brainstrust
the brain cancer people

What to expect if you are diagnosed with a suspected brain tumour

Information about what will happen next

Being told that you may have a brain tumour is frightening and will most likely cause uncertainty. This can feel like a new emotion – your world seems outside of your control, and you don't know what you want or need to know. There are many things that may be going through your mind at this point.

At *brainstrust*, we understand how frightening and how isolating this can be. Please do not hesitate to call or email us if you want to talk.

Tel: **01983 292 405**
Email: **hello@brainstrust.org.uk**
Web: **brainstrust.org.uk**

The aim of this leaflet is to explain what will happen next and to help you feel a little more in control while your doctors are gathering information to confirm your diagnosis. This will include the results of any investigations (such as scans) that you may have had. The doctors and nurses involved in your care want to share the right information with you, and sometimes it takes a few days to gather that information. It is always better to get things right than quickly.

This leaflet explores how you may feel, what will happen next and who to contact if you are worried. In this leaflet, we will try to answer some of the practical questions that you may have in terms of next steps and potential treatment options. Sometimes focusing on what you can influence helps you feel able to manage things.

> ***'I'm so anxious –***
> ***I have no clue what is going to happen.'***

Patient

What will happen next

If you are reading this, you will probably have had a scan that has shown an abnormality in your brain. This may be a brain tumour. You will only be kept in hospital if necessary. Any scans or investigations you need will be arranged just as quickly whether you are in hospital or at home. Whether you stay in hospital or go home, you should be given a key worker, whom you can talk to about your care. They will keep you informed of what will happen next. This can vary from hospital to hospital and from patient to patient.

> ***'I made an appointment to see my GP. It gave me the space to talk through some of my questions.'***

Caregiver

Scans

You will have had a scan because of the symptoms you have had. The scan will be reviewed by a radiologist (a doctor who interprets scans) and discussed with a specialist.

Depending on the results of your scan, you may be required to have further investigations. The results of these investigations give the doctors and nurses more information to support the discussion of your case at the multidisciplinary team (MDT) meeting. This is a meeting where a variety of clinicians are present, such as a neurosurgeon, neurologist and neuro-oncologist. You can read more about MDT meetings in our patient guide: diagnosis (**brainstrust.org.uk/wp-content/uploads/2019/05/2-brainstrust-pg2019-diagnosis-8pp.pdf**).

Following an MDT meeting you will be contacted to arrange an appointment for you to be seen in a clinic with a neurosurgeon and a clinical nurse specialist to discuss any potential treatment options. This may be an online consultation. There are many different types of brain tumours, and some may not require an immediate appointment. Some brain tumours are found by accident and are not causing an immediate problem, so you may find that your appointment does not take place as quickly as you would wish. Discuss this with your key worker, or call *brainstrust* to talk this through.

> ***'This is the worse time. We have some information but not enough to make a plan. Just acknowledging this helped me to cope.'***

Caregiver

Your treatment plan will depend on your symptoms and the results of any investigations you have had.

Steroids

You may have been started on steroid tablets, called dexamethasone. These will help to reduce swelling within the brain and should make you feel better fairly quickly.

Steroids are helpful in managing symptoms but can have some side effects. You will be started on a high dose, which will be reduced after a few days. This will help to minimise some of the possible side effects, such as the following:

Insomnia:

Steroids can keep you awake at night and can cause extremely light sleep. It is important to take them with food. Try to avoid taking them after 12pm if possible.

Stomach irritation:

Steroids can irritate the lining of the stomach and can cause symptoms such as heartburn or acid indigestion. You will be started on medication to help reduce this symptom. Take this in the morning, half an hour before your steroids.

Diabetes:

Steroids can affect the way that the body deals with glucose, causing glucose levels to rise. If you become very thirsty or need to urinate more frequently you should contact your key worker. If you are already diabetic, you may need adjustments to your diabetic medication to help reduce glucose levels.

