



The Clatterbridge
Cancer Centre
NHS Foundation Trust

Cancer of Unknown Primary

General information



A guide for patients and carers

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This leaflet is for patients who have a provisional diagnosis known as Cancer of Unknown Primary (CUP). This leaflet explains what is meant by CUP and details what investigations and potential treatments you may receive. CUP means that a secondary cancer has been found but as yet we have not been able to identify the primary cancer.

- Primary cancer is usually named after the part of the body where a cancer has started
- Secondary cancer means that the cancer has spread to another site, other than where it originated. A secondary cancer can sometimes be known as a metastases

What is CUP?

CUP is a general term that covers many different types of cancer. It affects about 3-5% of people diagnosed with cancer.

People with CUP often have more than one secondary cancer. It is more common in older people but younger people can also get CUP.

Your doctor may suspect you have CUP if early tests don't find the primary cancer, but the diagnosis won't be certain until you've had all the appropriate tests. Cancer doctors will try to find the primary cancer, because it helps them plan the most effective treatment for you. Some people with suspected CUP may be too unwell to have lots of tests.

Sometimes, tests will find the primary cancer. When this happens, the cancer is no longer called CUP. It is named after the primary cancer and treated accordingly.

Even when the primary cancer cannot be found, your specialist may be able to suggest a probable part of the body where the cancer has started. This will be based on your specialist's experience, where the secondary cancers are, your symptoms and the test results.

Why the primary cancer can't be found

There are different reasons why a primary cancer can't always be found:

- The secondary cancer or cancers have grown and spread very quickly, but the primary is still too small to be picked up on scans
- The cancer has been growing in more than one area of the body for some time, making it difficult to see where it started
- The primary cancer might have disappeared, even though it has spread to other parts of the body

Symptoms of cancer of unknown primary

People affected by advanced cancer may have some of these symptoms:

- Unexplained weight loss
- Loss of appetite and/or feeling sick



- Feeling extremely tired all of the time
- Looking pale
- Persistent pain
- A cough that doesn't go away
- Breathlessness caused by fluid collecting around the lungs (pleural effusion)
- Yellowing of the skin and eyes (jaundice)
- Swelling of your tummy (ascites)
- Your lymph glands (glands in your neck, groin or under arms) may be swollen and feel hard or cause pain if they're pressing on tissue or nerves nearby
- Headache, confusion and loss of balance
- Bowel changes
- Nausea and vomiting

Investigation/tests

Having tests can take up a lot of your energy and time. You will only be put through tests if they are likely to make a difference to your overall treatment or care.

We will endeavour at all times to include you and your family in decisions regarding further tests and the benefits of treatment.

Common tests are:

- X-rays
- CT scan (computerised tomography) this takes lots of x-rays of an area of your body to create a detailed picture. The scan may last 10-30 minutes. You may be given a drink or an injection of dye beforehand
- MRI scan (magnetic resonance imaging) uses magnetism to build up a set of pictures instead of x-rays. You will be asked to lie flat inside the tunnel scanner, for sometimes up to an hour
- Ultrasound scan, this is using sound waves to create a picture of an area inside your body. It involves putting gel onto your abdomen and then rubbing a small device over the area
- Blood tests, taking a small sample of blood from your arm
- Biopsy, this involves taking a small tissue sample from the cancer. If you require a biopsy, you will be given more information on the procedure

Treatments

CUP is a cancer that has already spread to other parts of the body and treatment for CUP is given to improve symptoms and prolong life but does not usually cure it. The aims of treatment would be to slow down the growth of the cancer, relieve any symptoms and help you live longer. This is referred to as palliative treatment.



Chemotherapy, radiotherapy, surgery, steroids and other anti-cancer treatments can all be used for palliative treatment.

A) Chemotherapy - The use of anti-cancer drugs to destroy cancer cells in the body or control the disease. Chemotherapy is given through a drip, or as a tablet. Chemotherapy is the treatment most often offered in cancer of unknown primary because it circulates the whole body by travelling through the bloodstream. If chemotherapy is considered, the cancer doctor may suggest giving you chemotherapy to treat a certain type of cancer. This is because even when the primary cancer cannot be found, sometimes the test results give an indication of what type of cancer it may be.

B) Radiotherapy - The use of high energy rays (like an x-ray) to destroy cancer cells. Radiotherapy can also be used to reduce pain and other symptoms if targeted at a certain area that the cancer is affecting. Radiotherapy and surgery are targeted to a small area and therefore are not often used in treating cancer of unknown primary. However, they may be used to relieve symptoms in a specific area.

C) Surgery - Is an option if the secondary cancer affects localised area of the body or if removing the secondary cancer is likely to relieve symptoms or improve outcome.

Sometimes, chemotherapy, radiotherapy and surgery are not appropriate and the doctor will discuss with you what other palliative medicines may be given. This may be due to many factors and could be because the disadvantages of treatment outweigh the benefits.

