the tests are unable to locate where the cancer originated. Investigations and tests are only performed if your doctor feels they are necessary and may be beneficial to your care. You should feel comfortable to ask any medical staff what the tests are for and what the results might show. You can decide whether to go through with the tests or not. If tests do not reveal where the primary cancer is, doctors may commence treatment and focus on controlling your symptoms.

## Q What are the causes?

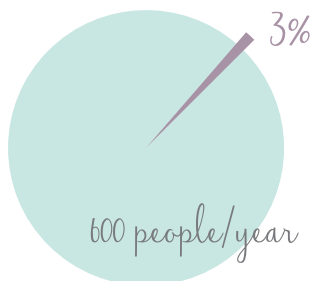
This can be a difficult question to answer. In most cases there is no specific cause identified. Different forms of cancer have different risk factors, these include smoking, alcohol, getting older, some forms of infection and being overweight. Although they may increase your chance of cancer they are not always a direct cause.

## Q What are the symptoms?

People can have different symptoms depending on where the secondary cancer is found. Some common symptoms include being tired, shortness of breath, pain, noticing a lump or mass or a cough. Some people have no symptoms and the cancer is found incidentally on a scan or test.

## Q How common is CUP?

Approximately 11 people per week or 600 per year are diagnosed with CUP each year in Ireland. It accounts for approximately 3% of all new cancers each year.



# DIAGNOSIS AND TESTS

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Most patients with CUP will first see a GP before being referred in to see a specialist. Sometimes CUP can be diagnosed after a medical emergency such as anaemia (low haemoglobin in your blood), a blood clot or a collapse. A specialist will need to ask you some detailed information regarding your symptoms, previous medical history and family history.

## BLOOD SAMPLE AND URINE TEST

These may have been done by your GP prior to seeing a specialist. Other common tests include X rays, CT scans and ultra sound scans. These are imaging tests, which are used to look inside the body to identify the size, location and development of any growths that may be present.

Different forms of CUP will require different tests. Your doctors will decide which of the following tests you may/ may not require. Other potential investigations include:

**BIOPSY** This is where a sample of tissue is taken from the tumour in order to examine the cancer cells more closely under a microscope.

Doctors make every effort to make sure this test is as pain free as possible and use local or general anaesthetics to minimise any pain or distress.

**ENDOSCOPY** This procedure uses a special form of camera to look inside the bowels, lungs or bladder. A small sample of tissue or biopsy may be taken at the same time.

**IMAGING TESTS** Further imaging tests such as an MRI, bone scan or PET-CT can also be used. These are painless investigations. If at any stage these tests are able to discover where the original cancer is located, the diagnosis is no longer CUP but is named after the primary cancer type.

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## BLOOD AND URINE TESTS

Common blood tests look at the different levels of red blood cells, white blood cells and platelets. Bloods tests also examine the function of the kidney and liver and can look for any signs of inflammation or infection. Urine samples may look for abnormal cells, blood or proteins, which provide information on the kidney and bladder. Some types of cancer have specific tumour markers that can be found in the blood. Your doctor may decide to test for these. Unfortunately not every type of cancer can be detected by a blood test. Depending on your sex and symptoms your doctor may or may not order the following blood tests.

### PROSTATE SPECIFIC ANTIGEN (PSA):

high PSA levels can be found with prostate cancer.

### ALPHA-FETOPROTEIN (AFP):

high AFP levels may indicate testicular or liver cancer.

### HUMAN CHORIONIC GONADOTROPIN

(HCG): high levels of HCG can correlate with testicular cancer or a rare type of ovarian cancer.

### CARCINOEMBRYONIC ANTIGEN (CEA):

high CEA levels can sometimes be found with a number of cancers including bowel, lung, pancreatic, stomach, ovarian, breast, thyroid and liver.

### CANCER ANTIGEN 125 (CA125):

CA125 levels may be increased with ovarian cancer.



## BIOPSY

A biopsy occurs when a sample of the growth is removed from the body for detailed examination under a microscope and in the laboratory. It is often required in most forms of cancer as it can give doctors a lot of information including cell types and how rapidly the tumour is growing. It sometimes can be used to identify where the primary tumour is located. Medical staff will try to make sure removing the tissue sample is as pain free as possible. Strong painkillers and sedative medication may be used.

Different types of biopsies include:

### FINE NEEDLE ASPIRATION

removes cells using a thin needle.

### CORE BIOPSY

removes tissue using a wide needle.

### INCISIONAL BIOPSY

cuts out only part of a tumour.

