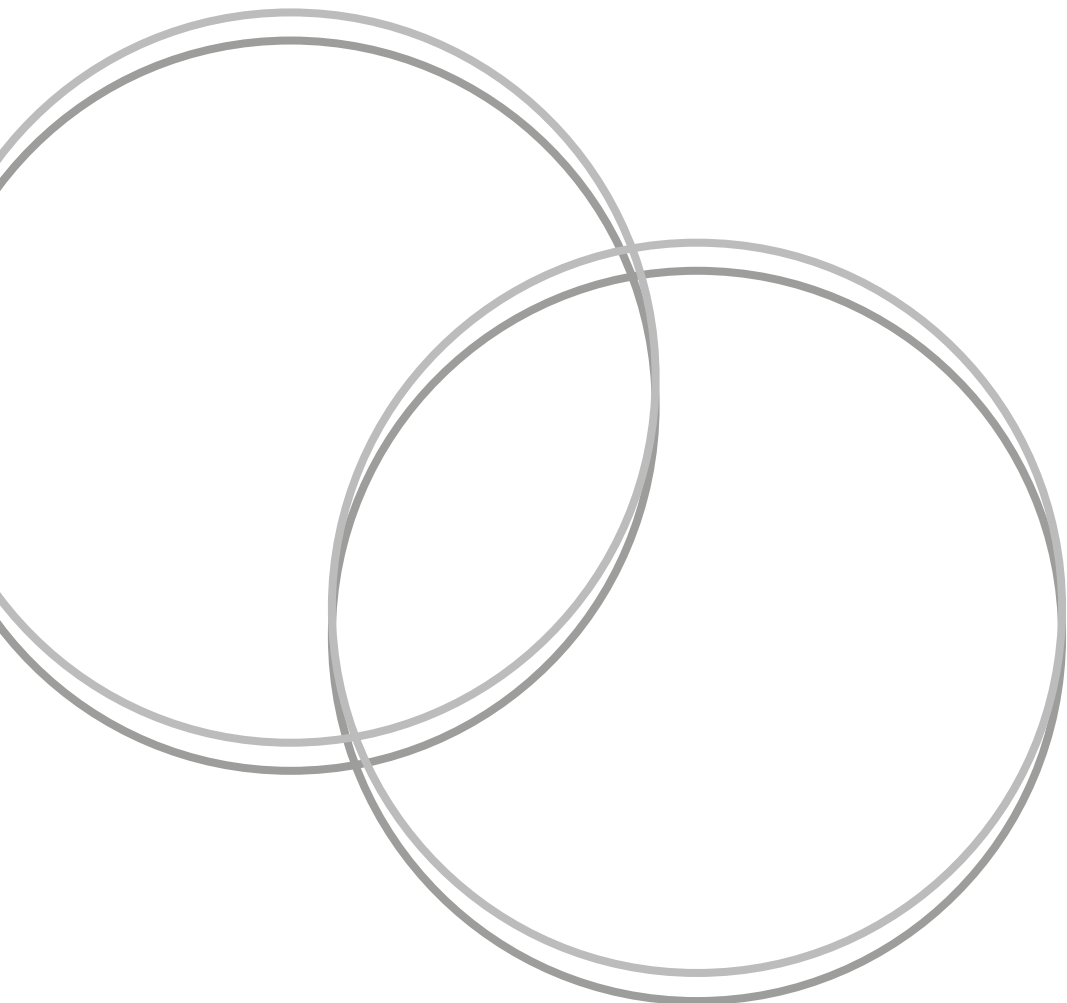




Oxford University Hospitals
NHS Foundation Trust

Cancer of Unknown Primary (CUP)

Information for patients



Cancer of unknown primary (CUP) is a term used when 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 to include the liver, lungs and bones.

With a CUP, despite many tests the primary site of the cancer cannot be found.

Why can't the primary cancer 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 (e.g. 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 treatment 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 shows what type of cancer you have.
- **Chest X-ray and sometimes X-rays of other areas of your body.**
- **Imaging scans – CT scans, MRI scans and PET scans.**
Each has their own value and may be requested by the doctor caring for you.
- **Urine and stool (faeces/poo) specimens may be collected.**
These can show abnormal cells (in urine) or hidden blood (in stools).

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

You may decide that you do not want to have treatment, in which case, you will not be offered further tests. If you decide to choose this option you will be offered palliative care. This aims to control your symptoms and help you to keep your quality of life. You may be referred to the community palliative care team for support when you leave hospital.

You may be discharged home from hospital whilst you await test results and further investigations. You will be asked to come back to clinic to meet your doctor and discuss your onward care and treatment options.

Treatment for CUP

After the 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 symptoms of the disease or the treatment itself.

You will be supported throughout your care by the CUP team. You will have a key-worker who is usually a specialist nurse. 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 carers.

Overleaf are the CUP specialist nurses' contact details and other useful resources.

Contact details

CUP Specialist Nurses

Churchill Hospital

Telephone: **01865 235 058**

Please leave a message on the answerphone.

John Radcliffe Hospital

Telephone: **01865 235 037**

Please leave a message on the answerphone.

The Specialist Nursing Team is not an emergency service.

For urgent help or advice, please contact an out-of-hours GP or emergency services.

Alternatively, you can contact the Oncology Triage Service on:

Telephone: **01865 572 192**

(open 24 hours a day, 7 days a week)

Useful information

Macmillan Cancer Support

Telephone: **0808 808 0000**

(8am to 8pm, 7 days a week)

Website: www.macmillan.org.uk

Maggie's Cancer Information Centre

Churchill Hospital, Oxford

Telephone: **01865 225 690**

Website: www.maggiescentres.org

CancerHelp UK (patient information website of Cancer Research UK)

Website: www.cancerhelp.org.uk

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

Website: www.cupfoundjo.org

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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May 2024

Review: May 2027

Oxford University Hospitals NHS Foundation Trust
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