Understanding cancer of unknown primary (CUP)

About this booklet

This booklet is about cancer of unknown primary (CUP). CUP is when doctors find a secondary cancer but cannot find where the cancer started.

This booklet is for anyone who has been diagnosed with CUP. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of CUP. It explains how it is diagnosed and how it may be treated. It also has information about looking after yourself and getting support.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 102 to 114, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 115 to 116).

Quotes

In this booklet, we have included quotes from people who have been diagnosed with CUP, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations.

To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

About cancer of unknown primary

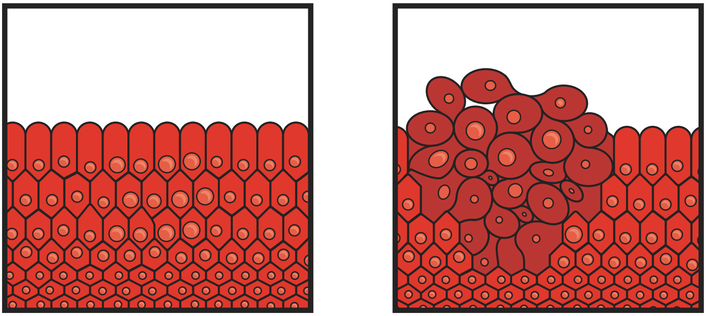
What is cancer?

To understand cancer of unknown primary (CUP), it helps to know more about cancer and the difference between primary and secondary cancers.

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow and repair. Cells receive signals from the body telling them when to divide and grow, and when to stop growing. When a cell is no longer needed or cannot be repaired, it gets a signal to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump called a tumour.

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancerous. Doctors can tell if a tumour is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors look at the sample under a microscope to look for cancer cells.

A tumour that is not cancer (benign) cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A tumour that is cancer (malignant) can grow into nearby tissue and spread to other parts of the body.

Primary cancer

Cancers are named after the part of the body where they first started. For example, a cancer that starts in the lung is called a primary lung cancer. The part of the body where the cancer first started to grow is called the primary site.

Secondary cancer

Sometimes, cancer cells spread from where the cancer first started to other parts of the body. This is called secondary cancer or metastasis. The cancer cells travel through the bloodstream or lymphatic system (page 8). When the cells reach another part of the body, they may start to grow and make another cancer.

Secondary cancer can spread to more than 1 part of the body.

A secondary cancer is made up of the same type of cancer cells as the primary cancer. For example, a cancer that starts in the lungs and spreads to the liver is made of lung cancer cells, not liver cancer cells. That means the secondary cancer is still treated as a lung cancer. It might be called metastatic lung cancer.

The lymphatic system

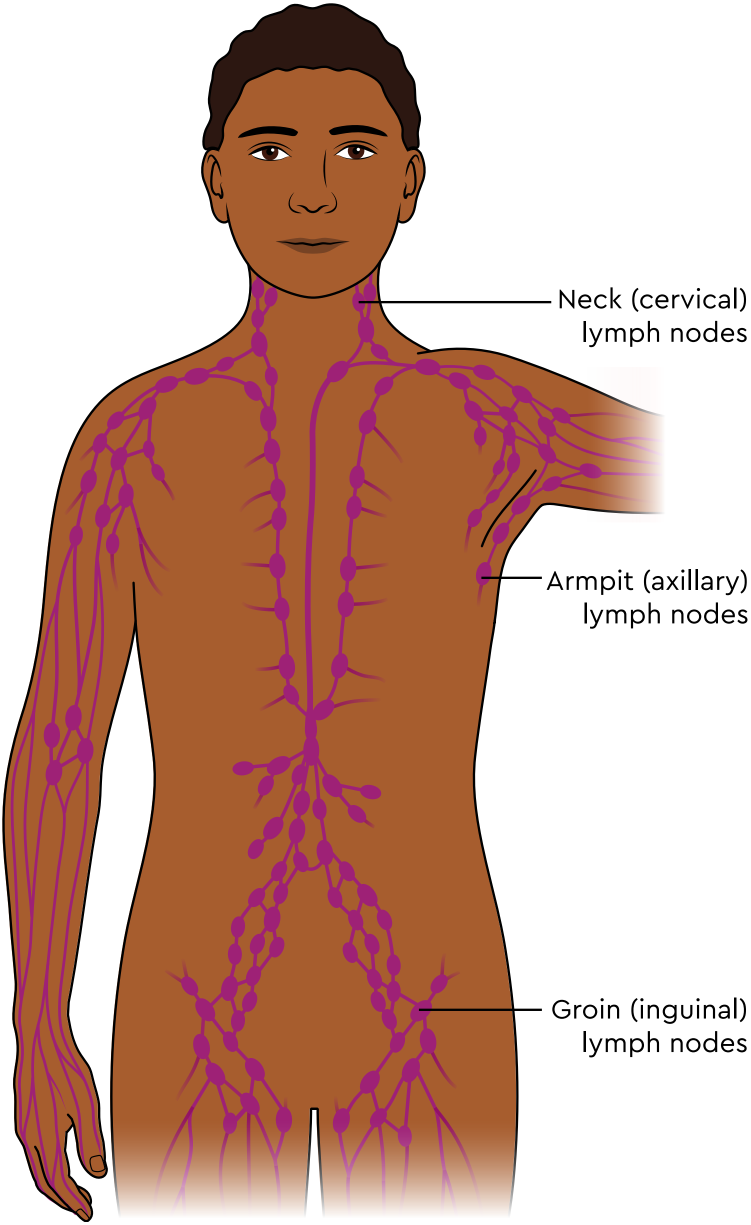
A primary cancer can spread to nearby lymph nodes (sometimes called lymph glands) through the lymphatic system.

The lymphatic system helps protect us from infection and disease. It also drains lymph fluid from the tissues of the body, before returning it to the blood.

The lymphatic system is made of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection.

The lymphatic system



Cancer of unknown primary (CUP)

Around 8,600 people are diagnosed with cancer of unknown primary (CUP) in the UK each year. It can affect people of all ages, but is most common in people aged 75 or over.

Cancer of unknown primary means that your doctor is not sure where the cancer started. They have found a secondary cancer but have not been able to find the primary cancer (page 7). People with CUP sometimes have secondary cancer in more than 1 part of the body.

When a doctor diagnoses cancer, it is not always clear what type of cancer it is. You will have tests to find out whether it is:

- primary cancer
- secondary cancer – a cancer that has spread from a primary cancer somewhere else in the body
- CUP – a secondary cancer where the primary cancer cannot be found.

