The ROYAL MARSDEN
NHS Foundation Trust

Low grade glioma

Children’s Unit

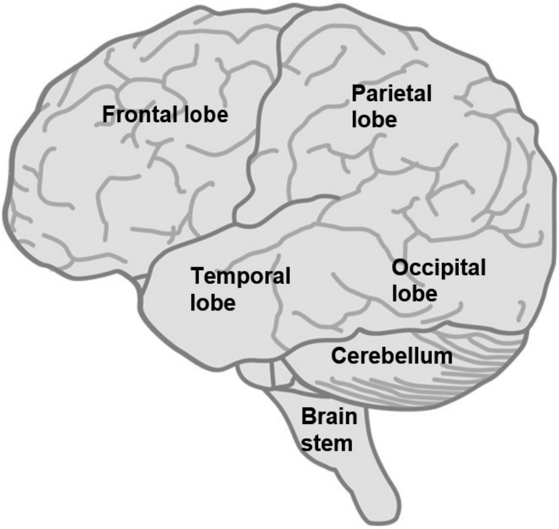
Patient Information

NHS

What is a low grade glioma?

Low grade gliomas are benign (non-cancerous) tumours (grade I or II), that develop from brain cells called astrocytes. Astrocytomas are the most common type of glioma. You will often hear the terms astrocytoma and glioma used interchangeably. Different types include pilocytic, pilomyxoid and fibrillary astrocytomas.

In children, more than 80% of astrocytomas are low grade. Low grade astrocytomas usually develop only where they originated and grow slowly over a period of time. These tumours can form anywhere in the brain or spinal cord. The most common areas for them to occur are the cerebral hemispheres (frontal, parietal, temporal lobes) and the cerebellum. They can spread to other areas of the brain or spinal cord in the cerebrospinal fluid (CSF), although this is rare. Tumours can be solid or part cystic (fluid-filled).



The brain

Who gets a low grade glioma?

This is the most common type of brain tumour in children, representing 40% of all childhood brain and spinal cord tumours. There are about 150 cases of childhood low grade gliomas a year in the UK. Although adults also develop low grade gliomas, they behave and are treated very differently. Like most brain tumours, the cause of low grade gliomas is unknown in most cases. However, some are associated with a genetic condition called neurofibromatosis type 1 (NF1).

What are the signs and symptoms?

The symptoms depend on where the tumour is located and also whether there is increased pressure in the head (raised intracranial pressure). Symptoms include:

- nausea and vomiting (most common)
- lethargy and irritability
- headaches
- clumsiness
- seizures (fits)
- difficulty with tasks such as handwriting
- gradual decline in school work
- changes in personality and behaviour
- abnormal gait (the way the child walks).

If the tumour spreads or is located in the spinal cord, the signs and symptoms may include:

- back pain
- difficulty walking
- problems with bowel and bladder control.

What tests (investigations) will be carried out?

We will need to carry out some tests to find out as much as possible about the type, position and size of the tumour. This will help us to decide on the best treatment for your child. These tests include:

- **CT scan** – it is likely a CT scan of your child's brain was the first specific test carried out at your local hospital. Although MRI scans are usually the best way of seeing the tumour and the effects of treatment, sometimes CT scans are also useful. For more information, please see The Royal Marsden leaflet *CT scan*.
- **MRI scan** – this scan allows us to see the brain and spine in great detail and is used regularly to diagnose and follow the effect treatment is having on your child's tumour. For more information, please see The Royal Marsden leaflet *MRI scan*.

Staging

Staging is a measure of how far the tumour has spread beyond its original site. It is most important to know whether the tumour has been removed by the neuro-surgeon and whether the tumour has spread to the CSF and spine.

How do you treat a low grade glioma?

The treatment used depends on the location of the tumour and the age of the child. Common treatments include:

Surgery

Most children will have an operation to confirm the diagnosis, relieve pressure and to try and remove as much of the tumour as possible. However, if the tumour is deep in the brain, only a biopsy may be carried out to confirm the diagnosis. This is to try and avoid further damage to the child's brain. If the neuro-surgeon can remove all or most of the tumour, this may be the only treatment needed and observation with brain scans will be arranged.

Radiotherapy

Radiotherapy is commonly used after surgery to destroy any remaining tumour cells. Radiotherapy is usually directed locally to where the tumour is or was. Radiotherapy is very effective at controlling the tumour but does have some potential significant long-term side effects, especially in young children. Please see The Royal Marsden booklet *Radiotherapy; your questions answered* for more details on this type of treatment.

Proton beam therapy

Children with low grade glioma may benefit from receiving proton beam therapy. Proton beam therapy delivers radiotherapy in a way that may reduce the radiation to healthy tissue outside the treatment area. This can mean that children have fewer long-term side effects. In the UK, proton therapy is delivered at University College Hospital, London and The Christie Hospital, Manchester. If your child is eligible for NHS funding, you will be able to discuss what this will involve with the medical team. Proton therapy is not available at The Royal Marsden.