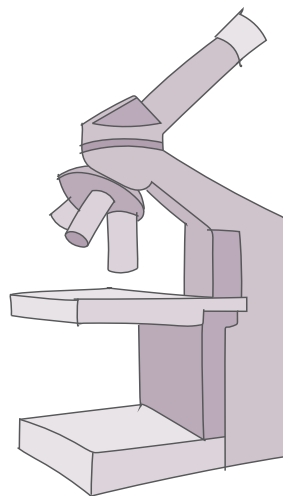
### EXCISIONAL BIOPSY

cuts out the whole tumour.

Tissue samples are taken to the lab and looked at under a microscope. Different stains and genetic tests may be used to attempt to identify where

the tissue originated. These tests can take many days and sometimes weeks to complete. It may feel like you are waiting longer than normal for biopsy results, this is a feature of this difficult diagnosis, keep in touch with your doctor/nurse so they can update you regularly.

Sometimes, depending on where the tissue is located and how unwell you are, a biopsy may be too difficult. For example if a growth is located next to your heart or a major blood vessel a biopsy may not be in your best interests.



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## ENDOSCOPY

An endoscope is a thin tube with a light and a camera on one end which is inserted into your body (usually without the need for surgery) so that your doctor can see the tissues more clearly. You must fast before this test. If your bowel is being tested, it must be empty

so that your doctor can see the lining of your bowel clearly. Depending on the part of your body being tested, you may be given a light sedative to relax you beforehand. There are many different types of endoscopies:



DOCTOR PERFORMING ENDOSCOPY

OESOPHAGOSCOPY	looks at your gullet (oesophagus)
GASTROSCOPY	looks at your stomach
COLONOSCOPY	looks at your large bowel
SIGMOIDOSCOPY	looks at the lower end of your bowel
PROCTOSCOPY	looks at your back passage (rectum)
LARYNGOSCOPY	look at your larynx (voicebox)
BRONCHOSCOPY	looks at your lung airways
MEDIASTINOSCOPY	looks at the space behind your breastbone between your lungs
CYSTOSCOPY	looks at your bladder

## IMAGING TEST

**CT SCAN** (or CAT scans) take x-rays from different angles around your body, creating a series of cross-section pictures or 'slices'. Putting these slices together can help build a very accurate picture of the location and size of any tumours, and how close other internal organs may be. They can be used to look at any part of your body including your brain, lungs or bowels. Before the scan, you may be asked to not eat or drink for up to 4 hours. You may also be given a special drink or an injection with a safe, high-contrast material to help certain areas of your body show up more clearly.

### HOW CT SCANS WORK

You'll be asked to lie on an x-ray table and to remain as still as possible. The table will then slide forwards and backwards through the doughnut-shaped CT scanner until all the pictures are taken. CT scans do not hurt, although some people may feel a bit claustrophobic when passing through the scanner – you will be able to communicate with the radiographer via an intercom or buzzer if you need to.

CT scans take around half an hour per scan and most people will be able to go home immediately afterwards.

**MRI SCAN** MRI uses magnetic energy to build up a picture of the tissues inside your body and can be used to scan any part of your body including your brain, lungs, bowels, etc. Before the scan you may be asked not to eat or drink beforehand, and you will need to remove any hair clips, jewellery, prosthetics or anything else that might contain metal. Those who have certain medical devices in their body, like a pacemaker or metal pin, are not suitable for the test. If you have a nicotine patch or other drug patch you may be asked to remove it to prevent a skin burn.

### HOW MRI SCANS WORK

You may get an injection before your scan that will allow certain areas of your body to show up better. During the scan you'll be asked to lie on a table and to stay as still as possible, but you will be able to breathe as normal. The table will then move either

all or part of the way into the tube-shaped scanner. The scanner is very noisy and will make a constant clanging sound so the radiographer will give you earplugs or headphones. You will also have an intercom or buzzer so you can alert them if you need to. MRI scans don't hurt although some people may feel a bit claustrophobic when passing through the scanner – you can ask for a mild sedative ahead of time if needed. Each scan lasts for around 30 minutes and most people will be able to go home immediately afterwards.

### WHAT CANCERS DO MRI SCANS CHECK FOR?

An MRI is good at detecting many different types of cancers. Sometimes your doctor will use a CT scan and an MRI scan to build a clearer picture of your organs.

**PET SCAN** A PET scan uses a low dose of radioactive sugar to measure the activity in your cells and can give your doctor more information about a cancer already found in your body. It is also used to diagnose or determine the stage of a number of different cancers.



