

Low Grade Glioma

Providing support and information for patients and their families

What is a low grade glioma?

A glioma is a type of brain tumour made up from supportive tissue of the brain, known as GLIAL cells. These cells support the nerve cells and help them perform their functions.

Gliomas are classified in four grades: I, II, III and IV. The treatment and prognosis of each tumour depends on its grade. Grade I or II are low grade gliomas, or LGG.

A tumour just means a lump that would not be there normally. It is a descriptive word and does not necessarily mean how serious it is. For example, a tumour describes benign conditions like warts as well as malignant cancers.

What are the different types of low grade gliomas?

Pilocytic astrocytomas These tumours occur almost exclusively in people who are younger than 25 years of age. It is important to distinguish pilocytic astrocytomas from other low grade gliomas because these tumours tend to progress very slowly.

Diffuse astrocytomas Diffuse astrocytomas are the most common low grade glioma. They are usually diagnosed in persons in their late thirties.

Oligodendrogliomas Oligodendrogliomas have two genetic changes that separate them from other low grade gliomas. Oligodendrogliomas are usually slow-growing tumours.

Gangliogliomas These tumours have features of both gliomas and of tumours arising from neurons, the other type of cell within the brain. These tumours tend to grow very slowly.

How fast will a low grade glioma grow?

Most LGG grow by 1—2% a year. Some people may have them for many years without being aware of them. **The cause for a tumour is often unknown.**

What sort of tests will I have to diagnose a low grade glioma?

You will usually have a CT (Computed Tomography) scan, or an MRI (Magnetic Resonance Imaging) scan, when you first show symptoms of a LGG. This gives information such as the location of the tumour.

You may have an electroencephalogram [EEG]. This is a test that measures the electrical activity coming from the brain.

To find out what type of tumour it is, you may have a biopsy. A biopsy is a procedure where a small amount of the tumour is removed so it can be looked at under a microscope.

All of these tests are done to find out more about the tumour, and what treatments can be safely offered.

How will the tumour be monitored?

When an image is taken of your tumour, we will have a snapshot of what it looks like at a particular point in time, but we need to monitor how it progresses. We do this by repeating the scans every two to three months and then extending that to six and twelve month intervals.

To get a better understanding of what part of the brain the tumour is affecting, you may require additional MRI scans (fMRI). These scans map the functional areas of the brain, for example the parts that control your movement, your speech or your memory. This is to see where they are in relation to your tumour.

We can also arrange for you to have a neuropsychology review. This helps to assess your cognitive (brain) strengths and weaknesses. If you are having difficulties such as remembering things, reading, or problem solving, you can be referred for an assessment by a member of the team looking after you.

What is a neuropsychological assessment?

Your assessment will be completed by a Neuropsychologist or Clinical Psychologist.

A neuropsychological assessment helps you to understand more about how your brain functions and how we can support you. It is not an invasive test (you won't have things done to you). The assessment will involve paper and pencil tasks like completing puzzles, copying drawings, remembering things and solving problems. These will help to build a picture of your brain functions including: concentration, language, memory and mood.

The neuropsychologist may also ask for information from your close friends and family, as you may not be aware of some of the things you are having difficulty with.

The aim of the test is to highlight your strengths but also to identify areas where you might be weaker and provide you with strategies to help you on a daily basis.

What are the possible treatment options for an LGG?

Surgery: The first treatment option for low grade gliomas is surgery. Evidence shows that surgery completed within six months of when you are first diagnosed will give you the best outcome. Many, but not all, tumours are suitable for surgery. This depends on the size, shape and position of the tumour within the brain.

The aim of the surgery is to remove as much of the tumour as is safe, causing as little damage to the brain as possible. This is called debulking.

In certain circumstances, it may be an option for the surgery to be preformed while you are awake so that your speech and movement can be tested. **This is not a painful procedure.** If this is the case then the procedure will be discussed in full with you.

Active monitoring or watchful waiting: Your Consultant may decide that surgery is not the right option for you at the moment as these tumours are typically slow growing and may not cause symptoms for many years. Or it may be in an area that is difficult to operate on. You may also decide you do not want any treatment for the time being. If this plan is agreed with the multidisciplinary team (MDT) you will have regular MRI scans, usually every six months, to monitor the tumour, and watch for changes.

What therapies will I have after my treatment?

