

National Institute for Health and Clinical Excellence

Mid City Place
71 High Holborn
London
WC1V 6NA

Tel: 020 7067 5800
Fax: 020 7067 5801
nice@nice.org.uk

www.nice.org.uk

PRESS RELEASE

NICE guidance set to improve services for children and young people with cancer

The National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Cancer (NCC-C) have today launched guidance which aims to standardise services for children and young people with cancer in England and Wales.

Cancers in children and young people are rare but the impact on family life during therapy can be significant. Each year in the UK there are approximately 1500 new cases of cancer diagnosed in children under the age of 15, according to the United Kingdom Children's Cancer Study Group (UKCCSG). Overall survival rates for children are now approximately 70%. This guidance, the seventh in the *Improving Outcomes in Cancer Series*, 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 NHS services required to meet their needs.

Key recommendations include:

- All care for children and young people under 19 years old must be provided in age-appropriate facilities.
- All children and young people must have access to tumour specific or treatment-specific clinical 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 culture appropriate format.
 - assessing and meeting their needs for support.

Peter Littlejohns, Executive Lead for this guidance said: “The distinct needs of young people with cancer have been increasingly recognised over recent years. Many young people do not feel comfortable within the paediatric setting, but they have unique needs that may not be addressed within adult services. This guidance identifies the specific age-related services that need to be provided to ensure that children and young people with cancer receive the best care and their families the support they need no matter where they live in England or Wales. “

Professor Mike Richards, National Cancer Director said: "I welcome the new guidance from NICE on services for children and young people with cancer. We already have some excellent services in this country, but this guidance will provide a framework for further development. I will be working closely with colleagues from the NHS and the Voluntary Sector to ensure that the guidance is implemented”.

Dr Cerilan Rogers, National Director, National Public Health Service for Wales and Guideline Development Group Chair said: “The diagnosis and treatment of cancer in children and young people is complex and often lengthy. Care must be coordinated by services to ensure improved outcomes, particularly for older children and young people. The guidance will help to achieve this.”

Dr Meriel Jenney, Consultant Paediatric Oncologist and Lead Clinician on Guideline Development Group said: “This guidance is an opportunity to build on the existing good practice around the country. Its focus on team working within and across organisations will help to ensure that all patients get access to appropriate expertise and standards of care, but it also makes clear that all children and young people need to be treated in an age-appropriate environment.”

Rachel Hollis, Senior Sister, St James's Hospital said: “We see implementation of this guidance as an important first step towards making sure that the right services are accessible to children and young people and their families across the many different stages along the cancer journey. In particular we welcome the opportunity to focus on the role of the key worker, a role that for most of these patients will be taken by a nurse.”

Simon Davies, Chief Executive Officer, Teenage Cancer Trust said: “The recognition that teenagers and young adults with cancer have a right to specialist facilities finally brings health services in line with other walks of life. The fact that NICE has recommended that age appropriate, safe and effective services are provided alongside training for health professionals at every stage, at all levels, is music to our ears. Our collective challenge now is to turn guidance into practice as quickly and smoothly as possible”.

Christopher C. Gibbs, Chair – National Alliance of Children’s Cancer Parent Organisations (NACCPO) and User/Carer Representative on the Guidance Development Group said: “From the patient and parent/carer perspective the production of this guidance is a positive step in the right direction, not least through its recognition that children and young people warrant a separate approach within the overall national cancer strategy. We are confident that the recommendations will mean that all children and young people with cancer have access to the most effective and appropriate specialist treatment and facilities, which will improve their chances of survival and their quality of life by ensuring best practice and better coordinated care networks.”

Ends

Notes to Editors

About the guidance

1. Service guidance for improving outcomes in children and young people with cancer is the seventh in the Improving Outcomes in Cancer series and is the first to be produced by the National Collaborating Centre for Cancer (NCC-C).
2. Cancer service guidance define how services should be organised to ensure that people with cancer, their families and other carers receive support to help them cope with cancer and its treatment. Although NICE cancer service guidance does sometimes refer to appropriate forms of investigation and treatment, it doesn't provide detailed information on these areas. More detailed information on investigations and treatment for different kinds of cancer can be obtained elsewhere
3. The Service guidance for improving outcomes in children and young people with cancer

was developed by the National Collaborating Centre for Cancer, a professionally-led group with the experience and resources to develop guidance for the NHS on behalf of NICE. The National Collaborating Centre for Cancer is based at Velindre NHS Trust in Cardiff, and involves the following partners:

- Velindre NHS Trust
- University of Wales College of Medicine
- Cancer BACUP
- National Cancer Alliance
- Royal College of Nursing
- National Council for Hospice and Specialist Palliative Care
- Royal College of Pathologists
- Royal College of Physicians
- Royal College of Radiologists (Faculty of Clinical Oncology)
- Royal College of Surgeons
- University of Glamorgan
- Royal College of General Practitioners

4. The Collaborating Centres follow international standards of guideline development. They establish an independent group to develop each guideline consisting of representatives of people with the condition, health professionals working in the NHS and health service researchers. The group reviews the published clinical research alongside current clinical practice and the experience of people with the condition. Professional and patient/carer groups whose members are likely to be affected by the guideline were able to submit information and comment on the recommendations before they were finalised.

About NICE

5. On 1 April 2005 the National Institute for Clinical Excellence took on the functions of the Health Development Agency to form the National Institute for Health and Clinical Excellence (NICE). NICE is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.
6. NICE produces guidance in three areas of health:
 - **public health** – guidance on the promotion of good health and the prevention of ill health for those working in the NHS, local authorities and the wider public and voluntary sector
 - **health technologies** – guidance on the use of new and existing medicines, treatments and procedures within the NHS
 - **clinical practice** – guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS.

Obtaining copies of the guidance

7. Electronic copies of the manual and electronic copies of the information for the public leaflet that accompanies the guidance can be found on the NICE website from 24 August 2005 at www.nice.org.uk/csgcyp.
8. Hard copies of the guidance and a CD version will be distributed to the NHS shortly after 24 August 2005 and will be available to order from the NHS response line on 0870 1555 455 from that date, by quoting reference number N0897 (manual), N0898 (CD ROM) and N0899 (information for the public).