

UNDERSTANDING CANCER OF UNKNOWN PRIMARY



About this booklet

This booklet is about cancer of unknown primary (CUP). It is for anyone who has been diagnosed with CUP.

Cancer sometimes spreads from where it started (primary cancer) to another part of the body (secondary cancer). CUP is when doctors find a secondary cancer but cannot find where the cancer started. If the primary cancer cannot be found after you have had different tests, it is diagnosed as a cancer of unknown primary.

This booklet talks about the signs and symptoms of CUP. It explains how it is diagnosed and how it may be treated. We hope this booklet 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 100 to 111, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see page 112).

Quotes

In this booklet, we have included quotes from people who have had CUP, which you may find helpful. Some are from our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). The others are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

Cover

The cover of this booklet shows consultant nurse and unknown primary team lead, Gillian.

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](https://www.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](https://www.macmillan.org.uk/otherformats) or call **0808 808 00 00**.

Contents

About cancer of unknown primary	5
Diagnosing cancer of unknown primary	17
Treating cancer of unknown primary	39
Your feelings and relationships	75
Work and financial support	87
Further information	95



ABOUT CANCER OF UNKNOWN PRIMARY

What is cancer?	6
The lymphatic system	8
Cancer of unknown primary (CUP)	10
Symptoms of CUP	13

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.

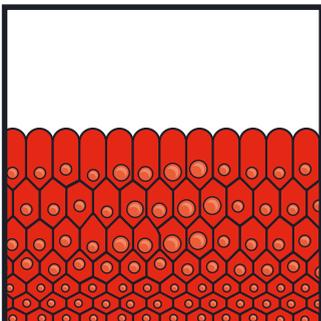
Cancer starts in cells in our body. Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body 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.

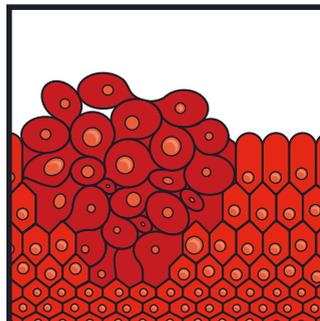
Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

Cells forming a tumour

Normal cells



Cells forming a tumour



A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

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

Primary cancer

The cancer type is usually named after the part of the body where it first started to grow. For example, a cancer that starts in the lung is called a lung cancer. This is called a primary cancer or primary site.

Secondary cancer

A secondary cancer happens when cancer cells separate from a primary cancer and spread to another part of the body. The cancer cells travel through the blood or lymphatic system (see pages 8 to 9). They keep dividing and form a new cancer somewhere else in the body.

A secondary cancer is also called a metastasis. A secondary cancer can spread to more than one part of the body.

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

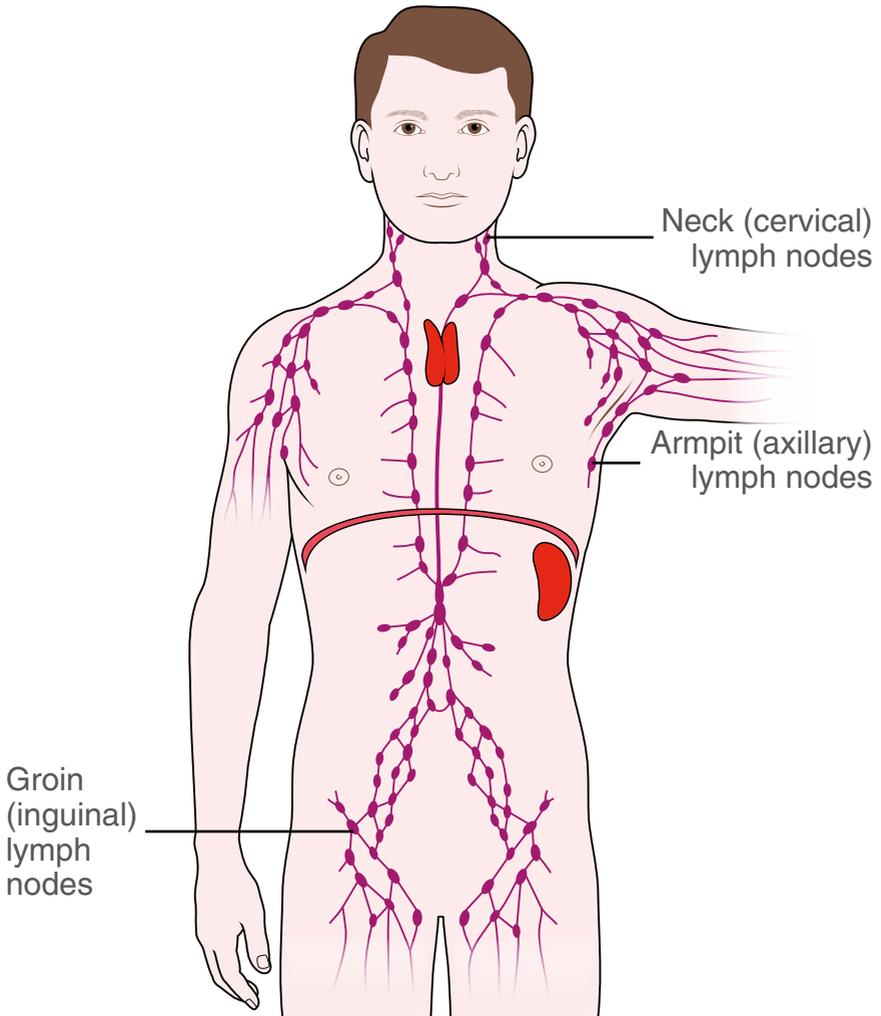
The lymphatic system

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

The lymphatic system helps to 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 up of fine tubes called lymphatic vessels. These vessels 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, some lymph nodes may swell as they fight the infection.

The lymphatic system



Cancer of unknown primary (CUP)

Cancer of unknown primary affects 2 in 100 people diagnosed with cancer in the UK (2%). It can affect people of all ages, but is most common in people aged 60 or over.

Cancer of unknown primary means 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 (see page 7). People with CUP sometimes have more than one secondary cancer.

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:

- a primary cancer
- a secondary cancer – the primary cancer might be found after the secondary cancer
- a CUP – a secondary cancer where the primary cancer cannot be found.

