



**The Leeds
Teaching Hospitals**
NHS Trust

Cataracts in infancy and childhood

Information for parents
and carers



Leeds Centre for
Ophthalmology

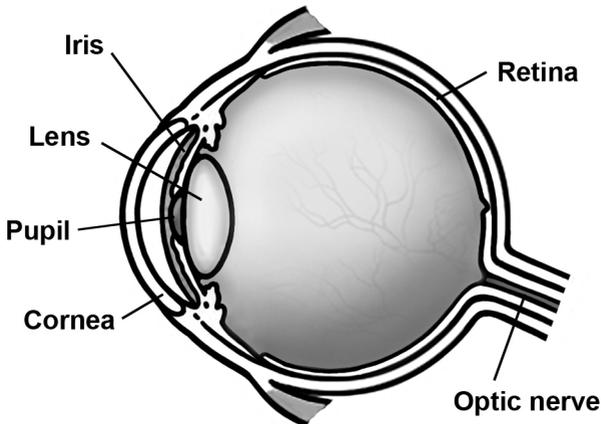
Introduction

This booklet is designed to provide you with information and advice about childhood cataracts and the affects that they may have upon your child. It is always worrying to discover that your child is affected by a rare condition but we hope that this booklet will help you to understand the diagnosis. It will also explain the available treatments and support which you will be given.

The normal eye

The eye is composed of a number of parts that help focus light and enable us to see. Normally, light rays enter the eye through the cornea and the pupil. The rays are then focussed by the lens onto retina at the back of the eye. The retina sends signals to the brain which are interpreted and allow an image to be formed. If the light rays are obstructed before they land on the retina, then vision may be impaired.

The diagram below shows a cross section through a normal eye.



What are cataracts?

Cataracts are cloudy (opaque) patches in the lens of the eye that prevent light from effectively passing through. Cataracts that can be diagnosed in a newborn baby are known as congenital cataracts. Cataracts that develop in babies and children over time are called developmental or juvenile cataracts. Both forms can affect either one (unilateral) or two (bilateral) eyes.

Cataracts in children are very rare and affect approximately 1 in 10,000 children; however, if they are left untreated this will prevent the development of normal vision, especially in very young children. The extent of the visual defect will depend upon the size, density and location of the cataract on the lens. Consequently, it is important to diagnose cataracts early so that treatment can be commenced.

Why does my child have a cataract?

Cataracts form when the protein in the lens of the eye clumps together. The cause of the majority of cataracts is unknown; however, genetic factors are thought to be largely responsible in many cases. A cataract gene abnormality may potentially be inherited from a parent or start in the child. Other rarer causes of cataracts include traumatic injury, inflammation (iritis), diabetes, metabolic abnormalities, certain drugs (e.g. steroids) and infection during pregnancy (e.g. rubella, cytomegalovirus, chicken pox).

How will I know if my child has cataracts?

Your child should have had a routine examination soon after birth and this is the point at which most cases are detected. Congenital cataracts are screened for within the first 72 hours after birth and also at 6 - 8 weeks old; however, it is important you contact a doctor if you notice any of the following:

- Your child has a white spot in their pupil
- Your child does not respond to large visual stimuli
- Your child appears to have difficulty focusing on objects
- A member of your family has been affected with congenital cataracts
- Your child suffers from a syndrome that is associated with visual problems

The symptoms of childhood cataracts can differ considerably and severity may vary, from mild cataracts that do not affect vision significantly, to others that should be operated on within a few weeks.

The severity of symptoms will depend upon:

- the density of the cataract;
- if it affects one (unilateral) or two (bilateral) eyes; and
- the position of the opacity within the lens.

How will the doctor diagnose cataracts in my child?

A doctor who specialises in treating eyes (ophthalmologist) will examine your child if any problems are suspected. Drops will be used to temporarily enlarge (dilate) your child's pupils before the doctor uses a special instrument (ophthalmoscope) to see inside the eyes. The ophthalmologist may diagnose cataracts if they see cloudiness in the lens or an absence of the 'red reflex'. The red reflex is a reflection from the back of the eye that is often seen in flash photographs.

Sometimes, the cataracts are so thick that it is impossible for the doctor to see the back of your child's eyes and consequently, he or she will have arranged or performed an ultrasound examination to make sure that the back parts of the eye appear healthy.

What are the treatments?

The treatment will largely depend upon the severity of the cataract and if one or two eyes are affected. Surgery is one of the most common first line treatments that may be offered to your child, if their vision is likely to be affected. In young babies, it may be important to remove the cataract as soon as possible as the visual system is still rapidly developing. Using microscopic techniques, an ophthalmologist will carefully remove the affected lens by making a small opening in the side of the cornea. In some cases, a replacement lens is put into the eye (Pseudophakia) but this is not always done in babies or children with small eyes; therefore, they will be without a lens (Aphakia). This surgery will be performed under a general anaesthetic. Children can generally go home the same day but will need to be seen again the next day.

