

Cancer of Unknown Primary

Information for patients

This leaflet is about the Cancer of Unknown Primary (CUP) Team and helps to explain what we do and what you can expect from us. Please contact us using the telephone numbers below if you have any questions about your cancer or treatment plan/management. If we are not able to answer there is an answer machine on all the numbers for you to leave a message and we will call you back.

Dr Sally Clive	Consultant Medical Oncologist	0131 537 2263 (secretary)
Dr Colin Barrie	Consultant Medical Oncologist	0131 537 2194 (WGH secretary) 01506 523 560 (SJH secretary)
Dr Marj Maclellan	Consultant Clinical Oncologist	0131 537 1036 (secretary)
Gillian Knowles	Nurse Consultant	0131 537 3793
Rachel Haigh	Nurse Specialist	0131 537 1341
Jac Brown	Nurse Specialist	0131 537 3578

For questions about appointments, please contact your consultant's secretary Monday to Friday during office hours.

What is CUP?

When a cancer starts growing in one part of the body we call this the primary cancer. We often call the cancer the name of that body part (e.g. bowel cancer, lung cancer). Sometimes cancers can spread from this primary site into other parts of the body and we call this secondary or metastatic cancer. Normally the primary cancer grows the quickest and is the first to cause problems. But sometimes secondary cancers are found in one or more parts of the body and there is no obvious primary cancer. We often examine you and do tests to try to find where the cancer started. Sometimes we take a bit of the cancer (a biopsy) and look at it with a microscope. If these tests find a primary cancer then we may ask a specialist in that cancer to meet with you to discuss this further. If a primary cannot be found after these tests we say this is a cancer of unknown primary (CUP).

Although we may not be able to tell you where your cancer started we can learn enough about your cancer from these tests. This means we are still able to talk to you about what this means for you, how best to manage your cancer and any possible treatment options.

You can read more about CUP and cancer on these websites, or please ask us for an information booklet:

Macmillan Cancer Support: www.macmillan.org.uk

Cancer Research UK: www.cancerresearchuk.org

CUP Foundation: www.cupfoundjo.org

Maggie's Centre: www.maggies.org/

What we do

CUP clinic

CUP clinics are held on a Monday afternoon and a Wednesday morning at the Edinburgh Cancer Centre, Western General Hospital and on a Friday morning at St John's Hospital. You will meet with members of the CUP team at the clinic, usually one of the consultants and one of the nurses. We can have other health care staff working with us such as trainee doctors or medical and nursing students who you may also meet.

At the first clinic we will ask you about your general health, medical history and current symptoms. We will give you as much or as little information about your cancer as you wish and will answer your questions openly and honestly. Please tell us if there is anything you do not want to talk about. It can also be helpful to write down any questions you may have and bring these with you to the clinic. You are welcome to bring family members or friends with you.

Thinking about your answers to the following questions can help you when we talk to you about your care:

- What do you know about your illness at the moment?
- What really matters to you when you think about your health?
- What matters to you the most when thinking about the future?

Cancer team meeting

The CUP Team meet on a Monday morning to review cases and discuss any scan and biopsy/test results. At this meeting specialist doctors and nurses piece this information together. This helps us to start planning the best way to manage your cancer. The meeting is for NHS staff only. If your case is being discussed we will telephone you after the meeting to update you, or will arrange to meet you at a future clinic. We also send a letter to your GP or will telephone them to let them know what was discussed at the meeting.

Managing CUP

Sometimes we need to have more information and we might arrange for you to have more tests. We will make sure this is the right thing for you. It can take a few days or up to a few weeks for test results to be ready. We know that waiting for results can be a worrying time so we will let you know when results are available.

We will meet again in clinic once we have all the information to discuss with you the best way to manage your cancer and your symptoms. Depending on the type of cancer and your general health we may talk to you about chemotherapy (cancer drug treatment) or radiotherapy (X-ray treatment) to try to slow down the cancer growth or to help you feel better. We will give you information about the possible benefits and downsides of any treatment and will talk to you about possible side effects. You should take time to decide if these treatments are the right choice for you.

We may also talk to you about any relevant clinical trials or research projects.

Sometimes we do not think that chemotherapy or radiotherapy will help you. We will talk to you about symptom control and the best way to support you and your family. This is often called 'best supportive care'. We often ask the palliative care team to meet with you in hospital or at home as they can help give advice on symptom management. We work closely with your GP and district nurses and together we can help to keep you in your own home as much as possible, rather than spending time in hospital.

Please let us know what is important to you during these discussions.

Other resources

You may wish to visit Maggie's Centre or the Macmillan Cancer Information and Support Centre for free practical, emotional and social support and information including help with benefits and finances. Both centres are on the Western General Hospital site. Please ask us for further details about any of these services or contact:

- **Maggie's Edinburgh** (www.maggies.org/our-centres/maggies-edinburgh/)
The Stables, Western General Hospital, Edinburgh, EH4 2XU
Telephone: 0131 537 3131
- **Macmillan Information and Support Centre**
South Corridor, Western General Hospital, Crewe Road, Edinburgh, EH4 2XU
Telephone: 0131 537 3907

We can also give you information about support services across Lothian:

Macmillan – Improving the Cancer Journey Service

NHS Lothian and Macmillan Cancer Support want to offer everyone affected with cancer (including families and carers) time with a Link Worker to think about 'what matters to them' and access to the support they need. This service is for anyone affected by cancer at any point on their cancer journey and is based in the community. To find out more about how they can help or to book an appointment, please contact:

Telephone: 07977 307 286 / 07929 784 315 or email: loth.icj@nhslothian.scot.nhs.uk

Information booklets

You might find the following cancer information booklets helpful which you can pick up from the Edinburgh Cancer Centre, Maggie's Centre or the Macmillan Centre. Copies can also be downloaded or ordered free of charge from Macmillan Cancer Support (www.macmillan.org.uk, telephone 0808 808 0000):

- *Understanding Cancer of Unknown Primary* - a practical guide to understanding cancer
- *Coping with Advanced Cancer* - a practical guide to living with and after cancer.

Translation Services

This leaflet may be available in a larger print, Braille or your community language.