



Healthcare services for people with brain and other central nervous system tumours

Understanding NICE guidance – information for the public

Introduction

The National Institute for Health and Clinical Excellence (also known as NICE) has issued guidance on how healthcare services for people with brain tumours, or other tumours in the central nervous system (CNS, see below for a description), should be organised. The guidance recommends which healthcare professionals should be involved in treatment and care, and the types of hospital or cancer centre that are best suited to provide that healthcare – this type of guidance is called ‘service guidance’.

It is important to remember that many service guidance recommendations made by NICE require large-scale changes in the way that sections of the NHS work. Although such changes can’t be made overnight, the NHS is working to put all the NICE guidance recommendations into practice.

The key recommendations from the guidance on improving outcomes for people with brain and other CNS tumours are summarised in the following sections. More information on these and the other recommendations is given in the full manual, *Improving Outcomes for People with Brain and Other CNS Tumours*, which is available from the NICE website (www.nice.org.uk) or from the NHS Response Line (see page 4). The full report also includes a summary of the evidence, which included evidence from patients and carers, that was considered when the recommendations were being prepared.

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 brain

and other CNS tumours can be obtained elsewhere. NHS Direct Online (www.nhsdirect.nhs.uk) is a good starting point, with links to other sources of information on brain and other CNS tumours. People with concerns about their own health should contact their GP.

Brain and other CNS tumours

CNS stands for central nervous system. It includes the brain and the spinal cord and is the control centre for the body’s functions. The guidance NICE has prepared mainly covers arrangements in the NHS for adults with malignant tumours (cancers) and non-cancerous tumours (benign tumours) that have started in the brain or other parts of the CNS. Tumours that start here are known as primary CNS tumours. The NICE guidance also looks at healthcare services for people with cancer that has spread to the brain or other parts of the CNS from other sites in the body and who need to have complex treatment for the effects of these ‘secondary’ cancers (which are also called metastases).

Primary CNS tumours are rare. The most common types develop in the brain, but these make up fewer than 2 out of 100 of all cancers that develop in people in England and Wales. The treatment that may be offered depends on the type of tumour and where it is located.

The distinction between malignant (‘cancerous’) and benign (‘non-cancerous’) tumours is not as relevant for CNS tumours as it is for tumours at most other sites in the body, as the problems caused by CNS tumours are almost always due to growth of the tumour itself. For the most common CNS tumours, called gliomas, the appearance of the tumour when looked at with a microscope is very important. This will show if the

glioma is 'high grade' (growing quickly) or 'low grade' (growing slowly).

Treatments may include medication for symptoms, specialised surgery and radiotherapy. Chemotherapy may be given in some circumstances.

Key recommendations

Care should be coordinated across healthcare services

The treatment and care of people with brain or other CNS tumours should be organised so that everyone has the same high-quality level of care. The people involved in this should be:

- a 'lead' senior healthcare professional who coordinates services for all the hospitals in the trust (trusts are organisations that run the NHS at a local level)
- healthcare professionals working in specialist multidisciplinary teams (these teams are explained below)
- a key worker (who is likely to be the clinical nurse specialist) or other healthcare professional who has the closest contact with the patient. (The key worker may change as the patient's condition changes, but the patient and their family and carers should always know who it is.)

A multidisciplinary team is a team of healthcare professionals who work together to provide the full range of specialist services that patients with a particular condition need. Two types of multidisciplinary team should be involved in the treatment of people with brain or other CNS tumours.

- The neuroscience team (usually based at a specialist neuroscience centre), which is responsible for the diagnosis and first stages of care (surgical and non-surgical) for most adults with brain or other CNS tumours. The neuroscience team is responsible for agreeing a plan for the treatment and care of the patient (this is called a management plan).
- The cancer network team, which is responsible for non-surgical care, including carrying out treatment such as radiotherapy or chemotherapy and other aspects of the management plan.

Both types of teams should include a clinical nurse specialist who can provide patients and their families

with support and information, especially in the early stages of care. The clinical nurse specialist can also talk to other healthcare professionals involved in a person's care on behalf of the person with the brain or CNS tumour or their families.

The multidisciplinary teams should also include healthcare professionals who specialise in palliative care. Palliative care helps to relieve pain and other symptoms to make a person's quality of life as good as possible. These specialist professionals can help and advise on specific problems, for example, they can advise on headache, seizures, pain, nausea and other symptoms. They also provide emotional, social, spiritual and financial advice and support for patients and their carers.

The neuroscience team should be involved if a scan shows a possible tumour

Following a scan (taking images of the inside of the body), if it is suspected that someone has a brain or other CNS tumour, the neuroscience multidisciplinary team should be involved in a discussion about the best course of action for that person's care. They can advise on whether more tests are needed to confirm the diagnosis, and on the best type of treatment and care for the person. These discussions should happen for every patient.

