



Children with cataracts

Information for families



NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust





This leaflet from Great Ormond Street Hospital explains cataracts (cloudy lens) in children and how they can be treated. It also gives a reminder about contact lens use after surgery. This booklet has been produced to help parents and carers of all children with cataracts. As each child is different, not all sections will be relevant. When specific products are mentioned in this leaflet, this does not constitute endorsement by GOSH. However, we recommend that you follow instructions given by your clinician and check before using other products.

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Section 1: General information

Words shown in **bold** on this page are shown in Figure 1 and an explanation for words in *italics* can be found in the Glossary at the end of the booklet.

What are cataracts?

In the eye, the **cornea** (front of the eye) and lens focus objects on the **retina** and the image formed is then transmitted via the **optic nerve** to the brain. The **lens** should be transparent and able to change its focus from distance objects to near. However, in some children the lens is opaque or cloudy, a bit like the cooked

white of an egg. This is a cataract, and it stops light and images from reaching the **retina**. This means that vision will be reduced as the images formed on the **retina** are not clear so only a poor image is transmitted along the **optic nerve** to the brain. As a result, normal visual development cannot occur.

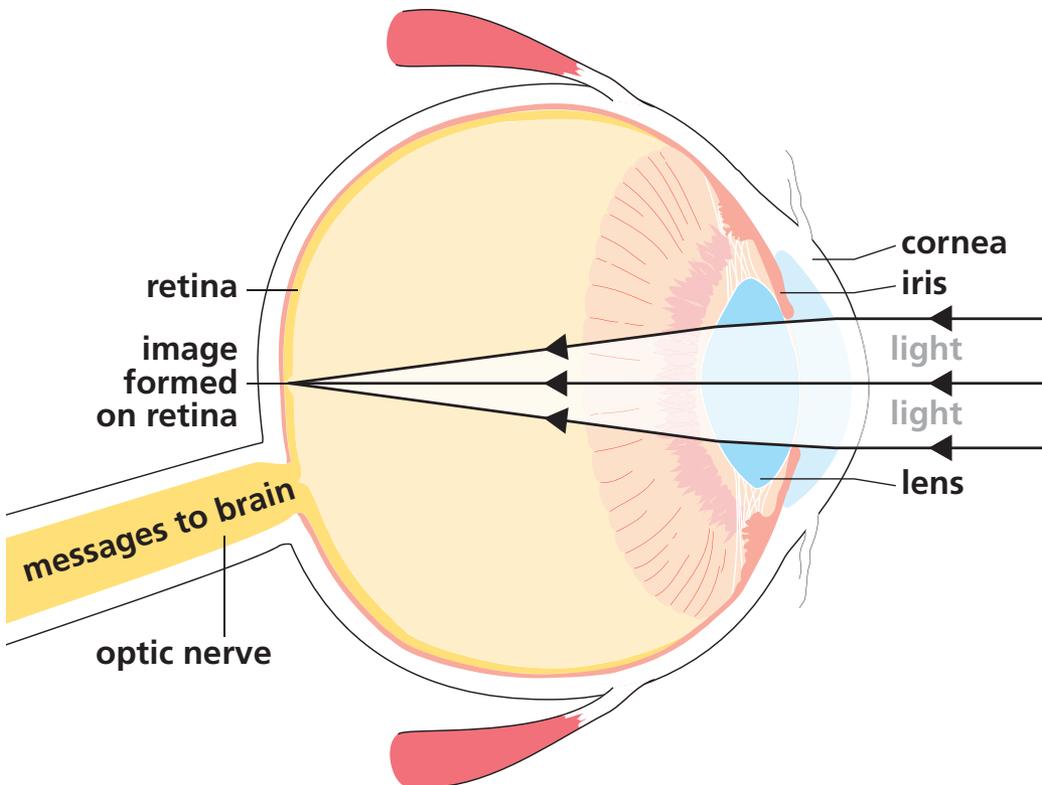


Figure 1: How the eye forms an image

(Lines with arrows represent the image being viewed and focused by the eye)





In some children, the lenses are completely opaque (*dense cataract*) so there is almost no vision except for light. In others, the lens opacities are only mild (*partial cataract*) so a reasonable image can still be formed on the retina, for example, the child may find it harder to see in bright light in the same way it is hard to see through a dusty window in sunshine. Children with partial cataracts need regular check-ups to make sure that the vision is developing well.

