

Ependymoma (in children)

What you need to know



Ependymoma is a fairly common type of childhood brain tumour. The average age of diagnosis is 5 years old and at least one quarter of diagnoses happen before the age of 2. However, they can develop in people of any age.

The information in this fact sheet gives an overview of ependymoma in children and answers the questions you may have about this type of tumour.



CARE CAN'T WAIT

If you'd like to talk to someone about how you're feeling, or would like to find out where you can get further support (including details of support groups), you can contact The Brain Tumour Charity's Information and Support Team:

Phone: **0808 800 0004**

(free from landlines and most mobiles)

Email: support@thebraintumourcharity.org

Live chat: thebraintumourcharity.org/live-chat

Website: thebraintumourcharity.org/getsupport

Closed Facebook groups: bit.ly/FBSupportGroups

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What is an ependymoma?

Ependymomas are a type of brain tumour that are formed from a type of cell in the brain called an ependymal cell.

Ependymal cells are found lining the ventricles of the brain (the fluid-filled spaces in and around the brain). Their job is to produce cerebrospinal fluid (CSF).

Ependymal cells belong to a larger family of cells called glial cells. This is why you might hear your child's ependymoma be called a glioma. A glioma is a tumour arising from glial cells.



For more information, see the Brain cells page on our website:

thebraintumourcharity.org/brain-cells

Most childhood ependymomas are found in the hindbrain, which is sometimes called the posterior fossa. This is the lower part of the brain which controls functions, such as balance and movement, and vital functions, such as breathing and blood pressure.

Are there different types of ependymoma?

There are 4 different types of ependymoma, so you might hear your child's doctor call the brain tumour by a more specific name. The different types are:

- Myxopapillary ependymoma (grade 1)
This type of ependymoma is relatively uncommon in children and develops more often in the lower part of the spinal column rather than the brain.
- Subependymoma (grade 1)
Subependymomas are also relatively uncommon in children and appear most often near a ventricle.
- Ependymoma (grade 2)
ependymomas are the most common type of ependymal tumour and usually appear close to, or in, a ventricle in the hindbrain.
- Anaplastic ependymoma (grade 3)
Anaplastic ependymomas are the fastest growing type of ependymal tumour and also commonly grow in the hindbrain.



For more information about how brain tumours are graded:

thebraintumourcharity.org/how-brain-tumours-are-graded

What symptoms do ependymomas cause?

Most child ependymomas develop along the ventricle in the hindbrain known as the fourth ventricle.

Depending on where in the fourth ventricle the tumour is located, your child might have 1 or more of the following symptoms:

- Wry neck - their head seems to be twisted or tilted.
This is called torticollis.
- Loss of balance
This is called ataxia.
- Problems speaking
This is called dysarthria.
- Difficulty swallowing
This is called dysphagia.
- Making overly clumsy movements
This is called dysmetria.

How are ependymomas treated?

Surgery

The first treatment your child is likely to have is surgery. Their neurosurgeon will aim to remove as much of the tumour as possible.

You might hear this surgery be called a resection. A resection to remove a brain tumour is a complex operation which takes several hours. Any risks will be explained to you by your child's surgical team.

If the tumour is low grade and the surgeon is able to remove all the tumour, your child may not need any other treatment.

However, if it's not possible to remove all the tumour, or if the tumour is high grade, then your child's healthcare team will advise radiotherapy to treat any tumour cells that may be left.

This is also the case if surgery is not possible at all. Sometimes the tumour is in a place in the brain that makes it too difficult to reach or it's not safe to operate on. Radiotherapy is used instead.

However, if your child is under 3 years old, radiotherapy is generally avoided. Then chemotherapy will be used instead.



For more information on surgery, see the Neurosurgery for children fact sheet thebraintumourcharity.org/treatment/neurosurgery-children

Or watch the Jake informational animation: bit.ly/Jake-Neurosurgery

Radiotherapy

Radiotherapy, or radiation treatment, uses controlled doses of high-energy beams to destroy tumour cells, while causing as little damage as possible to surrounding healthy cells.

Radiotherapy may be used where surgery isn't possible, or more commonly, after surgery to kill any remaining ependymoma cells. This is to make the tumour less likely to recur (come back).

Radiotherapy does have some potential long-term side-effects on the brain, particularly in children as their brains are still developing. The risks and benefits for each child have to be weighed before deciding if radiotherapy should be given in any form.

As a result, radiotherapy isn't commonly given to children under the age of 3 as they're more likely to develop long-term side-effects.



For more information on radiotherapy, see the Radiotherapy for children fact sheet

thebraintumourcharity.org/treatments/radiotherapy-children

Or watch the Jake informational animation:

thebraintumourcharity.org/animations

Chemotherapy

Chemotherapy is a treatment which involves drugs that have been developed to kill tumour cells. It is generally only used to treat ependymomas in children who cannot have radiotherapy. It is rarely used to treat adults with ependymoma.

Chemotherapy drugs can be taken orally (by mouth). This can be as a pill, but can be given as a liquid if your child is too young to swallow pills. Chemotherapy can also be given intravenously (into a vein). The treatment cycle is usually spread over a set period of time.



For more information on chemotherapy, see the Chemotherapy for children fact sheet thebraintumourcharity.org/treatment/chemotherapy-children/

Or watch the Jake informational animation: thebraintumourcharity.org/animations

There's ongoing research on the possible benefits of different combinations of chemotherapy drugs and radiotherapy in treating childhood ependymomas. Your oncologist may offer your child the chance to take part in a research study (clinical trial).



Take a look at our website for more information about clinical trials:

thebraintumourcharity.org/clinical-trials

What side-effects can treatment cause?

The symptoms that you may have seen in your child before treatment can be known to worsen after surgery. Other symptoms include headaches and feeling sick and tired.

Radiotherapy and chemotherapy also come with their own side-effects. These can include hair loss, tiredness and a reduced appetite.

If you're worried about your child after treatment, speak to your child's oncologist for advice and help with treating symptoms.

Hearing that your child may have long-term side-effects, due to treatment, might be hard to hear. But your child's healthcare team will have taken these into consideration and will only give treatment where the benefits outweigh the risks.



You can find out more about short-term and long-term side-effects of treatment on our website:

thebraintumourcharity.org/treatments-for-children



Molly's story

“Honestly, when I was first diagnosed, the biggest feeling I experienced was relief. I finally felt as though the doctors were listening to me instead of telling me I was making up or exaggerating symptoms. Receiving a diagnosis, although devastating for my family, meant that I could now focus on what had to be done next with the help and support of my medical team, family and friends.”

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard - an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology. Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you've already been given. Please do continue to talk to your medical team if you're worried about any medical issues. If you'd like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on 0808 800 0004 or support@thebraintumourcharity.org

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About The Brain Tumour Charity

Going further for a cure

As the UK's leading brain tumour charity, we're here to accelerate a positive change in how people affected by brain tumours are diagnosed, supported and cured.

At The Brain Tumour Charity, we believe that no-one should have to live with a brain tumour or lose a loved one to a brain tumour. Advances in both treatments and quality of life care need to be made - and they need to be made quickly.

We know that if we put our heads together, we're more than up to the challenge. So we're building a movement of people from every walk of life - all coming together to accelerate a cure.

Find out more and get involved:
thebraintumourcharity.org



Notes

**WE'RE
HERE FOR YOU
AT EVERY STEP**

thebraintumourcharity.org

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