You may be offered additional treatments after your initial surgery. These could include radiotherapy or chemotherapy. The aim of these treatments is to slow down regrowth of the tumour. Sometimes further surgery is also considered. However, each case is looked at on an individual basis and always discussed with you and your family.

The treatment decision depends on:

- The tumour type and grade
- Your age
- Your general health
- Whether you have seizures (fits) caused by the tumour

If I have epilepsy as a result of my tumour, how can I manage it?

As a result of tumours, some people can experience seizures, or fits, which can disrupt the electrical activity in the brain.

Seizures can happen in many different ways. For example, a tingling sensation on one side of the body, loss of speech, a funny smell or taste. It can also mean that you pass out, make involuntary jerking movements, or lose muscle control throughout your body.

You will see a Neurologist who will be responsible for assessing and treating your seizures and you will be prescribed medicine

to help manage this. Your Neurologist and Nurse Specialist are there to support you through this. It is important to keep them updated about any side effects you may be experiencing, or if you notice an increase in the number of seizures that you have. **Antiepileptic drugs (or AEDs) may give you side effects, including changes in mood, fatigue, headache, skin rashes and vomiting or diarrhoea. But there are lots of different medication choices, so you can change your AED.**

You could try keeping an epilepsy diary, as it is sometimes difficult to remember what has happened between one appointment and the next. You can find epilepsy diaries on the Brainstrust charity website: bit.ly/Brainstrustepilepsy.

What other symptoms might I have?

The symptoms you might experience depend on the location of the tumour. These include headaches, weakness, lethargy and irritability, clumsiness and difficulty concentrating. Please contact your nurse specialist if these get worse.

Can I still drive?

Your diagnosis of a low grade glioma could affect your ability to drive. You may be asked to surrender your licence for a short time, or even permanently. You should contact the DVLA as soon as possible to tell them your diagnosis.

Look at these sites for further information:

- www.gov.uk/driving-medical-conditions
- www.gov.uk/giving-up-your-driving-licence
- The Brainstrust has produced a table with more information about driving and brain tumours: bit.ly/drivingtable.

Who will be looking after me?

You will be looked after by a multi-disciplinary team.

See below for their names and what they do:

Mr Sorin Bucur and Mr Giles Critchley	Consultant Neurosurgeon	A Neurosurgeon specialises in the surgical treatment of tumours. They work closely with all members of the MDT to co-ordinate your care.
Dr Julia Aram	Consultant Neurologist	Neurologists specialise in problems relating to the brain, spinal cord and nerves in the body. They are experts in managing seizures and headaches.
Dr Juliet Brock	Consultant Neuro-oncologist	Neuro-oncologists specialise in treatments including radiotherapy and chemotherapy treatments.
Dr Karren Towgood	Clinical Neuro-psychologist	Neuropsychologists have detailed knowledge of how the brain works and how different conditions may affect your behaviour, thinking and personality.
Ruth Smith Katie Wright	Neuro Clinical Nurse Specialist or Neuro-oncology Nurse Specialist	A Clinical Nurse Specialist (sometimes called a Neuro-oncology nurse) acts as a point of contact for you, your family and the rest of the MDT. On your behalf they liaise with all members of the MDT to ensure good communication between the MDT and other health professionals, for example, your GP, as well as between the team and you. Your CNS will be able to help with any questions or concerns you may have about your treatment.
Dr Catriona Good	Neuroradiologist	Neuroradiologists expertly interpret x-rays, MRI, and CT scans of the brain.

Where can I find more information and support?

Please see below for some useful websites for more information about brain tumours:

www.thebraintumourcharity.org

www.brainstrust.org.uk

www.brainandspine.org.uk

www.braintumoursupport.co.uk

We also have a Brighton-based support group called Brightsparks:

www.bspark.co.uk

Who can I call for more information?

Ruth Smith, Neuro Clinical Nurse Specialist

Telephone: **01444 441881 Ext. 68466** or **07876 392543**

Katie Wright, Neuro-Oncology Clinical Nurse Specialist.

Telephone: **07769 884957**

Email: uhsussex.neuro.oncology.nurses@nhs.net

This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath

© University Hospitals Sussex NHS Foundation Trust

Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

Ref number: 2038

Publication Date: June 2021

Review Date: June 2024



carer and patient information group approved