



Oncology Service

What is Cancer of Unknown Primary (CUP)?

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CUP is a general term that covers many different types of cancer. It affects about 3-5% of people with cancer.

Cancer can spread to more than one part of the body and this is common in people with CUP.

It is more common in older people, but it can affect people who are younger.

Your doctor may suspect you have CUP if early tests do not find the primary cancer (where the cancer originated from). The diagnosis however, will not be certain until you've had all the appropriate tests. Doctors will try to find the primary cancer because it helps them plan the most effective treatment for you. Some people with suspected CUP may be too unwell to have lots of tests.

Sometimes, tests will find the primary cancer. When this happens, the cancer is no longer called CUP. It is named after the primary cancer and treated accordingly.

Even when the primary cancer cannot be found, your specialist may be able to suggest a probable part of the body where the cancer started. This will be based on your specialist's experience, where the secondary cancers are, your symptoms and test results.

Why the primary cancer can't be found

There are different reasons why a primary cancer can't always be found:

- The secondary cancer or cancers have grown and spread very quickly, but the primary is still too small to be seen up on scans.
- The cancer has been growing in more than one area of the body for some time, making it difficult to see where it started.
- The primary cancer might have disappeared, even though it has spread to other parts of the body.

Symptoms of cancer of unknown primary

Symptoms of CUP will vary depending on where the secondary cancer (or cancers) are.

Secondary cancer in the lung - you may have a cough that doesn't go away, breathlessness or fluid collecting around the lungs (pleural effusion).

Secondary cancer in the bone - you may experience a dull, persistent pain in the bone that's often worse at night. Sometimes if a bone is weakened by cancer it will break (fracture).

Secondary cancer in the liver - symptoms include swelling and discomfort in the tummy (abdomen), feeling sick and loss of appetite, yellowing of the skin and eyes (jaundice), and fluid collecting in the abdomen (ascites).

Secondary cancer in the lymph nodes (glands) - Your lymph nodes may be swollen and feel hard or cause pain if they're pressing on tissue or nerves nearby. The most common lymph nodes to be affected are the nodes in the neck, armpit, chest or groin.

General symptoms

You may also have some general symptoms including:

- Unexplained weight loss
- Loss of appetite
- Feeling extremely tired all the time
- Looking pale, feeling tired and breathless due to a lack of red blood cells (anaemia).

All the symptoms mentioned here can be caused by conditions other than cancer, but it's important to see your doctor and get them checked.

How cancer of unknown primary is diagnosed

We can't list all the possible tests you may have, but we've included those most likely to be used depending on your symptoms. You'll be given information by your hospital about how to prepare for any tests and what to expect.

Biopsy

During a biopsy, a small piece of tissue or a sample of cells is removed so that it can be examined under a microscope.

Fine needle aspiration (FNA) biopsy

This is a quick, simple procedure that can be done in the out-patient clinic. The doctor inserts a fine needle into the lump and removes a sample of cells.

Removing fluid for testing

Some people have a build-up of fluid next to the lung or fluid collecting in the tummy area. A sample of the fluid can be taken to check for cancer cells.

X-rays

These are taken to check your lungs or other parts of the body, such as the bones.

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. It is often used to investigate CUP. You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly.

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. It is sometimes used to look for a cancer in the breast if there is cancer in the lymph nodes in the armpit.

PET/CT scan

PET scans use 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.

Ultrasound scan

Ultrasound scans use sound waves to build up a picture of organs such as the abdomen, liver and pelvis.

Endoscopy

During an endoscopy, an endoscope - a thin flexible tube with a camera at the end - is used to look inside the gullet, stomach, small bowel or large bowel. The endoscope also has a small cutting instrument on the end that allows the doctors to take biopsies of any abnormal areas.

Bronchoscopy

A doctor or specially trained nurse uses a thin flexible tube with a camera on the end of it (bronchoscope) to examine the inside of the lung airways and take samples of tissue (biopsies).

Mammogram

A mammogram is a low-dose X-ray of the breast. In CUP it is done if a woman has symptoms of breast cancer, such as cancer in the lymph nodes in the armpit. The radiographer (person who takes the X-ray) will position you so your breast is against the X-ray machine and compressed with a flat, clear, plastic plate. Two mammograms (from different angles) are taken of each breast.

Blood tests

You will also have tests done on your blood and your urine.

These are done to check:

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

Tumour markers

Some cancers produce chemicals that can be measured in the blood called tumour markers. These can also be raised in conditions other than cancer, so they aren't always reliable.

Treatment

The aim of treatment is to try to control the cancer, help you live longer and treat your symptoms.

When CUP is definitely confirmed it can be very hard to accept that even with tests, the primary cancer still cannot be found. You will probably be coping with difficult feelings, so it's important to get the support you need. Some people may feel relieved that the tests are over and treatment can now start.

Your specialist will take into account different factors before advising on the best treatment for you. This includes where the secondary cancer or cancers are, how likely you are to benefit from the treatment and how you will cope with its side effects.