PATIENT HAVING A MRI SCAN

## HOW PET SCANS WORK

Before the scan, you may be asked not to eat or drink anything for a few hours. When you arrive for your scan, you will be given an injection of radioactive sugar, usually into your arm.

You'll then be asked to lie down for around an hour so that the sugar can travel to all the cells in your body, so it's a good idea to bring some music to listen to.

As cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found. The scan itself doesn't hurt and may take up to 1 hour. PET is safe to use and there are no side effects.

**ULTRASOUND** An ultrasound uses sound waves to build up a picture of your internal tissues, and can be used to scan any part of your body. There is usually no preparation required for an ultrasound unless you are having a rectal ultrasound to examine

your prostate. In this case you may be given some medicine to make sure your bowels are clear before the scan.

## HOW ULTRASOUNDS WORK

When you arrive you may change into a hospital gown. You'll then be taken to the scanning room and you'll be asked to lie down, usually on your back, and a gel will be spread over the area to be scanned. A small device like a microphone is moved back and forth over your skin to take the scan. This device makes sound waves that are changed into a picture on a computer. If you are having a rectal or vaginal ultrasound, the technician will use a different type of microphone that can be inserted. They may have to rotate or move the microphone to scan everything, which may be slightly uncomfortable but shouldn't hurt. Ultrasounds can take from 10 minutes to half an hour and you can go home immediately afterwards.

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Remember you may only need some of the above tests, your doctor will advise you which tests are necessary for your individual needs. If you do have any concerns regarding the tests, please feel free to discuss with your doctor or nurse.

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# PROGNOSIS

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A prognosis is the expected time course of an illness. Each patient and presentation may have a different prognosis. It is best to discuss your individual case with your treatment team. Unfortunately, it is never possible to predict the exact outcome of any disease process, especially with cancer.

Prognosis is effected by the growth rate and position of the tumour, the response to treatment and many others factors such as age, fitness and any other medical conditions you may have. Although it is currently impossible to cure most cancers of unknown primary, some forms of CUP can be controlled for months or years. There are some forms of localised CUP (e.g. a lymph node in the groin) that can be cured with surgery and extensive chemo-radiation treatments.

Regardless of the prognosis, cancer and palliative care teams can provide medication to minimise pain and suffering and maximise quality of life. See the palliative care section for further information.

*“I’ve been having palliative treatment for five years. I’m not trying to get rid of the disease, just keeping it under control. My quality of life is excellent.”*  
Kate

# MAKING TREATMENT DECISIONS

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Often when the diagnosis of cancer is made, everything seems to happen very fast. Deciding on different treatment options can be difficult so make sure to check with your doctor the best treatment option for you. Ask when your treatment should start and take as much time as possible before making a decision.

Gathering information about the disease process, the treatment options and their potential side effects can assist you in this decision. Discussing the options with family and friends can also play an important role on deciding what is right for you and your

personal lifestyle. At any stage it is possible to stop or decline a treatment. Some people choose to start treatment even if it may be minimally effective and some people decide not to commence extensive chemotherapy or radiotherapy treatments at all.

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## DISCUSSION WITH DOCTORS

It is normal when you are first told you have cancer to not remember any more details from the appointment. It can be helpful to have a relative or friend with you for appointments to ask questions or just to listen. Some people like to take notes or record the discussion. If at any stage you do not understand the information given to you, please do not hesitate to ask for clarification or

for more detailed information. There are some suggested questions at the end of this booklet that you may find useful. When the primary cancer cannot be found some patients may want another opinion to ensure there is no other options. Doctors are used to people requesting this. Your first doctor may still treat you after taking a second opinion.

## YOUR TREATMENT TEAM

You will most likely see a lot of new faces once you are diagnosed. Who you see can depend on your form of cancer and the services available in

your location. Sometimes some of the team and their roles can be confusing. Here are some of the people that can be involved in your care.

### MEDICAL ONCOLOGIST

This is a doctor that specializes in cancer care. They prescribe and co-ordinate chemotherapy and other medical treatments.

### DIETICIAN

Recommends an eating plan to follow.

### RADIATION ONCOLOGIST

This is a doctor who prescribes and monitors radiotherapy.

### OCCUPATIONAL THERAPIST

Assist with physical and practical problems.

### RADIATION RADIOGRAPHER

This is a person who specializes in the delivery of radiation.

### SOCIAL WORKER

Links you to support services and helps with emotional, physical or practical issues.

### CANCER CARE COORDINATOR OR CLINICAL NURSE SPECIALIST (CNS)

Coordinates your care, liaises with members of the multi-disciplinary team (MDT), and supports you and your family throughout treatment (this may not be available to all patients).

