

Cancer of Unknown Primary

Cancer of Unknown Primary (CUP) is a term used when cancer has been diagnosed but the original site of the cancer cannot be found, despite all appropriate investigations. CUP accounts for approximately 2-3% of cancer diagnoses. In patients with CUP, symptoms are caused by one or several secondary cancers, and despite many tests the primary cancer cannot be found.

Why can't the primary cancer be found?

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

- The primary cancer may be too small to be seen on a scan.
- The primary cancer may have disappeared although it has already spread. This can happen because it was unable to maintain its own blood supply.
- Your own immune system may have destroyed the primary cancer but not the secondary cancers.

Your CUP Multidisciplinary Team

Your care will be provided by a group of experts called a multidisciplinary team (MDT), including:

- Oncologists (specialist cancer doctors)
- Radiologists (doctors who specialise in X-ray tests and scans)
- Pathologists (doctors who specialise in identifying different types of cells using a microscope)
- Palliative Care team
- Specialist Nurses (sometimes called key workers)

We specialise in the treatment of CUP and work closely together to make decisions about your care. We have a weekly meeting, held on a Wednesday, called the MDT meeting, where we discuss all our patients' cases very carefully and decide what the best next steps are.

The consultant who will be caring for you depends on the treatment that you receive. Your consultant may change if you go on to receive another type of treatment. If you are ever unsure about who is in charge of your care, please ask a member of staff.

More information about CUP is available in:

Macmillan booklet: Understanding cancer of unknown primary. The aim of this leaflet is to give you some information about our team and the services available.

Information for Patients

Outpatient appointments

Appointments take place either at the Queen Elizabeth Hospital Birmingham (QEHB) in the Cancer Centre, Heritage Building or Good Hope Hospital. We will send you an appointment letter and may also contact you by telephone to tell you which clinic you need to attend.

We will try not to keep you waiting on the day of your appointment, but delays can sometimes happen. You may want to have another person with you; this may be a relative or friend, who can help you remember the information the doctor gives you. If you have any questions, it may be helpful to write them down and bring them with you.

Support from your Specialist Nurse (key worker)

You will receive a contact card informing you who your specialist nurse or key worker is and how to contact them.

Your specialist nurse will have specialist knowledge and experience of CUP. They will support you and those close to you, through your diagnosis and any treatment you may have.

At your first meeting with your specialist nurse, you will be offered a Holistic Needs Assessment in order to identify your individual concerns around diagnosis and treatment.

The specialist nurses are available in the clinic area and will often join you when you see your doctor. They can also offer you appointments separately and are happy to speak to you on the phone if you prefer.

Information and Support

Support Group

There is currently no support group available at the University Hospitals Birmingham for CUP. There are websites with information regarding CUP and these can be accessed either via www.macmillan.org.uk or via CUP foundation at www.cupfoundjo.org.

Psychology Services

Some people may find it beneficial to be able to talk to someone about the emotional effects that having a cancer diagnosis can cause as cancer can affect the whole person, not just their body.

A cancer diagnosis can also affect other members of the family so even if it is not, you yourself who has cancer but someone close to you, they may benefit from talking to someone in confidence. You can either access this support by contacting your CNS on 07718863905 and asking her to refer you to the Clinical Psychology service at QEHB

Oncology University Hospitals Birmingham
Mindelsohn Way, Edgbaston, Birmingham B15 2GW
Telephone: 0121 627 2000

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email interpreting.service@uhb.nhs.uk