If your doctor thinks you have a secondary cancer, but they do not know where the cancer started, this is called malignancy of unknown origin (MUO). You will be referred to a specialist team who will arrange tests to try and find out where the primary cancer started.

The specialists will look at all your test results. They may arrange more detailed tests, such as an endoscopy, scans or a biopsy, to find out what type of cancer it is (pages 28 to 43).

If these tests confirm cancer but do not find out where the primary cancer started, the diagnosis may change to cancer of unknown primary (CUP). You will then be referred to a hospital team that specialises in CUP.

It can be difficult to know the best treatment for CUP. This is because cancer treatment usually depends on where the primary cancer started. For example, if you have lung cancer that has spread to the liver, you will have lung cancer treatments.

The test results still give the doctors more information about the cancer. This helps them plan your treatment. The doctors may also be able to suggest the most likely part of the body where the primary cancer started. This will be based on:

- your symptoms (pages 13 to 15)
- where the secondary cancer is
- the biopsy results (pages 24 to 31).

When CUP is diagnosed, cancer has already spread from 1 part of the body to another. In many cases, this means the cancer is already advanced.

It is not usually possible to cure cancer that is advanced and has spread to other parts of the body. But it may be possible to control it for some time.

The most important part of your care is to manage any symptoms to help you feel better. Your GP, the hospital doctors or the palliative care team can give you advice and help with controlling symptoms.

Sometimes further tests find the primary cancer. When this happens, the cancer is no longer CUP.

Reasons the primary cancer cannot be found

Sometimes doctors cannot find out where the primary cancer started. This may be because:

- the primary cancer is too small to be seen on scans
- the primary cancer is hidden by a larger secondary cancer
- the body's immune system has destroyed the primary cancer, but it has already spread.

Doctors might stop looking for the primary cancer if:

- you are not feeling well enough to have tests
- further test results are unlikely to change your treatment plan.

Symptoms of CUP

Symptoms of cancer of unknown primary (CUP) depend on where the secondary cancer (or cancers) is in the body. The most common places for cancer to spread to are the:

- lungs
- bones
- liver
- lymph nodes (pages 8 and 9).

You may notice general symptoms of cancer. Or you may have symptoms in the area affected by the secondary cancer.

All the symptoms mentioned here can be caused by conditions other than cancer. But it is important to visit your GP and get them checked.

> **“I found a lump in my throat when I was shaving. My first thought was that my glands were up, so I just dismissed it. About a month later, it was still there, so I went to see my GP.”**
>
> John, diagnosed with CUP

General symptoms of cancer

General symptoms of cancer include:

- unexplained weight loss
- loss of appetite
- feeling extremely tired all the time
- pain that does not go away or has no obvious cause
- looking pale, and feeling tired and breathless – this may be caused by a low level of red blood cells (anaemia).

Secondary cancer in the lung

Symptoms of secondary cancer in the lung include:

- a cough that does not go away
- breathlessness
- pain or discomfort in the chest that does not go away
- coughing up blood.

Secondary cancer in the bone

Symptoms of secondary cancer in the bone include:

- a dull, persistent pain in the bone which is worse at night
- weak bones – if a bone is weakened by cancer, it might break (fracture) without an obvious accident or fall
- feeling sick, very tired or very thirsty – this may be caused by a raised level of calcium in the blood.

Secondary cancer in the liver

Symptoms of secondary cancer in the liver include:

- swelling and discomfort in your tummy (abdomen)
- feeling sick or losing your appetite
- feeling full quickly when eating
- yellowing of the skin and eyes (jaundice).

Secondary cancer in the lymph nodes

Symptoms of secondary cancer in the lymph nodes include swollen or hard lymph nodes (glands). If they are pressing on tissue or nerves nearby, they may also be painful.

Having a chest x-ray

Diagnosing cancer of unknown primary

How CUP is diagnosed

If you have symptoms, you usually start by seeing your GP. They will examine you and ask about your symptoms. If they think you might have cancer, they will refer you to hospital for tests. You will be seen by a specialist.

The type of specialist doctor you see depends on your symptoms. For example, if you have bowel or stomach symptoms, your GP will refer you to a gastroenterologist. They treat problems of the digestive system. If you have kidney or bladder symptoms, you will see a urologist. They treat problems of the urinary system.

If you have no specific symptoms and your GP thinks a cancer diagnosis may be a possibility, they may refer you directly to a particular hospital team. This could be:

- the malignancy of unknown origin (MUO) team
- the cancer of unknown primary (CUP) team
- a rapid diagnostic centre.

Your GP may have already done some tests before this happens.

If you have symptoms that are making you very unwell, you may be admitted to hospital straight away. In this situation, you will have tests while you are staying in hospital as an inpatient.

At the hospital

The specialist will ask about your general health and your family's medical history. They may consider any risk factors. These include:

- whether you have a strong family history of cancer
- whether you have a condition that increases your risk of cancer
- your lifestyle, for example whether you smoke or drink large amounts of alcohol
- whether you have been exposed to asbestos or chemicals that increase the risk of certain cancers.

Tests to diagnose cancer

The specialist doctor will examine you. You may also have blood tests, x-rays and scans.

The tests you have depend on your symptoms. Doctors may look for the most common types of primary cancers first. These include breast and prostate cancer.

If tests show that you might have cancer, you may have some tissue or cells removed. This is called a biopsy (pages 24 to 27).

The tests might show you have secondary cancer, but the doctors may still not be able to find where in the body the primary cancer started. In this situation you will be referred to a specialist CUP team.

We have more information about tests used to diagnose cancer at **macmillan.org.uk/tests-scans**

> “I think I already knew that it was cancer. The consultant was just confirming it. Strangely, it was almost a sense of relief. I could immediately ask the question: ‘What shall we do next?’ „

John, diagnosed with CUP

CUP specialist

Your CUP specialist may want to do more tests to find out more about the cancer. They use national guidelines to decide which tests are right for you.

If the cancer is confirmed as CUP, you will be cared for by a specialist CUP team. You will be given contact details for a named nurse who specialises in this type of cancer. They can offer support and help answer any questions you may have.

Making decisions about tests

Having tests can take up a lot of energy and time. You and your cancer doctor can talk about which tests may be the most useful in your situation. Some tests might give more information about the cancer. But they might not change what treatment you will be offered or your overall care. In this situation, you may choose not to have them.

Your cancer doctor might recommend that you start treatment:

- instead of having more tests
- while you are still having tests.

They will explain which option they think will help most in your situation. For example, if you are too unwell to have more tests, they may suggest you start treatment to relieve symptoms, rather than treat the cancer. If this happens, your cancer doctor will refer you to a palliative care team.