If your doctor thinks you have a secondary cancer, you will have tests to try and find a primary cancer. They may refer you to a doctor who specialises in treating CUP, if the primary cancer cannot be found.

The specialist will look at all your test results. They may arrange more detailed tests, such as an endoscopy (see page 36), scans (see pages 30 to 35) or a biopsy (see pages 22 to 24). If these tests do not find a primary cancer, the diagnosis is confirmed as CUP.

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
- where the secondary cancers are
- the biopsy results.

It can be difficult to know what the best treatment might be for cancer of unknown primary. This is because 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. But if you have cancer that started in the liver (primary liver cancer), you will have liver cancer treatments.

When CUP is diagnosed, cancer has already spread from one 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 (see pages 40 to 42).

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 a CUP.

Why can the primary cancer not be found?

A primary cancer cannot always be found. This may be because:

- it is too small to be seen on scans
- it is hidden beside or behind a larger secondary cancer
- the body's immune system has got rid of it, but the secondary cancer is still growing.

'One of the hardest challenges I faced was that in order for me to be able to accept my diagnosis, I felt like I needed more information.'

Judith

Symptoms of CUP

Symptoms of 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.

Symptoms of secondary cancer in the lung

Symptoms of secondary cancer in the lung include:

- a cough that does not go away
- breathlessness – this may be caused by a build-up of fluid under the membrane that covers the lung (pleural effusion)
- pain or discomfort in the chest.

Symptoms of secondary cancer in the bone

Symptoms of secondary cancer in the bone include:

- a dull, persistent pain in the bone which is often 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.

Symptoms of secondary cancer in the liver

Symptoms of secondary cancer in the liver include:

- swelling and discomfort in your tummy (abdomen) – this may be caused by a collection of fluid in the tummy, called ascites
- feeling sick or losing your appetite
- feeling full quickly when eating
- yellowing of the skin and eyes (jaundice).

Symptoms of secondary cancer in the lymph nodes

Symptoms of secondary cancer in the lymph nodes include:

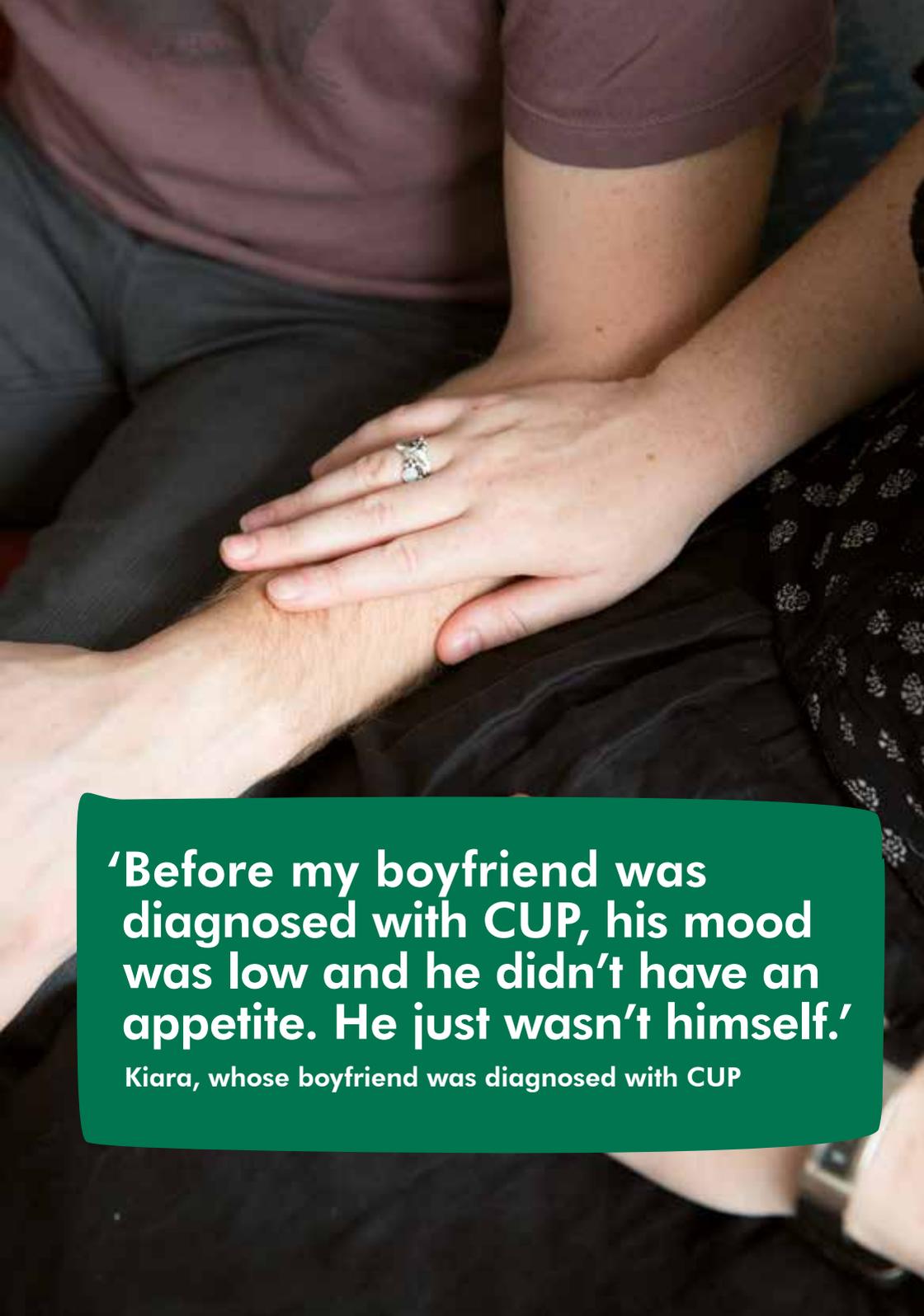
- swollen or hard lymph nodes (see pages 8 to 9), which may also be painful if they are pressing on tissue or nerves nearby.

General symptoms of cancer

General symptoms of cancer include:

- unexplained weight loss
- loss of appetite
- feeling extremely tired all the time
- looking pale, and feeling tired and breathless – this may be caused by a low level of red blood cells (anaemia).

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



'Before my boyfriend was diagnosed with CUP, his mood was low and he didn't have an appetite. He just wasn't himself.'