Seizures

Seizures can occur because a brain tumour can disrupt the normal function of the brain. Where the brain tumour is may affect the type of seizure. For example, if it is within the area of the brain responsible for controlling movement, this may result in twitching of your arm or leg. Brain tumours can also cause a loss of awareness or absence, which may last seconds. Tell your doctor or nurse as soon as possible if you are having seizures or if you are worried that you may be having seizures.

If you have had a seizure, you will be offered anti-seizure medication. If you are started on anti-seizure medication, then it is extremely important to take the medication as directed by your doctor or nurse.

If you develop a rash not long after starting an anti-seizure medication, you must inform your doctor or nurse immediately. Do not stop the medication suddenly, as this may cause more seizures.

You can find out more about brain-tumour-related epilepsy (brainstrust.org.uk/epilepsy).

> ***'It's easy to let seizures define you and you stop doing things that are important to you. Find work arounds e.g. if you exercise, find someone to go with you.'***

Patient

Driving

If you have a brain tumour, the DVLA will not allow you to drive. You need to talk with your clinical team about driving. Your team will give you more detailed information about your investigation results and your treatment plan and will discuss how long you cannot drive for.

Our Know How about driving (brainstrust.org.uk/knowhows/driving) will provide you with more information.

> ***'Being told I couldn't drive was almost worse than being told I had a brain tumour. It's a double whammy.'***

Patient

Top tips

Here are some ideas that people who have been through this have shared.

- Google your hospital to find out more about it.
- Focus on routines that you have in place already e.g. work. These are anchors.
- Search for others on Facebook who have a brain tumour.
- Decide how to share your news, if you want to. As soon as you share it, it won't be your news to own anymore. Email is good – it gives people time to process.
- If you lose your driving licence, invest in an e bike.
- Don't tolerate toxic positivity. For more info about this, visit **brainstrust.org.uk/toxic-positivity**.
- Talk to *brainstrust*.
- Plan to do small things that make your heart sing.
- Write down all the thoughts that are in your head. Turn these into questions for your clinical team.

Where to find support

We recognise that this is an extremely stressful time for you and for your family. You have some information but not enough information to understand what is happening to you, or to make any decisions about what the next steps might be.

brainstrust – the brain cancer people is a charity that supports anyone who is affected by a brain tumour diagnosis. We're here for you and your family.

We believe in a world where people with a brain tumour and their loved ones are involved, resourced, confident and connected. We provide personalised support and resources that help people live the life they want after diagnosis. We work with people in the clinical setting to secure the best possible care for people living with a brain tumour and we campaign to solve real issues, because we understand what challenges people with a brain tumour face. If you need further support at this uncertain time then please email **hello@brainstrust.org.uk**, or call **01983 292 405** any time. While we cannot remove the uncertainty, we can help you manage this situation.

Our patient guide: diagnosis (**brainstrust.org.uk/wp-content/uploads/2019/05/2-brainstrust-pg2019-diagnosis-8pp.pdf**) will help you to understand what to expect, provides useful advice about where to get help, and suggests questions that you might like to ask your doctors or nurses.

You may also find our information about navigating your way at diagnosis (**brainstrust.org.uk/diagnosis-symptoms**) helpful. This explains symptoms and signs, how a diagnosis made and the tests you might be offered, as well as a glossary.

brainstrust
the brain cancer people

> ***‘Being told you have a brain tumour is not what anyone wants to hear. Being part of* brainstrust *has made it a better place. If you do one thing, email or call* brainstrust*.’***

Patient

Sources:

Lancashire Teaching Hospitals NHS Foundation Trust

The Walton Centre NHS Foundation Trust

St Helens and Knowsley Teaching Hospitals

National Institute for Health and Care Excellence (NICE) guideline NG99 *Brain tumours (primary) and brain metastases in adults*

If your query is urgent, or you become unwell, outside of these hours please call **NHS 111** or access NHS 111 via the website **111.nhs.uk**

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