Healthcare services for brain and other central nervous system tumours

The paragraphs in the draft are numbered for the purposes of consultation. The final version will not contain numbered paragraphs.

This information is based on the second consultation draft of the manual.

Understanding NICE guidance – information for the public

Contents

Introduction

1. 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 page 4 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’.

2. 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.

3. **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 in Brain and Other CNS Tumours*, which is available from the NICE website (www.nice.org.uk) or from the NHS Response Line (see page 10). 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.

4. 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

5. CNS stands for central nervous system. It is the part of the nervous system that 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 Health Service 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).**[18]**

6. The distinction between malignant ('cancerous') and benign ('non-cancerous') tumours is not as important for CNS tumours as it is for tumours at most other sites. CNS tumours can spread (metastasise) outside the CNS, but this is very rare. The problems caused by CNS tumours are almost always due to local growth. For the most common CNS tumours, called gliomas, the appearance of the tumour when looked at with a microscope is very important. Gliomas are described as being 'high grade' (grow quickly) or 'low grade' (grow slowly).

7. Primary CNS tumours are rare. The most common type develop in the brain, but these make up less 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 in the CNS. **[21] [47]**

8. 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

9. The treatment and care of people with brain or other CNS tumours should be coordinated so everyone should have access to the same high-quality level of care. The people involved in this should be:

   - a ‘lead’ healthcare professional who works at a trust level, coordinating services for all the hospitals in the trust

   - healthcare professionals working in specialist multidisciplinary teams (these teams are explained below)

   - a key worker, who is likely to be the clinical nurse specialist **[11]** or other healthcare professional who has the closest contact with the patient **[107]** (the key worker may change as the patient’s condition changes, but the patient should always know who it is).**[108, 109]**

10. Multidisciplinary teams are teams of healthcare professionals with all the relevant skills, knowledge and experience related to a particular area of healthcare. Two types of multidisciplinary team should be involved in the treatment of people with brain or other CNS tumours:

    - the neuroscience team, which is usually based at a specialist neuroscience centre and is responsible for the diagnosis and first stages of care (surgical and non-surgical) for most adults with brain or other CNS tumours

    - the cancer network team, which is responsible for non-surgical care (tumours that need radiotherapy or chemotherapy). **[6]**

11. Both types of teams should include clinical nurse specialists who can provide support and information, especially in the early stages of care. They can also talk to other healthcare professionals involved in a person’s care on their behalf. **[11]**

12. The multidisciplinary teams should also include healthcare professionals who specialise in palliative care. Palliative care helps to relieve pain and discomfort to improve the patient's quality of life when it is not possible to cure the disease. These professionals can help and advise on how to care for a person (for example, they can advise on seizures, spasms, pain relief and the sort of care that would help with specific symptoms). **[13]**

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

13. Following a scan, 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 even if it is thought that the person won't need specialist treatment.**[7]**

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

14. In most cases, images from scans (called MRI or CT scans), X-rays and so on 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.**[153]** 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, or from a tumour that has been surgically removed. These procedures should be available for all patients who need them. **[9]**

15. Before a patient has surgery, wherever possible the neuroscience multidisciplinary team should discuss the best way of carrying out the

surgery and obtaining samples of the tumour for analysis. **[9]** 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. **[8]**

16. 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. **[8]**

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

17. 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 and information from healthcare professionals and patient organisations **[395**] should be available for any problems like these. **[12]**

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

18. 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.**[14]**

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

19. At different stages in a person’s illness, a healthcare professional should sit down and talk with the person about what is happening, the options available to them, and what is likely to happen in the future. This includes the care that will be available to the person as they approach the end of their life, if this is appropriate. Patients and carers should also have access to good, clear, and relevant written information to help them with these issues. High-quality written information should also be available to healthcare professionals so that they can pass on accurate information. **[10]**

Standard guidelines should be developed

20. Groups should be set up at a national level to develop standard guidelines on the investigation, treatment and research into rare tumours in the brain and other parts of the CNS.**[17]**

Information should be shared to increase the knowledge base

21. Many tumours affecting the brain or other part of the CNS are rare,**[21]** and so experience of treating and caring for people who have them can be limited. Systems for collecting information about individual cases should be put in place so that information on all patients with a confirmed brain or other CNS tumour can be collected. 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. **[15]**

More clinical trials are encouraged

22. The National Cancer Research Institute Clinical Studies Group on brain tumours is a group that coordinates clinical trials looking at the treatment and care options for people with brain tumours. The NICE guidance encourages this group to set up more 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. (Healthcare professionals should fully explain the options available to patients before a patient agrees to take part in a clinical trial.) Processes are to be put into place to check whether these things are happening.**[16]**

Further information

23. 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.

24. 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 N0xxx). The Guidance manual, *Improving Outcomes in Brain and Other CNS Tumours* (reference[XXX]) and a CD with all documentation including the research evidence on which the guidance is based (reference [XXX]) are also available.

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