Kiara, whose boyfriend was diagnosed with CUP



Having an x-ray

DIAGNOSING CANCER OF UNKNOWN PRIMARY

How CUP is diagnosed	18
Having a biopsy	22
Looking at cells under a microscope	26
Tests and scans	30

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 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 if you smoke or drink large amounts of alcohol
- if you have been exposed to asbestos or chemicals that increase the risk of certain cancers, for example in your job.

You might find it helpful to read our booklet **Cancer genetics: how cancer sometimes runs in families** (see page 96).

Tests to diagnose cancer

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

The tests you have will depend on your symptoms. Doctors may look for the most common types of primary cancers first. This includes breast or prostate cancer (see page 96 for how to order more information about these cancer types).

If tests show you might have cancer, you may have some tissue or cells removed. This is called a biopsy (see pages 22 to 24). A pathologist looks at the tissue sample under a microscope to check for cancer cells. A pathologist is a doctor that specialises in studying tissue samples and cells.

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

CUP specialist

The CUP specialist doctors may want to do more tests. Your specialist 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.

If your cancer is confirmed as CUP, you will be introduced to a nurse who specialises in this type of cancer. You will get their contact details.

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, rather than have more tests
- start treatment 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 keep having 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 to improve or maintain your quality of life (see pages 62 to 63). Palliative care is often given alongside treatment such as chemotherapy or radiotherapy.

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 of your tests to be ready. You may find it helpful to talk with your partner, family or a close friend.

Your specialist nurse can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

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. You can find more information at [macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry)



Having a biopsy

If your specialist 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.

Most types of biopsy can be done as an outpatient at a clinic or in the x-ray department. You will usually be given 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 a scan or ultrasound 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 and need to stay 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 (see pages 26 to 29). They will look for cancer cells.

It is not always possible to do a biopsy. Sometimes the cancer is too difficult to reach, or a person is too unwell. Your specialist doctor will discuss this with you and arrange other tests if you need them.

'The tissue sample from my thyroid and the growths in my throat didn't match. Therefore it is not thyroid cancer. There was a cancerous lump, but it wasn't enough to make the primary cancer thyroid cancer.'

John

Removing fluid for testing

Some people have a build-up of fluid around the lung. This is called a pleural effusion. Or they may have a collection of fluid around the tummy (abdomen). This is called ascites. If there is a build-up of fluid, a sample of it can be taken and checked for cancer cells.

You have an injection of local anaesthetic to numb the area. The doctor uses a needle to remove some fluid. Sometimes the doctor uses an ultrasound 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 breast bone (sternum).

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

You may feel bruised after having a sample of bone marrow taken and have an ache for a few days. Taking mild painkillers can help with this.

Not everyone needs to have a bone marrow test. If this test is likely to be useful in your situation, your cancer doctor or specialist nurse will explain the test in more detail. We also have more information on our website – visit [macmillan.org.uk](https://www.macmillan.org.uk)



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 specialises in studying cells. They look at the sample under a microscope to check for cancer cells.

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 cancer diagnoses, 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 have spread to the liver usually still look like breast cancer cells. With CUP, doctors cannot always tell which part of the body the cancer cells are from.

But cancers are made up of different types of cells. These can be grouped based on the type of cells they are made up of. Knowing the type of cell can give the doctors a better idea about where the cancer may have started. This helps them to plan the best treatment.

Carcinomas are the most common type of cancer cell. About 85% of all cancers in the UK are carcinomas. They are cancer cells that start in the epithelial tissues. The epithelial tissues cover or line all the organs in the body. Our skin and the linings of cavities inside the body, such as the chest cavity, are also made of epithelial cells.

There are a few different types of carcinomas, which we explain below and on the next page.

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 one 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 the head and neck area.

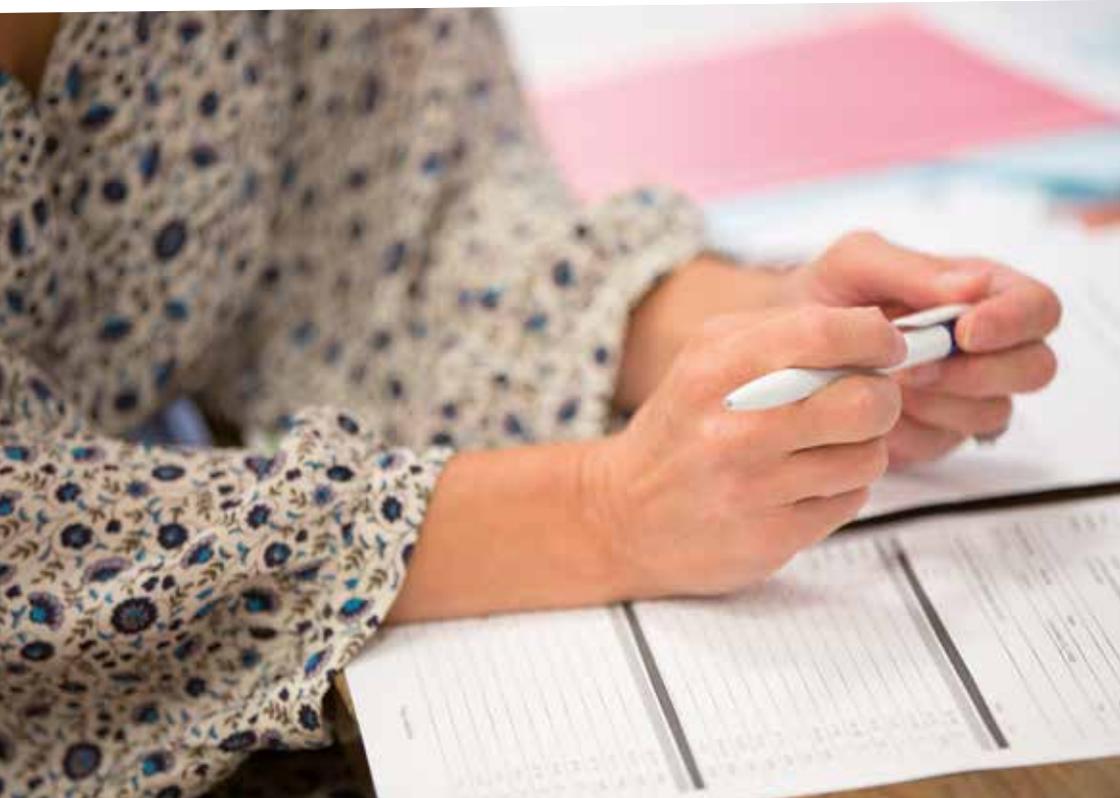
Neuroendocrine carcinomas

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

Poorly or undifferentiated cancer cells

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

Both poorly and undifferentiated cancer cells make it difficult to tell the type of primary cancer. Further tests may sometimes tell the doctors more.



