



What is Rb?

## Signs and symptoms of retinoblastoma

Spotting one of the signs or symptoms of retinoblastoma can be really worrying for any parent or relative. Do remember that retinoblastoma is rare and that all of these symptoms can be caused by other things, but it's always best to have your child's eyes checked out by a health professional as soon as possible.

### *White eye or glow*



You might see a white glow in the eye, a white pupil or white reflection in a photo where a flash has been used, or when your child is in artificial light or a darkish room. This may only be seen once but in some cases it's present all the time. There are other, more common causes of this – read more about [what causes white eye](#).

### *Squint*



A squint or lazy eye, where one eye looks in or out, can sometimes be a symptom of retinoblastoma. In many cases, it's nothing more than a squint but it's always worth having it checked out just to be sure.

### *Red, sore or swollen eye*



Your child's eye may become very red and inflamed for no obvious reason – and with no sign of infection. This symptom is usually accompanied by one or more of the other signs described here.

***Change in iris colour***



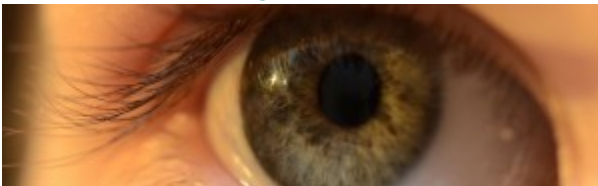
The iris – the coloured part of the eye – can change colour in one eye, sometimes only in one area.

***No red eye***



In a photo where one eye has “red eye” (which is normal), the other eye may look black. This can be a sign that something is not right.

***Deterioration in sight***



Your child's vision may begin to deteriorate, or they may have had poor vision from birth. You may notice that they don't focus, fix and follow as well as other children of the same age.

## Diagnosing retinoblastoma

If you're worried that your child is showing a symptom of retinoblastoma take them to your GP, a local optician/optometrist or an ophthalmology department to have their eyes examined as soon as possible.

Although optometrists are trained to test children of all ages, some may choose not to test babies and younger children, so you may have to try a few before finding one happy to check your child's eyes for you. Some ophthalmology departments have a walk-in or A&E clinic, but others will need a referral from your GP.

Retinoblastoma is a very rare condition, so you may need to explain to the medical professional you see that you are concerned you've seen a sign in your child's eye(s) or in a photo, and that you would like them to be fully tested in order to rule this out.

### ***What to take with you***

If you have any unusual photos of your child's eye/s, take these with you, along with a copy of our [I Spy awareness leaflet](#). You can also download our [See Red poster](#), which explains how a professional should check children's eyes for retinoblastoma using a red reflex test.

### ***At your appointment***

At your appointment, your health professional should carry out the red reflex test in a darkened room using a medical torch (ophthalmoscope) to check the retina at the back of both eyes. If they have any concerns they should refer your child urgently (within two weeks) to the local ophthalmology (eye) department for further investigation.

If you feel you are being delayed at any stage during the process, either in seeing someone initially or when waiting for a referral, or you don't feel fully reassured that retinoblastoma has been ruled out, then ask for a second opinion until you are satisfied or have received an urgent referral.

### ***What happens next?***

At the ophthalmology department your child may be seen by an ophthalmologist (consultant eye doctor/surgeon) and in some cases a children's (paediatric) ophthalmologist. They may do another [red reflex test](#). They will use eye drops which increase the size of the pupil, opening up their view into your child's eye so that they can have a really good look at the back of the eyes.

Some ophthalmologists will do an ultrasound to help them make a diagnosis. This involves a gel being put on the outside of the eyelid and then an ultrasound probe placed onto the eyelid. This allows the ophthalmologist to scan the eye and is not usually painful.

The pressure in your child's eye may also be checked. This can be done in two ways – either a special puffer is used to puff air directly at the eye and the response to indicate a change in pressure, or yellow eye drops can be administered and then an instrument with a blue light is used to touch the front of the eye and the pressure is read using this tool.

In some cases the ophthalmologist may decide your child needs to be checked while under anesthetic so that they can have a better look at the retina. This will have to be

done on a day care ward but the appointment and procedure will be explained to you. Your child may also have a vision test. This will probably be carried out by an orthoptist.

### If retinoblastoma is suspected

If retinoblastoma is suspected, an urgent referral will be made for your child to be seen at one of the two retinoblastoma treatment centres in the UK – [The Royal London Hospital](#) in Whitechapel, or [Birmingham Children’s Hospital](#).

An appointment will be made for your child to be seen within a week and the retinoblastoma service team will contact you, usually by telephone, before your appointment. Your child will need a general anaesthetic at this stage so that their eyes can be thoroughly checked to confirm or rule out retinoblastoma.

### Just diagnosed

If you’ve just been given the news that your child has retinoblastoma, you may find our [just diagnosed](#) section useful. We know that this is a very distressing and frightening time, and if you need to talk to someone, please call us on 0207 377 5578 or email [support@checht.org.uk](mailto:support@checht.org.uk). We are here to help.

### Retinoblastoma treatment

There are a number of different treatment options for retinoblastoma, depending on a child’s individual needs. If your child has been recently diagnosed, your consultant will discuss this with you fully. Options include:

- Cryotherapy
- Laser
- Chemotherapy
- Enucleation

Please have a look at our [retinoblastoma treatment section](#) for more information about this.

### Support and further information

Please have a look at our [resources section](#) for more information about retinoblastoma. If you’re worried about retinoblastoma and you’d like to talk to someone, we are here to help. You can call us on 020 7377 5578, email [support@checht.org.uk](mailto:support@checht.org.uk) or have a look at our [support pages](#) to find out more.