



Chasing the primary

Nicola James and John Symons welcome a new guideline to improve the management of patients with unknown cancers

NOT EVEN the most cynical person can deny that the delivery of cancer services has improved in the UK over the past ten years. Multidisciplinary teams, specialist nurses, patient information, clearly identified referral and diagnostic pathways with stringent waiting time targets – all have been developed for each major cancer. Except for one: carcinoma of unknown primary (CUP), which is the fourth most common cause of cancer death in England and Wales (National Institute for Health and Clinical Excellence (NICE) 2010).

Historically, the CUP patient's pathway has been disjointed, often with no one taking responsibility for co-ordinating care as the person passes from one team to another in an ad hoc process of eliminating each cause of the cancer.

In chasing the primary, patients may be subjected to unnecessary, sometimes uncomfortable and expensive tests. They often report that little attention is paid to their psychological and palliative care needs early in the pathway.

The first NICE CUP guideline – Diagnosis and Management Of Metastatic Malignant

Disease of Unknown Primary Origin (NICE 2010) – offers an evidence-based approach to managing and treating CUP. The diagnosis is defined in three phases:

- Malignancy of undefined primary origin: metastatic malignancy without a probable primary site identified on the basis of a limited number of tests.
- Provisional carcinoma of unknown primary (provisional CUP): metastatic epithelial or neuroendocrine malignancy identified on the basis of histology/cytology, with no primary detected after an initial screen of investigations.
- Confirmed carcinoma of unknown primary (confirmed CUP): no primary detected despite further specialised tests and specialist reviews.

Diagnostic tests

The guideline covers, in detail, the diagnostic tests for particular clinical presentations, specific treatments and factors influencing management decisions.

A key recommendation is that the organisation of services and support is built around the establishment of a

CUP team in the cancer unit or hospital. The team, consisting of an oncologist, a palliative care physician and a CUP specialist nurse or key worker, as a minimum, will take responsibility for ensuring that there is a management plan for appropriate investigations, symptom control and support for each patient.

The CUP team's named lead clinician will, among other things, ensure that each patient has an identified point of contact in the team. Every cancer network is asked to establish a network site-specific group responsible for managing all stages of CUP.

The lead clinician will represent the hospital in CUP matters at the CUP network site-specific group and the specialist CUP network multidisciplinary team.

The CUP specialist nurse or key worker will take a major role in co-ordinating the patient's care in line with the guideline.

He or she will be an advocate for the patient at CUP team meetings and ensure action is taken to smooth the patient's diagnostic and treatment pathway while recognising palliative care, spiritual and psychosocial concerns.

There has been nothing more unfair to patients, and more challenging for doctors and nurses, than the ad hoc approach to CUP. It is hoped that all who are passionate about improving cancer services will place the implementation of the NICE guideline at the top of their agenda.

There will be savings to be made in terms of cutting inappropriate testing and reducing length of stay, which are good reasons to help persuade trusts commit to the guideline recommendations.

This Cinderella of syndromes can finally be removed from exclusion.

Nicola James is a Macmillan nurse consultant at Chesterfield Royal Hospital and John Symons is director of the Cancer of Unknown Primary Foundation. Both were members of the CUP guideline development group

Reference

National Institute for Health and Clinical Excellence (2010) *Diagnosis and Management of Metastatic Malignant Disease of Unknown Primary Origin*. NICE, London.

Find out more

The guideline can be downloaded at www.nice.org.uk