brainstrust
the brain cancer people

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Treatment

Patient Guide

What happens?

This Patient Guide covers treatment of tumours that behave as:

- low-grade glioma (grades 1 and 2 in the World Health Organization (WHO) classification)*
- high-grade gliomas (WHO grades 3 and 4)*
- meningiomas

After your tumour has been diagnosed, clinicians will discuss what treatment options are most appropriate for your tumour, taking into account its size, location, cell type, grade, and any further molecular or genetic information. Treatment may include periods of observation/surveillance, surgery, radiotherapy, chemotherapy, and combinations of all or some of these treatments in different ways. Your lead consultant will discuss the options with you; this may be a neurosurgeon, oncologist or neurologist.

Your options will have been discussed with a team of experts at a multidisciplinary team meeting (MDT). This is an internal hospital meeting where surgeons, oncologists, radiographers and clinical nurse specialists discuss your case. For more information about MDT meetings visit brainstrust.org.uk/navigating-your-pathway.

What is the optimum standard of care for low-grade gliomas (LGGs) (World Health Organisation (WHO) grades 1 and 2) according to the NICE guidelines?

For more information on tumour types, visit section 3 on brainstrust.org.uk/anatomy-tumour-types.

The optimum standard of care states the minimum level of care we should expect. Sometimes, for a variety of reasons, our health service may not be able to meet the standards.

This is the optimum standard of care:

- A holistic approach to your treatment plan.
- The neuroscience MDT (for more information about MDTs, visit brainstrust.org.uk/navigating-your-pathway) will be responsible for deciding on your surgery and adjuvant therapy (treatment after surgery in order to lower risk of tumour recurrence). The cancer network MDT (different to the neuroscience MDT) is responsible for your care, including chemotherapy, radiotherapy and coordination of supportive care.
- On the cancer network MDT will sit the following people:
  - neurologist(s)
  - radiologist(s)
  - radiographer(s)
  - oncologist(s)
  - clinical nurse specialist(s)
  - specialist allied health professionals (AHPs)
  - coordinator(s)
  - links to palliative care, where appropriate.
- Either watchful waiting or early surgical intervention.
- A maximum of 1 month (31 days) from decision to treat to first definitive treatment, if a decision to treat has been made.
- A maximum of two months (62 days) from urgent GP referral to first definitive treatment, if a decision to treat early has been made.
- Possible radiotherapy.
- Possible chemotherapy.
- To be told about any relevant clinical trials.
- The opportunity to discuss potential preservation of fertility where treatment may have an impact on your fertility.

Recommendations from the NICE guideline 2018 for low-grade gliomas

- Surgery to remove all or part of your tumour may be considered as part of initial management (within 6 months of being diagnosed by a scan). This is different to a biopsy. A biopsy takes a small amount of tissue. It allows for histological and molecular diagnosis, which provides information on how your tumour is likely to behave and how it's likely to respond to treatment, and removal of as much of the tumour as safely as possible. Surgery to remove the tumour also allows for a biopsy and also aims to remove all or part of your tumour. This will be discussed in the MDT meeting and with you and with anyone else you wish to involve. How much tumour to remove is a balance of potential benefits versus the risk of disability.
- Technical aids to surgery and imaging may be used to help safely remove as much tumour as possible, such as ultrasound or intraoperative MRI, or diffusion tensor imaging (see the glossary for help with these words: brainstrust.org.uk/glossary).
- An awake craniotomy may be considered to preserve neurological function. This will be discussed with you. An awake craniotomy is when neurosurgery is done with the patient awake for all or part of the surgery. This is a preferred technique for operations to remove tumours close to, or involving, functionally important areas of the brain. The overall aim is to minimise the risks of such operations. The risks of awake surgery for a brain tumour are the same as those for conventional surgery, but there is also a small risk of seizures during surgery that might in rare circumstances require conversion to general anaesthetic. Some people too may find the thought of an awake craniotomy very stressful. Your suitability for this surgery will be will be discussed with you. Other specialists, such as neuropsychologists and speech and language therapists, will be involved with your care before, during and after awake craniotomy.