### PSYCHIATRIST

Provides emotional support and assistance.

### PSYCHOLOGIST

Can help with anxiety and depression.

### PALLIATIVE CARE SPECIALISTS AND NURSES

Help control symptoms, side effects of treatments, and help patients to maintain a good quality of life.

### PASTORAL CARE

Can help you work through spiritual matters if necessary.



# TREATMENT

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When a decision is made to commence treatment for CUP there is a variety of options used. Some people although disappointed that no primary has been found are relieved that the tests are over and treatment can commence. Your treatment will be based on numerous factors including:

- The location and form of your CUP
- What will give you the best outcome
- Test results
- Your preferences
- Your general health
- How likely it is to be a certain type of cancer

Most patients with CUP will have chemotherapy. Other treatments include radiotherapy, hormone therapy, surgery or targeted therapies. It is common to have a combination of therapies.

It is important to note that for some people, CUP is diagnosed at an advanced stage. Treatment may be unable to cure it but is aimed at controlling it and improving symptoms and maintaining quality of life.

*“I found it complex to talk to people about my cancer. I can explain it, but they find it hard to understand. It does seem incomprehensible to have a cancer that has spread but no named starting point.”*

*Jane*

## CHEMOTHERAPY

Chemotherapy involves using cytotoxic drugs to kill cancer cells. It can treat cancer cells anywhere in the body because it circulates in the blood. There are many types of chemotherapy drugs that can be given individually or in combination. Chemotherapy can also be used in conjunction with other treatments, including radiotherapy, hormone therapy and biological drug therapies.

### Why chemotherapy?

Chemotherapy can be given for different reasons, depending on your cancer.

- It can be used to destroy the cancer completely.
- It can be given before or after surgery or radiotherapy, to ensure that cells that cannot be seen are killed, thus reducing the chance of the cancer returning.
- Where a cure is not possible, chemotherapy can be given to control the growth of the cells. This is known as palliative chemotherapy.

### How is chemotherapy given?

Chemotherapy drugs are administered in various ways:

- By injection, or infusion, into a vein **INTRAVENOUS CHEMOTHERAPY**
- By injection into a muscle **INTRAMUSCULAR CHEMOTHERAPY**
- Under the skin **SUBCUTANEOUS CHEMOTHERAPY**
- By injection into the fluid around the spinal cord **INTRATHECAL CHEMOTHERAPY**
- Directly into a body cavity, e.g. the bladder **INTRACAVITY CHEMOTHERAPY**
- Orally as a tablet or capsule
- Applied as a cream to the skin.

A lot of chemotherapy drugs can be given on an outpatient basis; however, some treatments require a stay in hospital.



## Methods of injection

There are different ways of injecting chemotherapy into the bloodstream.

- **CANNULA:** the nurse or doctor inserts a very fine tube into the patient's arm or hand and the chemotherapy is given through this. The cannula is usually removed on the same day.
- **Picc LINE:** (peripherally-inserted central catheter, also called Groshong) this is a flexible tube that is inserted into a vein in the arm and advanced up until the tip sits in the right atrium of the heart. This catheter can be left in position for a number of months.
- **CENTRAL LINE:** inserted through the skin in the chest into a major vein, this line can also be left in place for a number of months.
- **PORT:** (also known as a portacath): this has a small reservoir implanted under the skin; it does not have an external catheter. A needle is inserted into the reservoir and removed at the end of the treatment. The port can be used for as long as needed.

## Side-effects of chemotherapy

There are many side effects of chemotherapy including nausea, vomiting, hair loss, mouth ulcers, a low immune system, low red blood cells and easy bruising. Please refer to the chemotherapy section of the Irish Cancer Society website for more information including an informative video.

[www.cancer.ie/cancer-information/treatments/chemotherapy](http://www.cancer.ie/cancer-information/treatments/chemotherapy)



## RADIOTHERAPY

Radiotherapy is the use of high-energy rays to control cancer; it's a very common cancer treatment in Ireland and worldwide.

### What is radiotherapy?

The beams of radiation in radiotherapy are more powerful than ordinary x-rays. They aim to destroy the cancer cells with as little damage as possible to normal cells.

- Radiotherapy can be given on its own or with surgery, chemotherapy, hormone therapy or monoclonal antibody therapy. It can be given before surgery to shrink the tumour or after surgery to treat any residual disease.
- Radiotherapy can be given from outside the body (externally) or from inside (internally).
- Radiotherapy in general is safe. Depending on the type of radiotherapy, you may need to take special precautions after treatment.
- Radiotherapy may cause side effects that can last for a short or a longer period.

