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Diagnosis

If you have unexplained neurological symptoms or a brain tumour is suspected, perhaps following a change in your health, or, for example, a sudden onset of seizures, you should expect to have a diagnostic brain scan. This could be during an emergency admission to hospital or after referral to a specialist such as a neurologist. Sometimes brain tumours are found by chance when other things are being investigated.

You can find out more about symptoms, signs and diagnosis here: brainstrust.org.uk/symptoms-diagnosis.

How are brain tumours diagnosed? What happens?

Brain tumours are identified using a CT or MRI scan. An expert who interprets scans (radiologist) will be able to see if you have an abnormality, sometimes referred to as a 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 via surgery called a biopsy. This is sometimes done at the same time as more extensive surgery – a resection – where the tumour is removed or partially removed if surgery is considered, having weighed up the risks, as the best option.

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, about your diagnosis, and what to expect.

What is the optimum standard of care for all brain tumours (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.

- Timely and efficient compliance with national cancer waiting times.
- Your scans and care should be discussed without delay* at a neuroscience multidisciplinary team (MDT) meeting 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 professionals (AHPs), e.g. physiotherapist
 - coordinator(s) of the multidisciplinary team (MDT).
- MDT meetings are often held weekly. You should receive a diagnosis within 1 working day (if you are an inpatient) or 5 working days (as an outpatient) AFTER the MDT meeting.
- A written summary of your proposed management plan should be sent out within 1 working day of the MDT meeting to your GP and your referring clinician.

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

- 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 and services offering psychological, social and spiritual/cultural support.
- Your psychological and social wellbeing 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.

Recommendations

- You should be offered standard structural magnetic resonance imaging (MRI) as the initial diagnostic test, unless MRI is not possible. A structural MRI is a non-invasive way of examining the structure (anatomy) and nature (pathology) of the brain. It is different from functional magnetic resonance imaging (fMRI) which looks at brain activity. So another way of saying this is that structural MRI looks at space, and fMRI looks at time. Both produce images that can be used for clinical radiological reporting as well as for detailed analysis.

- Advanced MRI techniques may be used to assess whether a tumour that looks like a low-grade tumour on a standard structural MRI is changing to a high-grade tumour.
- CT imaging may be considered for meningioma to see if bone is involved.
- Imaging other than brain imaging might be done if it is suspected that the lesion might be a brain metastases, from cancer somewhere else in your body. This may change treatment options.
- If a brain metastases is found, then your case will be discussed at the tumour site speciality multidisciplinary team meeting, and a biopsy will be recommended. If there is no other safe place to biopsy, then you will be referred to the neuro-oncology MDT to discuss suitability for a biopsy.

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.
- The opportunity to explore options and ask questions with your clinicians. You may need to discuss options on more than one occasion, and at different times, during active monitoring and treatment periods; it's ok to ask the same questions more than once.
- The opportunity to request a copy of your scans and medical record, if you would like them. Your hospital will explain the process; there may be a small fee. It is your data, and you should feel confident and exercise your right to obtain copies of your scans and medical records.
- Clear signposting to support services, which includes *brainstrust*.
- A clear care pathway mapped out.
- An assessment of rehabilitation needs, if appropriate.

What questions could I ask?

- Can you explain my scans to me?
- What will happen next?
- Will I have a biopsy to determine what the tumour is?
- If you're going to operate, are you planning to take out all or part of my tumour as well as doing a biopsy? If so, how much do you plan to take out?
- If having a biopsy, how can I donate my tissue to research?
- What type of brain tumour do I have?
- Are there any other tests that will help select the most appropriate treatment and provide information about how my tumour will behave and a likely prognosis?
- Is it a primary or secondary (metastatic) tumour?
- If I have cancer in another part of my body, is this tumour related to that?
- What grade and type 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?
- Has my case been discussed at a multidisciplinary team meeting?
- What services are available to help me and my family cope?
- Am I entitled to any benefits?
- Can I still drive?
- Should I think about a second opinion?
- Are there any clinical trials suitable for me?
- How do I explain this to my family? My young children? Elderly parents?
- Do I have to agree/decide now?

Diagnosis sources

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Mike, Tom, Rebecca, Charlie & Sophie



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