If your child has been diagnosed with bilateral cataracts, then both eyes will usually be operated on within a few days of each other.

Once the lens has been removed treatment can be commenced to help the child focus light onto the retina. This is known as refractive correction. A substitute for the missing lens may be achieved with the use of contact lenses or glasses. The implantation of a clear, plastic artificial intraocular lens (IOL) may also sometimes be used, similar to the one's commonly used in adults. The decision of which type of refractive correction your child is given will be made by the consultant. Occasionally, the decision is changed during the operation.

In babies, many parents would prefer an IOL implant because there is less reliance on contact lenses or thick glasses; however, there is a three times increased risk of further surgery being required in babies who have an IOL implanted at the time of surgery compared to those that don't. Visual outcome is no better whether an IOL is implanted or not.

Even with an IOL placed at the time of surgery, your child may need to wear contact lenses or glasses. This is because a child's eye will grow; therefore, your child will have been left deliberately long-sighted at the time of the original surgery and will need glasses or contact lenses. As your child's eye grows, he or she will become less long-sighted and consequently, the strength of a contact lens on the front of the eye or glasses will be reduced. The power of the glasses or contact lens will be regularly monitored by the optometrists. Glasses will always be needed for close work, as without a natural lens, your child will be unable to change focus from distance to near.

Whilst the child is young, we will give refractive correction for near vision as this is most useful in a young child. As your child gets older, we will probably prescribe bifocal glasses. This will enable the vision to be clear at both distance and close-up without having to keep putting glasses on and off.

Postoperative (after the operation)

Following the operation, the eye may look red and feel itchy. Your child will wake up from his or her anaesthetic with a shield and patch taped over the eye that has been operated upon.

The day after surgery, your child will be examined by a member of the medical staff who will remove the patch and shine a light in your child's eye to make sure all looks normal. A small bubble of air may be left in the front part of your child's eye, which will dissolve over a 3 - 5 day period. This is part of the procedure itself.

Cataract surgery is not a particularly painful operation to undergo and consequently, most children will only suffer from the after-effects of the anaesthetic rather than the surgery itself. You will be given some drops to put into the eye between 2 and 6 times per day. There may be more than 1 bottle to use and sometimes, a cream. You will be given a plastic shield to tape over your child's eye at night so that he/she cannot rub the eyes whilst in bed.

Risks of Infection (endophthalmitis)

There are risks of infection and bleeding following cataract surgery and although the risks of these are very small (less than 1 in a 1,000), they can be very serious and may lead to permanent visual problems. Inflammation after cataract surgery can sometimes be severe and aggressive in children and that is why your child will have been given strong steroid drops to use after surgery. Sometimes, these drops will need to be carried on for 2 - 3 months after surgery.

It is therefore important to keep the eye clean and free from dirty water, or other chemicals such as shampoo to minimise infection risk. You will be given information on how best to clean and care for your child's eye after surgery.

If you notice swelling, bleeding, excess stickiness, pain or redness around the eye, then seek medical help, promptly.

Are there any complications after surgery?

Generally, the earlier that cataracts are detected the more effective the treatment will be; however, complications may still arise. Some of the complications after cataract removal include:

- **lazy eye (amblyopia)** - if sight is weaker in one eye, then the brain begins to develop vision in the stronger eye over the weaker one. This can lead to visual loss unless treated with patching;

- **increased pressure inside the eye (glaucoma)** - this is one of the most common complications and may be seen in up to 10% of children after cataract surgery. It occurs when fluid in the eye is not drained properly. It can be controlled with medication but may require drainage surgery;
- **a squint (strabismus)** - this may develop as a result of amblyopia. Further surgery or treatment may be required;
- **irregular pupil** - an irregularly shaped or off-centre pupil may be detected after surgery;
- **problems with intra ocular lens** - occasionally, the lens inside the eye can move over a period of months, which can lead to visual problems. This may necessitate removal of the lens and its replacement or management with a contact lens. Sometimes (less than 1 in a 100), it is not possible to implant a lens at the time of surgery in which case your child will be converted to the more traditional type of surgery with removal of the lens. In this case, your child will have a contact lens to replace the full value of the lens that has been removed;
- **rubbing the eye** - occasionally, a child may rub his or her eye so vigorously that the stitches holding the eye intact can break. In this case, the eye will no longer be a ball and will become soft, which may require further surgery;
- **posterior capsule opacification** - this can occur when the fluid near the back of the eye becomes cloudy and requires further surgery; and
- **retinal detachment** - this is a separation of the retina from the back of the eye and can present with reduced vision.