### When you may need radiotherapy

Your doctor may prescribe radiotherapy to destroy the tumour: this is called CURATIVE RADIOTHERAPY. You may also have radiotherapy to relieve symptoms (like pain): this is called PALLIATIVE RADIOTHERAPY.

Radiotherapy can be given before or after surgery. When it is given before surgery, it is called NEO-ADJUVANT THERAPY. When given after, it can prevent any cancer cells left in your body from growing, and is called ADJUVANT THERAPY.

You can get radiotherapy in special cancer treatment centres. The radiotherapy unit may not be located in the hospital where you receive your cancer diagnosis. As a result, you may have to travel to a special radiotherapy centre for treatment. The Irish Cancer Society can assist with travel arrangements if needed.

Please see [www.cancer.ie/support/volunteer-driver-service](http://www.cancer.ie/support/volunteer-driver-service) for detailed information.



## Types of radiotherapy

There are different ways to give radiotherapy. It can be given from outside the body (externally) or from inside (internally). Sometimes both are used to treat cancer, for example, in the breast or prostate gland.

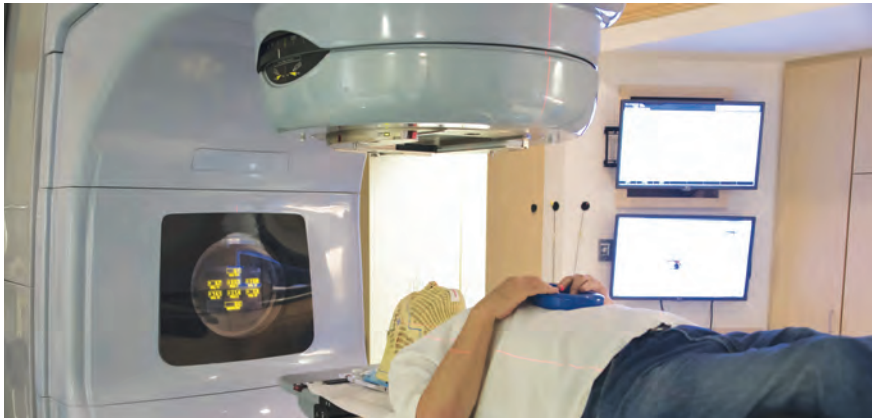
## External beam radiotherapy

Giving radiotherapy externally is called external beam radiotherapy and a course can last 4–8 weeks. The rays come from a machine called a linear accelerator or other machines called cobalt. The different types of external beam radiotherapy include:

- **CONFORMAL RADIOTHERAPY** This is also called 3D conformal radiotherapy. Here CT or MRI scans are used to make a three-dimensional (3-D) computer image of your tumour and nearby tissues. The radiotherapist puts metal blocks in the path of the radiation beam; the blocks change the shape of the beam so that it conforms more closely to the shape of the tumour. This allows a higher dose of radiation to be given to the cancer and a much smaller dose to normal tissue. This helps to reduce the risk of long-term side effects.
- **INTENSITY-MODULATED RADIOTHERAPY (IMRT)** With IMRT, your specialist can change the dose and match the shape of the rays to the shape of your tumour. The entire tumour gets the same dose of radiation, while healthy tissues close to the tumour receive a lower dose. This helps to prevent long-term side effects.
- **STEREOTACTIC RADIOTHERAPY** is a way of targeting radiotherapy very precisely at your tumour. This type of treatment is not available at all hospitals because it needs specialist equipment and skills.

## Side effects of radiotherapy

- The side effects of radiotherapy depend on the area of the body being treated and the dose of radiation.
- Common side effects include nausea, loss of appetite, diarrhoea, tiredness and shortness of breath. It can also make your skin dry and itchy in the area treated. Your skin may look red or sunburnt.
- Side effects tend to develop as you go through treatment, and most improve or go away after treatment is finished. Talk to your doctor or nurse about ways to manage them.



PATIENT HAVING RADIOTHERAPY

## HORMONE THERAPY

Hormones are substances that are found naturally in the body. Sometimes when cancer develops certain hormones stimulate the cancer cells to grow. Hormone therapies stop the hormone being released or prevent it acting on the cancer cells. If laboratory tests show that a secondary cancer is hormone dependant, hormone therapy may be given. These can be taken as tablets or injections. It can also be used alongside other treatments such as chemotherapy.

### Side effects of hormone therapy

Side effects of hormone therapy will depend on which hormone is taken but symptoms can include nausea, vomiting, diarrhoea, weight gain and mood and appetite changes.

