

## On the right track

## Patients with cancer of unknown primary are starting to get the care they deserve, say Nicola James and John Symons

HISTORICALLY, LACK of knowledge about cancer of unknown primary (CUP) and how to manage it led to an ad hoc approach to the care of patients and, consequently, suboptimal treatment.

One of the authors (NJ) undertook a retrospective audit (James 2007) of 14 sets of casenotes of patients with CUP in Chesterfield Royal Hospital, Derbyshire, in 2007, and argued for a more co-ordinated approach to its management.

Despite poor prognosis and the complex nature of the disease, there was no CUP multidisciplinary team (MDT) or specialist nurse, and there were no clinical guidelines. Tests were often duplicated and patients tended to be shunted between MDTs. There was little or no focus on palliative care needs as the search for the primary eclipsed every other aspect of management.

In 2009, Symons *et al* explored the dilemmas associated with treating CUP patients and, in 2010, we reported on the recommendations of the first National Institute for Health and Clinical Excellence (NICE) CUP guideline (James and Symons 2010). So where are we now? Recent events

are starting to change the picture for CUP patients and those who treat them:

- The NICE (2010) CUP guideline recognised the validity of CUP patients having the same service infrastructure as site-specific cancers.
- Since April 2011 Cancer Research UK (CRUK) and the National Cancer Intelligence Network have included CUP incidence and mortality in their 'top ten' data sets. This is significant because, without representation of the disease in national statistics, it is difficult to argue for research funding and patient support. CUP was the fourth most common cause of cancer death in the UK in 2009 after lung, colorectal and breast disease (CRUK 2011).
- In December 2011, a draft of the peer-review measures for CUP was issued for consultation by the National Cancer Action Team. Final measures are likely to be published this year and will be used in the assessment of cancer services.

In 2010, in line with NICE guideline recommendations, Chesterfield Royal Hospital NHS Foundation Trust established a CUP clinician, a CUP MDT, a dedicated Members of Chesterfield's multidisciplinary team for cancer of unknown primary include consultant David Brooks and nurses Joanne Froud (centre) and Emma Waterfield

CUP clinic and allocated specialist nursing time. Patients with CUP are now referred directly to the CUP clinician either from primary care or from inpatient teams.

Audit of these changes (Hughes *et al* 2011) shows that having a dedicated CUP pathway has cut length of stay, increased the number of patients who die at home and, according to relatives, improved care.

Interaction with the hospital's palliative care team is immediate and discussions about treatment take place in a setting involving specialist palliative care and an oncologist with a special interest in CUP. Tests are no longer duplicated and, crucially, the focus is on the patient rather than an often futile search for the primary site.

Cancer networks, and hospitals in networks, have responded at different speeds to the NICE guideline. However, as the Chesterfield experience shows, there are benefits. Patients with CUP want to be treated by a specialist, not a generalist, and supported by nursing staff who understand this difficult diagnosis.

Nicola James is a Macmillan nurse consultant at Chesterfield Royal Hospital, Derbyshire, and John Symons is director of the Cancer of Unknown Primary Foundation. Both were members of the National Institute for Health and Clinical Excellence Cancer of Unknown Primary guideline development group

## References

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Cancer of Unknown Primary Foundation: www.cupfoundjo.org

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