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### **PRESS RELEASE**

## **NICE guidance set to improve services for patients with brain & other CNS tumours**

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 improve delivery of services for patients with brain and other central nervous system (CNS) tumours in England and Wales.

This is the latest guidance document in the Improving outcomes in cancer series and gives advice on the key aspects of services required to achieve the best outcomes for adult patients with tumours of the brain and CNS from diagnosis onwards.

Although brain tumours are uncommon and account for only 1.6% of cancers in England and Wales, care of these patients can often be fragmented and uncoordinated. The management of less common tumours of the CNS often requires access to highly specialised services. This guidance makes specific recommendations on all types of brain and CNS tumours to improve the way that care of these patients is organised and to ensure that they are delivered consistently across England and Wales in an effort to improve their clinical outcome.

Key recommendations include:

- All patients' care should be co-ordinated through a designated multi-disciplinary team (MDT)
- All diagnostic investigations should be provided to patients within the national cancer waiting times targets

- All patients should have face-to-face contact with healthcare professionals to discuss their care at critical points in their care pathway, and be provided with high quality written information to support this
- All patients should have a clearly defined key worker
- Clinical nurse specialists should be core members of the neuroscience brain and other CNS tumours MDT and the cancer network brain and other CNS tumours MDT. They are likely to take on the role of key worker for many patients especially during the early stages of their clinical care
- Patients should have ready access to specialist care services as appropriate, i.e:
  - access to specialist neuropsychology and neuropsychiatry for the assessment and management of complex cognitive, emotional and behavioural problems
  - access to specialist healthcare professionals for problems patients may experience such as epilepsy, headaches, functional loss, speech and language problems, or visual problems
  - rapid access to allied health professional (AHP) assessment and rehabilitation services as the patient's condition changes
  - Immediate access to specialist equipment as necessary
- Palliative care specialists should be core members of the neuroscience brain and other CNS tumours MDT and the cancer network brain and other CNS tumours MDT
- Cancer networks should ensure that clinical trials on brain tumours carried out by the National Cancer Research Institute (NCRI) are supported and patient entry into these studies actively monitored

**Gillian Leng, Implementation Director and Executive Lead for this guidance**

**said:** "Improving Outcomes in brain and other CNS cancers is the final publication in our Cancer Service guidance series and completes the set. Cancer service guidance supports the implementation of The NHS Cancer Plan for England, and the NHS Plan for Wales Improving Health in Wales. In publishing these cancer service guidance documents, we hope to be able to identify gaps in local provision and to check the appropriateness of existing services."

**Prof Mike Richards, National Cancer Director, said:** "The 'Improving Outcomes

Guidance' reports on cancer services have been an essential component of the drive to improve the quality of care for cancer patients over recent years. Publication of the guidance on brain tumours completes the series. I am very grateful to everyone who has been involved in this process and to NICE for overseeing it."

**Dr Penny Bridger, Chair of the Guidance Development Group:** "This guidance gives recommendations for improving the way services for patients with brain and other CNS tumours are organised and delivered. Implementation will help to ensure that care of these patients, who often have complex needs, is coordinated and includes access to appropriate support and rehabilitation services."

**Dr Sean Elyan, Lead Clinician for the Guidance Development Group:** "With the assistance and support of NICE and the hard work of the GDG we have reviewed the current service provision for these patients and recommended new pathways to improve their care. As a working clinician I feel confident that implementation of the guidance nationally will represent a major step forward in the global management of patients with this group of conditions."

**Dr Juliet Britton, Neuroradiologist on the Guidance Development Group said:** "There are a large number of pathologically different tumours which may arise within the brain or spine and the speed with which they progress and their susceptibility to treatment is variable. Accurate assessment with neuroradiological imaging and neuropathology is key to reaching the correct diagnosis so that proper management can be instigated. This guidance should ensure that all patients with a potential diagnosis of a brain tumour will benefit from these specialist services."

**Emma Townsley, Macmillan Clinical Nurse Specialist said:** "Improving patients' quality of life is a priority. This document promotes an inter-professional approach to treatment, rehabilitation and supportive care, which will positively affect the experience of patients and their families and carers. The key worker recommendation aims to meet the support needs of patients, maintain continuity of care and facilitate access to specialist services; this recommendation endorses the work of clinical nurse specialists."

**Angela Dickson, Trustee - The Samantha Dickson Research Trust and patient representative on the GDG, said:** "Brain cancer is on the increase and yet it is an area that has been sadly under-funded in the last 30 years. I am optimistic that these guidance will help the NHS address the main concerns of many patients diagnosed

with a brain tumour. Once implemented there should be fewer delays in diagnosis, quicker assessment by experts in the field of neurology, leading to faster treatment, access to more information, and more support through the patient pathway. This will hopefully lead to an increase in the overall survival rate of patients.”

**Ends**

## **Notes to Editors**

### **Additional quotes**

**Prof Garth Cruickshank, Professor of Neurosurgery, said:**” For Patients with a possible brain tumour accelerating the access to imaging and then to an appropriate specialist team are the key elements for deriving the benefits from early prompt diagnosis. These patients can now have confidence that implementation of this Guidance will not only speed up their pathway to treatment but also ensure a sustained specialist care program throughout. As a neurosurgeon, I welcome the appreciation of the complex nature of these rarer cancers and the comprehensive approach of the Guidance to subgroups of patients and to their specialist needs. This Guidance will, if fully implemented, achieve its aim of improving outcomes for this neglected Cancer group.”

**Dr Sharon Swain, Brain and Spine Foundation said:** “We very much welcome this service guidance; it is an important step towards ensuring that all patients diagnosed with a brain tumour obtain access to high quality services. One significant source of stress for patients and carers is trying to facilitate communication between all of the healthcare services they are in contact with. The appointment of a key worker, who will co-ordinate care throughout the patient journey, should significantly help to address this issue.”

**Dr Martine Meyer, Consultant in Palliative Medicine said:** “Although brain and other CNS tumours are rare, for most people it is a serious diagnosis. Thanks to this guidance there will be increased recognition that active treatment needs to go hand in hand with supportive care for the patient and for their family or carer. This includes access to rehabilitation where potential exists, and to specialist palliative care, recognising and addressing emotional, psychosocial, spiritual and financial needs as well as control of physical symptoms such as pain.”

### **About the guidance**

1. Service guidance for improving outcomes in brain and other CNS cancers is the twelfth in the Improving Outcomes in Cancer series and is the fourth 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 brain and other CNS cancers 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
- Cardiff University
- Cancer BACUP
- Macmillan Cancer Voices
- 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 28 June 2006 at [www.nice.org.uk](http://www.nice.org.uk).
8. Hard copies of the guidance and a CD version will be distributed to the NHS shortly after 28 June 2006 and will be available to order from the NHS response line on 0870 1555 455 from that date, by quoting reference number N1047 (manual), N1049 (CD ROM) and N1048 (information for the public).

#### Additional Information

9. National cancer waiting times targets were outlined by the Department of Health in 2005 in "Cancer waiting targets: A Guide", which can be found on the Department of Health's website: <http://www.dh.gov.uk>