Other tests on the biopsy

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

- **Immunohistochemistry test** – this test finds out whether there are particular proteins (antibodies) on the surface of the cell. These may be linked to some cancer types.
- **Cytogenetic test** – this test looks at the changes in the chromosomes in a cell. Changes in the structure of some chromosomes can be linked to some cancer types.
- **Hormone and protein receptor test** – this test looks at cancer cells with receptors. Some cancer cells have receptors which certain types of hormones or proteins to 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 taken at biopsy. 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. Doctors are still trying to find out how best to use them. The results may help narrow down which type of cancer it is, but cannot tell doctors the exact type of primary cancer. GEBP may still help doctors make decisions about which other tests you should to have, and which treatments to use.

At the moment, gene profiling tests for people with CUP are not available on the NHS. But you may be able to have them as part of a clinical trial (see pages 71 to 72). Or GEBP may be available privately or covered by private health insurance companies.

Tests and scans

The tests you have will depend on your symptoms. Your cancer 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 know which area of the body it might be helpful to scan. For example, if the liver or kidneys are not working properly your doctors may decide to scan those areas.

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.

Tumour markers

Some cancers produce chemicals. These can sometimes be measured in the blood with a blood test. These chemicals are called tumour markers. 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 specialist may use. These may include the following:

- **PSA (prostate-specific antigen)** – this is to check for prostate cancer.
- **Human chorionic gonadotrophin (HCG)** – this is to check for germ cell tumours, which are a rare type of cancer that can start in the testicles or ovaries.
- **Alpha-fetoprotein (AFP)** – this is to check for some types of germ cell tumour and some types of primary liver cancer.
- **CA125** – this is to check for ovarian cancer.

X-rays and scans

X-rays

X-rays are used to take pictures of the inside of your body. They can show breaks or 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 having more specific tests (see the photo on page 16).

Mammogram

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

You have two 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 with a clear, plastic plate. 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 (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body (see the photo below). The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You will probably be able to go home as soon as the scan is over.



A CT scanner

PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc. You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear, and speak to, the person operating the scanner (see the photo on the next page).

An 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.

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. Some women have a vaginal ultrasound instead of a pelvic one. You do not need to have a full bladder for this.

Cameras that look inside the body

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. 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.

The most common types of endoscopy include the following:

- Upper gastro-intestinal endoscopy – this looks into the food pipe, which runs from your mouth to your stomach (oesophagus), the stomach and the upper part of the small bowel (duodenum).
- Bronchoscopy – this test looks inside the windpipe and lungs, by passing a scope gently into your nose or mouth and down the airways.
- Colonoscopy – this test looks inside the large bowel.
- Nasendoscopy or laryngoscopy – these tests look at the back of your mouth and larynx (voicebox). The doctor passes an endoscope up your nose for a nasendoscopy, or through your mouth and up over the back of your throat for a laryngoscopy.
- Cystoscopy – this test looks at the inside of the bladder.

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 about 2cm long in the skin. They carefully put the laparoscope into your tummy (abdomen). This allows the doctor to look at the outside of your 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. The doctor makes a small cut between the ribs, which is less than 2.5cm (1in). They then pass a thoracoscope through the cut. A thoracoscope is a thin, flexible tube with a light and a camera on the end. It can help doctors see the outside of the lungs and organs nearby. The doctor 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	40
Chemotherapy	46
Radiotherapy	54
Other treatments	59
Controlling symptoms	62
Managing symptoms	64
Complementary therapies	70
Clinical trials	71
After treatment	73

Treatment overview

When CUP is diagnosed, cancer has already spread from one 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 if the cancer cannot be cured, it may be possible to control it for some time.

The aim of treatment for CUP is to try to:

- control the cancer
- help you live longer
- treat your symptoms.

Your cancer doctor will consider the following things before explaining your treatment options:

- where the secondary cancer(s) is
- how you might benefit from treatment
- how you might cope with any side effects.

The main treatment for CUP is chemotherapy (see pages 46 to 53). This is because chemotherapy goes into the bloodstream, so it can reach most parts of the body. Radiotherapy (see pages 54 to 58), hormonal therapies (see page 59), targeted therapies (see page 60) and sometimes surgery (see page 61) may also be used. You may be asked to take part in a clinical trial to try newer treatments (see pages 71 to 72).

Supportive or palliative care is an important part of treatment if you have CUP. This is when medicines are used to control your symptoms (see pages 62 to 63). It is sometimes given alongside chemotherapy or radiotherapy treatment.

When CUP is diagnosed, you might find it hard to accept that even with tests, the 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.

It is important to have information to help you make decisions about treatment.

Treatment for certain types of cancer

In some cases, the doctors may have a strong indication of where the cancer started. This is based on:

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

In this situation, your doctors may plan treatment that is often used for that 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.

Palliative care to control symptoms

The aim of palliative care is to control symptoms to improve or maintain your quality of life (see pages 62 to 63). Palliative support 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. Some people may be too unwell to have treatment. In this situation, your cancer doctor may suggest you have palliative care on its own, instead of treating the cancer.



Small secondary cancers

Even when the primary cancer cannot be found, you may have a much better outcome with treatment. But this is only in certain situations. It is usually when the secondary cancer is only in a very small area of the body. In this situation, the secondary cancer is usually close to where the primary cancer might be, such as in the lymph nodes. Here are some examples of this:

- **Squamous cell lymph nodes in the neck** – this may mean the primary cancer is in the head and neck area. You will be referred to a head and neck specialist team for assessment. 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 one armpit** – this may mean the primary cancer is in the breast tissue. You will be referred to a specialist breast cancer team for assessment. You may have surgery or radiotherapy to the lymph nodes, then chemotherapy and hormonal therapy.
- **Squamous cell lymph nodes in the groin** – this may mean the cancer started in the groin area or in the back passage. You will be referred to a specialist surgeon to have the nodes removed, which may be followed by radiotherapy.

