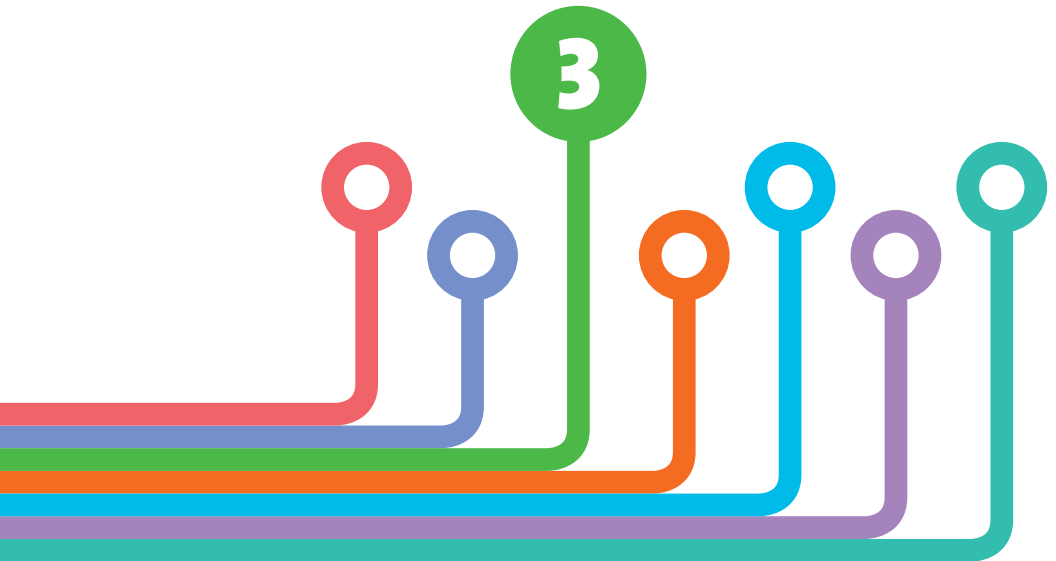


Patient Guide

Treatment



What happens?

After your tumour has been diagnosed, the clinicians will discuss what treatment options are available. You and those around you may wish to be involved in discussions and decisions about your care, which is absolutely fine.

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

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

- A holistic approach to your treatment plan.
- The Neuroscience MDT should be responsible for your deciding on surgery and adjuvant therapy (treatment after surgery in order to lower risk of tumour recurrence). The Cancer network MDT 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 AHP(s).
 - Coordinator(s).
 - Links to Palliative care are made where appropriate.
- Either watchful waiting or early surgical intervention.
- A maximum one month (31-day) from decision to treat to First Definitive Treatment.

- A maximum two month (62-day) from urgent GP referral to First Definitive Treatment if a decision to treat early has been made.
- Possible radiotherapy.
- Role of chemotherapy uncertain.
- To be told about any relevant clinical trials.

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

- 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 lower risk of tumour recurrence). The Cancer network MDT for your care including chemotherapy, radiotherapy and coordination of supportive care.
- A maximum one month (31-day) wait from diagnosis to First Definitive Treatment.
- A maximum two month (62-day) wait 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 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 biopsy too risky, then radiotherapy may be given in the absence of histology.
- Chemotherapy may be considered.

- To be told about any relevant clinical trials.
- Healthcare professionals should discuss the use of complementary therapies with you, your relatives and carers to help identify possible side effects or interactions with conventional treatment.

What is optimum standard of care for meningiomas according to the IOG?

- 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; invasion by tumour of adjacent brain or extensive invasion of other tissue; a second or subsequent relapse; a contraindication to surgery.
- To be told about any relevant clinical trials.

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? Perhaps even abroad?
- 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 do?
- 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?
- What complimentary therapies 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?

Watch and wait specific questions

- What are you waiting for?
- What are the benefits of waiting? And the drawbacks?
- How often will I have scans?
- 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 operating a specialist in brain tumour surgery?

Radiotherapy specific questions

- What type of radiotherapy do you suggest?
- What will the side effects be? And when will they kick in? Physical and emotional.
- 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? If not Temozolomide, why not?
- What will the side effects be? When will they kick in? Physical and emotional.
- If chemotherapy is offered, you can ask for molecular testing to see if your tumour will respond to the treatment.
- How long will it take for me to recover from the treatment?

Treatment sources

The Beatson, West of Scotland Cancer Centre, *Neuro Oncology*
www.beatson.scot.nhs.uk/content/default.asp?page=s18_1_10

National Cancer Institute, *Adjuvant Therapy*,
www.cancer.gov/dictionary?cdrid=45587

National Cancer Peer Review Programme Manual for Cancer Services:
Brain and CNS Measures Version 1.2

National Cancer Waiting Times Monitoring Data Set, available at
[www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/
data_sets/national_cancer_waiting_times_monitoring_data_set_fr.asp](http://www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/national_cancer_waiting_times_monitoring_data_set_fr.asp)

NCAT, *Rehabilitation Care Pathway Brain CNS*, 2009, available at
ncat.nhs.uk/sites/default/files/NCAT_Rehab_BrainCNS.pdf

NICE, *Improving Outcomes for people with brain and other CNS tumours*,
June 2006, available at [www.nice.org.uk/nicemedia/live/10905/
28963/28963.pdf](http://www.nice.org.uk/nicemedia/live/10905/28963/28963.pdf)



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