The aim of palliative care is to control symptoms and give you the best possible quality of life. Palliative care is often given alongside treatment such as chemotherapy (pages 54 to 61) or radiotherapy (pages 62 to 66).

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results to be ready. You may find it helpful to talk with a partner, family member or close friend.

Your specialist nurse or a support organisation (pages 102 to 113) can also provide support. Or you can talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

> **"In order for me to be able to accept my diagnosis, I needed more information. I needed to know what type of cancer I had, at the very least."**
>
> Judith, diagnosed with CUP

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry.

This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely.

It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 114).

Having a biopsy

If your cancer doctor thinks you may have a secondary cancer, they may need to take a sample of cells or tissue. This is called a biopsy. The sample is taken from the abnormal area that looks like secondary cancer. This might be:

- an obvious lump or swelling
- something the doctor can feel when they examine you, such as an enlarged liver
- something that can be seen on a scan.

There are different types of biopsy. Your doctor will explain which is best for you.

Not everyone has a biopsy as the first test. Sometimes it is possible to see areas that might be cancer on scans. If your doctor thinks it could be cancer, they will then arrange a biopsy to confirm.

Most types of biopsy can be done as an outpatient, at a clinic or in the x-ray department. You usually have a local anaesthetic to numb the area first. The doctor then uses a needle to remove a small piece of tissue or a sample of cells. The doctor may use an ultrasound or other scan to help guide a biopsy needle to the exact area.

If the suspected cancer is small and near the surface of the body, the doctor may remove the whole thing. This may mean removing a swollen lymph node rather than a tumour.

If the suspected cancer is deeper in the body, you may have a general anaesthetic for the biopsy. This might mean you need to stay in hospital overnight. The doctor may remove the whole tumour. Or, if the lump is large and difficult to remove, they may only take a small part of it.

The sample is sent to a pathologist, who examines it under a microscope (page 25).

If the cancer is too difficult to reach, or you are too unwell, it may not be possible to do a biopsy. Your cancer doctor will discuss this with you and arrange other tests if you need them.

> **"The consultant told me that the lump they had removed from my thyroid and the nodules in my throat didn't match. Therefore it was not thyroid cancer."**
>
> John, diagnosed with CUP

Removing fluid for testing

You may have a build-up of fluid in your body. If the fluid collects around the lung, it is called a pleural effusion. A collection of fluid around the tummy (abdomen) is called ascites. Doctors can take a sample of this fluid and check it for cancer cells.

You have a local anaesthetic injection to numb the area. The doctor uses a needle to remove some fluid. Sometimes the doctor uses an ultrasound scan to help find the best area to get a sample from.

Bone marrow test

You might have a bone marrow test to check whether the cancer is affecting the bone marrow. Bone marrow is a spongy material in the middle of our bones. It is where blood cells are made.

You have a local anaesthetic injection to numb the area. A doctor or nurse uses a syringe to take a small sample of bone marrow from the back of the hip bone (pelvis) or sometimes the breastbone (sternum).

You may also have a small core of marrow taken. This is called a trephine biopsy.

After having a sample of bone marrow taken, you may feel bruised and achy for a few days. Taking mild painkillers can help with this.

Not everyone needs a bone marrow test. If this test is likely to be useful for you, your cancer doctor or specialist nurse will explain the test in more detail.

Looking at cells under a microscope

When a biopsy has been taken, it is sent to a pathologist at a laboratory. A pathologist is a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The results from the biopsy help you and your cancer doctor find out more about the type of cancer you have.

Identifying cancer types

For most secondary cancers, doctors can find out where the cancer cells have spread from by looking at them under a microscope. For example, cells from a primary breast cancer that has spread to the liver usually still look like breast cancer cells.

With cancer of unknown primary (CUP), doctors cannot always tell which part of the body the cancer cells are from.

Cancers are made up of different types of cells. Most cancers of unknown primary (and 85% of all cancers in the UK) are carcinomas. They are cancers that start in tissues made of epithelial cells. The epithelial cells cover or line all the organs in the body. They also line the cavities inside the body, such as the chest cavity, and form the outer layer of our skin.

Knowing where a carcinoma may have started helps doctors to plan the best treatment.

There are a few different types of carcinomas.

Adenocarcinomas

These cancers grow from gland cells that line or cover some organs in the body. Gland cells make substances that the body needs, such as hormones. Adenocarcinomas are the most common type of cancer cell found in people with CUP. Adenocarcinomas usually start in 1 of the following areas:

- breasts
- lungs
- bowel
- pancreas
- kidneys
- liver
- stomach
- ovaries
- womb.

Squamous cell carcinomas

These cancers develop from flat cells that are usually found on the surface of the skin or in the inner lining of organs. They can develop in organs such as the lungs, gullet (oesophagus), cervix and head or neck.

Neuroendocrine carcinomas

These are rarer types of cancer. They are made up of nerve cells that produce hormones.

Poorly differentiated or undifferentiated cancer cells

Poorly differentiated cancer cells look very different from normal cells. Undifferentiated cancer cells look extremely different from normal cells.

When cancer cells are poorly differentiated or undifferentiated, it is difficult to tell the type of primary cancer. Further tests may tell the doctors more.

Tests on the biopsy sample

Some tests on a biopsy sample may give doctors more information about the type of cancer you have. You may have one of the following tests:

- Immunohistochemistry test – this uses antibodies to find out whether there are particular proteins on the surface of the cell.
- Cytogenetic test – this looks at the changes in the chromosomes in a cell.
- Hormone and protein receptor test – this looks at cancer cells with receptors. Some cancer cells have receptors which certain types of hormones or proteins attach to. Identifying these may help doctors find out where the cancer cells came from.

Gene expression-based profiling (GEBP)

GEBP looks for patterns of genes in the secondary cancer tissue. These patterns can help doctors find out what the primary cancer might be. This can help them decide which treatments are most suitable for you.

These types of tests are still being developed. It is not clear how helpful they are for everyone. In some cases, the results may help narrow down which primary cancer it is likely to be. GEBP may help doctors make decisions about which other tests you should have, and which treatments to use.

At the moment, gene profiling tests for people with CUP are not usually available on the NHS. They may become more widely used in the near future. But you may be able to have them as part of a clinical trial (pages 69 to 71). GEBP may be available privately or covered by private health insurance companies.

You can find further information about gene expression-based profiling on the Cancer of Unknown Primary Foundation website. Visit **cupfoundjo.org**

Having blood taken

Tests and scans

The tests you have depend on your symptoms. Your doctor will use national guidelines to decide which tests are right for you. The results of one test may suggest that another one would be useful.

