



# Papilledema in children and young people

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## Information for parents from Child Health

Your child has been referred to the hospital, as their GP or optician suspect they may have a condition known as papilledema. This leaflet will explain:

- what papilledema is
- what causes the condition, and
- what the treatment options are.

We hope this leaflet helps to answer some of the questions you may have. If you have any questions or concerns, please speak to your child's doctor.

### What is papilledema?

Papilledema is a condition where increased pressure in or around the brain causes part of the optic nerve inside the eye to swell. This can be seen by examining the back of your child's eye.

If swelling is found, it is important:

- to look for causes of raised pressure in your child's head, and
- assess whether their vision is being affected by the swelling.

### What are the symptoms of papilledema?

For most people with papilledema there is no effect from the nerve swelling. However, your child may have other symptoms caused by pressure in their head, which is also causing the nerve swelling. These symptoms can include headaches and vomiting.

If the cause of the nerve swelling is not found and treated, damage to vision can occur over time. Damage can include loss of colour vision and losing some of their normal field of view.

## What causes papilledema?

Some of the causes listed below are serious but rare. The next steps by your medical team will be to confirm whether there is any sign of more serious problems.

Increased pressure in your child's brain can be caused if:

- There is too much cerebrospinal fluid (CSF) in the brain (too much is produced or it is not absorbed fast enough). Idiopathic intracranial hypertension (IIH) is a condition in which this happens without any underlying cause. More information on **IIH** is available on the Trust web site (<https://leaflets.ekhufnhs.uk/idiopathic-intracranial-hypertension-iih/html/>).
- There is an obstruction (blockage) to the flow of CSF.
- Something is taking-up more space alongside the brain, such as a bleed or a tumour.
- There is swelling of the brain, for example from a head injury.
- There is an abnormality of the skull, which stops it growing as the brain grows.
- The optic discs appear swollen, but there is no true swelling. In these cases you can be reassured that papilledema is not present.

## What are the next steps?

- An eye doctor should examine your child to confirm the condition.
- A paediatric doctor will examine your child for any signs of problems with their nerves or brain.
- The paediatric team will normally order an urgent MRI scan (<https://www.ekhufnhs.uk/services/radiology/>) of your child's brain.
- If the MRI scan is normal, your doctor will consider whether your child should have a lumbar puncture. A lumbar puncture measures the pressure of the fluid around the brain. This test is the only way to diagnose IIH, which will not be seen on an MRI scan. Your medical team will discuss this procedure with you in detail.

More information is available in the **Lumbar puncture (child)** leaflet. (<https://leaflets.ekhufnhs.uk/lumbar-puncture-child/html/>)

- If your child is not having headaches or other symptoms, and the MRI scan is normal, your team may recommend that we hold off doing the lumbar puncture. They may suggest that you wait until an eye doctor (who specialises in child health) has seen your child. This is usually done within 6 weeks, which is a safe time to wait. The eye doctor will assess whether the appearance is true papilledema or not.

## When will we get the results of these tests?

The doctors will explain your child's results straight after each test.

However, the MRI scan is normally completed within 1 week (often sooner), and the results should be given to you within 24 hours. The MRI should highlight any conditions which need urgent attention. If the MRI result is

normal, follow-up with the paediatric eye specialist and / or lumbar puncture will be arranged in an outpatient clinic.

If your child needs a lumbar puncture, the doctor caring for them will discuss with you when it is best to do this. They will consider:

- how bad your child's symptoms are
- whether they will need anaesthetic, and
- what your own thoughts are.

The pressure measurement from the lumbar puncture will be available on the same day.

### **What treatments will my child need?**

This will depend on the outcome of the tests.

- If the MRI scan finds what is causing the pressure, you will discuss this with a specialist team.
- If the MRI is normal and the paediatric eye specialist confirms that true papilledema is not present, no further action will be needed. The eye specialist may follow-up with your child in clinic if there is any doubt.
- If IIH is found on lumbar puncture, a specialist in paediatric neurology will discuss this with you, and start treatment. IIH normally responds to treatment with tablets.

If you have further questions, please speak to the doctors caring for your child.

**This leaflet has been produced with and for patients.**

**Please let us know:**

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

**You can let us know this by:**

- Visiting the Trust web site (<https://www.ekhft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

**Any complaints, comments, concerns or compliments**, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email ([ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)).

**Patients should not bring large sums of money or valuables into hospital.** Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

**Further patient information leaflets** are available via the East Kent Hospitals' web site (<https://www.ekhft.nhs.uk/patient-information>).

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