University College Hospital

Cancer of an Unknown Primary Service
Information for patients, relatives and carers
If you need a large print, audio, braille, easy read, age-friendly or translated copy of this booklet, contact us on 020 3447 4791. We will do our best to meet your needs.

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1. Introduction
This booklet is for patients who use the Cancer of Unknown Primary Service at University College London Hospital NHS Foundation Trust (UCLH). The service provides expert, specialised and holistic care and information.

You may have been referred to the service by your GP, your local hospital consultant or through our Accident and Emergency (A&E) Department. This booklet outlines some of the people you may meet and the tests you may have. Your doctor will discuss any specific tests or treatments with you, including the risks and benefits, and offer you written information to support this.

2. What is cancer of an unknown primary?
The term primary cancer refers to the area of the body where the cancer starts (for example breast). When cancer cells spread to other areas of the body, this is known as secondary cancer.

Cancer of unknown primary (CUP) is a term used when cancer has been diagnosed but the original site of the cancer cannot be found.

Cancer with an unknown starting point is referred to in different ways. It may also be called tumour of unknown origin or carcinoma of unknown primary.

About 5% of cancer patients will have a CUP diagnosis. CUP patients will develop symptoms caused by a secondary cancer but despite many tests, the primary cancer cannot be found.

Why can’t my primary cancer be found?
There are many reasons why the primary cancer can’t be identified:
• It may be too small to be seen on the scan.
• It may have disappeared although it has already spread.
• Your own immune system may have destroyed the primary cancer but not the secondaries.
3. Multidisciplinary team
A multidisciplinary team (MDT) is a team of professionals who will be caring for and supporting you at University College Hospital. This team consists of experts in different areas of medicine and care, such as doctors and nurses.

Clinical nurse specialist and key worker
Clinical nurse specialists (CNSs) are qualified nurses with training and extensive experience in supporting patients with your diagnosis. You will have a named CNS, referred to as your key worker. Your key worker will be your main point of contact for any questions or concerns you may have about your tests or treatment, and they will support you throughout your care.

Your CNS/key worker is: _______________________________

Telephone: _________________________________________

Consultant medical and clinical oncologists
Oncologists are specialists in the chemotherapy or radiotherapy treatment used to treat cancer.

The lead consultant for CUP is Dr Kai-Keen Shiu

Contact via PA: 020 3447 9093

Macmillan support worker
The Macmillan support worker works alongside the CNS. They will help to support you and be a consistent and additional point of contact for you.

Telephone: ___________________________________________________________________

4. CUP multidisciplinary team meeting (MDM)
This is a weekly meeting where the multidisciplinary team, including your CNS and doctor, discuss your care and review your treatment.
5. Investigations

You have already had various physical examinations, imaging tests, biopsies and blood tests to confirm that you have cancer but the original site of the cancer isn’t known.

In the Cancer of Unknown Primary Clinic, you will have a physical examination by the doctor and further specialised tests to try to identify the primary site. This is important as different cancers are treated differently, and if the primary site is identified you will be treated by the appropriate team who specialises in that tumour group.

What tests will I have?

• Some cancers produce proteins which can be measured in the blood (called tumour markers) so you will have **blood tests** to check for those. The tumour markers may give us more information to find the primary cancer.

• You may be offered a **biopsy** where a small piece of tissue is taken from a secondary cancer site. This is a very important test as it may give us more information about your cancer and help us identify the primary site. Further genetic or molecular profiling tests may be carried out on your biopsies. These tests look at the structure of your tumour cells and may help to determine the type of tumour you have, and where the primary site is. If you are going to have these tests, your doctor will explain them in more detail.

• There are a number of **scans** that can help with the investigations – ultrasound scans, CT scans, MRI scans and PET scans. Each scan is chosen for their specific value and specific reasons, and is carried out at a specific stage during your treatment. You will be given written information about what to expect.
Depending on your health history, you may only need one or two of these tests, or you may need all of them. However, the tests may not always reveal the primary site of your cancer.