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## TARGETED THERAPIES

At present there is a new group of therapies that focus on cancer cells and results in little harm to healthy cells. There is ongoing research in this field but it is not yet known how useful these therapies may be for CUP. Clinical trials may give us more information about the potential benefits of these new medications.

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## CLINICAL TRIALS

A clinical trial is the term used to describe a research study. Research into new ways of preventing, screening and treating cancer goes on all the time. Clinical trials look at using new drugs or combinations of currently used drugs to treat cancer. Clinical trials also look at diagnostic techniques, surgical techniques and radiotherapy treatments.

The aim of clinical trials is to improve treatments for cancer, and give patients with cancer a better quality of life. Many cancer patients take part in clinical trials. Even though the words 'research' and 'trial' sometimes scare people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many steps to make sure it is safe to use. If the early stages of research suggest that a new treatment might be more effective than the current or 'standard' treatment, doctors and researchers compare the new treatment with the standard treatment. A clinical trial is one of the final stages of this long and careful research process.

If you are interested in taking part in a clinical trial, speak to your doctor. They are in the best position to advise you about any trials that may be suitable for you and your cancer.

## Why are clinical trials needed?

The idea for a cancer trial usually comes from looking at current research. Based on what they already know, researchers identify gaps and find new questions that need to be answered. The researchers then set about 'designing' the trial, this is known as a trial protocol.

The treatments we currently use for cancer have been tested in clinical trials. Without ongoing clinical trials it would not be possible to develop new and more effective treatments. Once a clinical trial has shown that a treatment is effective, further trials are often carried out to find better ways of using it, for example using different doses or combining it with other treatments. Cancer trials often require thousands of patients and can take a number of years to complete.

This is because the researchers want to be sure that a new treatment or new way of giving an existing treatment is better than the standard treatment.

Sometimes, despite the large numbers of patients involved and years required, the improvements in treatment are important but small. However some trials do result in significant changes to cancer treatments. This is why it is so important that researchers continue to design new trials and patients agree to take part.

## Trial safety and regulation

In Ireland, all medicines must successfully complete a clinical trial before they are granted a license. Researchers must register with and submit their trial protocol along with relevant scientific and medical information to the Health Products Regulatory Authority (HPRA).

The HPRA reviews their application and decides whether or not the trial can be conducted. The application must also be sent to an approved ethics committee, for new medicines this process is supervised by the Department of Health and Children. The ethics committee ensures that the rights and well-being of the patients who are taking part in the trial are preserved.

Once the trial application has been passed by the HPRA and the ethics committee, the researchers can begin the trial. At any time the HPRA can audit the trial to ensure it is being carried out properly with the patients' safety in mind.

## How long does a clinical trial take?

Clinical trials can take many years to complete. Even though your treatment as part of the trial is complete, all final results of the whole trial may not be known. This can be frustrating for patients, doctors and researchers. However it is necessary that a trial be run for long enough to recruit enough patients and then have the results analyzed to ensure the results are reliable. Your doctor will discuss the details of your treatment with you, including how long it will take.

Once you have completed your treatment, you will be monitored by your doctor and they will continue to report back to the researchers.

Remember trials can require hundreds or thousands of patients and each patient starts their treatment at a different time and must be monitored during and after their treatment. Results are published in medical journals. Your consultant will be able to tell you what the final results are once they have been published. If a trial treatment is proven to produce better results than the standard treatment it will be licensed and become the new standard treatment.

Sometimes clinical trials are run involving the consultant oncologist and a pharmaceutical company directly, ask your doctor about this.

If you would like to know more information on clinical trials please see the "clinical trials" section on the Irish Cancer Society website.

[www.cancer.ie/cancer-information/treatments/clinical-trials](http://www.cancer.ie/cancer-information/treatments/clinical-trials)

You can also find out what trials are available in Ireland by contacting Cancer Trials Ireland who are one of the leading research trials organizations in Ireland.

[www.cancertrials.ie](http://www.cancertrials.ie)

For free, confidential advice and support for any type of cancer please call the Irish Cancer Society Nurseline Freefone 1800 200 700.



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## SURGERY

Surgery can be used in many types of cancer if it is found at an early stage. Advanced cancers such as CUP have spread beyond the original site so surgery is not as useful. Sometimes surgery can be used to relieve or control symptoms such as bowel blockages and nerve compressions.

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## PALLIATIVE TREATMENT

Palliative care aims to slow the spread of cancer, maximise quality of life and minimise symptoms and side effects, without trying to cure the disease. Most people with CUP receive some form of palliative care, which can be used at any stage of treatment. Palliative care comprises a team of caregivers including nurses, doctors, physiotherapists and emotional support workers. It is not just end of life care. It is often helpful to contact the palliative team as early as possible. They can provide important information about support for you and your relatives that can be useful now or in the future.