Your cancer doctor or specialist nurse can explain what the aim of your treatment is.

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, who specialises in radiotherapy and chemotherapy and other drug treatments
- a medical oncologist, who specialises in chemotherapy and other drug treatments
- a palliative care specialist, who specialises in symptom control
- a pathologist, who advises on the type and extent of the cancer
- a radiologist, who specialises in x-rays and scans
- a clinical nurse specialist, who gives information and support.

It may also include other professionals such as a dietitian, physiotherapist, occupational therapist, counsellor or psychologist.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it is important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You do not have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is the most commonly used treatment for 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 (see pages 26 to 29). 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 may have chemotherapy and radiotherapy together (see pages 54 to 58).

We have more information on individual chemotherapy drugs and combination chemotherapy on our website at [macmillan.org.uk](https://www.macmillan.org.uk)

How chemotherapy is given

You may have chemotherapy drugs as an injection into a vein (intravenously) or sometimes as tablets. The drugs go into the bloodstream and can reach most parts of your body. This means the drugs 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 short, thin tube that the nurse puts into a vein in your arm or hand (cannula)
- a long, thin tube that the nurse puts under the skin of your chest and into a vein close by (a central line)
- a fine tube that the nurse puts into a vein in your arm and goes up into a vein in your chest (PICC line)
- a thin tube with an opening (port) attached to it that the nurse puts into a vein on your chest or arm (implantable port or portacath).

There is more information about the different ways of having chemotherapy in our booklet **Understanding chemotherapy** (see page 96).

Most people can have chemotherapy as an outpatient. But some people may 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 a 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.

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.

Risk of infection

Chemotherapy 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 called neutropenia.

If you have an infection, it is important to treat it 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.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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 or reduce the dose slightly.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them 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. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.



Feeling tired

Feeling tired is a common side effect. 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.

There is more information in our booklet **Coping with fatigue (tiredness)**. This is also available as an audiobook – see page 96.

Feeling sick

You may feel sick in the first few days after treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. 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 and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Diarrhoea

If you have diarrhoea, contact the hospital for advice. Try to drink at least 2 litres (3½ pints) of fluids every day. It can help to avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods.

Sore mouth

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

If your mouth 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.

Hair loss

Some chemotherapy drugs may cause hair loss. Some people have complete hair loss. This means they also lose the eyelashes and eyebrows. Other people may lose only some of their 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 will 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 hair loss and how to look after your scalp. We can also send you our booklet **Coping with hair loss** (see page 96).

Early menopause

Younger women may find chemotherapy causes an 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 in our booklet **Cancer treatment and fertility – information for women** (see page 96).

Contraception

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

Fertility

Some chemotherapy 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 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 is sometimes given to try and cure CUP. This might be if the cancer is in one area of lymph nodes, such as the neck, armpit or groin (see pages 8 to 9). It may be given on its own or together with other treatments, such as surgery. You will usually have this type of radiotherapy over a few weeks.

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

- external beam radiotherapy is given from outside the body by a radiotherapy machine (see page 56)
- internal radiotherapy is when a radioactive material is placed inside the body.

Internal radiotherapy is not commonly used to treat CUP. Your cancer doctor will explain more about internal radiotherapy if it is an option for you.

There is more information about these types of radiotherapy in our booklet **Understanding radiotherapy** (see page 96).

Palliative radiotherapy

If the cancer has spread to more than one place in the body, you may have radiotherapy to help improve symptoms. For example, radiotherapy can help improve symptoms such as 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 the following symptoms:

- **Pain** – radiotherapy shrinks the cancer and relieves the pressure that is causing the pain.
- **Breathlessness** – radiotherapy may relieve breathlessness if the cancer is affecting the lungs.
- **Difficulty swallowing** – radiotherapy can help with swallowing difficulties 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** – radiotherapy can be used to treat a secondary cancer in the brain. It reduces swelling and can help to improve symptoms.

How radiotherapy is given

External beam radiotherapy

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 (see the photo below). 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 in our booklet **Understanding radiotherapy** (see page 96).



Having radiotherapy

Side effects of radiotherapy

The side effects of palliative radiotherapy (see page 55) 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 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. We also have more information about side effects in our booklet **Understanding radiotherapy** (see page 96).

Skin reactions

Your skin in the treatment area may become dry, itchy and feel sensitive or sore. Your skin may become red or get 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 radiographers will check your skin regularly.

Tiredness (fatigue)

You may feel very tired during treatment. This can continue for weeks after treatment finishes. Try to balance resting and doing some gentle exercise. Even short walks can help to increase your energy levels and keep your muscles working.

There is more information in our booklet **Coping with fatigue (tiredness)**. This is also available as an audiobook – see page 96.

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.

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
- eat smaller amounts more often, rather than large meals.

Radiotherapy to the head and neck may also cause sore or dry mouth and taste changes. These 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.

There is more information in our booklet **Eating problems and cancer** – see 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.

There is more information in our booklet **Coping with hair loss** (see page 96).

Other treatments

Hormonal therapies

Sometimes hormonal therapies are used to treat CUP.

Your cancer doctor might suggest hormonal therapy if tests show the cancer has hormone receptors (see pages 26 to 29). If the 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 therapies reduce the amount of hormones in the body, or stop 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.

We have more information about coping with these side effects in our booklet **Side effects of cancer treatment** (see page 96). There are different types of hormonal therapies. Your specialist may try a different type if the first one does not work for you.