Chemotherapy

Chemotherapy may be given together with surgery and or radiotherapy to treat the tumour. Treatment with anti-cancer drugs is used to destroy the tumour cells. It is mostly given by injections and drips into a vein (intravenous infusion). Chemotherapy is often outpatient based and lasts over a year but is quite well tolerated and children can usually continue to attend school. If your child takes part in a clinical trial, the treatment is explained in more detail in the specific trial information sheet. We will give you an outline of the treatment in the form of a ‘road map’, known as a protocol.

What are clinical trials?

Clinical trials are medical research trials involving patients that are carried out to try and find new and better treatments. In cancer, clinical trials are most commonly used to try and improve different forms of treatment such as surgery, radiotherapy or chemotherapy.

The treatment being tested may be aimed at:

- improving the number of people cured (for example, trying new types of surgery or chemotherapy)
- improving survival
- relieving the symptoms of the cancer
- relieving the side effects of treatment
- improving the quality of life or sense of wellbeing for people with cancer.

Clinical trials may also involve research aimed at understanding more about the tumour's biology. You may be asked to allow us to do research on the tumour sample removed at surgery, or on blood samples.

Well-run clinical trials have led to a significant improvement in the treatment of children with cancer. You can find more general information in The Royal Marsden booklet *Clinical trials*. If you are asked to consider entering your child into a clinical trial, you will be given specific information about the trial before deciding whether to take part. There is no obligation to take part and the care your child receives will not be affected by your decision.

General side effects of chemotherapy

Bone marrow suppression (myelosuppression) – chemotherapy drugs decrease the production of blood cells by the bone marrow for a variable period of time. This results in low red blood cells (anaemia), low white blood cells (neutropenia) and low platelets (thrombocytopenia). Your child may need blood or platelet transfusions and will be at increased risk of infections. The doctors and nurses caring for your child will tell you more about these side effects.

Nausea and vomiting – some of the chemotherapy drugs used may make your child feel sick or vomit. We will give anti-sickness drugs at the same time to stop nausea and vomiting which are usually very effective.

Sore mouth (mucositis) – some of the chemotherapy drugs make the lining of the mouth and throat very sore and ulcerated. We will give your child painkillers for this, and explain how to care for your child's mouth during treatment.

Hair loss – temporary hair loss is common.

Weight loss – nausea, vomiting, mucositis and taste changes may result in your child losing weight. A dietitian will help you to support your child's nutrition during this time.

Chemotherapy drugs

For details of the side effects of individual drugs, please see the Macmillan individual drug information factsheets available from the Macmillan website or via your Clinical Nurse Specialist (CNS).

What is the outlook (prognosis)?

The majority of low grade gliomas are not life threatening, but some inoperable tumours (often in young children) can prove to be very difficult to treat. In up to half of cases, although initially controlled, low grade gliomas can grow back and need further therapy.

What are the possible long-term effects?

Low grade gliomas cause long-term problems related to where they are located. Tumours can result in growth, hormonal and behavioural changes with possible learning problems and difficulties with coordination. Hearing and visual disturbances can result from both tumour and treatments. Physical disabilities and seizures can be a problem even when the tumour is controlled. These need to be monitored. Treatment can reduce fertility and there is a small risk of developing a second cancer later in life.

All children are followed up after treatment is finished in the 'long-term brain tumour follow up clinic'. Your child will be seen at regular intervals in this clinic, indefinitely, so that we can help with any long-term effects of the treatment.

Contact details

Children and Young People's Unit

24 hour Helpline: **020 8915 6248**

Other sources of information and support

General information on chemotherapy, hair loss and side effects is also available from the PALS Help Centre, via *www.royalmarsden.nhs.uk* and in the 'Parent held record'.

Macmillan Cancer Support

Macmillan Support Line: **0808 808 0000**

Website: *www.macmillan.org.uk*

Macmillan provides a range of free information and support on all aspects of cancer including:

- advice on benefits and other kinds of financial support
- information on local cancer support groups and organisations near you.

The Children's Cancer and Leukaemia Group (CCLG)

Website: *www.cclg.org.uk*

CCLG is a national professional body responsible for the organisation of the treatment and management of children with cancer in the UK. They coordinate national and international clinical trials. They also provide information for patients and families and produce a quarterly magazine called Contact.

The Brain Tumour Charity

Website: *www.thebraintumourcharity.org*

Support and information line: **0808 800 0004**

The Brain Tumour Charity is a UK charity, committed to fighting brain tumours. They fund scientific and clinical research into brain tumours and offer support and information to those affected, whilst raising awareness and influencing policy.

Young Lives vs Cancer

Website: *www.younglivesvscancer.org.uk*

Support line: **0300 303 5220**

Young Lives vs Cancer is a UK charity for children, young people, and their families, which provides clinical, practical, financial and emotional support to help them cope with cancer.

Brains Trust

Website: *www.brainstrust.org.uk*

Brainstrust is a UK brain tumour charity which is dedicated to helping people affected by a brain tumour. They aim to provide support and advice from the point of diagnosis.

Nerve Tumours UK

Website: *www.nervetumours.org.uk*

Nerve Tumours UK provides information and support to patients and their families who have Neurofibromatosis type 1 (NF1).

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone:	Chelsea	020 7811 8438 / 020 7808 2083
	Sutton	020 8661 3759 / 3951
Email:	patientcentre@rmh.nhs.uk	

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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