



Juvenile nasopharyngeal angiofibroma (JNA)

ABOUT THE CONDITION

What is juvenile nasopharyngeal angiofibroma?

Juvenile nasopharyngeal angiofibroma (JNA) is a very rare **benign** tumour or growth in the back of your child's nose. JNA mostly affect teenage boys.

Although JNA is not a cancer, it is an aggressive tumour as it may grow into the sinuses, eye sockets and the brain.

What causes JNA?

We do not know what causes JNA. It might grow from cells left deep inside the nose during early pregnancy.

What symptoms can a JNA give?

Your child may present with a **blocked nose** and **repeated nosebleeds** on one side. JNAs are full of blood vessels. Other symptoms can include **swelling of the face**, **facial pain**, **headaches**, **double vision**, **reduced hearing**, or **reduced sense of smell**.

How is JNA diagnosed?

Your child should be referred to an ear nose and throat (ENT) specialist. The ENT specialist will look in your child's nose using a thin, flexible camera called a **flexible nasal endoscopy** (check the dedicated leaflet for more information). They may also want to get some scans such as **CT and MRI scans**. A **biopsy** from the tumour is not usually needed to make a diagnosis and can cause a lot of bleeding.

ABOUT THE PROCEDURE

How is JNA treated?

JNA is mainly treated by surgery. Sometimes, the whole tumour cannot be removed. This is because of the high risk to blood vessels, nerves, the eyes and the brain. Any JNA tissue left may need further treatment in the future. If so, your child's specialist will give you more information should this be the case.

Are there any alternative treatments?

JNAs can be treated with radiotherapy. This is a type of special x-ray treatment usually used to treat cancer and may be effective in treating JNA.

However, radiotherapy in this area may cause severe complications. These can include blindness and brain injury. It can disturb the growth of the face. Cancer can sometimes develop in the area where radiotherapy was given later on in your child's life.

Radiotherapy is only used when the JNA cannot be removed safely and completely by surgery.

Deciding whether to have the treatment

The decision to have surgery is based on your doctor's recommendation, yours and your child's wishes, taking into consideration your child's circumstances. You may wish to change your mind about the surgical procedure at any time and signing a consent form does not mean your child must have the operation.

If you would like to have a second opinion regarding the treatment, you can discuss with your specialist, who can arrange for this. You may wish to ask your own GP to arrange a second opinion with another specialist.

What happens before my child's operation?

- 1. **Preassessment:** You may be sent a health check questionnaire to see if your child requires any tests before the operation.
- 2. **Fasting instructions:** You will be told when your child can eat and drink before the operation. You must follow this so that the surgery can be done safely.
- 3. **Blood tests**: Your child will need blood tests to check their blood group. A blood transfusion may be needed during or after surgery.
- 4. Embolisation: JNAs contain a lot of blood vessels and can bleed a lot during surgery. A procedure called embolisation performed a couple of days before the operation may help reduce the risk of bleeding. This is done by putting particles via thin tubes to block the main blood vessels feeding the tumour.

What happens during my child's operation?

Surgery is performed through the nose. A thin camera and light are used to help the surgeon see into the nose. This is called an **endoscopic approach**. Thin surgical tools are used to remove the tumour.

An **open approach** means there will be a cut on the face. This should heal well over time.

Large tumours might need both an open and endoscopic approach.

In most cases, a **dressing** is left inside the nose to reduce the risk of nosebleeds. Some types of dressing will dissolve on their own. Others will need to be removed. Young children may need to have dressings removed from their nose under a short general anaesthetic. Older children may be able to have the dressing removed in the outpatient clinic with the help of local anaesthetic.

What can I expect after my child's operation?

After the operation, your child will be taken to the recovery area. They will be monitored while the anaesthetic wears off. When they are fully awake, they will go back to the ward.

Your child may feel **pain and discomfort** in the **face and nose**. This can be treated with painkillers. Pain and discomfort should improve over time.

Your child may have a **blocked nose**. This could be because of dressings, secretions (snot) or old blood. The lining of the nose could be swollen. The nose should feel less blocked within a week.

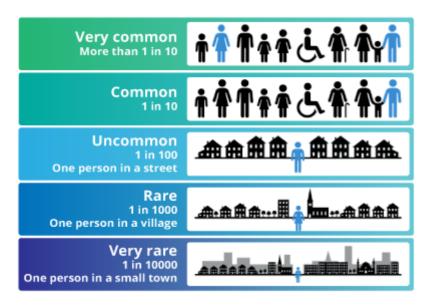
Crusts and blood clots could form within the nose. Your child should rinse their nose with salt water to help soften and clear this.

You can expect some **blood-stained mucous** from the nose in the first week after surgery. Your child should avoid blowing their nose for the first few days.

ABOUT THE RISKS

Are there any complications to this operation?

All surgery involves some risks. Complications fall into the following groups.



Bleeding:

During surgery, the tumour may bleed a lot. Reducing the flow of blood to the tumour by embolisation before surgery should help reduce the risk of a significant bleed. Blood transfusions can be given if needed.

Your child's surgeon has tools to control bleeding during the operation. In rare cases, a lot of bleeding can mean it is unsafe to continue the operation. If this happens, the surgeon will pack your child's nose. They will be kept asleep in an intensive care unit (ICU) for a couple of days until the bleeding settles.

If your child has a severe nosebleed after surgery, you must take them to the nearest Emergency department straight away.

Eye injury:

JNA can grow into the sinuses which are very close to the eye sockets. There may be bruising around the eye when a JNA is removed. This usually goes away without treatment.

Serious damage is very rare and can cause swelling of the eye, double vision, and loss of sight. Serious eye complications may need more surgery.

Cerebrospinal fluid (CSF) leak:

The sinuses are very close to the base of the skull and brain. Nose and sinus surgery carries a rare risk of damaging the base of the skull. This can cause the fluid around the brain to leak into the nose. This rare complication can go away on its own but usually needs further surgery.

Other complications from surgery may include **infection**, **watery eyes**, and **facial numbness**.

Regrowth:

After surgery, the tumour can regrow. This can happen in up to 46 out of 100 cases. It usually depends on the size of the tumour. Most tumours that regrow will do so within 12 months of surgery. Follow-up MRI scans should take place every 3 to 6 months for at least 3 years. These will help spot any regrowth.

General anaesthetic:

The operation takes place under general anaesthetic. This is very safe for children. Your child's preassessment team will inform you about the risks of a general anaesthetic. For more information, click here.

AFTER THE PROCEDURE

How long will my child stay in hospital?

Your child may be in hospital for up to a week. This may be for longer depending on the extent of the surgery.

How long will my child be off school?

Keep your child off school for a minimum of 2 weeks. Most children return to normal activity 7 to 10 days after surgery. Avoid heavy lifting and physical activity for at least 2 weeks after surgery and then start slowly. Your doctor will give you advice on this as this depends on the extent of the surgery.

Follow up

Your surgical team will tell you before your child goes home when their follow-up appointment will be.

Your child may be monitored for a while with flexible nasal endoscopy in clinic and sometimes with scans.

Will my child need further treatment?

Your child's specialist will inform you if your child may need further treatment after the surgery.



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FEEDBACK SURVEY



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