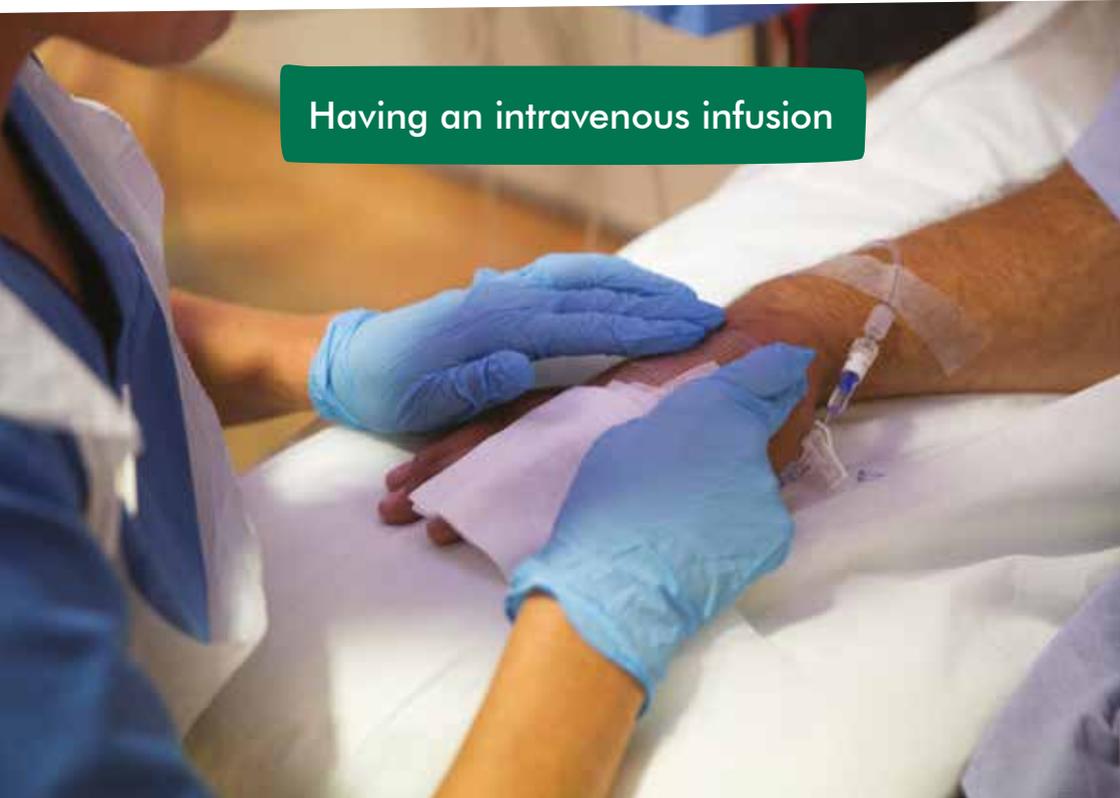
We have more information about hormonal therapies on our website – visit macmillan.org.uk

Targeted therapies

Targeted therapies are drugs that affect how cancer cells grow. There are different types of targeted therapies. They work slightly differently. Targeted therapies may be given as tablets or by injection or drip into a vein in the arm (intravenous infusion – see the photo below).

Targeted therapies are not often used to treat CUP. Some clinical trials have shown that they may be useful (see pages 71 to 72). But we need to know more about them before they can be used as a treatment.

We have more information about targeted therapies on our website – visit [macmillan.org.uk](https://www.macmillan.org.uk)



Having an intravenous infusion

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
- lymph nodes with cancer in them 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 or chemotherapy. 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 CUP specialist will talk to you about what other treatments might be suitable.

We have more information about different surgeries in print and on our website (see page 96).

Controlling symptoms

For many people with CUP, the main aim of 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.

Palliative care

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.

There is more information about this in our booklet **Coping with advanced cancer** – see page 96.

'I like to look at things positively whenever I can. Right now I am feeling well, and although I have cancer I can still live my life and do things.'

John

Managing symptoms

The symptoms of CUP are usually helped with cancer treatment. Sometimes this works quickly. You may notice an improvement within a few days. But sometimes it may take a few weeks before you feel better.

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

There are different symptoms, and many of them depend on where the secondary cancer is. You will not get all the symptoms mentioned here.

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.

There are things you can try to help reduce your fatigue:

- Get enough good quality sleep and rest when you feel tired.
- Do some regular physical activity – this can give you more energy and help you sleep. We can send you our booklet **Physical activity and cancer** (see page 96).

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. There is more information about this on page 68.

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.

There is more information in our booklet **Coping with fatigue (tiredness)**. This is also available as an audiobook – see 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 specialist nurse or cancer doctor. 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 three 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 types of 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 **Recipes for people affected by cancer** and **Eating problems and cancer** – see page 96.



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. We have more information about managing constipation on our website – visit macmillan.org.uk

Cancer treatments such as chemotherapy (see pages 46 to 53) or radiotherapy (see pages 54 to 58) 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.

There is more information in our booklet **Managing cancer pain** (see page 96).

Feeling sick (nausea)

This can usually be helped by anti-sickness drugs (anti-emetics). There are different types of anti-sickness drugs. Your doctor will find the one that suits you best.

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.

Denosumab, a targeted therapy drug, is another treatment that may be used if a cancer has spread to the bones. It is given as an injection under the skin (subcutaneously).

We have more information about bisphosphonates and denosumab on our website – visit [macmillan.org.uk](https://www.macmillan.org.uk)

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. They are sometimes also used as part of chemotherapy treatment.

Steroids can be taken as tablets or given as an injection. It is important to take them exactly as your doctor tells you. 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. It is for emergencies, so another doctor will know you are having steroid treatment. A card is not necessary if you are only having a short course of steroids.

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

For more information, visit [macmillan.org.uk/steroids](https://www.macmillan.org.uk/steroids)

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** (see page 96).

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a 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.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

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

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information in our booklet **Understanding cancer research trials (clinical trials)** – see page 96.

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have. Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

After treatment

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

- If the aim of treatment was to cure the cancer, you may see your cancer doctor or specialist nurse every few months for up to 2 years.
- If the aim of treatment was to control the cancer, you may see your cancer doctor or specialist nurse less often.

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 (see pages 78 to 79). It may help to get support from family, friends or a support organisation (see page 77).

There is more information in our leaflet **What to do after cancer treatment ends** (see page 96).

'There was no way I was going to let cancer take another day away from me. When I had the all-clear, I celebrated with Christmas dinner with all the trimmings.'

John



YOUR FEELINGS AND RELATIONSHIPS

Emotional support	76
Your feelings	78
If you are a family member or friend	82
Talking to children about cancer	83
Who can help?	85

Emotional support

You might have lots of different feelings. You will also probably be managing symptoms and your treatment. Or you may be worried about practical issues, such as work or finances (see pages 88 to 93).

Coping with CUP can be difficult because there is so much uncertainty. It can be hard to understand the illness and make sense of the different tests you are having. Trying to explain things to your family and friends when you do not have clear answers yourself can also be difficult.

It is important to get the support you need during treatment. You may be able to get support from:

- your healthcare team
- your partner
- family
- friends
- support groups.