Blood tests

Blood tests can help doctors find out:

- how organs such as the liver and kidneys are working
- the number of different blood cells you are producing (your full blood count).

Blood tests can help your doctors decide which area of the body to scan. For example, if the liver or kidneys are not working properly, your doctor may decide to scan them.

A low number of red blood cells (anaemia) may mean that there is some bleeding inside the body. This could be from a cancer in the bowel or stomach.

> **"It was suspected to be testicular cancer, but later tests found no cancer there. They tested me for other cancers – I had biopsies and blood tests. They even took some of my pelvis bone to test."**

Martin, diagnosed with CUP

Tumour markers

Some cancers produce chemicals called tumour markers. These can sometimes be measured with a blood test. High levels of a marker may suggest you have a certain type of cancer. But the marker levels can be high for reasons other than cancer. So high levels of a tumour marker does not definitely mean you have a certain type of cancer. You will have this blood test alongside other tests to find this out.

There are many different tumour markers your doctor may use. These include:

- prostate-specific antigen (PSA) – to check for prostate cancer
- human chorionic gonadotropin (hCG) – to check for germ cell tumours, a rare type of cancer that can start in the testicles or ovaries
- alpha-fetoprotein (AFP) – to check for some types of germ cell tumour or primary liver cancer
- CA125 – to check for ovarian cancer.

We have more information about blood tests on our website. Visit **macmillan.org.uk/blood-tests**

X-rays and scans

Doctors may use some of the following scans to help them find a primary cancer, or understand more about the type of cancer you have.

X-ray

X-rays are used to take pictures of the inside of your body. They can show broken bones or other problems with your bones and joints. They can also show changes in other body tissues and organs, such as the lungs. You often have x-rays before more specific tests.

Mammogram

A mammogram is a low-dose x-ray of the breast. You might have this test if your symptoms suggest breast cancer, such as cancer in the lymph nodes in your armpit.

You have 2 x-rays of each breast. The radiographer positions you so your breast is on the x-ray machine. Next, your breast is gently but firmly pressed between 2 clear plastic plates. This keeps your breast still and helps to get a clear picture. You might find this uncomfortable or sometimes painful. But this should only last for as long as the mammogram takes.

CT scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information at **macmillan.org.uk/ct-scan**

Preparing for a CT scan

PET or PET-CT scan

A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

If you are pregnant or breastfeeding, call the scanning department before the scan for advice.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer.

The radiographer will encourage you to drink water. This helps move the tracer around your body.

Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The scan takes about 30 to 60 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

The amount of radiation used is very small. But the radiographer will advise you not to have close contact with pregnant people, babies and young children for up to 24 hours after the scan.

We have more information about PET and PET-CT scans on our website. Visit **macmillan.org.uk/pet-ct-scan**

MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of the body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips. Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of a dye called a contrast. This helps show certain areas of the body more clearly.

During the scan, you need to lie still on a bed inside a long cylinder (tube). If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan.

The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

We have more information about MRI scans on our website. Visit **macmillan.org.uk/mri-scan**

Ultrasound scan

Ultrasound scans use sound waves to build up a picture of the inside of the body. A doctor spreads gel on the skin and passes a small handheld device over the area being scanned. For example, to see inside the pelvis, the device is held on the surface of your lower tummy (abdomen). The doctor moves the device around to try and get the best picture.

The scan is not painful and only takes a few minutes. But some people find the pressure a little uncomfortable. A picture of the area is then shown on a screen.

An ultrasound can also be used to guide a biopsy (pages 24 to 27).

If you have a pelvic ultrasound, you will be asked to drink plenty of fluids before the scan. This is so your bladder is full. This helps to give a clearer picture. If you have a vaginal ultrasound instead of a pelvic one, you do not need to have a full bladder for this.

Having an ultrasound

Depending on the part of the body being scanned, you may be asked to either:

- not eat or drink for a few hours before the scan
- drink plenty of water but not go to the toilet until after the scan.

You may also be asked to change into a hospital gown.

The scan takes between 15 and 45 minutes. After the scan is finished, you can usually go home.

If you had a sedative, you should:

- not drive for 24 hours
- have someone to take you home
- have someone to stay with you overnight.

If you have had an anaesthetic, you may have to stay in hospital for a few hours.

We have more information about ultrasound scans on our website. Visit **macmillan.org.uk/ultrasound**

Cameras that look inside the body

Tests that look inside the body can help doctors understand more about what is causing your symptoms. We have more information about all of these tests at **macmillan.org.uk/tests-scans**

Endoscopy

An endoscopy is a test that looks inside the body. An endoscope is a thin, flexible tube with a camera on the end. The endoscope may also have some small tools that allow the doctor to take biopsies.

The most common types of endoscopy include the following:

- Upper gastro-intestinal endoscopy – this looks into the food pipe between the mouth and stomach (oesophagus), the stomach, and the upper part of the small bowel (duodenum). It uses an endoscope passed through the mouth.
- Bronchoscopy – this looks inside the windpipe and lungs, by passing an endoscope into the nose or mouth and down the airways.
- Nasendoscopy – this looks at the back of the mouth, by passing an endoscope up the nose.
- Laryngoscopy – this looks at the larynx (voicebox), by passing an endoscope through the mouth and up over the back of the throat.
- Colonoscopy – this looks inside the large bowel by passing an endoscope into the rectum (back passage).
- Cystoscopy – this looks inside the bladder by passing an endoscope through the urethra (the tube that carries urine out of the body).
- Hysteroscopy – this looks at the cervix and into the uterus, by passing an endoscope into the vagina.

Before the test, you may be given a sedative to help you relax. It will make you feel sleepy. You usually have an endoscopy as an outpatient, so you can go home the same day. But some people need to stay in hospital overnight.

Laparoscopy

This test involves a small operation that is done under a general anaesthetic. You may need to stay in hospital overnight. It uses a thin tube with a tiny video camera on the end called a laparoscope.

The surgeon makes a small cut in the skin. The cut is about 2cm long (less than 1 inch). The surgeon carefully puts the laparoscope through this cut and into the tummy (abdomen). This allows them to look at the outside of the stomach and the organs nearby. They may also take biopsies.

Video-assisted thoracoscopic surgery (VATS)

This is a small operation that is done under a general anaesthetic. It uses a thoracoscope, which is a thin, flexible tube with a light and a camera on the end.

The surgeon makes a small between the ribs. The cut is less than 2.5cm long (1 inch). They then pass a thoracoscope through the cut. It can help them see the outside of the lungs and organs nearby. They may also take biopsies to check for cancer cells.

