



Royal Berkshire
NHS Foundation Trust

Cancer of Unknown Primary (CUP)

Information for patients,
relatives and carers

This information is for people with cancer of unknown primary (CUP) and covers symptoms, investigations / tests and treatment options. If there is anything you do not understand, please ask your doctor or nurse specialist.

What is cancer of unknown primary?

Cancer of unknown primary is a term that covers many different types of cancers. It affects around 3-5% of people with cancer. People who have a cancer of unknown primary often have more than one area of cancer. CUP is more common in people aged 60 and over, but it can also affect people younger than this.

When a new tumour is found it is not always obvious what type of cancer it is. There will need to be tests and investigations to find out whether what has been found is a primary cancer or a secondary cancer. Sometimes, doctors find where the cancer has spread but cannot find where in the body the cancer first began to grow. This type of cancer is called a cancer of unknown primary (CUP) or occult primary tumour.

If the doctors are not sure where the primary cancer is they may be able to suggest a part of the body where the cancer may have started. This information will be based on where the secondary cancers are found, the symptoms which you are experiencing or from test results. The test results can also tell how the cancer will behave. This will then help a specialist doctor to organise your treatment plan.

What are primary and secondary cancers?

The place where a cancer starts growing in the body is known as the primary site. Cells from the primary site can break away and spread to the other parts of the body through the blood or lymphatic system. These form other cancers known as secondary cancers or metastases.

The lymphatic system is part of the immune system which is the body's natural defence against infection and disease. Lymph nodes (glands) are part of this system. They exist throughout the body and are linked by a network of tiny tubes called ducts that carry fluid known as lymph.

The secondary cancer is named according to the primary site. For example, a cancer that starts in the lung is known as a lung cancer but if it spreads to the liver it is still known as lung cancer. The secondary cancer in the liver would be made up of the lung cancer cells and not liver cancer cells.

Secondary cancers of metastases are usually treated according to the primary cancer. Knowing where the cancer starts helps doctors to know which treatment is needed.

Why can't my primary cancer be found?

There are several different reasons why a primary cancer cannot always be found. It may be that the primary cancer is too small to be seen on a scan or it may be hidden behind a larger secondary cancer. It also may have disappeared even though it has now spread to other parts of the body. This can sometimes happen if the body's immune system has successfully disposed of it.

If your primary cancer is found then you will be passed on to the relevant team for treatment and be directed to the correct specialist nurse team.

Symptoms of cancer of unknown primary (CUP)

Symptoms of cancer of unknown primary will differ depending on where the secondary cancer is found. General symptoms include:

- Unexplained weight loss.
- Reduced appetite.
- Feeling very tired all the time
- Feeling breathless or looking pale usually due to lack of red blood cells in the blood, known as anaemia.

- Secondary cancer can also cause different symptoms to different parts of the body depending where the cancer is.

Secondary cancer to the liver

If the secondary cancer is in the liver you may find that you get:

- Swelling in your tummy (abdomen).
- Feel sick or have a lack of appetite.
- Yellowing of the skin or eye known as jaundice
- Have a collection of fluid in the abdomen known as ascites.
- Secondary cancer in the bone
- This may cause a dull pain in the bones, more commonly at night. If bones are weakened by cancer they can break more easily.

Types of cancers of unknown primary (CUP)

The doctor may request a sample of the tissue from the secondary cancer site; this is known as a biopsy. Looking at the appearance of the biopsy under a microscope and doing other tests of the tissue, it makes it easier to determine the type of cancer which has been found. This will assist the doctors to give them more information about the likely behaviour of the cancer and how to treat it.

The pathologist views the tissue under a microscope to look for cancer cells and to find out the type of cancer, such as:

- **Adenocarcinoma:** Most cancers of unknown primary are known as adenocarcinomas (a type of carcinoma) which make up between 60-90% of cancers. Adenocarcinomas develop from the gland cells that cover certain parts of the body. The most common parts of the body for them to be are: the lungs, pancreas, bowel, kidneys, liver and stomach. In women they can also be seen in the ovaries, womb and breasts.
- **Poorly differentiated carcinomas:** Poorly differentiated means that the cells look very different from normal cells so it is difficult to distinguish what type of cancer the primary is.

- **Squamous cell cancers:** These develop from flat cells usually found on the surface of the skin or in the lining of internal surfaces of your body. Only 1 in 20 people with CUP have this cancer. These can be found in the lung, skin, head, neck, oesophagus and cervix.

Tests and diagnosis

As previously mentioned tests may need to be performed to determine a diagnosis.