### Symptoms and Side Effects

Different patients will have different experiences with the initial diagnosis and the side effects of the treatment. Some people have only minor side effects whereas some people can experience many. Doctors and nurses will try their best to prevent and treat each one. Remember the palliative care team are the experts in symptom and side effects control. Here are some of the common symptoms and side effects.

# PAIN

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This is probably one of the most common worries patients will have. There are some extremely effective medications available that can minimise and potentially completely remove any pain. Depending on where the CUP is, pain may not be a feature at all or it can be in different sites and it can come and go.

Some of the commonly used medications include:

Oral pain medicines such as paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs), opiates including rapid acting and slow release formulas.

Topical medication, slow release pain relief can be achieved by putting a patch on the skin, which can be very effective.

An injection of pain-relieving drugs into the spinal canal. (epidural or spinal block)

Some patients find alternative therapies such as relaxation techniques, meditation, massage or hypnotherapy help with symptom relief.

Chemotherapy, radiotherapy or surgery can also help to directly reduce the size and inflammation surrounding the tumour.

Many patients use a combination of the above treatment options and this combination may vary over time. Your GP, oncologist or palliative care team are often very specialised in managing pain. If you find one treatment doesn't work be sure and ask for help, this can be through increasing the dose of your medication or by trying a different method. There is also some further information on the Irish Cancer Society website.  
[www.cancer.ie/support/coping-with-cancer/cancer-pain](http://www.cancer.ie/support/coping-with-cancer/cancer-pain)

# NAUSEA

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Feeling sick or like you want to vomit (nauseated) is a common symptom and can be caused either by the cancer itself or as a side effect of chemotherapy. Other less common causes include drugs such as morphine, the kidneys not working properly, stress or a build up of pressure in the brain. There are multiple treatment options available for nausea. If you experience this make sure and discuss this with your treatment team.

## Tips for helping nausea

Eat small portions of food as often as you can.

Cold foods, such as milkshakes, jelly, fruit or sandwiches can be easier than warm foods.

Ginger, either in tablet form or in food or drinks such as ginger biscuits, cake tea or ginger ale.

Take anti-nausea medication such as ondansetron before pain medication and before meals if possible.

Some people find techniques such as meditation or relaxation can increase their appetite.



# FATIGUE

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Tiredness or fatigue is a very common symptom for people with CUP. It can be concerning both for the patient and for their family and friends. There are many different causes of tiredness, which are often present in combination. These include:

- Anaemia (low levels of red blood cells)
- The CUP itself
- Poor diet and nutrition
- Lack of sleep
- Medication such as pain relief
- Chemotherapy or radiotherapy
- Anxiety

## Tips for fatigue

Please talk about your tiredness with friend's relatives and carers to assist them understanding how you feel. Try to pace yourself and save your energy for the things you want to do or that need doing. If possible try to do some gentle exercises such as small slow walks or keeping your legs moving when sitting down or in bed can help. By balancing rest with some physical activity it will help increase your energy levels.



## WELLBEING

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Any cancer diagnosis causes significant emotional and physical stressors. Make sure and look after your mood and mental health also. Common ways of doing this include:

### COMMUNICATION

Discuss your emotions and thoughts with your team, family and friends. This will help them better understand your mood and behaviours. It can be very helpful to maintain relationships as much as possible.

### NUTRITION

Diet can play a very important role both in maintaining physical and mental health. Healthy food can also help with symptoms and side effects. An excellent booklet on cancer and nutrition is available at this link.  
[cancerwa.asn.au/resources/2016-07-29-nutrition-and-cancer.pdf](http://cancerwa.asn.au/resources/2016-07-29-nutrition-and-cancer.pdf)

### EXERCISE

Staying active can play a major role in reducing tiredness, elevating mood and increasing appetite. Exactly how much and what type of exercise you do can vary depending on your site and stage of CUP. Discuss this with your treatment team and for further information this webpage has some excellent videos and suggestions.