Support and long-term care

It is essential that your child has regular check-ups and their vision is tested by specialists. This might include the fitting of contact lenses, glasses or patching (occlusion therapy). Ophthalmologists, orthoptists and optometrists will make up some of the professionals who see your child in an outpatient setting for follow-up care. This will enable any change in your child's vision to be monitored and treated accordingly.

If your child requires a contact lens, an optometrist will teach you the methods for inserting and removing your child's contact lens.

Orthoptists are specialists in assessing children's vision and they will play an integral role in the development of the vision in your child.

At each visit, it is likely that you will see an orthoptist who will assess your child's vision and an optometrist to test and check your child's contact lens / glasses. They will also check the intraocular pressure of the eye. On most of these occasions, particularly in the first year, you will see an ophthalmologist as well, although that may not happen at each visit.

Occlusion (patching) treatment

Patching or occlusion therapy is a technique used in most children after surgery, especially if only one eye is affected. Amblyopia or lazy eye is a condition that occurs when the brain prefers one of the two eyes. This can be due to a problem with an eye such as a cataract. The brain will have a tendency to use and develop the stronger eye over the weaker one and if left untreated will lead to poor vision in the weaker eye.

Amblyopia can also occur in two eyes if there are unclear images in both. Patching is used to force the brain to use the weaker eye and develop its vision. Patching will be used for a number of hours during the day and will continue for a number of years. The orthoptist will monitor the vision in both eyes to ensure that the vision is improving, but also that the unaffected eye continues to have normal vision. They will advise you on how long the patch should be worn as it depends upon a number of factors and is different for each child. Very occasionally, the vision in the patched eye stops developing. This is easily remedied by changing the patching routine. Correct contact lenses / glasses and rigorous patching, particularly in unioocular cataract are essential to improvement of the weaker eye. If patching is not done, then the eye will always have poor vision.

Patching regime

Generally the patching regime is employed as described below for unioocular cataract but this may change according to the results seen by the orthoptist.

1st Month of life (assuming surgery and optical correction already done) - 1 hour per day

2nd Month of life - 2 hours

3rd Month of life - 3 hours

4th Month of life - 4 hours

5th Month of life - 5 hours

6th Month of life - 6 hours

From then on, 6 to 8 hours daily is the baseline even when measured visions appear equal as the aphakic / pseudophakic eye is at a massive disadvantage.

If the visions are unequal, the patching will need to be at least 75% of waking hours or even full-time.

It is quite common for patching to become more difficult between the ages of 18 months and 3 years. Your child will be developing a mind of its own and will begin to object to the patch ("terrible twos"!). There is evidence to show that if you persevere with as much patching as you can at this time, even if you feel that you are not doing enough, the difficult period will pass, patching will become easier again and a good visual outcome can be attained. Always discuss your problems with the orthoptist. We will understand your difficulties!

Please remember:

The treatment of a child with congenital or developmental cataract begins at the time they have their surgery. Contact lenses / glasses, patching and regular hospital visits will be a feature of your child's life for a number of years. Your role as a parent or carer for your child is crucial for the success of the operation. It is also imperative that we see your child regularly in the clinic. The success rate of congenital cataract surgery in terms of how well your child will see is increasing all the time. Each individual case will be different and a surgeon will have discussed the prognosis with you. Things can change during the postoperative period and consequently, it is very important that we see you and your child regularly.

Glossary

Here are some words that you may hear from time to time:

Aphakia	No lens
Pseudophakia	An artificial lens has been implanted in the eye
IOL	Stands for Intra-Ocular Lens (or implant)
Lensectomy	Removal of the whole lens without the use of an implant
Hypermetropia	Long-sighted (sees better in the distance)
Myopia	Short-sighted (sees better for things close to)
Occlusion	Covering one eye with a patch
EUA	Examination Under Anaesthesia (looking at your child whilst he / she is asleep)
Monocular	Only seeing out of one eye
Bilateral	Both sides (a cataract in both eyes)
Unilateral	One side (a cataract in one eye only)

Further information and contact details

We hope you have found this booklet useful. It is important to remember that the majority of children affected by cataracts will go on to live normal lives and are still able to read, play and work.

If you have any further questions or queries, then your hospital doctor or GP should be able to advise you.

Alternatively, there is additional information available from:

- **Orthoptic and Children's Eye Clinic,**
St. James's University Hospital

Telephone: **(0113) 2064736**
(Monday - Friday, 8.30 am - 4.30 pm)
Email: **Leedsth-tr.ortho@nhs.net**

- **The Royal College of Ophthalmologists**

Website: **www.rcophth.ac.uk**

- **The Royal National Institute of the Blind**

Telephone: **020 7388 1266** Website: **www.rnib.org.uk**

- **The Paediatric Glaucoma and Catract Family Association**

Website: **www.pgcf.org**

- **LOOK UK**

Telephone: **0121 428 5038** Website: **www.look-uk.org**

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