Try to be honest about how you are feeling. Tell your cancer doctor or specialist nurse about any concerns you have, if you think you may be depressed (see page 79) or if you are very anxious (see pages 78 to 79). They can support you or give you advice on getting more help. Some people find it helpful to talk to someone experienced in helping people with cancer with their emotional problems. This may be a counsellor or psychologist. Your cancer doctor or specialist nurse can usually arrange this.

Support groups

Self-help or support groups are a chance to talk to other people who may be in a similar situation. They may be facing the same challenges as you or understand how you feel.

For more information about cancer support groups in the UK, visit [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups) or call us on **0808 808 00 00**.

Online support

Many people now get support through the internet. There are online support groups, social networking sites, forums, chatrooms and blogs for people affected by cancer. You can use these to ask questions and share your experience.

You can use our Online Community to talk to people in our forums, blog, make friends and join support groups (see page 98). There is a group specifically for people affected by CUP – visit [community.macmillan.org.uk/cancer_types/unknown-primary-cancer](https://www.community.macmillan.org.uk/cancer_types/unknown-primary-cancer)

'Having cancer has been a life-altering experience, but there have been some amazing positives. I now truly understand the value of time and of the people around me. I have also had the opportunity to make positive changes, which I may never have done otherwise.'

Judith

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with.

It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

'I think I'd have found it much better if someone could have said, "You have tonsil cancer and the lumps in your neck are secondary". But it was primary unknown.'

John

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people affected by cancer on our Online Community. Visit **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 96).

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 might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more. We also have more information in our booklet **Talking with someone who has cancer** (see page 96).

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 in our booklet **Looking after someone with cancer** (see page 96).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children depends on their age and how mature they are. It may be best to start by giving them small amounts of information, then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website riprap.org.uk offers information and support for teenagers who have a parent with cancer.

There is more information in our booklet **Talking to children and teenagers when an adult has cancer** (see page 96). We also have a video on our website about talking to children – visit macmillan.org.uk



Who can help?

Many people can help you and your family and friends:

- district nurses work closely with GPs and, if needed, they can visit your home regularly
- the hospital social worker can give you information about social services and benefits you may be able to claim
- you may be entitled to Meals On Wheels, a home helper or money to help with hospital transport costs
- the hospital social worker may be able to help arrange childcare during and after treatment, or help with the cost of childminders
- our cancer support specialists can tell you more about services in your area – visit [macmillan.org.uk/inyourarea](https://www.macmillan.org.uk/inyourarea) or call **0808 808 00 00**.

'My advice is to seek help and be open about your emotions. Macmillan has a number of services which are there to help, and they do. Call the support line when you aren't sure how to process what's going on.'

Kiara, whose boyfriend was diagnosed with CUP



WORK AND FINANCIAL SUPPORT

Financial help and benefits	88
Work	92

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Scotland or Wales, or **nidirect.gov.uk** if you live in Northern Ireland.

Below and opposite are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

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, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £380, but this may change. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Travel and cancer** and **Insurance** (see page 96). Our Online Community travel insurance forum may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

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 one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 104).

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

'A Macmillan welfare rights adviser sent me information about financial advice. It helped me navigate the financial maze of living with cancer.'

Judith

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 96). There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

Employment rights

If you have or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 96).

MACMILLAN
CANCER SUPPORT

PELVIC RADIOTHERAPY IN WOMEN



FURTHER INFORMATION

About our information	96
Other ways we can help you	97
Other useful organisations	100
Your notes and questions	112

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](https://www.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](https://www.be.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](https://www.be.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**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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. Our cancer support specialists 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.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

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's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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](https://www.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](https://www.macmillan.org.uk/community)

The Macmillan healthcare team

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.

Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit [publications.macmillan.org.uk](https://www.macmillan.org.uk/publications) and search 'book reviews'.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

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

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

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 a financial guide or benefits adviser, or to find out more about Macmillan Grants.

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 work and cancer

Whether you're 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 (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

There are lots of other organisations that can give you information or support.

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 Black Care

Tel 0208 961 4151

www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus

Northern Ireland

Helpline 0800 783 3339

(Mon to Fri, 9am to 1pm)

Email

nurseline@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline 0808 800 4040

(Mon to Fri, 9am to 5pm)

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

(Mon to Fri, 9am to 5pm)

Email info@

cancersupportscotland.org

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 Centres**Tel** 0300 123 1801**Email**

enquiries@maggiescentres.org

www.maggiescentres.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.

Penny Brohn UK**Helpline** 0303 300 0118

(Mon to Fri, 9.30am to 5pm)

Email

helpline@pennybrohn.org.uk

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap**www.riprap.org.uk**

Developed especially for teenagers in the UK who have a parent with cancer.

Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus**Helpline** 0808 808 1010

(Daily, 8am to 8pm)

Email

info@tenovuscancercare.org.uk

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.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 Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline 0800 224 488

(Mon to Fri, 8am to 10pm,
Sat and Sun, 9am to 5pm)

www.nhsinform.scot

NHS health information site for Scotland.

Patient UK

www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300

Email bacp@bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at itsgoodtotalk.org.uk

UK Council for Psychotherapy (UKCP)

Tel 0207 014 9955

Email info@ukcp.org.uk

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

(Mon to Fri, 9am to 6pm)

Text 86463

Email info@mind.org.uk

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.

Cancer registries

The cancer registry

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

Tel 020 7654 8000

Email enquiries@phe.gov.uk

www.ncras.nhs.uk

Tel (Ireland) 021 4318 014

www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel 013 1275 7777

Email nss.csd@nhs.net

www.isdscotland.org/

Health-Topics/Cancer/

Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500

Email

general.enquiries@wales.nhs.uk

www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028

Email nicr@qub.ac.uk

www.qub.ac.uk/nicr

Financial support or legal advice and information

Benefit Enquiry Line

Northern Ireland

Helpline 0800 022 2450

(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)

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. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

Carer's Allowance Unit

Tel 0800 731 0297

Textphone 0800 731 0317

(Mon to Fri, 8am to 6pm)

**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 in the phone book or by contacting:

England

Helpline 0344 411 1444

www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060

www.cas.org.uk

Wales

Helpline 0344 477 2020

**www.citizensadvice.org.uk/
wales**

Civil Legal Advice

Helpline 0345 345 4345

(Mon to Fri, 9am to 8pm,
Sat, 9am to 12.30pm)

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

(Mon to Fri, 9am to 5pm)

Textphone 0800 012 1574

nidirect.gov.uk/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 0800 022 4250

(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)

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.