- If it isn't possible or not considered appropriate to get a diagnosis of a low-grade tumour via biopsy, then active monitoring will be followed. This means regular scanning of the tumour at set intervals. If the tumour shows progression (so it looks like it is growing or the cells are changing), the MDT meeting will discuss whether surgery to remove some or all of the tumour, or biopsy, is now appropriate. This will then be discussed with you.
- After surgery, if you are 40 or over or you have a tumour over 2cm left behind, you may be offered a course of radiotherapy, followed by up to 6 cycles of chemotherapy. Active monitoring may be considered for patients aged under 40. For more information about these treatments, visit brainstrust.org.uk/therapies.
- If you have not had radiotherapy before, and if the disease is progressive or you have seizures that don't respond to medication, then radiotherapy may be considered, followed by 6 cycles of PCV chemotherapy. Your care team will agree the order of chemotherapy and radiotherapy with you.

Note that every case is reviewed individually and there are many more options for treatment based on the tumour type, grade, and age and health of the person with the brain tumour.

What is the optimum standard of care for high-grade gliomas (HGGs) (WHO grades 3 and 4) according to the NICE guidelines 2018?

- A holistic approach to your treatment plan.
- The neuroscience MDT should be responsible for deciding on your surgery and adjuvant therapy (treatment after surgery in order to slow down tumour recurrence). The cancer network MDT is responsible for your care, including chemotherapy, radiotherapy and coordination of supportive care.

- A maximum of 1 month (31 days) from diagnosis to first definitive treatment.
- A maximum of 2 months (62 days) from urgent GP referral for suspected tumour to first definitive treatment.
- Surgery, if appropriate. This may include:
  - urgent surgery (i.e. emergency surgery)
  - planned surgery (biopsy, partial or maximum removal, or removal plus insertion of chemotherapy wafers into the tumour).
- If, on balance, the risks of treatment outweigh the benefit or will affect quality of survival, a discussion about supportive and palliative care will take place with referral to the appropriate specialists.
- Radiotherapy may be considered following pathological diagnosis, unless a biopsy is too risky; then radiotherapy may be given in the absence of histology.
- Chemotherapy may be considered.

Recommendations for high-grade gliomas

- Technical aids to surgery and imaging may be used to help achieve surgical resection, such as ultrasound or intraoperative MRI, or diffusion tensor imaging (see the glossary for help with these words: brainstrust.org.uk/glossary).
- An awake craniotomy may be considered to preserve neurological function. This will be discussed with you. An awake craniotomy is when neurosurgery is done with the patient awake for all or part of the surgery. This is a preferred technique for operations to remove tumours close to, or involving, functionally important areas of the brain. The overall aim is to minimise the risks of such operations. The risks of awake surgery for a brain tumour are the same as those for conventional surgery, but there is also a small risk of seizures during surgery that might in rare circumstances require conversion

to general anaesthetic. Some people too may find the thought of an awake craniotomy very stressful. Your suitability for this surgery will be will be discussed with you. Other specialists, such as neuropsychologists and speech and language therapists, will be involved with your care before, during and after awake craniotomy..

- After surgery for grade 3 gliomas, you will be offered radiotherapy. This is usually 30–33 treatments daily over 6 to 7 weeks. This is often followed by chemotherapy. The type used depends on the molecular subtype. If the tumour has a codeletion of 1p19q, then 4 to 6 cycles of PCV is used. For those without, up to 12 cycles of tablet Temozolomide is given. This is usually 5 days in every 28 for up to 12 months.
- After surgery for grade 4 gliomas, patients may be offered radiotherapy with Temozolomide starting at the same time, followed by up to 6 or 12 cycles of adjuvant Temozolomide. The course of treatment depends on fitness and scientific features of the tumour.
- Best supportive care alone may be considered as the best option for patients aged 70 or over with a grade 4 glioma, particularly if the brain tumour is causing significant disability.
- Your performance status (how well you perform activities of daily living) will be assessed throughout the period following surgery, and treatment options will be reviewed if your performance status changes.
- If you have a recurrent high-grade glioma, chemotherapy may be considered, using either Temozolomide or PCV.
- Best supportive care alone may be considered the best option if you have a recurrent high-grade glioma and if other treatments are not likely to be of benefit, or if you would prefer this.
- The MDT may consider further surgery or radiotherapy for recurrent high-grade gliomas. They may take into account your performance status, where the tumour is and how large it is. Also how long it has been since your initial surgery and radiotherapy.