VATS can also be used to drain a build-up of fluid between the lung and the membrane that surrounds it. This is called a pleural effusion.

Treating cancer of unknown primary

Treatment overview

In people with CUP, cancer has already spread from 1 part of the body to another. In many cases, this means the cancer is already advanced. It is not usually possible to cure cancer that is advanced and has spread to other parts of the body. But even if the cancer cannot be cured, it may be possible to control it for some time.

Before explaining your treatment options, your doctor will consider:

- where the secondary cancer is
- how active treatment such as chemotherapy (pages 54 to 61) or radiotherapy (pages 62 to 66) might help
- how you might cope with any side effects
- any risks of treatment
- whether less invasive treatments to control your symptoms would help you.

Making decisions about your treatment can be difficult. You may need to discuss whether you wish to have treatment with your doctor. If you choose not to have active treatment, you can have supportive (palliative) care to control any symptoms.

Active treatment for CUP aims to:

- control the cancer
- help you live longer
- relieve your symptoms
- improve your quality of life.

Supportive or palliative care is an important part of treatment if you have CUP. This is when medicines are used only to control your symptoms. It is sometimes given alongside chemotherapy or radiotherapy treatment.

The main treatment for CUP is chemotherapy (page 54 to 61). This is because chemotherapy goes into the bloodstream and can reach most parts of the body. Radiotherapy, hormonal therapy, targeted therapy and sometimes surgery may also be used (pages 62 to 68). You may be asked to take part in a clinical trial to try newer treatments (pages 69 to 71).

If you have CUP, you might find it hard to accept that even after testing, doctors still do not know what the primary cancer is. Or you might feel relieved that the tests are over, and treatment can now start. Everyone is different.

We have more information in our booklet **Coping with advanced cancer** (page 96).

Treatment for certain types of cancer

In some cases, doctors may have a good idea where the cancer started. This is based on:

- where the secondary cancer is
- your symptoms
- the type of cancer cell
- your test results.

In this situation, doctors may plan treatment for the most likely type of cancer.

For example, if you have a raised PSA level and adenocarcinoma in the bones, you may be treated with hormonal therapy for prostate cancer. This is because PSA is a protein produced in the prostate gland, and it is common for prostate cancer to spread to the bones.

> **“The doctors couldn't come to any concrete diagnosis, so they decided to treat it as testicular cancer.”**
>
> Martin, diagnosed with CUP

Palliative care to control symptoms

The aim of palliative care is to control symptoms and give you the best possible quality of life. Palliative care is often given alongside treatment such as chemotherapy or radiotherapy.

When cancer is very advanced, the disadvantages of treatment, such as side effects, may outweigh the possible benefits of treating the cancer. If you are too unwell to have treatment, your doctor may suggest you have palliative care on its own, instead of treating the cancer.

Localised secondary cancers

In certain situations, treatment may give you a better outcome even if the primary cancer cannot be found. If the secondary cancer is only in a very small area of the body, such as the lymph nodes, it is usually close to the primary cancer. Your cancer doctor or specialist nurse can explain the aim of your treatment. Here are some examples of this.

Squamous cells in lymph nodes in the neck

This may mean the primary cancer is in the head and neck area. You will see a specialist head and neck team. You may have surgery to remove the lymph nodes or have radiotherapy. Or you may have both. You might also have chemotherapy.

Adenocarcinoma in lymph nodes in 1 armpit

This may mean the primary cancer is in the breast tissue. You will see a specialist breast cancer team. You may have surgery or radiotherapy to the lymph nodes, then chemotherapy and hormonal therapy.

Squamous cells in lymph nodes in the groin

This may mean the cancer started in the groin area or in the back passage (rectum). You will see a specialist surgeon to have the nodes removed, and may have radiotherapy.

How treatment is planned

Most hospitals have a multidisciplinary team (MDT) of specialists who diagnose and treat people with CUP. They will meet to discuss the best treatment options for you. The MDT may include a:

- clinical oncologist – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer
- medical oncologist – a doctor who uses chemotherapy and other anti-cancer drugs to treat people with cancer
- palliative care doctor – a doctor who helps with symptom control
- pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer
- radiologist – a doctor who looks at scans and x-rays to diagnose problems
- clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.

It may also include other professionals such as:

- a dietitian
- a physiotherapist
- an occupational therapist
- a counsellor or psychologist.

Talking about your treatment plan

After the MDT meeting, you will usually see your doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards.

We have more information about talking to your healthcare team at **macmillan.org.uk/questions**

Your doctor should explain:

- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed. You may need more than 1 meeting with your doctor or nurse to talk about your treatment plan.

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (page 51).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor.

Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have had all the information you need to make your decision.

You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about. We have more information about getting a second opinion at **macmillan.org.uk/second-opinion**

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is the most common treatment for cancer of unknown primary (CUP). The aim of chemotherapy is to shrink the cancer and relieve symptoms.

Even though doctors do not know the primary type of cancer, tests may have shown which type of cancer is most likely. This means they can choose the chemotherapy that works best for that cancer type. For example, if the primary cancer is most likely breast cancer, you will have chemotherapy that is usually used to treat breast cancer.

You may have a chemotherapy drug on its own, or you may have a combination of drugs. Some people have chemotherapy and radiotherapy together. This is called chemoradiation.

How chemotherapy is given

You may have chemotherapy drugs as an injection into a vein (intravenously) or as tablets. The drugs go into the bloodstream. This means they can reach most parts of your body and treat cancer cells in different areas.

A nurse will give you intravenous chemotherapy as an injection, or as a drip (infusion) directly into a vein.

It can be given through:

- a cannula – a short, thin tube put into a vein in the back of your hand or lower arm
- a central line – a long, thin tube put into a vein in your chest
- a PICC line – a fine tube put into a vein in your arm and threaded through to a vein in your chest
- an implantable port or portacath – a thin tube put into a vein, with an opening (port) under the skin on the chest or arm.

Most people have chemotherapy as an outpatient. But some people need to stay in hospital for a few days.

Central lines, PICC lines and implantable ports can be put in as a day patient. The line or port will stay in until you have finished all your treatment.

Some chemotherapy drugs are given continuously through a central line or PICC line that is attached to a small pump. The pump allows a low dose of the drug to be given during the day and at night while you are at home. It can be carried in a small bag, strapped around your waist or over your shoulder.

Chemotherapy is usually given as several sessions of treatment. You usually have a rest period between sessions. These can be from 1 to 4 weeks, depending on the chemotherapy. Your doctors will explain how often you will have your treatment.

