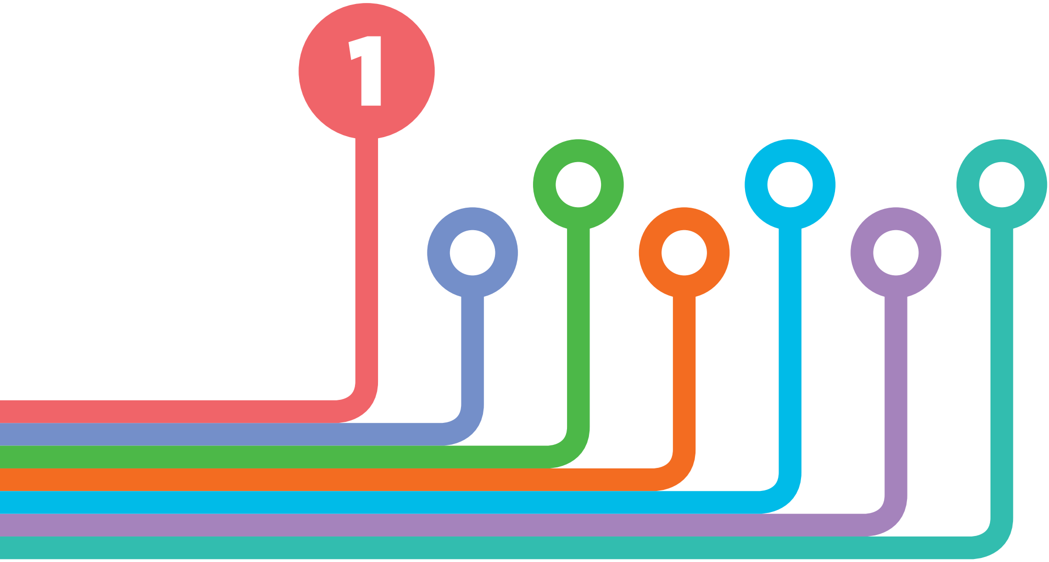
brainstrust
the brain cancer people

Patient Guide

Diagnosis



www.brainstrust.org.uk

What happens?

After a CT or MRI scan, an expert in interpretation of scans (radiologist) will be able to see if you have an abnormality, sometimes referred to as lesion, which they may call a tumour. They will only be able to discover exactly what type of tumour it is if they take a sample. This is called a biopsy. This is sometimes done at the same time as a resection – where the tumour is removed or partially removed if surgery is an option.

It is a good idea to take someone with you when you receive your scan result. They can help listen and be your advocate.

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

- Timely and efficient complying with national cancer waiting times.
- Your scans and care should be discussed without delay* at a neuroscience multidisciplinary team meeting (MDT) where the following people will be present:
  - Neurosurgeon(s).
  - Neuroradiologist(s).
  - Neuropathologist(s).
  - Neurologist(s).
  - Oncologist(s).
  - Clinical nurse specialist(s).
  - Palliative care (if appropriate).
  - Neuropsychologist.
  - Specialist Allied Health Professions AHP(s) e.g. physiotherapist.
  - Coordinator(s) of the Multidisciplinary Team (MDT).

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* Without delay means that all diagnostic imaging suggestive of a brain tumour should be referred to the MDT within 2 days.

- MDT meetings are usually held weekly. You should receive a diagnosis within 1 working day (if you are an inpatient) and 5 working days (as an outpatient) AFTER the MDT meeting.
- A written summary of your proposed management plan should be sent out within one working day of the MDT meeting to your GP and your referring clinician.
- You should be given a clearly defined key worker (probably a Clinical Nurse Specialist (CNS)) within 1 working day (inpatient) or 5 working days (outpatient) of the MDT meeting.
- You should have face-to-face communication with healthcare professionals to discuss your care at critical points in your care pathway.
- You should be given the opportunity to have a permanent record.
- You should have the opportunity to ask questions.
- You should be provided with clear, high quality written information to support you and your relatives and carers which includes local support groups, services offering psychological, social and spiritual/cultural support.
- Your psychological and social well-being should be considered.
- You should have ready access to specialist care services as appropriate (e.g. an epilepsy nurse, or neuropsychology services).
- You should have ready access to a neurosurgical biopsy or resection service, if your clinicians think this is appropriate.
- You should be given clear, accurate and relevant information throughout the course of your illness.

What does *brainstrust* think I should expect?

- Scan results to be delivered in 2 weeks. It depends on when the scans are done in relation to the next MDT meeting.
- A copy of your scans if you ask for them. There may be a small fee.
- Clear signposting to support services, which includes *brainstrust*.
- A clear care pathway mapped out.
- The opportunity to explore options and ask questions with your clinicians.
- An assessment of rehabilitation needs, if appropriate.

What questions could I ask?

- Can you explain my scans to me?
- Will I have a biopsy to determine what the tumour is?
- If you're going to operate, are you planning to resect my tumour? If so, are you planning to do a complete or partial resection?
- If having a biopsy, how can I donate my tissue to research?
- What type of brain tumour do I have?
- Is it a primary or secondary (metastatic) tumour?
- What grade of tumour do I have? What does this mean?
- Who will be part of my healthcare team and what do they do?
- Who will coordinate my overall treatment and overall care?
- Will you attend a multidisciplinary team meeting to discuss my case?
- What services are available to help me and my family cope?
- Am I entitled to any benefits?
- Can I still drive?
- What happens next?

Diagnosis sources

The Beatson, West of Scotland Cancer Centre, *Neuro Oncology*
www.beatson.scot.nhs.uk/content/default.asp?page=s18_1_0

brainstrust, *Brain tumour symptoms and diagnosis*, available at www.brainstrust.org.uk/advice-symptoms.php

Cambridge University Hospitals, *Living with a brain tumour: Brain tumour diagnosis and tests*, available at www.cuh.org.uk/resources/pdf/patient_information_leaflets/PIN1624_brain_tumour_diagnosis_and_tests.pdf

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

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

NHS Choices, *Preparing for your Cancer Test Results*, www.nhs.uk/Livewell/cancer/Pages/Gettingyourresults.aspx

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

Notes

Notes

Health & care
information
you can trust

The Information Standard

Certified
Member

Registered Charity No. 1114634
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