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Receiving diagnosis after biopsy

Patient Guide

What happens?

If you have had a biopsy, a specialist in interpreting the pathology of brain tissue (neuropathologist) will examine the cells in your tumour's tissue in the laboratory. The pathologist will be able to see what cell type and grade of tumour you have.

Histopathology is the study of diseased tissue at a minute (microscopic) level. For more information about a neuropathologist, visit brainstrust.org.uk/who-is-who.

It is a good idea to take someone with you when you receive your scan result. A good person would be someone who can be your advocate, help listen and maybe take notes, help you to ask the questions that are important to you and discuss the consultation with you afterwards. It can help to take the same person with you each time, as they will be able to support you when you are at home, including helping you to explain your diagnosis and what to expect to other people that are important to you.

You have a legal obligation to notify the DVLA if you have a brain tumour. For more information visit <https://www.gov.uk/brain-tumour-and-driving>

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

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.

- All tumours diagnosed on imaging need to have a confirmed histopathological diagnosis (through biopsy) unless the neuroscience multidisciplinary team (MDT) decides that a biopsy would be too risky or is otherwise inappropriate. More information about MDTs can be found here: brainstrust.org.uk/navigating-your-pathway.

- Timely and efficient compliance with national cancer waiting time targets (one hospital, for example, returns histopathology results in 4–7 days). Some additional tests may take longer, and may be sent to other hospitals for examination.
- The histopathological findings of your tumour will be discussed in an MDT meeting and compared with images and clinical disease features. MDT meetings are usually held weekly. Your case will be discussed within 1–2 weeks after surgery. A final report is then written. This report should also be sent to your GP.

Recommendations

- Brain tumours will be reported using the latest version of the WHO classification.
- As well as a histopathological assessment, molecular markers will also be included in a diagnosis. These markers are important because the information they provide can help decide what would be the best treatment to have.
- In gliomas (a type of brain tumour), MGMT methylation will be tested for to inform prognosis and guide treatment. Testing for TERT mutations may also be considered in IDH-wildtype gliomas to inform prognosis. Other markers that guide prognosis and treatment options include 1p19q.

You can read more about molecular markers here: brainstrust.org.uk/molecular-analysis.

What does *brainstrust* think I should expect?

- You should receive a diagnosis based on the pathology results within 1 working day if you are an inpatient, and 5 working days as an outpatient, AFTER the MDT meeting.

What questions could I ask?

Before asking questions, think carefully about how much you truly want to know. Once you have knowledge, this cannot be undone.

- What is the tumour type?
- What grade of tumour do I have? What does this mean?
- Where is it in my brain? How will its position potentially impact on me? Does this explain my symptoms?
- Can you explain my pathology reports to me?
- Who has reviewed my tumour sample?
- Has any molecular testing been done? If not, why not? (For information on molecular testing, visit brainstrust.org.uk/molecular-analysis.)
- How can I have this testing done if it hasn't been done?
- If molecular testing has been done, does it suggest a particular course of treatment?
- How will this testing impact on my treatment plan?
- Can I receive copies of letters (if you wish).

Once you leave the consultation, you may feel a range of strong emotions. There is a lot of information to take on board. It takes time to process this, and over the next few days, you will have lots of thoughts and questions. Write them down and have them ready to ask at your next appointment. In the meantime, contact your *brainstrust* support specialist for help, or email hello@brainstrust.org.uk.

Receiving diagnosis after biopsy sources

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Notes

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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