Information about cancer with an unknown primary site (CUP)

Information for patients
This booklet answers common questions about cancer with an unknown primary site (CUP). If you would like further information, or have any particular worries, please do not hesitate to ask your nurse or doctor.

In all cases, a doctor will explain the condition to you and answer any questions you may have.

**What is a CUP?**

**Cancer of unknown primary (CUP)** is a term used when a cancer has been diagnosed, but the original (or primary) place where the cancer started cannot be found.

Cancer with an unknown primary site is referred to in different ways:

- cancer of unknown primary (CUP)
- metastatic malignancy of unknown origin
- carcinoma of unknown primary.

Approximately 5% of cancer diagnoses are cancers of unknown primary. In patients with a CUP, symptoms are caused by a cancer that has spread. This is called a secondary cancer. Often this will have spread to more than one place in the body. Common areas where cancer can spread include the liver, lungs and bones. With a CUP, despite many tests the primary site of the cancer cannot be found.
**Why can the primary cancer not be found?**

There can be many reasons why the primary cancer cannot be located:

- It may be too small to be seen on a scan.
- Although it has already spread it may now have disappeared. This usually happens if the cancer had its blood supply cut off.
- Your own immune system may have destroyed the primary cancer, but not the secondary sites.

**Investigations**

Initially, when you go to your GP or hospital with symptoms, several investigations will be done including a physical examination. Your diagnosis of cancer may have been found by imaging (eg a CT scan or x-ray) or specific blood tests.

There are many different types of CUP and many possible treatments. Because of this, a diagnosis may take longer to be made.

Finding out as much as we can about where the cancer may have come from helps to make treatments as effective as possible.
What tests will be done?
This will vary for every person but often includes the following:

- Blood tests: to detect substances in your blood called ‘tumour markers’ which are made by some cancers.
- Biopsy: a small piece of tissue will be taken from a tumour using a needle. This is one of the most important tests and aims to find out what type of cancer you have.
- Imaging scans, including x-ray, CT, MRI and PET scans.

Each has their own value and may be requested by the doctor caring for you.

Your doctor will select the tests at each stage when they feel it is the best time to carry them out. However, these tests often do not reveal the primary cancer.

If the results of the tests are not likely to affect which treatment you are offered, this will be discussed with you.

If you are in hospital, you may be discharged home while you await test results and further investigations. You will be asked to come back to clinic to meet your doctor and discuss your care and treatment options.
You may decide that you do not want to have treatment, in which case you will not be offered further tests, but you will still be supported by the CUP team.

You will be referred to the palliative care team in the hospital or the community. These are nurses and doctors who are specialists in managing symptoms, providing emotional and psychological support for you and your family and help you to maintain a good quality of life.

**Treatment for CUP**
After investigations, if the primary site of the cancer is found, you will be referred to a consultant who specialises in that area. They will take over your ongoing care and treatment.

If the primary cancer is not found, then cancer of unknown primary (CUP) is confirmed. Even though the primary site has not been identified, tests may suggest possible places where the cancer may have started and your consultant can offer treatment based on this information.

Treatment for CUP may help to control the disease for some time, but does not offer a cure. The CUP team will consider where your secondary cancer is, whether you are likely to benefit from treatment and whether you are well enough to manage any side-effects.
The most common treatments for CUP are chemotherapy, radiotherapy and hormonal therapy. Use of these will depend on factors such as your personal health and medical history.

Support for people diagnosed with CUP
Being diagnosed with cancer of unknown primary can be particularly difficult because of the uncertainty surrounding it. Sometimes it may be hard to make sense of what is happening to you and can be difficult to explain to other people. Getting to the point of diagnosis may have been lengthy and exhausting. As well as coping with this you may have difficulty dealing with the symptoms of the disease of the treatment itself.

You will be supported throughout your investigations and treatment by the CUP team. You will have a clinical nurse specialist (CNS) who will be your point of contact. They will co-ordinate your care, including arranging any tests, investigations and treatments you might need. They can also offer support to you and your family or cares.

If you have any questions or particular worries, please do not hesitate to speak to your CNS.
Macmillan information and support centre
Offers advice, support and provides practical, medical, emotional and financial help to anyone affected by cancer.

Helpline: 0808 808 0000

Barnet Hospital:
Level 1, inside main entrance
Open Monday to Friday, 10am-4pm

Royal Free Hospital:
Oncology out-patients, ground floor
Open: Monday, 1-4pm
      Tuesday-Thursday, 10am-4pm
      Friday, 10am-1pm

Cancer of Unknown Primary (CUP) Foundation:
www.cupfoundjo.org

Royal Free London website
For more information about cancer services at the Royal Free London, visit our website:
www.royalfree.nhs.uk/services/services-a-z/cancer-services
Contact details
Your CNS can be contacted on the numbers below. You can either contact them by telephone (you may need to leave a message on the answerphone) or by using the hospital bleep system.

Barnet Hospital
Tel: 020 8216 4600 and ask to speak to the acute oncology team

Royal Free Hospital
Tel: 020 7794 0500 ext 38789 or ask for bleep 2748

If you have any feedback on this leaflet or for a list of references for it, please email: rf.communications@nhs.net

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please ask a member of staff.

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