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## Diffuse midline glioma

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**Children's Unit**

**Patient Information**



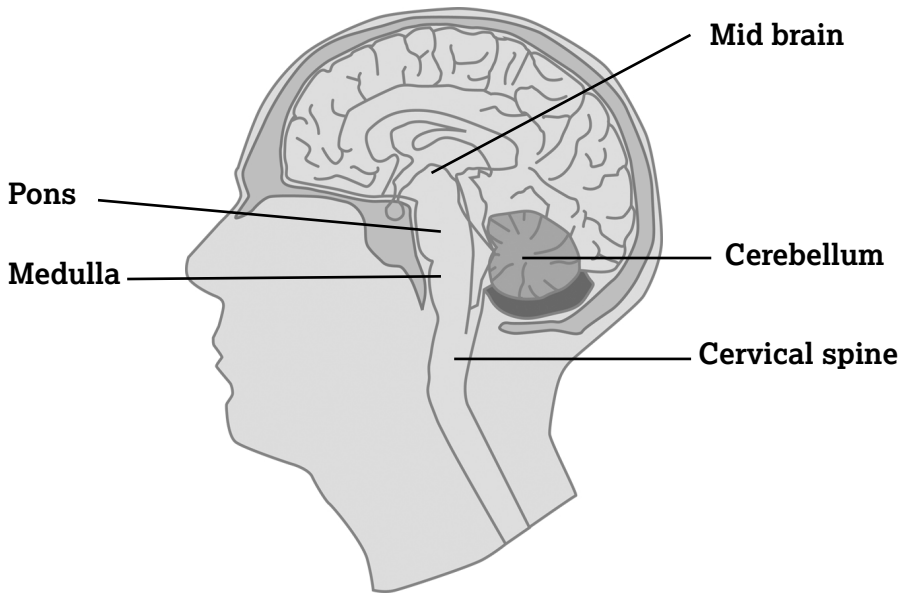
**NHS**



## What is a diffuse midline glioma?

Diffuse midline gliomas are malignant (cancerous) tumours that originate from the part of the brain known as the brain stem (pons). They develop from cells called astrocytes. Astrocytomas are the most common type of glioma. You will often hear the terms astrocytoma and glioma used interchangeably.

If a biopsy is carried out, they are usually found to be high grade gliomas and are classified according to the grade of aggressiveness (how quickly they grow) as either anaplastic astrocytomas (grade III) or glioblastoma multiforme (GBM). These tumours grow amongst the normal nerve cells of the brain stem making them impossible to remove surgically. The brain stem is a vital area of the brain that controls many body functions.



**The brain**

## What are the signs and symptoms?

The symptoms are related to the internal pressure that the tumour applies on the brain stem. Occasionally the tumour can cause increased pressure in the head (raised intracranial pressure). Rarely they spread in the spine. Symptoms include:

- squints
- swallowing problems
- slurred speech
- facial weakness
- abnormal gait (the way the child walks)
- difficulty with tasks such as handwriting
- gradual decline in school work
- changes in personality and behaviour.

If there is increased pressure in the head:

- headaches
- nausea and vomiting.

If the tumour spreads to the spine:

- 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*.

## How do you treat a diffuse midline glioma?

Unfortunately very few children are cured from diffuse midline glioma. The only proven treatment is radiotherapy which can improve a child’s symptoms in up to 75% of cases. However, the benefit is usually short lived and the tumour starts to grow again after a few months. Surgery is often not possible due to the tumour’s position in the brain stem, growing amongst vital nerve cells. Chemotherapy has had little effect on this tumour but new agents are being investigated in clinical trials.

### **Surgery**

This may be limited to a biopsy to take a small piece of tissue to confirm the diagnosis (if necessary) and also for research purposes as part of some clinical trials.

### **Radiotherapy**

Radiotherapy is routinely used to try and destroy the cancer cells. See The Royal Marsden booklet *Radiotherapy; your questions answered* for more details on this type of treatment.

### **Chemotherapy**

Chemotherapy is usually only used as part of a clinical trial in diffuse midline glioma. Treatment with anti-cancer drugs is used to try and destroy the tumour cells. It may be given by injections or by mouth. If your child takes part in a clinical trial, the treatment is explained in more detail in the specific trial information sheet. You will be given 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** – experiencing nausea and vomiting and mucositis may cause your child to lose weight. We can arrange for you to meet with a dietitian if you have concerns about your child's nutrition.

## Chemotherapy drugs

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

## What is the outlook (prognosis)?

Unfortunately very few children are cured from diffuse midline glioma. The only proven treatment is radiotherapy which can improve a child's symptoms in up to 75% of cases. However, the benefit is usually short lived and the tumour starts to grow again after a few months. Clinical trials are ongoing to improve the outcome.

## 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](http://www.royalmarsden.nhs.uk) and in the 'parent held record'.

### **Macmillan Cancer Support**

Macmillan Support Line: **0808 808 0000**

Website: [www.macmillan.org.uk](http://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](http://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](http://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.

## Notes and questions

## 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](mailto: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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[royalmarsden.org](http://royalmarsden.org)

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