Local 'cancer networks' are responsible for making sure that there are systems and procedures in place to make sure that the discussions with the neuroscience multidisciplinary team take place without delay. (In the NHS, 'cancer networks' have been set up to organise healthcare for patients with cancer. They bring together the services offered by hospitals and in the community, including those provided by voluntary organisations and local authorities.)

Specialist surgical, laboratory and scanning services should be available at key stages to help with diagnosis and care decisions

In most cases, images from scans (called MRI or CT scans) are used to spot or confirm that a person has a brain or other CNS tumour. A specific diagnosis is made by analysing samples of the tumour under a microscope. This specific diagnosis is important as people with different types of CNS tumour need different types of treatment and care. Samples for analysis are taken either by a biopsy procedure

(surgically removing a small piece of a tumour), or from a tumour that has already been surgically removed. These procedures should be available for all patients who need them.

Before a patient has surgery, wherever possible the neuroscience multidisciplinary team should discuss the best way of carrying out the surgery. They should also discuss the best methods of obtaining samples of the tumour for analysis. This may involve analysing samples of the tumour during the operation, to get an initial diagnosis for surgical purposes. However, the full analysis is done after the operation.

Health services should be organised so that images and tumour samples can be obtained whenever they are needed, so the results are available when they are of most help. The specialists involved in producing the results should be involved in discussions with the neuroscience team before, during and after surgery.

Specialist help should be available for other problems linked with CNS tumours

Depending on their location and size, brain and other CNS tumours can cause problems such as epilepsy, headaches, speech and language difficulties, problems with muscle weakness and movement, and disturbed vision. A person may not be able to carry out the same tasks they could before. Tumours in the brain or other parts of the CNS can also affect a person's behaviour, emotions and feelings, and awareness of what is happening. Specialist help from healthcare professionals should be available for any problems like these.

Help should be rapidly available if a person's needs change

If a person's condition changes, healthcare professionals should quickly assess the effects of the changes on the person's life and whether further support or equipment is needed. If specialist equipment is required, it should be available for the person as soon as he or she needs it.

Face-to-face communication and high-quality written information should be available

At different stages throughout a person's illness, a healthcare professional should discuss with them (and their carer when appropriate) what is happening, the

options available to them, any questions they may have and what is likely to happen in the future. If appropriate, this includes the care that will be available to the person as they approach the end of their life.

Patients and their families and carers should also have access to good, clear, and relevant written information to help them with these issues. Healthcare professionals should also have access to these information sources.

Improving knowledge about brain and CNS tumours

Many tumours affecting the brain or other part of the CNS are rare, and so experience of treating and caring for people who have them can be limited. NICE recommends that there should be systems in place so that healthcare professionals can collect data on the treatment and care of people with a confirmed brain or other CNS tumour. Healthcare professionals should be able to access this information and draw on the experience of other healthcare professionals who have treated or are treating patients with similar tumours. (The information available for sharing would not include data that would identify an individual patient.)

The National Cancer Research Institute Clinical Studies Group on brain tumours is a group that coordinates clinical trials (research studies) looking at the treatment and care options for people with brain and other CNS tumours. The NICE guidance encourages this group to set up new clinical trials. If they are to provide useful information, clinical trials also need to have the support of healthcare professionals, and patients need to agree to take part. The decision about whether or not to take part is entirely up to the patient, who should receive full written information about the purpose of the trial and what it involves (including any risks) before making up his or her mind. Cancer networks should have processes in place to ensure clinical trials are supported and to monitor the entry of patients into the trials.

Standard protocols should be developed

Groups should be set up at a national level to develop standard procedures and methods ('protocols') for the investigation and treatment of and research into rare tumours in the brain and other parts of the CNS. These groups should also maintain national systems to keep records of these tumours.

Further information

It's important to remember that your local services may be a little different from those described here – the NICE guidance sets out the way in which cancer services should develop over the coming years.

If you have any questions about your health or the health of a member of your family or a friend, speak to your GP. If you, or a friend or relative has a brain or other CNS tumour and you have questions about the information here, or about treatment and healthcare in general, talk to a member of the team looking after you, or your key worker if you have one. In addition, further information on brain and other CNS tumours (including some signs and symptoms) and support groups is available from NHS Direct (which you can access on the Internet at www.nhsdirect.nhs.uk or by telephone on 0845 46 47).

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Copies of this document are available from the NICE website or from the NHS Response Line (telephone 0870 1555 455 and quote reference N1048). The Guidance manual, *Improving Outcomes for People with Brain and Other CNS Tumours* (reference N1047) and a CD with all documentation including the research evidence on which the guidance is based (reference N1049) are also available.

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