

Follow-up

Patient guide



What happens?

Following diagnosis, many people have treatment, while for some people the most appropriate care is active monitoring, or active surveillance (also called ‘watchful waiting’). When you move into this follow-up phase, you most likely will have regular clinical reviews, which will be a scan followed by an appointment with consultants. This will be based on the specific type of tumour, and how it is likely to behave.

You may expect life to return to how it was before you were diagnosed with a brain tumour, but it takes time to recover from treatment and come to terms with the diagnosis. Many people find that although life never returns to the ‘normal’ they knew, they start living a ‘new normal’ – a way of life that is normal to you now. For some people the tumour is gone or stable and is likely to remain. For others it’s a process of coming to terms with a longer-term condition and a reality that it is not going away.

And, for some, this can open up new opportunities. Others, however, describe this time as ‘falling off the edge’, and they feel isolated and unsupported. It’s probably a bit of both. Whichever it is, it’s important to know how you and those around you can feel resourced, supported and prepared.

What is the optimum standard of care according to the NICE guidance?

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

This is the optimum standard of care:

- Routine imaging.
- Regular clinical reviews to assess changes in your physical, psychological and cognitive well-being.
- Ready access to assessment and rehabilitation services for problems such as epilepsy, headaches, and speech or visual problems.
- Ready access to specialist neuropsychology and neuropsychiatry services.
- Immediate access to specialist equipment that would assist rehabilitation as necessary.
- Clear information on who to contact and how if you are concerned about your condition.
- Follow-up as close to home as possible.

Recommendations from the NICE guidance

- The timing of regular clinical reviews will be based on any brain tumour that is left after treatment, life expectancy, your preferences, previous treatments, available treatment options and the specific type of tumour.
- MRI scans may be used as part of regular clinical review. Additional scans using advanced MRI techniques may be used if the findings from standard imaging are unclear.

- Scanning for a glioma will be done at regular intervals depending on the type of glioma.

Grade I tumours – scanning will be done at 12-month intervals for five years.

Grade II and III tumours – scanning will be done at three, six and 12 months for year one and then either every six months or annually, depending on the tumour.

Grade IV tumours – scanning will be done at three, six and 12 months for year one and then either every six months or annually.

- Scanning for a meningioma will be done at regular intervals depending on the type of meningioma.

Grade I meningioma – scanning will be done at three months and then at 12-month intervals for three to five years, followed by once every two years.

Grade I meningioma after radiotherapy – scanning will be done at six months after radiotherapy and then at 12-month intervals for three years, followed by once every two years.

Grade II and III meningioma – scanning will be done at three, six and 12 months for year one and then either every six months or annually, depending on the tumour.

- You will be made aware that imaging can be difficult to interpret and results can sometimes be uncertain. Having routine imaging and waiting for results may cause anxiety. Sometimes this can outweigh the benefits of having a scan.
- For all types of glioma, a baseline MRI scan will be considered within 72 hours of surgical resection, and three months after the completion of radiotherapy.
- A clinical review with appropriate imaging will be arranged for patients who develop new or changing neurological symptoms or signs at any time.

- Health and social care professionals will address additional complex needs during or after treatment and throughout follow-up. These include:
 - changes to cognitive functioning
 - fatigue
 - loss of personal identity
 - loss of independence
 - maintaining a sense of hope
 - potential for change in personal relationships
 - the challenges of living with uncertainty
 - the impact of brain-tumour-associated epilepsy on well-being.
- Your risk of developing late side effects of treatment will be assessed when you finish treatment. Such side effects can develop months or years after treatment and may include cataracts, cavernoma, cognitive decline, epilepsy, hearing loss, hypopituitarism, infertility, neuropathy, radionecrosis, secondary tumours and stroke. Advice will be given to you on how to monitor for late-onset side effects based on individual needs.

What does *brainstrust* think I should expect?

- Regular, ongoing holistic support, which encompasses physical, emotional, spiritual and cognitive needs.
- If you are concerned your brain tumour might be returning, an urgent re-referral.
- Information on how to access allied health professional assessment.
- Your primary care (such as your GP) to signpost supportive resources to you.
- Support for your caregiver and close persons.

- Timely assessments so that you can be proactive, not reactive, based around functional and neurological assessments.

What questions could I ask?

- What follow-up care can I expect?
- Who will look after me when I'm discharged back home?
- Which doctor should I see, and how often?
- Are there any post-treatment symptoms I should be aware of?
- What do I do about symptoms that worry me?
- What can be done to relieve pain, fatigue or other problems after treatment?
- How long will it take me to feel more like myself?
- Is there anything I can do to stop the tumour coming back?
- When will my next scan be?
- Who can I get in touch with if I have any questions?
- When can I go back to work?
- When can I drive again?

Additional questions you may want to ask

- What are the chances that the tumour will come back?
- If it does, what are my options?
- What will happen with the tumour that couldn't be removed? Will it grow? If so, when is this likely to happen?
- What treatment will be likely, or might be possible, in the future?

Follow-up sources

The Scottish Adult Neuro-Oncology Network. 2021. Guidelines. [online] Available at: <<https://www.sanon.scot.nhs.uk/guidelines/>> [Accessed 1 Aug 2021].

Department of Health and Social Care. 2013. *Living With and Beyond Cancer: Taking Action to Improve Outcomes*. [online] Available at: <<https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes>> [Accessed 1 Aug 2021].

National Cancer Institute. 2018. *Facing Forward: Life After Cancer Treatment*. [online] Available at: <<https://www.cancer.gov/publications/patient-education/facing-forward>> [Accessed 1 Aug 2021].

National Cancer Peer Review Programme Manual for Cancer Services, Version 1.0. [online] Available at: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216117/dh_125890.pdf> [Accessed 1 Aug 2021].

National Institute for Health and Care Excellence. 2006. *Improving outcomes for people with brain and other CNS tumours*. [online] Available at: <<https://www.nice.org.uk/guidance/CSG10>> [Accessed 1 Aug 2021].

National Institute of Health and Care Excellence. 2018. *Brain tumours (primary) and brain metastases in adults*. [online] Available at: <<https://www.nice.org.uk/guidance/ng99>> [Accessed 1 Aug 2021].

***braintrust* 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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