[cancer.org.au/about-cancer/living-with-cancer/exercise-for-people-living-with-cancer.html](http://cancer.org.au/about-cancer/living-with-cancer/exercise-for-people-living-with-cancer.html)

### COMPLEMENTARY THERAPIES

Therapies such as massage, meditation and relaxation can help with mood and anxiety. Discuss these options with your treating team or see this Irish Cancer Society link [www.cancer.ie/cancer-information/treatments/cancer-complementary-therapies#sthash.fH1I5mqK.dpbs](http://www.cancer.ie/cancer-information/treatments/cancer-complementary-therapies#sthash.fH1I5mqK.dpbs)



## SUPPORT

### Living with a CUP diagnosis

Patients diagnosed with CUP will have a range of emotions throughout the investigations and treatment stages. These include denial, fear, sadness, frustration, depression, loneliness and anxiety. Talk about these emotions with both your treatment team and your family and friends. Other support services include:

COUNSELLOR

SOCIAL WORKER

PSYCHOLOGIST

SPIRITUAL OR RELIGIOUS ADVISER

GENERAL PRACTITIONER

Many people can get multiple offers of support. It can be challenging to know what can be useful. Some patients prefer to ask a friend or family member to coordinate offers of assistance. While some people can be very supportive, others may not know what to say or do. This can be hard and can make you feel confused or upset. This is a normal reaction but being honest and open is often helpful.

The Irish Cancer Society has information about coping with your emotions – you can visit their website for more information. Further assistance, such as help around the house, financial advice and transport assistance is available through the Irish Cancer Society. For further information please visit their website [www.cancer.ie/support](http://www.cancer.ie/support)

## Talk to someone who's been there

Talking to someone who has been in a similar situation can be very beneficial. No one knows more about the impact cancer can have on your life than those who have been through it themselves. Talking to someone who has been in a similar situation may help you feel supported, understood and to know you are not alone. Sharing tips and advice can also be beneficial. Feelings of isolation after a CUP diagnosis is common so finding support groups can be very helpful.

## Friends, relatives and carers

This booklet is meant to be read both for those diagnosed with CUP and their friends, relatives and carers. Caring for someone with cancer can be difficult and cause stress and anxiety. It is important that carers also look after themselves by seeking support and taking rests. It is important to discuss your concerns and thoughts with friends, counsellors or doctors. There are many support groups available for carers. These can be very beneficial to meet people in similar circumstances and share ideas, experiences and methods of both caring and coping.

## Useful websites

The Internet has many useful resources, although not all websites are entirely reliable. The websites listed below are good sources of support and information.

Irish Cancer Society	<a href="http://www.cancer.ie">www.cancer.ie</a>
CUP Foundation UK, Jo's friends	<a href="http://www.cupfoundjo.org">www.cupfoundjo.org</a>
Cancer Council (AUS)	<a href="http://www.cancer.org.au">www.cancer.org.au</a>
American Cancer Society	<a href="http://www.cancer.org">www.cancer.org</a>
Cancer Research UK	<a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>
National Cancer Institute (US)	<a href="http://www.cancer.gov">www.cancer.gov</a>
Arc Cancer Support	<a href="http://www.arccancersupport.ie">www.arccancersupport.ie</a>
Cancer Trials Ireland	<a href="http://www.cancertrials.ie">www.cancertrials.ie</a>



## Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- Is there any sign of where the cancer might have started?
- What tests do you recommend and why? How invasive will they be? What information will these tests show?
- What happens if you can't find where the cancer started? How will this affect my treatment?
- Can you explain the results of the tests to me?
- If you find out where the primary cancer is, will my treatment change?
- What treatment do you recommend and why?
- What will treatment involve? When will it start? How long will it last?
- How much will treatment cost?
- Who will be coordinating my treatment?
- What are the likely side effects of treatment?
- What can I do to help prevent or reduce the side effects I may have from treatment?
- What will happen if I don't have treatment?
- Are there any clinical trials available to me?
- Are there any complementary therapies that might help me?

## How you can help

At the Sarah Jennifer Knott Foundation, we're dedicated to improving care for Cancer of Unknown Primary (CUP) patients in Ireland.

Our mission is to promote awareness of Cancer of Unknown Primary, to provide support for patients and families going through the uncertain diagnosis of CUP and to promote improved diagnosis and treatment of CUP.

When Sarah was diagnosed with CUP, aged 30, we (Sarah's family and friends) found it very difficult to get information regarding the diagnosis and treatment for CUP, hence why we have produced this booklet for patients and families. We hope it will be of help.



### MAKE A DONATION

Any donation, large or small, makes a meaningful contribution to our work in supporting people with CUP and their families now and in the future.

[www.sjkfoundation.org](http://www.sjkfoundation.org)

Registered Charity Number 20157838







SARAH JENNIFER KNOTT | FOUNDATION

Sarah Jennifer Knott Foundation  
Registered Charity Number 20157838  
[www.sjkfoundation.org](http://www.sjkfoundation.org)