

Malignancy of unknown origin (MUO) and cancer of unknown primary (CUP)



Information for patients

This leaflet explains the next steps to help us make a diagnosis where there are abnormalities in your initial test results and decide the best treatment for you. If you have any questions or concerns, please do not hesitate to speak to any member of the team caring for you.

- **Malignancy of unknown origin (MUO)** means that cancer is suspected but further tests are needed to determine where it originated.
- **Cancer of unknown primary (CUP)** means that cancer has been confirmed, however, despite further investigations the original site of the cancer (the primary cancer) cannot be identified.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.
Ensuring your safety is our primary concern.

Your test results may have shown some abnormalities. These may represent changes outside the normal expected results. We need to investigate what might have caused this. This includes ruling out the possibility of cancer.

Where cancer is suspected but further tests are needed to determine where it originated, this is called malignancy of unknown origin (MUO). This information leaflet explains what happens next, to help us reach a diagnosis and decide the best treatment for you.

What happens after you have been referred?

Once your referral has been received, we will review you and arrange a series of tests to help us make a diagnosis (please refer to the Macmillan 'Understanding cancer of unknown primary' booklet). You may need some or all of these tests depending on what the team thinks is best to help diagnose your condition.

To keep the number of appointments to a minimum, the team will review the results of these tests and, where appropriate, phone you to let you know the next steps in your pathway.

Please make sure we have your latest contact details so we can get in touch with you.

How will we make decisions about your diagnosis and treatment?

If cancer is ruled out then you will be discharged back to your GP. If you have other symptoms that need to be treated, you will be referred to the appropriate specialist.

If any of the investigations confirm a cancer diagnosis your case will be

referred to a specialist multidisciplinary team (MDT) meeting. This is where a team of specialist doctors and nurses will discuss all your results and decide on the best management.

You will then be offered an appointment with the specialist team who will help you with your diagnosis, explain the next steps in your care and let you know if you need any further tests.

In a small number of cases, we may be unable to identify an original site of cancer. This is known as cancer of unknown primary (CUP) (please refer to the Macmillan 'Understanding cancer of unknown primary' booklet). If so, your case will be referred to the CUP MDT at Guy's and St Thomas' Hospitals for their specialist opinion regarding all your test results and to decide on the most appropriate management (this may include further tests or investigations).

Who can you talk to?

If you are in hospital, you will be supported by the CUP/MUO/Acute Oncology team – a team of clinical nurse specialists (CNSs) and consultants. You may be visited on the ward to make sure that you understand what is happening. You and your family can ask questions or share concerns with this team.

If you are at home, you will be contacted by a CNS from the MUO and CUP team. You may also be offered an appointment to come and see us in clinic.

You can contact your CNS for psychological support and practical advice. If you have any questions about tests or what to expect from appointments, your CNS can help. We are here to support you and your family, so always contact us if you have any worries or concerns.

You and your family may find the uncertainty about what is happening stressful, so we will do our best to support you. If you have any questions or concerns, please do not hesitate to speak to the doctors or nurses looking after you.

Support from your clinical nurse specialist (CNS)

Your CNS will have specialist knowledge and experience of MUO and CUP. They will support you and those close to you through your diagnosis.

The CNS is 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.

Who to contact

- King's College Hospital patients: **020 3299 5467** (Monday to Friday, 9am to 5pm)
- Princess Royal University Hospital patients: **01689 864712** (Monday to Friday, 9am to 5pm)

If you are particularly concerned about your symptoms outside these hours, please dial 111 or attend your nearest A&E.

In an emergency dial 999.

Further information and support

You can also obtain further information and get additional support from the Macmillan Cancer Support Centre on **020 3299 5228** or via email: **kch-tr.macmillan1@nhs.net**

Feedback on your cancer care

If you would like to feedback on the cancer care you have received at King's or any aspect of our cancer services, we would love to hear from you.

Please get in touch by emailing us on **kch-tr.macmillan1@nhs.net**. We may contact you by phone for feedback once you have been discharged, if you don't wish to receive a call please speak to your nurse or contact

020 3299 3682 or email **kch-tr.kingsppi@nhs.net**

MyChart

Our MyChart app and website lets you securely access parts of your health record with us, giving you more control over your care. To sign up or for help, call us on **020 3299 4618** or email **kings.mychart@nhs.net**. Visit **www.kch.nhs.uk/mychart** to find out more.

Sharing your information

King's College Hospital NHS Foundation Trust has partnered with Guy's and St Thomas' NHS Foundation Trust through the King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas' hospitals. King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts share an electronic patient record system, which means information about your health record can be accessed safely and securely by health and care staff at both Trusts. For more information visit www.kch.nhs.uk.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams.

Tel: 020 3299 4618

Email: kings.pals@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Interpreting and Accessible Communication Support on 020 3299 4618 or email kings.access@nhs.net