

Malignancy of unknown origin (MUO) / Cancer of unknown primary (CUP)

Information for patients

This leaflet explains the next steps in helping us to make a diagnosis where there are abnormalities in your initial test results and in deciding the best treatment for you at Princess Royal University Hospital. To be read in conjunction with the Macmillan support booklet: 'Understanding cancer of unknown primary'. If you have any questions or concerns, please do not hesitate to speak to any member of the team caring for you.

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.

www.kch.nhs.uk

Your test results may have shown some abnormalities. These may represent changes to normal appearances outside the expected results and need to be investigated to determine what might have caused this, which includes ruling out the possibility of cancer.

Where the suspicion of cancer is found but further tests are required 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 how we decide the best treatment for you.

What happens after you have been referred?

Once a referral has been received, a member of the MUO/CUP team will review you and arrange a series of test 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 require treating then 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 meeting (MDM). 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 to see the team that is best able to 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). In this instance your case will be referred to the CUP MDM at Guy's and St Thomas' Hospitals for their specialist opinion regarding all your test results and 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. They will visit you 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 the CNS from the MUO 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 specialist nurse will be able to 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/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

Tel: 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 **07813 399714** 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**

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as 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'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

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. The PALS office is in the main hospital foyer at PRUH and they would be happy to advise you.

PALS at Princess Royal University Hospital, Farnborough Common, Orpington, Kent BR6 8ND

Tel: **01689 863252**

Email: kch-tr.palspruh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net

Networked Care

Corporate Comms: 3079