Sometimes it may not be appropriate to carry out certain tests. This is either because they will not be helpful in your case, or you may be too unwell to undergo further tests or treatments.

6. Treatment for CUP

If the primary cancer is found, you will be referred to a consultant who specialises in that tumour type. If it isn’t identified, cancer of unknown primary (CUP) will be confirmed.

Treatment for CUP may help to control the disease for some time but it will not cure it. Even though your primary cancer has not been identified, tests may suggest where the primary site is. If this is the case, your consultant may give you treatment for that specific primary site tumour.

The most common types of treatment for CUP are chemotherapy and radiotherapy. Treatment is always tailored to the individual patient.

7. Research trials

UCLH runs a range of clinical studies aimed at improving knowledge, treatment and outcomes in cancer care. Your doctor will talk to you about whether you are suitable to take part in a research study. If you decide to participate, you will have the right to withdraw from a study at any time. You will not have to give a reason for doing so and it will not affect your care in any way.
8. Holistic Needs Assessment
We know that having investigations and treatment can affect your quality of life in different ways. We will offer you a Holistic Needs Assessment (HNA) to help identify any particular issues or concerns you may have. This can help to ensure that we are offering you the most appropriate care plan. The assessment will include questions relating to your general wellbeing, social situation and support network. If you haven’t been offered an HNA but feel you may benefit from it, please speak to your key worker.

9. Communicating with your GP
We will inform your GP about your diagnosis within 24 hours and include them in all correspondence regarding your diagnosis, treatment and care. You will also be automatically copied into this correspondence.

10. Out-of-hours support
If you are currently receiving treatment and have a medical emergency out of hours, please go to your local A&E Department, or contact the oncology advice line on 07947 959020.
11. Macmillan Support and Information Service

The Macmillan Support and Information Service is based on the ground floor of the University College Hospital Macmillan Cancer Centre. It provides a relaxed and informal space where patients and their families and friends can ask questions and talk through their concerns with specialist staff. The team offers support at any stage of patient care – from diagnosis, throughout treatment and beyond.

You can access a range of information resources, including leaflets and booklets, and be referred onto appropriate services such as:

- complementary therapy
- wig and scarf tying advice
- diet and nutrition advice
- welfare and benefits, and
- psychological care and counselling.

There is also a programme of supportive activities on offer to help you manage the effects of treatment and meet other people who share similar experiences.

You don’t need an appointment to visit the Macmillan Support and Information Service and the team will see you as quickly as possible.

Telephone: **020 3447 8663**

Email: **supportandinformation@uclh.nhs.uk**

Opening hours: 9am to 5pm, Monday to Friday
12. Patient Advice and Liaison Service (PALS)

PALS is a patient-friendly, easy-to-access service designed to provide a personal contact point to assist patients, relatives and carers. If you have a problem that you have been unable to resolve, PALS can help you.

The University College Hospital PALS office is located on the ground floor of the main hospital building and is open from 9am to 4pm, Monday to Friday.

Telephone: 020 3447 3042
Email: uclh.PALS@nhs.net

13. Further information

Cancer of an Unknown Primary Foundation

Offers information and support to CUP patients, their families and friends.

www.cupfoundJo.org

Macmillan Cancer Support

Provides support and information on the practical, social and financial effects of cancer for patients and those close to them.

www.macmillan.org.uk
Telephone: 0808 808 00 00

Cancer Research UK

Provides information about cancer and clinical trials.

www.cancerresearch.org.uk
Telephone: 080 800 4040

University College London Hospitals NHS Foundation Trust cannot accept responsibility for information provided by external organisations.
14. Contact us

Cancer of Unknown Primary CNS
(Monday to Friday, 9am to 5pm)
Telephone: 020 3447 4791
Mobile: 07944 139704
Dr Kai-Keen Shiu via PA: 020 3447 9093

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London NW1 2BU

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Switchboard: 020 3456 7890
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15. Space for notes and questions
16. How to find us