Patient information

Cancer of Unknown Primary (CUP)

Cancer Services

You have for the time being been given a cancer diagnosis known as Cancer of Unknown Primary (CUP). This means that a secondary cancer has been found but as yet we have not been able to identify a primary cancer.

Primary cancer means where the cancer has started, with secondary cancer meaning that the cancer has spread to another site other than where it started.

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's more common in older people, but people in their 40s and 50s 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. 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's named after the primary cancer and treated accordingly.

Even when the primary cancer can't be found, your specialist may be able to suggest a probable part of the body where the cancer started. This will be based on your specialist's experience, where the secondary cancers are, your symptoms and 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 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 (ascities).
- 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 shouldn’t be put through these if they aren’t 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.

Common tests are:

- X-rays.
- CT scan (computerised tomography). 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. Sometimes the doctor may use a fine needle to do this or if the cancer is not near the skin surface, they need to use a scan to guide the needle.

Treatments

CUP is a cancer that has already spread to other parts of the body and therefore is not a curable illness.

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.

Palliative treatment does not necessarily mean any treatment. Chemotherapy, radiotherapy, surgery, steroids and other anti-cancer treatments can all be used palliatively.

- 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.
- 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.
- Surgery- An operation to remove an area of cancer. Not generally used in a cancer that has spread to other parts of the body.

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 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.

Radiotherapy and surgery are more localised treatments 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.

Sometimes chemotherapy, radiotherapy and surgery are not appropriate and the doctor will discuss with you what other palliative medicines maybe 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 best 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 on-going 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.

A. CUP Lead Clinician

Name:…………………………………………………………………

B. Your CUP Clinical Nurse Specialist

Name:………………………………………………………………….

Contact details:……………………………………………………….

C. The role of your CUP nurse is to act as a Key worker to:

- co-ordinate investigations / care
- liaise with your family doctor (GP) and community support services
- provide information, advice and support about diagnosis, treatment, palliative care, spiritual and psycho-social concerns
- be an advocate for the patient
- meet with you/family at an early stage
- Holistic Needs Assessment

D. Acute Oncology Secretarial Support

Name:…………………………………………………………………..

Contact details:……………………………………………………….

Holistic Needs Assessment

What Is A Holistic Needs Assessment (HNA)?

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

An HNA is a discussion with your 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 Doctor or Nurse will need information from you. However, you decide how much information you would like to share about your current situation.

An 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.

An HNA is undertaken, especially for those patients with a diagnosis of CUP, as a 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?

The team caring for you will offer an HNA to all patients with cancer. Many patients find having an assessment helpful, as it can help to identify what help is available. However, if you do not want to have an assessment, you do not have to have one.

When Will a Holistic Needs Assessment Take Place?

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 Nurse Specialist (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.

Feedback

Your feedback is important to us and helps us influence care in the future

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated

Services and General Information

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

General enquiries:
Tel: 020 7840 7840

Free phone to call Cancer Specialists:
Tel: 08088080000

Hard of Hearing text Phone
Tel: 0808 808 0121

Open between the hours of 9.00 am – 8.00 pm Monday to Friday.

Cancer Information Centres are based in hospitals and run by Macmillan, where a team of experts and trained volunteers are on hand to answer your questions.

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. http://www.cupfoundjo.org**
- **Macmillan Cancer Support, telephone;0808 808 00 00, www.macmillan.org.uk**
- **NHS Choices www.nhs.uk**
- **Cancer Research U.K. www.cancerhelp.org.uk**
- **Age UK. http://www.ageuk.org.uk/**
- **www.direct.gov.uk (detailed information about money and debt)**
- **NHS Direct www.nhsdirect.nhs.uk**
- **Citizens Advice. www.citizensadvice.org.uk**
- **Carers UK www.carersuk.org**
- **Wirral Holistic Care Services www.wirralholistic.org.uk/**

References

Akilade, C (2009). Understanding Cancer of Unknown Primary. Macmillan Cancer Support. 1st Ed.

Cancer Research (2011). Types of treatment for unknown primary cancer. Cancer Research UK
NICE (2010). Metastatic Malignant Disease of Unknown Primary Origin; diagnosis and management of disease of metastatic disease of unknown primary origin. NICE clinical guideline.

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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