We have more information about how chemotherapy is given, and about individual drugs on our website. Visit **macmillan.org.uk/chemotherapy**

Side effects of chemotherapy

Chemotherapy can cause side effects. These can often be controlled with drugs, and usually slowly improve after treatment has finished. Different drugs cause different side effects. Your cancer doctor or specialist nurse will explain what to expect in your situation.

The main side effects are described here, as well as some ways to reduce or control them. You may get some of these side effects, but you are very unlikely to get them all. Always tell your cancer doctor or specialist nurse about any side effects, so they can help.

We have more information in our booklet **Understanding chemotherapy** (page 96) or on our website at **macmillan.org.uk/chemotherapy**

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Sometimes doctors prescribe a drug called erythropoietin. This helps the body to make more red blood cells. It is given as an injection under the skin. But it is more common to have a blood transfusion for anaemia.

Feeling tired

Feeling tired is a common side effect of chemotherapy. It is often worse towards the end of treatment and for some weeks after it has finished.

Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

We have more information in our booklet and audiobook **Coping with fatigue (tiredness)** – page 96.

Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your chemotherapy. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

We have more information at **macmillan.org.uk/nausea-vomiting**

Diarrhoea

Chemotherapy may cause diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

If you have diarrhoea:

- try to drink at least 2 litres (3½ pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

Sore mouth and throat

Chemotherapy may cause a sore mouth or throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth and throat.

Sucking ice chips may sometimes help relieve mouth or throat pain. But if you are having radiotherapy to the head or neck, do not suck on ice. It can cause damage.

We have more information at **macmillan.org.uk/dry-mouth**

Hair loss

Some chemotherapy drugs may cause hair loss. You may have complete hair loss. This means you lose all the hair from your head and your eyelashes and eyebrows. Or you may lose only some of your hair or have hair thinning.

How much hair you lose depends on which chemotherapy drugs you are having. Your cancer doctor or specialist nurse can tell you more about what to expect.

If you do have hair loss, it almost always grows back. You usually have a full head of hair about 3 to 6 months after treatment ends. It may grow back differently. For example, your hair may grow back:

- straighter
- curlier
- finer
- a slightly different colour.

Your specialist nurse can give you advice about coping with hair loss and how to look after your scalp. We have more information in our booklet **Coping with hair loss** (page 96) and on our website at **macmillan.org.uk/hairloss**

Early menopause

For some people, chemotherapy may cause early menopause. This can be difficult to cope with. You may find it helpful to speak to your cancer doctor or specialist nurse. We have more information about early menopause at **macmillan.org.uk/menopausal-symptoms**

Contraception

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell you more about this.

Fertility

Some cancer drugs can affect whether you can get pregnant or make someone pregnant. If you are worried about this, it is important to talk with your cancer doctor before you start treatment.

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells while doing as little harm as possible to normal cells. Doctors can give radiotherapy to try to shrink and control the cancer, and stop it from growing any further. It may also be given to try and improve any symptoms (palliative radiotherapy).

Radiotherapy may be given on its own or together with other treatments, such as surgery (page 68). You will usually have this type of radiotherapy over a few weeks.

Radiotherapy is directed at specific parts of the body. There are 2 ways of giving radiotherapy:

- external beam radiotherapy is given from outside the body by a radiotherapy machine
- internal radiotherapy uses a radioactive material placed inside the body.

People with CUP may have external radiotherapy to help control the cancer and improve symptoms. Internal radiotherapy is not commonly used to treat CUP.

If it is an option for you, your cancer doctor will explain more about radiotherapy. We have more information in our booklet **Understanding radiotherapy**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Preparing for radiotherapy

Palliative radiotherapy

If the cancer has spread to more than 1 place in the body, you may have radiotherapy to help improve symptoms. For example, radiotherapy can help relieve pain caused by cancer in the bones. This is called palliative radiotherapy. It is usually given as a shorter course of treatment and has fewer side effects. Palliative radiotherapy can be used to treat:

- pain – by shrinking the cancer and relieving the pressure that is causing pain
- breathlessness – if the cancer is affecting the lungs
- difficulty swallowing – by shrinking a cancer that is pressing on the gullet (oesophagus)
- bleeding – radiotherapy may help to stop or reduce any bleeding that might be caused by a cancer in the bowel, cervix or womb
- brain swelling – if you have a secondary cancer in the brain, radiotherapy can reduce swelling and help to improve symptoms.

How radiotherapy is given

External beam radiotherapy is normally given as a number of short, daily treatments in the radiotherapy department. It is given using a machine that looks like a large x-ray machine or CT scanner. There are different types of radiotherapy machine, but they all work in a similar way.

You may only need a single treatment, or you might have a course of treatment. Each treatment takes 10 to 15 minutes. Your cancer doctor will talk to you about the treatment and possible side effects. We have more information about having external radiotherapy at **macmillan.org.uk/external-beam-radiotherapy**

Internal radiotherapy is not commonly used to treat CUP. If it is an option for you, your cancer doctor will explain more about it.

Side effects of radiotherapy

The side effects of palliative radiotherapy are usually mild. If you are having radiotherapy to control the cancer, the side effects will depend on the dose and the area being treated.

You usually have side effects for a few weeks after treatment finishes. They usually become slightly worse before they get better, but they will improve over time. Tell your cancer doctor, specialist nurse or radiographer about any side effects you have. They may be able to help reduce them.

Skin reactions

Your skin in the treatment area may become:

- dry
- itchy
- sensitive or sore
- red or darker, with a black or blue tinge.

Your specialist nurse or radiographer will give you advice on looking after your skin. If it becomes sore and flaky, let them know.

Skin reactions usually get better 2 to 4 weeks after radiotherapy finishes. Your radiographer will check your skin regularly.

Feeling tired

This treatment will make you feel very tired and you will need a lot of rest. You will get tired easily for some months after treatment has finished. Gentle exercise, like short walks, can give you more energy. The tiredness will slowly get better. If you feel sleepy, do not drive or use machinery.

Feeling sick

Some people find radiotherapy makes them feel sick (nauseous) or be sick (vomit). This is more likely to happen if the treatment area is near the stomach or the brain.

Your cancer doctor, specialist nurse or radiographer can prescribe anti-sickness (anti-emetic) drugs if this happens. Feeling sick usually improves once you have finished your treatment. Tell your cancer doctor or specialist nurse if you have any nausea or vomiting.

We have more information at **macmillan.org.uk/nausea-vomiting**

Eating problems

If you have radiotherapy to the chest, you may have difficulty swallowing. It might help to eat:

- soft foods, to make swallowing easier
- smaller amounts more often, rather than large meals.