Factors that influence treatment options are:

- Extent and location of secondary cancer (metastases)
- Potential benefits and risks of treatment for you
- Your general health and fitness
- Your wishes and consent

Although you may not be investigated further or offered any treatment, the team will always ensure that you have the optimum care and input required to keep you comfortable. Supportive care, such as medications for example anti-sickness, painkillers and steroids are an important part of treatment for people with CUP. As well as medication, you may be referred to the palliative care team and district nurses for further psychological and symptom control support, in addition to information regarding support groups and complementary therapies.

The doctor will discuss all available treatments with you and talk through the potential risks, benefits and side effects.

Multi-Disciplinary Team meetings

All patients with a diagnosis of cancer are discussed at an appropriate Multi-Disciplinary Team meeting (MDT). These meetings involve a group of health professionals who specialise in your particular diagnosis and a plan of action will be made. The MDT should also assign you a key worker, most commonly the clinical nurse specialist who is a clear point of contact and provides ongoing support.



CUP Team

There is a specialist CUP team who aim to see inpatients within 24 hours of receiving a referral and outpatients within two weeks in clinic.

The role of the CUP team is to:

- Request appropriate medical tests
- Offer symptom control
- Access to psychological support
- Provide information to patients and other medical teams
- Discuss at CUP MDT

Your CUP doctor is

Name: _____

Your CUP Clinical support worker is

Name: _____

Contact details: _____

The Role of your CUP support worker is to act as a key worker to:

- Coordinate investigations/care
- Liaise with your GP and community support services
- Provide information, advice and support about diagnosis, treatment, palliative care, spiritual and psycho-social concerns
- Be an advocate for you
- Meet with you/your family at an early stage
- Conduct a Holistic Needs Assessment

CUP Administration Support

Telephone - direct line: 0151 556 5031

Via switchboard: 0151 556 5000 (ask for Extension: 5031)



What is a Holistic Needs Assessment?

People with cancer often require care, support and information, in addition to the management of their actual cancer or condition.

A Holistic Needs Assessment (HNA) is a discussion with your cancer doctor or nurse to talk about your physical, emotional and social needs. The focus is on you as a whole – not just your illness. Your cancer doctor or nurse will need information from you. However, you decide how much information you would like to share about your current situation.

A HNA is an opportunity for you to talk about any worries or concerns you may have. It will help to clarify your needs and ensure that you are referred to the relevant services. A HNA is undertaken especially for those patients with a diagnosis of CUP, as this diagnosis of cancer is always very difficult. Not knowing where the cancer is or how it can be effectively treated can be psychologically, emotionally and physically difficult to cope with and comprehend. The HNA will enable the correct support advice and guidance to be given at an appropriate time for you.

Do I have to have a Holistic Needs Assessment?

An initial HNA will be offered around the time of diagnosis and, if necessary, during other stages of your care.

You can contact your clinical support worker (Key Worker) if you have any issues you wish to discuss.

With your agreement, the person carrying out your assessment will refer you to other services that may be of help. Alternatively, if you prefer, you will be given written information about these services to access when you feel ready. This may also include information and support for relatives and carers.

Services and general advice

If you have any questions about your CUP diagnosis or if you need information or support or someone to talk to, you can contact Macmillan Cancer Support.

Freephone to cancer specialists: **0808 808 00 00**

Open between the hours of 9am - 8pm, Monday - Friday.

The Macmillan Cancer Information Centre is based in the main reception on the Clatterbridge Cancer Centre - Wirral site and Liverpool site

Telephone: 0151 556 5570

The Macmillan Information Centres can provide:

- Booklets, advice and information free of charge
- Financial advice from a benefits advisor
- Information regarding support groups
- Complementary therapy services



Useful organisations

Jo's friends CUP Foundation

www.cupfoundjo.org

Macmillan Cancer Support

telephone 0808 808 00 00

NHS Choices

www.nhs.uk

Cancer Research UK

www.cancerhelp.org.uk

Age UK

www.ageuk.org.uk

Detailed info about money and debt

www.direct.gov.uk

Citizen's advice

www.citizensadvice.org.uk

Carers UK

www.carersuk.org

Wirral Holistic Care Services

www.wirralholistic.org.uk

St Helen's Cancer Support Group

01744 21831

The John Holt Cancer Support Foundation Warrington

01925 240054

www.jhcancersupport.com**Sunflowers**

0151 726 8934

www.liverpoolsunflowers.com**Sefton Cancer Support Group**

01704 876613 (24 hr. helpline)

www.seftoncancersupport.org.uk**Widnes & Runcorn Cancer Support Centre**

0151 423 5730

www.widnesruncorncsg.co.uk**Lyndale Knowsley Cancer Support Centre**

0151 489 3538

www.knowsley-cancer-support.co.uk**Maggie's Merseyside at Clatterbridge**

0151 334 4301

www.maggiescentres.org/merseyside

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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