- You should be advised that the current evidence does not support the use of cannabis oil, immunotherapy, ketogenic diets, metformin, statins and valganciclovir.
- The use of tumour treating fields (TTF) and bevacizumab is not supported.

What is the optimum standard of care for meningiomas according to the Improving Outcomes Guidance?

- Management depends on signs, symptoms, the patient's fitness, and site and size of the tumour.
- A holistic approach to your treatment plan.
- Maximum removal may be appropriate.
- Radiotherapy may be considered if a biopsy shows the tumour is WHO grade 2/3, there is invasion by the tumour into adjacent brain tissue or extensive invasion of other tissue, there is a second or subsequent relapse, or there is a contraindication to surgery.
- To be told about any relevant clinical trials.

Recommendations for meningiomas

- Management of meningiomas is based on the extent of surgery and the grade of the meningioma. Treatment may include active monitoring, further surgery and radiotherapy.
- Before a decision is made on radiotherapy, the following will be taken into account: comorbidities, life expectancy, neurological function, oedema, performance status, rate of tumour progression, size and location of tumour, surgical and radiotherapy morbidity, the patient's preferences, previous treatments.
- If the MDT thinks that radiotherapy is appropriate, the advantages and disadvantages of the treatment will be discussed with you.

What does *brainstrust* think I should expect?

- Treatment can vary depending on the exact nature of the tumour and can vary from patient to patient.
- A clear discussion about the best management for you, including the pros and cons for radiotherapy early or later and other more experimental treatments.

What questions could I ask?

- What are my brain tumour treatment choices? Which do you recommend for me? Why? Why are these different from the optimum standard (if applicable)?
- What options are available outside my locality?
- Which do you recommend for me? Why? How does that treatment work?
- If you or your family member had my type of tumour, what would you advise?
- Do I have to decide today?

- Can I wait to start treatment? What are the expected benefits of each kind of treatment?
- What can I do to prepare for treatment?
- Will I need to stay in the hospital? If so, for how long?
- What are the risks and possible side effects of each treatment? How can side effects be managed?
- How will treatment affect my normal activities?
- I might decide to seek a second opinion. What would the questions be that you would ask?
- Should I get a second opinion? Can you recommend other doctors who could give me a second opinion about my treatment options?
- Are there any complementary therapies that could help with the side effects of treatment?
- What if I choose not to have the treatment?
- If I am more interested in quality of life than length, what would you suggest?
- What are the long-term implications/side effects of treatment?
- How many brain tumours do you treat a year?
- Would a research study (clinical trial) be appropriate for me? If it isn't, why not?
- What support services are available to me? My family?
- Do you have any written information that would help me understand what is happening? Can you recommend any as an addition?
- After treatment, what follow-up tests will I need, and how often will I need them?
- Would neuropsychological tests be beneficial in seeing how my brain function is affected and what could be done to improve it?

Active-surveillance-specific questions

- What are you waiting for?
- What are the benefits of waiting? And the drawbacks?
- How often will I have scans?
- How long do I have to wait for the results?
- How long will it be until I do need treatment?
- What can I do to stay as healthy as possible?

Surgery-specific questions

- How long will I be in hospital for?
- What will happen to my tumour after you've removed it? Can I donate it to research?
- How long will it take for me to recover from the treatment?
- Is the surgeon a specialist in brain tumour surgery?

Radiotherapy-specific questions

- What type of radiotherapy do you suggest?
- What will the side effects be, physical and emotional? And when will they kick in?
- Should someone come with me to radiotherapy sessions?
- Will I lose my hair?
- How long will it take for me to recover from the treatment?
- Is stereotactic radiotherapy/radiosurgery suitable for me?

Chemotherapy-specific questions

- What chemotherapy am I being offered?
- What will the side effects be, physical and emotional? When will they kick in?
- If chemotherapy is offered, can I have molecular testing to see if my tumour will respond to the treatment?
- How long will it take for me to recover from the treatment?

Treatment sources

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Notes

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Mike, Tom, Rebecca, Charlie & Sophie

***brainstrust* patient guide**
This patient guide accurately reflects recommendations in the NICE guidance on brain tumours (primary) and brain metastases in adults.

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