Radiotherapy to the head and neck may also cause a sore or dry mouth and taste changes. These effects can make eating difficult. If you are struggling to eat or drink, talk to your cancer doctor or specialist nurse.

They may refer you to a dietitian. We have more information in our booket **Eating problems and cancer** (page 96).

Hair loss

Radiotherapy only causes hair loss in the area that is being treated. Radiotherapy to the brain causes hair loss on your head. Your hair usually grows back a few months after treatment finishes.

We have more information in our booklet **Coping with hair loss** (page 96).

Other treatments

Hormonal therapy, targeted therapy or surgery may also be used to treat CUP.

Hormonal therapy

If tests show that a cancer of unknown primary (CUP) has hormone receptors, your cancer doctor might suggest hormonal therapy. If a cancer has hormone receptors, it means some hormones produced naturally by the body may encourage the cancer to grow.

For example, oestrogen is a hormone that can encourage breast cancer cells to grow.

Hormonal therapy reduces the amount of hormones in the body, or stops hormones attaching to the cancer cells. Hormonal therapies are used to treat CUP when the most likely primary cancer is breast or prostate cancer. But they may also be used to treat cancer of the womb or kidney. They are usually given as tablets or injections.

The side effects depend on the individual drug. They can include:

- tiredness
- headaches
- feeling sick
- muscle or joint aches.

There are different types of hormonal therapy. If the first one does not work for you, your cancer doctor may try a different type.

We have more information about individual hormonal therapies at **macmillan.org.uk/hormonal-therapy**

Targeted therapy

Targeted therapy uses drugs to find and attack cancer cells. There are many different types of targeted therapy. Each type targets something in or around the cancer cell that is helping it grow and survive. Targeted therapies may be given as tablets or capsules, or by injection under the skin (subcutaneously) or drip into a vein in the arm (intravenous infusion).

Targeted therapies are not often used to treat CUP. Some clinical trials have shown that they may be useful. But we need to know more about them before they can be used as a treatment.

Surgery

Surgery is not often used to treat CUP. But you may have an operation to remove a secondary cancer if:

- there is a single tumour that can be easily removed
- cancer is affecting lymph nodes that are close together and in a single area, such as the armpit
- symptoms can be improved by removing the cancer, for example if the cancer is causing pain.

After surgery, you may have another treatment, such as radiotherapy (pages 62 to 66) or chemotherapy (pages 54 to 61). This is to treat any cancer cells that may be left behind.

Even if the cancer is in a single area, you may not be well enough to have surgery. In this situation your doctor will talk to you about what other treatments might be suitable.

Clinical trials

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms. We have more information at **macmillan.org.uk/clinical-trials**

Taking part in a clinical trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part.

They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

You can also find information about worldwide CUP clinical trials on the Cancer of Unknown Primary Foundation website at **cupfoundjo.org**

After treatment

When your treatment has finished, you will have regular check-up appointments. You may also have follow-up scans. How often you have them will depend on your treatment plan.

Your cancer doctor and specialist nurse will give you advice on what to look out for. If you have any problems or notice new symptoms between check-ups, tell them as soon as possible.

It is normal to feel anxious before appointments. It may help to get support from family, friends or a support organisation (pages 102 to 113).

Living with cancer of unknown primary

Living with CUP

People with cancer of unknown primary (CUP) can have many different symptoms. These can affect them in different ways.

If you have new symptoms, or if your symptoms get worse, always tell your cancer doctor or specialist nurse.

You may get help from supportive or palliative care specialists. They may be based in:

- hospitals
- the community
- hospices
- palliative care units
- pain clinics.

They work with your GP, district nurses and other healthcare professionals to try to make sure your symptoms are well controlled. In some areas, palliative care nurses can visit you at home. Your GP or cancer doctor can usually arrange this for you.

Palliative care nurses do not give daily nursing support. But they can help manage pain and other symptoms, and give emotional and practical support. Palliative care nurses are experienced in assessing and treating symptoms of advanced cancer.

Managing symptoms

For many people with CUP, the main aim of their treatment is to control symptoms. Symptoms can be treated using cancer treatments, such as radiotherapy. But they can also be managed using supportive treatments, such as painkillers or steroids.

Supportive care may also include help from healthcare professionals, such as dietitians or physiotherapists. They can help improve your quality of life.

You can have supportive care alongside cancer treatments, and after they are finished. You may decide to have supportive care on its own, without cancer treatments.

Tiredness (fatigue)

Fatigue is a feeling of tiredness or exhaustion. It is a common symptom. You are likely to be tired during treatment and for a while after it finishes. But this should slowly improve.

To help reduce your fatigue, try to:

- get enough good quality sleep
- rest when you feel tired
- do some regular physical activity – this can give you more energy and help you sleep.

Sometimes tiredness is caused by a low number of red blood cells. This is called anaemia. Your doctor can do a blood test to check this. They may prescribe drugs to treat anaemia. You may need to have a blood transfusion.

Coping with pain can also make you feel very tired. It may mean you are not sleeping well. Talk to your cancer doctor, specialist nurse or GP if you have pain. Managing pain can help improve your fatigue.

It is important to tell your doctors and nurses about your fatigue and how it makes you feel. Be honest and don't say you feel fine if you do not. There may be things they can do to help.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 96.

Eating problems

Many people with a secondary cancer have changes in their eating habits. These may include:

- loss of appetite
- changes in the way you smell and taste food
- difficulty swallowing
- feeling sick.

Even if you are eating well, you may lose weight. This is because the cancer can change the way your body uses the energy in your food.

If you are worried about losing weight or changes to the way you eat, talk to your cancer doctor or specialist nurse. There may be things they can do to help, such as prescribing anti-sickness drugs. You can also ask to see a dietitian. They can help you find ways to eat well.

Tips to help with eating problems

- Try having frequent snacks or small meals. These can be more manageable than 3 large meals a day.
- Do not worry if the food you feel like eating is not always healthy. It is better to enjoy some food and get some energy than not to eat at all.
- If you can only manage small amounts, choose foods or drinks that will give you energy and protein. This will help to get the most out of what you eat.
- If you do not feel like eating, try a nourishing drink or soup. You can add calories to soups and smoothies by adding fruit juice, cream or ice cream. These soft foods can also help if you have difficulty swallowing.
- Your cancer doctor, specialist nurse or dietitian can prescribe or recommend supplement drinks and puddings for you.

We have more information in our booklets **Eating problems and cancer** and **The building-up diet** (page 96). Or visit **macmillan.org.uk/eating-problems**

Pain

Pain can usually be well controlled. If you are in pain, it is important to tell your cancer doctor or specialist nurse. There may be treatments that can help.

