TAILORED SERVICES NEEDED FOR YOUNG PEOPLE WITH CANCER

New Department of Health guidance highlights key principles in commissioning services to improve care and outcomes for adolescents with cancer. Nerys Hairon reports

Young people with cancer have distinct needs that require a separate care approach. The Department of Health has published new guidance on commissioning services for teenagers and young adults with cancer (National Cancer Action Team, 2008). This guidance is intended to ensure equitable access to services that comply with NICE guidance on improving outcomes for this patient group (NICE, 2005a; 2005b).

The new guidance ‘strongly recommends’ a set of principles that should be applied when commissioning services and care pathways for young people with cancer (see box, p18 for selected key points). It also outlines key messages for commissioners in three areas: principal treatment centres; multidisciplinary teams (MDTs); and shared care.

NICE GUIDANCE
NICE (2005a) reported that overall survival rates for children with cancer are now around 70%. NICE’s (2005b) guidance provides recommendations for children from birth and young people in their late teens and early twenties presenting with malignant disease, and the whole range of services required to meet their needs.

Key recommendations include:
- All care for children and young people under 19 years must be provided in age-appropriate facilities. Young people aged 19 and over should also have unhindered access to age-appropriate facilities and support when needed;
- All children and young people must have access to tumour-specific or treatment-specific expertise as required;
- All aspects of care for children and young people with cancer should be undertaken by appropriately trained staff;
- Appropriately skilled, professional key workers should be identified to support individual children and young people, and their families, by:
  - Coordinating their care across the whole system and at all stages of the patient pathway;
  - Providing information in an age and cultural appropriate format;
  - Assessing and meeting their needs for support.
- Care should be delivered throughout the patient pathway by multidisciplinary teams (MDTs), including all relevant specialist staff.

The guidance also recommends that commissioners should ensure that principal treatment centres for each cancer type are identified for children and for young people, with associated referral pathways. These centres should also be able to provide a sustainable range of services, with defined minimum levels of staffing.

IMPLEMENTATION
On launching the new guidance, Mike Richards, national cancer director, points out that cancer services for teenagers and young adults is a particularly complex and challenging area. He adds it may require new clinical collaborations that cross cancer site-specialised practice models and adult and paediatric services. However, he argues that the need for young people with cancer to benefit from the expertise of both site-specific MDTs and the new teenage/young adult teams is an essential aspect of NICE (2005b) guidance.

Principal treatment centres
The key messages in relation to these treatment centres are outlined. Principal treatment centres for young people hosting
the teenage and young adult MDT will need to be in specific locations. These will be where established services for the most common cancers in this age group, adult site-specific MDTs and a treatment centre for children exist in the same city. Ideally all these services would be located in a single hospital trust but, if this is not possible, robust local solutions will be necessary.

Principal treatment centres will need to have an age-appropriate cancer facility (not with younger children or much older adults) with sufficient activity to sustain a teenage and young adult oncology workforce capable of delivering the most complex and intensive chemotherapy regimens. They should also have an on-site intensive care unit that provides critical care services for the centre’s defined age range.

Very careful and close collaboration will be necessary between the treatment centre and other adult cancer centres in each designated regional area.

The treatment centre will have a coordinating function for MDT review and notification to the national teenage and young adult cancer registry, treatment, psychosocial support and peer contact/support for young people with cancer.

**Multidisciplinary teams**

The DH recommends that all teenagers and young adults aged 16–24 inclusive should be discussed both at a site-specific MDT meeting and a teenage/young adult MDT meeting. In some treatment centres the age range for the teenage team may include those aged 13–15.

The diagnosis and treatment plan for young people will be determined in the site-specific MDT meeting and discussed and agreed with a teenage and young adult MDT. Jointly agreed treatment/care pathways for the most common clinical situations should be used. The order in which these discussions take place is less important than communication, collaboration and joint decision-making between the teams.

Coordinating the development and delivery of agreed patient-specific treatment plans for all teenagers and young adults with cancer is an important function of the teenage and young adults MDT. This will require setting up appropriate systems for joint working.

Each children and young people’s network will need to develop and agree guidelines for referral of young people by primary care staff to site-specific or teenage and young adult MDTs that are specific to service configuration in the area. These will need to be consistent with NICE (2005c) guidance on referral for suspected cancer.

To avoid diagnostic and treatment delay, mechanisms for rapid notification of all newly diagnosed young people to the principal treatment centre will need to be developed to ensure timely discussion at a teenage and young adult MDT meeting.

**Shared care**

The new guidance says that a single principal treatment centre for young people is likely to operate shared care with both child and adult services. Consistency between the levels defined for child and adult-based shared care is important for practical reasons, for clinical governance and to ensure that young people are not disadvantaged by the age limits of local services.

It is proposed that the levels of shared care for children’s services are extended to develop a parallel framework for shared care for young people with adult services.

Young adults aged 19 and over may make an informed choice to receive all their cancer treatment in adult services outside a principal treatment centre for young people. Treatment will be delivered within the local adult cancer service under the direction of an appropriate site-specific MDT, with ongoing communication and liaison with the treatment centre.

Teenage and young adult psychosocial MDT members (such as the CNS) will work to support the local MDT key worker to enable these young people to access age-appropriate psychosocial support whenever needed.

The guidance also contains illustrations of example care pathways (see www.dh.gov.uk for details).

**SUMMARY OF KEY PRINCIPLES**

- All patients with cancer aged 16–18 years inclusive should be referred to a principal treatment centre (young people) for treatment.
- All patients aged 19–24 years inclusive should be offered referral to such a centre for treatment.
- All patients aged 16–24 years inclusive should be discussed at both a site-specific MDT meeting and a teenage and young adult MDT meeting.
- Referral of patients to a young people’s treatment centre, or review by both these MDTs, should not be allowed to delay the start of urgent cancer treatment.
- For each patient, a lead medical clinician should be identified, who will have overall responsibility for their treatment.
- The teenage and young adult MDT at the treatment centre should have a role in coordinating treatment, psychosocial care and peer contact/support for young people wherever they are treated.
- Robust arrangements should be in place for planned transition between children and young people’s services and between young people’s and adult services.

Source: National Cancer Action Team (2008)