- **X-rays and CT scans:** X-rays and CT scans use a low level of radiation to take pictures of the inside of your body. This test is useful for doctors to see the whole of the body to look for the primary cancer or further secondary cancers.
- **Ultrasound:** An ultrasound scan will use sound waves. This test is painless and has no side effects. It is useful in finding abnormalities in the tummy (abdomen).
- **Biopsy:** If an area of abnormality is found then you may be asked to have a biopsy. This means taking a sample of tissue from the site either with help of an ultrasound or an endoscopy. This is the most important test when finding an unknown primary cancer.
- **Endoscopy:** An endoscopy is a camera test that looks inside your body. It is performed using an endoscope which is a long flexible tube with a tiny camera and light on the end. There are different types of endoscopes depending on which area of the body the doctor is looking at. When inside the body, it can also be used to take biopsies if needed.

Once a scan and a biopsy have been taken, the results will then be discussed at a multi-disciplinary team (MDT) Meeting.

Treatment options

There are different types of treatment for patients with carcinoma of unknown primary (CUP). For most patients with CUP, current treatments unfortunately do not cure the cancer.

Four types of standard treatment are used:

- **Surgery** (only in selected patients).
- **Radiation therapy:** a cancer treatment that uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing.
- **Chemotherapy:** a cancer treatment that uses drugs to stop the growth of cancer cells, by killing the cells.
- **Hormone therapy:** a cancer treatment that removes hormones or blocks their action and stops cancer cells from growing.

New types of treatment are being tested in clinical trials (if available).

The multi-disciplinary team (MDT)

It is the policy of the MDT that all patients (irrespective of age and stage of disease) with a new diagnosis of cancer of unknown primary (CUP) will be discussed at the multi-disciplinary team (MDT) meeting.

At this meeting the team will discuss each patient's scans or biopsies and organise treatment plans and follow-up arrangements to ensure that every patient with cancer receives multi-disciplinary management. These meetings will also be an opportunity to discuss difficult cases later in the patient pathway, if necessary.

In rare cases, urgent treatment may be needed to be carried out without an MDT decision. In these situations, efforts will be made by the relevant specialist team to discuss your treatment with other members of the MDT.

Who are the CUP MDT?

- Designated lead clinician (chair) who will take overall responsibility for the service.
- Designated surgeon(s).
- Gastroenterologist(s).
- Oncologist(s). Oncology expert in radiotherapy and chemotherapy.
- Radiologist.
- Histopathologist.
- Clinical Nurse Specialists. Information and support for patients.
- Dietitian. Provides specialist dietary advice.
- MDT Co-ordinator.
- User's issues and Patient Information Lead.
- Research Nurse. Provides information to the team on any trials.
- A Key Worker is appointed from the MDT members for each individual patient. The name of your current key worker will be recorded in your case notes. The Key Worker for CUP patients will be the Upper GI Clinical Nurse Specialists. Any changes to this will be made after discussion with the patient or if the primary cancer is found.

Useful numbers

Dr E Hill (Oncologist) – Secretary	Tel: 0118 322 7558
Mr M Booth (Surgeon) – Secretary	Tel: 0118 322 3075
Miss M Sampson (Surgeon) – Secretary	Tel: 0118 322 3075
Dr N Chandra (Gastroenterologist) – Secretary	Tel: 0118 322 1884
Dr J Booth (Gastroenterologist) – Secretary	Tel: 0118 322 1884
Adelaide Ward	Tel: 0118 322 7471
Sidmouth Ward	Tel: 0118 322 7468
Berkshire Cancer Centre (9am-5pm)	Tel: 0118 322 7888
King Edward Ward (8:30am-5pm)	Tel: 0118 322 7466
Radiotherapy Clinic (9am-5pm)	Tel: 0118 3227890
Bracknell Healthspace	Tel: 01344 662900

Your Key Worker/Clinical Nurse Specialist is:

Ruth Moxon, Emma Hogbin and Hilary Fagan

Tel: **0118 322 7748** or Pager: **07659 129407**

Support groups

Macmillan Cancer Support, Freephone 0808 808 00 00

www.macmillan.org.uk

Provides information, emotional support and practical advice by telephone or letter. Also provides information in other languages

British Association for Counselling

BACP House, 15 St John's Business Park, Lutterworth,
Leicestershire, LE17 4HB

Tel: 01455 883300 www.bacp.co.uk

Can provide a list of local counsellors for cancer patients and their families.

Cancer Research UK

Cancer Research UK Angel Building, 407 St John Street, London,
EC1V 4AD

Tel: 0300 123 1022 www.cancerresearch.org.uk/

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT BCC, January 2024. Next review due: January 2026