

What is cancer of unknown Primary?

Cancer of unknown primary (CUP) is a term used when a person is diagnosed with cancer that has spread within the body but the place in the body where the cancer started (the primary site) cannot be found, even after all the suitable tests have been carried out. Each year in the UK about 10,000 people are diagnosed with CUP. CUP is the 8th most common cancer for women and the 11th most common for men.

Why Can't the Primary cancer be found?

There are many reasons why the primary cancer cannot be found such as:

- The secondary cancer(s) have grown and spread very quickly, but the primary is still too small to be seen on a scan.
- 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 original site of the tumour may have disappeared although it has already spread. This can happen because it was unable to maintain its own blood supply or your immune system may have destroyed the cancer in the primary site but not the cancer that has spread to other areas of the body.

How Cancer of unknown primary is diagnosed

We can't include all the possible tests you may have, but we've included those most likely to be used depending on your symptoms.

CT (computerised tomography) scan

This scan uses multiple x-rays to build up a three dimensional picture. It is painless and usually lasts between 10-30 minutes. CT scans use a small amount of radiation; this is very unlikely to harm you and will not harm anyone you come into contact with. You may be given a drink or an injection to improve the images.

MRI (magnetic resonance imaging) scan

This scan uses magnetism to build up a detailed picture of areas of your body. During the scan you will be asked to lie very still on a couch inside a long tube, this scan lasts for around 30 minutes. It is painless but some people feel a bit claustrophobic, please feel free to speak to the people doing your scan if you feel nervous about this. It can be noisy. You may be given an injection of dye into a vein but this does not usually cause discomfort.

Biopsy

During a biopsy, a small piece of tissue or a sample of cells is removed so that it can be examined under a microscope. You are likely to have local anaesthetic prior to biopsy this procedure. Most types of biopsy are painless, although this depends on where from your body the sample is taken. You may experience a dull ache which can be treated with painkillers.

Removing fluid for testing

If you have a build up of fluid next to the lung or in your abdomen a sample of the fluid can be taken to check for cancer cells. This involves inserting a tube into the affected area. You will receive an injection of local anaesthetic to numb the area and stop the procedure from being painful.

What is the treatment for cancer of unknown primary?

The most common treatments are chemotherapy, radiotherapy and hormonal therapy but will depend on your unique situation. Treatment for most cancers of unknown primary may help control the disease, but these cancers can often be very difficult to cure.

Where will I have my treatment?

If you require chemotherapy or radiotherapy you may have to attend Velindre Cancer Centre which provides specialist cancer services to people in South East Wales. Patients referred to Velindre Cancer Centre come under the care of Clinical and Medical Oncologists. Oncologists specialise in the non-surgical treatment of cancer. Velindre Cancer Centre is the main centre for these services, however they also provide outpatient clinics and other out-based chemotherapy services at other sites included the Royal Gwent Hospital & Nevill Hall Hospital.

What support is available for patients with cancer of unknown primary?

If you are diagnosed with CUP your team can refer you to the Acute Oncology Service.

Patients with suspected and confirmed cancer of unknown primary may have lots of questions and concerns due to the uncertainty around it. It is sometimes hard to make sense of what is happening to you and can be difficult to explain to other people. As well as dealing with this you may have difficulty dealing with symptoms of the disease of the treatment.

The Acute Oncology Service is here to help answer your questions, address your concerns and support you through this difficult time. Throughout the investigation phase you will have a key worker from the Acute Oncology Service. This means you can contact them for any problems or questions you may have.

Your key worker is:

Contact number: 01633 234877 (Monday to Friday)

Is there any support for me when I am discharged home?

If you are discharged home with a confirmed Cancer of Unknown Primary then your key worker from the Acute Oncology Service can provide you with telephone advice for as long as required.

If following the investigation phase a primary tumour site is confirmed then you will be allocated a key worker from the site specific team who will be a point of contact for you for advice and support.

If you go on to receive chemotherapy or radiotherapy you will be given details of the 24 hour support line that is run from Velindre Hospital.

For support at home you may be referred to either St David's Hospice care or Hospice of the Valleys (depending on where you live). Sometimes being referred to palliative care services can be frightening it is worth remembering that palliative care is provided for people from diagnosis and not just at the end of their lives. It is likely that good palliative care at home will help you live independently and with well managed symptoms for longer and may prevent you from unnecessary admissions to hospital. Once referred to community palliative care you will be allocated a clinical nurse specialist they may well become your key worker and first point of contact for support and advice.

Can I find out more?

Information can be found on the internet, but should always be read in relation to what you have been told by your cancer specialist.

Cancer of Unknown Primary Foundation / Jo's Friends:

www.cupfoundjo.org

This is a group that exists to offer information and support to CUP patients, their families and friends.

Macmillan Cancer Support:

www.macmillan.org.uk

Velindre Cancer Centre <http://www.velindrecc.wales.nhs.uk/home>
02920615888

St David's Hospice Care www.stdavidshospicecare.org

01633 851079

Hospice of the Valleys www.hospiceofthevalleys.org.uk

01495 717277

If you have any questions or if there is anything you do not understand about this leaflet please contact.

Helen McMillan, Louise Tweedie or Samuel Clements on
01633 234877 (Monday to Friday)