Different types of painkillers can be used to treat different types of pain. You can have painkillers as:

- tablets
- liquid medicines
- skin patches
- an injection into the skin or muscle
- a drip (infusion) into a vein.

Painkillers often cause constipation. It is important to try to eat lots of fibre and drink plenty of fluids. Your doctor may also prescribe a laxative with your painkillers. This can help prevent constipation.

Cancer treatments such as chemotherapy or radiotherapy can also be used to relieve pain. They work by shrinking the cancer. But it may be a few weeks before the pain begins to improve.

Bone pain

If a cancer has spread to your bones, you might be given drugs called bisphosphonates. They help with bone pain and can help strengthen your bones. Bisphosphonates can be taken as tablets or capsules. Others are given as a drip into a vein, usually at an outpatient clinic.

A targeted therapy drug called denosumab may also be used if a cancer has spread to the bones. It is given as an injection under the skin (subcutaneously).

Steroids

Steroids are substances that are naturally produced in the body. But they can be made artificially as drugs. Steroids can be used to help improve some symptoms, such as nausea or pain. They are sometimes also used as part of chemotherapy treatment (pages 54 to 61).

Steroids can be taken as tablets or given as an injection. It is important to take them exactly as your doctor tells you to. You will have regular appointments to check how well the steroids are working.

If you have to take steroids for a long period of time, your doctor will give you a card to carry with you. You should keep the card with you at all times. In case of a medical emergency, it tells other doctors that you are having steroid treatment. If you are only having a short course of steroids, you do not need a card.

It is important not to stop taking steroids without checking with your doctor. The dose usually needs to be reduced slowly.

Complementary therapies

Complementary therapies are used alongside conventional medical treatments. They do not treat cancer. People use them to try to improve their physical or emotional well-being. Some people find that complementary therapies help them feel better and can reduce symptoms.

Some hospitals and hospices offer complementary therapies such as massage and relaxation. It is a good idea to talk to your cancer doctor, specialist nurse or GP before starting any complementary therapies. They can tell you if it is safe for you to use complementary therapies.

We have more information in our booklet **Cancer and complementary therapies** (page 96) and at **macmillan.org.uk/complementary-therapies**

Emotional support

As well as coping with symptoms or side effects of treatment, you may be dealing with different feelings. Coping with CUP can be challenging because there is so much uncertainty. Not knowing where the cancer started can make it difficult to understand what is happening to you. It can be difficult to explain things to your family or friends when you do not have clear answers yourself.

You might find it helpful to talk to others in a similar situation. Our online community has a group specifically for people affected by CUP. Visit **macmillan.org.uk/community**

The Cancer of Unknown Primary Foundation can help you connect with other people (page 102). This may help you feel less isolated.

> **"I don't dwell on the negatives. I look at things positively whenever I can. Right now I am feeling well, and although I have cancer, I can still live my life."**
>
> John, diagnosed with CUP

Your feelings and relationships

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet **How are you feeling? The emotional effects of cancer** (page 96).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups** or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on pages 98 to 100 about other ways we can help you.

> **"Having cancer has been a life-altering experience, but actually there have been some amazing positives. I now truly understand the value of time and of the people around me. „**
>
> Judith, diagnosed with CUP

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships online and in our booklets **Talking about cancer** and **Cancer and relationships: support for partners, families and friends**.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet **Talking with someone who has cancer**.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet **Looking after someone with cancer**.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Money and work

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 113).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (page 107 and 108).

Our booklet **Help with the cost of cancer** has lots more information (page 96).

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not usually affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit **macmillan.org.uk/grants**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (page 96). Our Online Community forum on **Travel insurance** may also be helpful. Visit **macmillan.org.uk/community**

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer** (page 96).

We have more information about work and cancer on our website. Visit **macmillan.org.uk/work**

Further information

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to find out more about Macmillan Grants.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

CUP support organisations

Cancer of Unknown Primary (CUP) Foundation – Jo's Friends

www.cupfoundjo.org
Offers support and information to people affected by CUP, as well as supporting research.

General cancer support organisations

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Marie Curie is the UK's leading end of life charity. It provides frontline nursing and hospice care, a free support line and a wealth of information and support on all aspects of dying, death and bereavement. Its staff can help you to talk, plan and prepare, to get things sorted in advance.

Penny Brohn UK

Tel **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Civil Legal Advice

Helpline **0345 345 4345**
Textphone **0345 609 6677**
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0300 200 7822**
Textphone **0800 587 1297**
www.nidirect.gov.uk/contacts/jobs-and-benefits-offices
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Law Centres Network

www.lawcentres.org.uk
Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland. You can also chat with someone about money worries. Talk to an adviser using webchat service, WhatsApp, Facebook Messenger, or email.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel **0344 892 0900**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity

Tel **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This (LTT)

www.livethroughthis.co.uk
Provides a safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is one in each country in the UK:

National Cancer Registration and Analysis Service (England)

digital.nhs.uk/ndrs/patients

Scottish Cancer Registry and Intelligence Service (SCRIS)

Tel **0345 646 0238**
beta.isdscotland.org/topics/scottish-cancer-registry-and-intelligence-service-scris

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu

Northern Ireland Cancer Registry

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Linda Bedford, Macmillan Consultant Radiographer for Palliative Radiotherapy; Dr Natalie Cook, Senior Clinical Lecturer in Experimental Cancer Medicine and Honorary Consultant; Ollie Minton, Macmillan Consultant and Honorary Senior Lecturer in Palliative Medicine; Dr Claire Mitchell, Consultant Medical Oncologist; Dawn Platt, Clinical Nurse Specialist; and John Symons, Director of CUP Foundation – Jo's Friends.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our information about cancer of unknown primary. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Fizazi K et al. Cancers of unknown primary site. ESMO clinical practice guidelines for diagnosis, treatment and follow up. 2015. Annals of oncology 26 (supplement 5): v133-v138.

National Institute for Health and Care Excellence (NICE). Metastatic malignant disease of unknown primary origin in adults: diagnosis and management. 2010.

UK Oncology Nursing Society (UKONS). Acute oncology initial management guidelines. [Internet], 2018. Available from: www.ukons.org/site/assets/files/1134/acute_oncology_initial_management_guidelines.pdf [accessed March 2022].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping.
   Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help.
   Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps.
   To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

MACMILLAN
CANCER SUPPORT

This booklet is about cancer of unknown primary (CUP). It is for anyone who has been diagnosed with CUP. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of CUP. It explains how it is diagnosed and how it may be treated. It also has information about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

Trusted
Information
Creator

Patient Information Forum