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.wlga.gov.uk/authorities

Macmillan Benefits Advice Service (Northern Ireland)

Tel 0300 123 3233

Money Advice Scotland

Tel 0141 572 0237

Email [info@](mailto:info@moneyadvicescotland.org.uk)

moneyadvicescotland.org.uk

www.moneyadvicescotland.org.uk

Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

StepChange Debt Charity

Tel 0800 138 1111

(Mon to Fri, 8am to 8pm,
Sat 8am to 4pm)

www.stepchange.org

Provides free debt advice through phone, email and the website, and online through live chats with advisers.

Unbiased.co.uk**Helpline** 0800 023 6868**Email**

contact@unbiased.co.uk

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.

Equipment and advice on living with a disability**British Red Cross****Tel** 0344 871 1111**Textphone** 0207 562 2050**Email**

information@redcross.org.uk

www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disabled Living**Foundation (DLF)****Helpline** 0300 999 0004

(Mon to Fri, 10am to 5pm)

Email helpline@dlf.org.uk**www.dlf.org.uk**

Provides free and impartial advice about all types of disability equipment and mobility products.

Disability Rights UK**Tel** 0330 995 0400

(Mon to Fri, 10am to 12.30pm,

then 1.30pm to 4pm)

Email

enquiries@disabilityrightsuk.org

www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Motability Scheme

Tel 0300 456 4566

(Mon to Fri, 8am to 7pm,
Sat, 9am to 1pm)

Textphone 0300 037 0100

www.motability.co.uk

The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

Scope

Helpline 0808 800 3333

(Mon to Fri, 8am to 8pm)

Textphone Use Type Talk by dialling 18001 from a textphone followed by 0808 800 3333

Email helpline@scope.org.uk

www.scope.org.uk

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for young people

CLIC Sargent

Tel 0300 330 0803

(Mon to Fri, 8am to 6pm)

www.clicsargent.org.uk

Provides clinical, practical, financial and emotional support to children with cancer in the UK.

Teenage Cancer Trust

Tel 0207 612 0370

(Mon to Fri, 9am to 5.30pm)

Email

hello@teenagecancertrust.org

www.teenagecancertrust.org

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for them, their friends and families.

Youth Access

Tel 0208 772 9900

Email

admin@youthaccess.org.uk

www.youthaccess.org.uk

A UK-wide organisation providing counselling and information for young people. Find your local service at **youthaccess.org.uk/find-your-local-service**

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)

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
(Mon to Fri, 10am to 10pm)
Email helpline@lgbt.foundation
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.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)

Email info@carers.org

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 (England, Scotland, Wales) 0808 808 7777
(Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland)
0289 043 9843

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.

Support with sight loss

Royal National Institute of Blind People (RNIB)

Helpline 0303 123 9999

(Mon to Fri, 8am to 8pm,
Sat, 9am to 1pm)

Email helpline@rnib.org.uk

www.rnib.org.uk

Offers support and advice to blind and partially sighted people in the UK.

Support with hearing loss

Action on Hearing Loss

Helpline 0808 808 0123

(Mon to Fri, 9am to 5pm)

Textphone 0808 808 9000

SMS 07800 000 360

Email informationline@hearingloss.org.uk

www.actiononhearingloss.org.uk

Offers support and practical advice to people in the UK with hearing loss and tinnitus.

Advanced cancer and end-of-life care

Hospice UK

Tel 0207 520 8200

Email info@hospiceuk.org

www.hospiceuk.org

Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline 0800 090 2309

(Mon to Fri, 8am to 6pm,
Sat, 11am to 5pm)

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre

Helpline 0196 271 2690

Email

rosie@naturaldeath.org.uk

www.naturaldeath.org.uk

Offers independent advice on aspects of dying, funeral planning and bereavement.

Bereavement support

Childhood Bereavement Network

Tel 0207 843 6309

Email cbn@ncb.org.uk

www.childhoodbereavementnetwork.org.uk

A UK-wide group of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

Cruse Bereavement Care

Helpline 0808 808 1677

(Mon, 9.30am to 5pm,
Tue to Thu, 9.30am to 8pm,
Fri, 9.30am to 5pm)

Email info@cruse.org.uk

www.cruse.org.uk

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Hope Again

Helpline 0808 808 1677

(Mon to Fri, 9.30am to 5pm)

Email hopeagain@cruse.org.uk

www.hopeagain.org.uk

Designed for young people by young people, Hope Again is part of Cruse Bereavement Care. It supports young people across the UK after the death of someone close. Offers a private message service from the website.

Widowed and Young (WAY)

www.widowedandyoung.org.uk

A UK-wide support network to help young widows and widowers rebuild their lives after the death of a partner.

Winston's Wish

Helpline 0808 802 0021

(Mon to Fri, 9am to 5pm)

Email ask@winstonswish.org

www.winstonswish.org.uk

Helps bereaved children and young people throughout the UK re-adjust to life after the death of a parent or sibling.

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.

With thanks to: Dr Catherine Coyle, Consultant Clinical Oncologist; Dr Amelie Harle, Consultant Medical Oncologist; Lucy Henderson, Macmillan Lead Nurse, Acute Oncology; Aga Kehinde, Clinical Nurse Specialist, Macmillan Acute Oncology Advanced Nurse Practitioner; Dr Nick Maisey, Consultant Medical Oncologist; Dr Claire Mitchell, Consultant Medical Oncologist; Dr Sarah Ngan, Consultant Medical Oncologist; 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

We have listed a sample of the sources used in the booklet below. 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.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



Share your cancer experience

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

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.

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?

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

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

/ /

Don't 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'd rather donate online go to macmillan.org.uk/donate

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

**This booklet is about cancer of unknown primary (CUP).
It is for anyone who has been diagnosed with CUP.
CUP is when doctors find a secondary cancer but cannot
find where the cancer started.**

**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 emotional, practical and
financial issues.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) 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.

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

© Macmillan Cancer Support, June 2019. 5th edition.
MAC11689_E05_N. Next planned review 2021.
Macmillan Cancer Support, registered charity in England and
Wales (261017), Scotland (SC039907) and the Isle of Man (604).
Also operating in Northern Ireland. Printed on sustainable material.
Please recycle.