Usually the main treatment for CUP is chemotherapy. Chemotherapy is a systemic treatment, which means it treats cancer in more than one area of the body. Radiotherapy, hormonal therapy and sometimes surgery may also be used.

Supportive care with medicines to control your symptoms is an important part of treatment for people with CUP. Sometimes doctors advise palliative care on its own rather than treating the cancer.

How treatment is planned

In our hospitals a team of specialists will talk to you about the treatment they feel is best for patients with CUP (CUP team) and you will be referred to them.

The CUP team may include a:

- Consultant Oncologist
- Palliative Care Consultant
- Radiologist
- Pathologist
- Specialist Nurse

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 do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual for people to need repeated explanations. It is 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.

The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of the side effects that can occur. However, these can usually be controlled with medicines.

Your doctor will explain the possible benefits of treatment and also the risks and side effects. In some people with CUP, treatment helps to control the cancer, improve symptoms and quality of life. It may also help some people live longer. But in others the treatment may have little effect on the cancer and they will get the side effects without any of the benefits.

Making a decision about treatment sometimes involves thinking about whether the side effects of treatment outweigh the possible benefits.

If you decide at any time not to have treatment, you will be given supportive (palliative) care with medicines to control your symptoms.

Living with cancer of unknown primary

After treatment – follow-up for CUP

When your treatment has finished you will have regular check-ups.

If you have any problems or notice any new symptoms between check-ups, let your doctor or nurse know as soon as possible. You may have a specific point of contact, such as a specialist nurse, who you can call if you have any problems.

Many people find that they get very anxious before these appointments. This is natural. It may help to get support from family, friends or an organisation during this time.

After cancer treatment many people need time to come to terms with the changes that have happened in their lives.

Coping with cancer of unknown primary

For many people with CUP, the main aim of their treatment is to control symptoms.

Treating symptoms is known as supportive care or palliative care. Some people with CUP may decide to have supportive care on its own without cancer treatments. But you can also have supportive care alongside cancer treatments and after it is finished.

Doctors and nurses who specialise in controlling pain and other symptoms are called palliative care specialists. They are based in hospitals, hospices, palliative care units and pain clinics. They work with your GP, district nurses and other healthcare professionals to make sure your symptoms are well controlled. Palliative care nurses can also come to visit you in your own home. Your GP or cancer specialist can usually arrange this for you.

Coping with CUP

As well as coping with side effects of treatment or some of the symptoms we have mentioned, you will probably be dealing with different feelings. Coping with CUP can be particularly difficult because there's so much uncertainty. It is often hard to understand the illness itself and to make sense of different tests you are having. Trying to explain things to your family and friends when you don't have clear answers yourself can be difficult.

You might find it helpful to talk to others in a similar situation. The Cancer of Unknown Primary Foundation - Jo's Friends has a 'meeting space' on its website where you can talk to other people, which may help you feel less isolated.

Support with your feelings

Some people need more than advice and support. You may find that the impact of cancer leads to depression, feelings of helplessness or anxiety. Specialist help is available to help you cope with these emotions. Often it is easier to talk to someone who is not directly involved with your illness. You can ask your cancer specialist or GP to refer you to a counsellor who specialises in the emotional problems of people with cancer, and their relatives.

Our cancer support specialists can tell you more about counselling and let you know about services in your area.

For further information regarding CUP:

Please contact the acute oncology service on: **0161 901 1460**.
The Acute Oncology Team working hours are: 9 to 5 pm
Monday to Friday except weekends and bank holidays.

No Smoking Policy

The NHS has a responsibility for the nation's health.

Protect yourself, patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted within any of our hospital buildings or grounds.

The Manchester Stop Smoking Service can be contacted on Tel: (0161) 205 5998 (www.stopsmokingmanchester.co.uk).

Translation and Interpretation Service

These translations say "If you require an interpreter, or translation, please ask a member of our staff to arrange it for you." The languages translated, in order, are: Arabic, Urdu, Bengali, Polish, Somali and simplified Chinese.

إذا كنت بحاجة الى مترجم، او ترجمة، من فضلك اطلب من احد موظفينا ترتيب ذلك لك

اگر آپ کو ایک مترجم، یا ترجمہ کی ضرورت ہے، تو برائے کرم ہمارے عملے کے کسی رکن سے کہیں کہ وہ آپ کے لیے اس کا انتظام کرے۔

আপনার যদি একজন দোভাষী, অথবা অনুবাদের প্রয়োজন হয়, দয়া করে আমাদের একজন কর্মীকে বলুন আপনার জন্য ইহা ব্যবস্থা করতে।

Jeśli Pan/Pani potrzebuje tłumacza lub tłumaczenie prosimy w tym celu zwrócić się do członka personelu.

Haddii aad u baahantahay tarjubaan, fadlan waydii qof ka mid ah shaqaalahayga si uu kuugu.

如果你需要翻译或翻译员, 请要求我们的员工为你安排



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