

# The role of the clinical nurse specialist and key worker for cancer of unknown primary

## Information for patients

### Introduction

This leaflet has been designed to give you information about the role of the clinical nurse specialist (CNS) for cancer of unknown primary (CUP). We hope it will answer some of the questions that you or those who care for you may have at this time.

This leaflet is not meant to replace the consultation between you and your medical team, but aims to help you understand more about what is discussed.

### What is a clinical nurse specialist?

The CUP CNS is an experienced nurse who specialises in the care and support of people with cancer of unknown primary. The CNS works closely with all members of the CUP multidisciplinary team (MDT) and provides links with other healthcare professionals, both in the hospital and in the community, to ensure continuity of care.

The CNS provides:

- emotional support in dealing with the diagnosis
- information and advice about CUP and its treatment
- advice about symptoms and their management
- information about other supportive organisations
- a link with other staff and services concerned with your care
- basic benefits advice, and they can put you in touch with benefits advisors

Your CNS will make every effort to ensure that you have your questions answered and concerns discussed. They can also provide information to your relatives and friends.

Your CNS may also be designated as your key worker. Your key worker is the point of contact for you and those who care for you during your illness.

### What does a key worker do?

There will be a number of different people involved in your care. Your key worker acts as a link between them throughout your treatment. They work closely with the hospital team and the specialist cancer services provided in your local area, such as your GP or district nurses. If required, your keyworker will refer you (with your consent), to other professionals. Your key worker may change during your treatment, according to your needs.

---

## Who will be my key worker?

In most cases it will be your CNS. However, it is not necessarily the same person throughout your treatment. Your key worker may change as your needs change, but it is very important that you know who your key worker is and how to contact them.

In some circumstances it may be more appropriate for another healthcare professional, other than your CNS, to be your key worker. This person could be a:

- chemotherapy nurse
- GP
- palliative care nurse
- social worker
- district nurse

## How do I contact the CUP CNS?

Imperial College Healthcare NHS Trust has a Macmillan navigator service for access to your CNS and other members of the clinical team. Navigators can also help with queries and provide a range of other information, help and support relating to your care. The service is available Monday to Friday 08.00–18.00 and 09.00–17.00 at weekends. Telephone: **020 3313 0303**



## Other sources of information and support

### **Macmillan Cancer Information and Support Service at Charing Cross and Hammersmith hospitals**

The information centre at Charing Cross Hospital and the infopod at Hammersmith Hospital provide emotional and practical support, as well as signposting advice to anyone affected by cancer. These drop-in services are set in friendly, non-clinical environments in which people affected by cancer can discuss private and emotional needs with dedicated Macmillan information professionals.

The **information centre** is located on the ground floor of Charing Cross Hospital and is open (except bank holidays):

- Monday and Friday, 09.00–17.00
- Tuesday, Wednesday, Thursday 09.00–16.00

Telephone: 020 3313 0171

The **infopod** is located on the ground floor of the Garry Weston Centre at Hammersmith Hospital and is open (except bank holidays):

- Monday and Tuesday 09.00-17.00
- Wednesday, Thursday, Friday 09.00-16.00

Telephone: 020 3313 4248

### **Maggie's Cancer Caring Centre**

Maggie's is a cancer charity that provides emotional, practical and social support that people with cancer may need. This drop-in centre combines striking buildings, calming spaces, professional experts offering support, and the ability to talk and share experiences with a community of people who have been through similar experiences.

---

Maggie's West London is located in the grounds of Charing Cross Hospital but please note it is independent of our hospital. The centre is open Monday to Friday, 09.00-17.00. For more information please call 020 7386 1750.

### **Macmillan Cancer Support Helpline**

This is a free helpline for people affected by cancer who have questions about cancer, need support or just someone to talk to. It is open from Monday to Friday, 09.00–20.00 (interpretation service available). Telephone: 0808 808 0000

### **Information Prescription Service**

This service contains reliable and accurate cancer information to help patients manage their health more effectively. Log onto [www.nhs.uk/ips](http://www.nhs.uk/ips) and enter your condition to start using the service.

### **Jo's Friends ([www.cupfoundjo.org](http://www.cupfoundjo.org))**

This foundation was established by those whose lives have been touched by CUP. For patients and carers they are friends in adversity, stronger for working together although physically apart. The foundation is committed to improving the situation and experience of CUP patients by a number of key activities including:

- providing information and support to CUP patients and those who care for them
- raising awareness of CUP
- promoting improved diagnosis and treatment
- undertaking, encouraging and supporting CUP research with the ultimate goal of seeing the end of CUP by 2020

## **How do I make a comment about my visit?**

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at [pals@imperial.nhs.uk](mailto:pals@imperial.nhs.uk). The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to express your concerns in **writing** to: Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY.

## **Alternative formats**

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on **020 3312 5592**.

We have a free and premium wi-fi service at each of our five hospitals. For further information please visit our website: [www.imperial.nhs.uk](http://www.imperial.nhs.uk)