

## **Background to the Community Care Review**

### **Context**

The NICE Guidance, "Improving Outcomes in Children and Young People with Cancer", published in August 2005, aims to "provide an acceptable blueprint to the NHS in England and Wales, and lead to significant and lasting changes to the care of children and young people with cancer that improve not only the clinical outcomes, but also the experience of the patients and their families".

NICE has developed this guidance on the healthcare services that should be provided for children and young people with cancer. It also acknowledges that Social Care is an integral element of cancer care in this client group. To date the guidance implementation group (and its various sub-groups) has been working on the detail relating to Principle Treatment Centres and Share Care Centres for the 0-15 year olds. More recently the specific needs of young people aged 16-24 years are being addressed, this work will be greatly enhanced by the appointment of the TCT funded programme manager posts within Specialist Commissioning Groups.

### **Community Support**

Across the United Kingdom children and young people with cancer, and their families, do not have equitable access to community-based support. There are great variations in the availability, accessibility and delivery of specialist cancer nursing, generic community nursing support as well as specialist cancer and generic psycho-social support in their local community and between cancer care settings.

The greatest variations and gaps in service provision exist in services for the 16 to 24 year olds. CLIC Sargent has been funding and providing both Paediatric Oncology Outreach Nurse Specialists and specialist Social Workers for over twenty-five years, the charity also provides an increasing number of specialist Young People's clinical and psycho-social professionals.

### **Proposal**

Following initial consultation, in which we proposed looking at the core components of specialist outreach nursing in the community and between care settings, it has become clear that a broader piece of work would be more beneficial. Whilst specialist outreach nursing is a pivotal service for children with cancer such a service does not widely exist for young people and the support needs of this group are not yet clearly identified.

Given the variations that exist in community service provision, both specialist and generic, CLIC Sargent has established a working group to develop a model or models for the delivery of community based support for children and young people with cancer. Having developed a model, or models, CLIC Sargent would then support a pilot in order to evaluate the benefits for all stakeholders.

The first piece of work will be to define the core components of community based care that may be required. This will be across the full age range covered by the guidance and all stages of the cancer journey.

### **Potential Benefits**

The defining of patient care and support needs in the community and the subsequent development of appropriate models for service delivery should offer the following benefits:

1. Community services focussed on the clearly defined needs of patients and families across the entire age range (0 to 24 years) and at all stages of the cancer journey.
2. Equity of access to high quality specialist and generic nursing and psycho-social care for children, young people and their families.
3. Clearer role definitions for Cancer Outreach Nurse Specialists and Specialist Cancer Social Workers to both avoid role duplication and gaps in service provision.
4. Build upon the excellent collaborative working practices that exist in some areas, particularly in relation to palliative care (this is particularly timely given the current developments in relation to Palliative Care following the recent Independent review).
5. Flexibility to identify and develop services specifically for each PTC in response to local need within a nationally agreed framework.

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