The ROYAL MARSDEN
NHS Foundation Trust

High grade glioma

Children's Unit

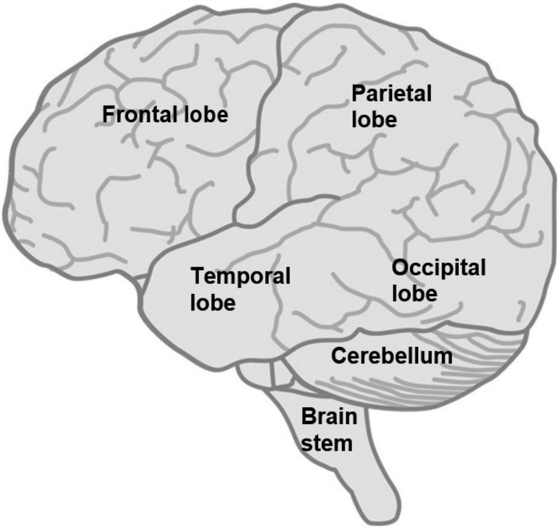
Patient Information

What is a high grade glioma?

High grade gliomas are malignant (cancerous) tumours that develop from brain cells called astrocytes. Astrocytomas are the most common type of glioma and you will often hear the terms astrocytoma and glioma used interchangeably.

In children, approximately 20% of gliomas are high grade. High grade gliomas are classified according to the grade of aggressiveness (how quickly they grow) as either anaplastic astrocytomas (grade III) or glioblastoma multiforme (GBM) (Grade IV). These tumours often spread into the healthy tissue that surrounds the tumour. This makes them difficult to remove surgically. They most commonly occur in the cerebral hemispheres (frontal, parietal and temporal lobes) or centre of the brain (thalamus). The tumour can spread to other parts of the brain and spinal cord.

High grade gliomas are the most common type of adult brain tumour and although they look the same under the microscope, they may be different biologically. Like most brain tumours, the cause of high grade gliomas is unknown.



The brain

What are the signs and symptoms?

The symptoms depend on where in the brain the tumour is 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 important to know in high grade glioma whether the tumour can be completely removed. This is rarely possible. Occasionally the tumour can spread to the cerebrospinal fluid (CSF) and spine.

How do you treat a high grade glioma?

These are very difficult tumours to treat due to the problems in completely removing the tumour and their resistance to radiotherapy and chemotherapy. As there is no ideal treatment, patients are often treated on clinical trials investigating new therapies. Common treatments include:

Surgery

All children will have an operation to confirm the diagnosis and if necessary to relieve pressure. The surgeon will try and remove as much of the tumour as possible without causing severe disability for the child.

Radiotherapy

Radiotherapy is routinely used after surgery to try and destroy any remaining cancer cells. In young children (especially under the age of three years), radiotherapy will be delayed, reduced or possibly avoided. Due to the significant effects of radiotherapy on a young child's brain, chemotherapy will be used instead. Please see The Royal Marsden booklet *Radiotherapy; your questions answered* for more details on this type of treatment.

Chemotherapy

Treatment with anti-cancer drugs is used to destroy the tumour cells for high grade glioma, and is usually given by mouth in tablet form. Chemotherapy may also be given by injection in clinical trials. 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.

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)?

Young children (under three years) appear to respond better to chemotherapy. Those children with grade III tumours (anaplastic astrocytoma) and a complete removal of the tumour respond better to both chemotherapy and radiotherapy. Unfortunately the prognosis is poor for many children with high grade gliomas. Clinical trials are ongoing to improve the outcome.

What are the possible long-term effects?

High grade gliomas can cause long-term problems related to where they are located and the treatment received. Tumours can result in growth, hormonal and behavioural changes with possible learning problems and difficulties with coordination. Physical disabilities and seizures can be a problem even when the tumour is controlled and 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.

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 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.

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
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Sutton 020 8661 3759 / 3951
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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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