Cataracts can occur in one or both eyes. Both *unilateral* (one eye) and *bilateral* (both eyes) cataracts in newborn babies prevent them from getting enough visual stimulation during an important stage of development. Surgery is needed to remove cataracts and if *dense cataracts* are not removed, or removed late, it can lead to permanent changes in areas of the brain where vision is controlled, resulting in reduced vision in one or both eyes. It is important, therefore, to carry out surgery as early as possible, preferably before three months of age or even younger in *unilateral cataracts*, although children operated after this age may still develop reasonable eyesight.

What causes childhood cataracts?

In the UK, the incidence of cataracts is approximately 2.5 per 10,000 of infants under 1 year of age. It may be difficult to find the cause of your child's cataracts but they may be inherited from a parent. Therefore, the parents, brothers and sisters of affected children are examined as other

members of the family may have a partial cataract, which is not affecting their vision.

Approximately a quarter of children, usually those who are born with cataracts in both eyes, have associated problems. For example, Rubella infection (German measles) in early pregnancy can cause multiple disabilities, one of which is cataracts.

Cataracts are common in young children with Down syndrome (trisomy 21), although they are not always bad enough to need to be removed.

A number of other rare general conditions (*syndromes*) can also be a cause of cataracts. Some of these can be checked for with a blood test. As some of these conditions are inherited many children with cataract, together with their families, are seen by a Geneticist (see page 19), who can help with diagnosis and provide advice about the risk of cataracts in future children.

Some affected eyes may be smaller than average (microphthalmos) or have another eye condition as well as the cataract.

Children can also develop cataract later in childhood. This can be due to injury, drug exposure or radiation, or in association with other eye problems such as retinal disease and uveitis (inflammation of the eyes). If no cause is found, it is possible that there were slight cataracts at an earlier age that were not noticed until they started to cause problems.





How is cataract diagnosed and treated in children

Careful visual assessment is carried out using simple methods, such as watching the steadiness of the eyes and whether the child prefers to use one eye more than the other. Special visual assessment cards (preferential looking cards – **Figure 2**) and electrodiagnostic testing (EDT) which pick up signals from the

brain's visual areas may also be used. None of these tests is painful or harmful for your child. For further information about the EDTs, please see our leaflet VEP/ERG: information for families which is available from the Eye Department or on our website at www.gosh.nhs.uk



Figure 2: Child being tested using preferential looking cards (Courtesy of Bronwen Walters).





What does the cataract operation involve?

Surgery is performed under a general anaesthetic. We are often asked about local anaesthetic but this would just mean numbing the eye and asking the child to stay still.

The main techniques used for childhood cataract surgery are explained below. The decision about which type of surgery is best for your child will be made by the surgeon and discussed with you. For reasons, also explained below, the final decision about the best type of surgery may not be made until the time of surgery.

Lensectomy (removal of lens – see **Figure 1**): The cataract is the cloudy lens of the eye so all cataract surgery involves removing the natural lens. The normal lens consists of a transparent bag (*lens capsule*) filled with a clear protein jelly. If the jelly has become cloudy (cataract) then there are no drops, medicines or lasers that will clear it, in much the same way that a cooked egg white cannot be changed back to a clear jelly. In older children and in adults, the nucleus (centre) of the lens becomes harder and needs to be broken up using ultrasound in the eye before it can be removed.

■ **Capsule preservation:** Most surgeons will try to leave the *capsule* in place, either to insert an artificial lens or *implant* (see **Figure 3**) at the first operation (primary lens implant) or at a second operation (secondary implant) when the child is older. Part of the capsule can become cloudy and appear as a white ring in the pupil a few weeks after surgery. In some patients,

the whole *capsule* may become cloudy and look like a cataract before it was removed. This is likely to require laser treatment or further surgery.

Intraocular lens implantation (IOL or implant) (Figure 3): In this operation, the cataract is replaced by a permanent plastic lens. This is not suitable for most very young babies (see below) and the vision does not necessarily develop any better than with other types of surgery. The operation is different from adult surgery in that a child's eye has yet to fully grow. So if a lens implant is used the child will still need to wear glasses, or occasionally a contact lens, to ensure that the eyes are well focussed.

If an implant is the preferred choice of surgery, before the operation an ultrasound measurement is taken of the eyes then calculations are carried out to determine the focus of the intraocular lens. The ultrasound scan will also look at other structures of the eye especially the retina.

Even if your child has been booked to have an implant, the surgeon may find that it is not possible or safe at the time of the surgery. One possible problem is that the lens capsule may break when the cataract is removed, so that the implant cannot be inserted safely.



Figure 3: An intraocular lens





- **Why some eyes are not suitable for lens implantation:** Lens implants are made for adults so one reason that a baby can't have an implant is that the eye is too small to safely implant the plastic lens. Lens implants are not made in small sizes because they need to remain in the eye as it grows as changing the implant is not recommended. Another reason for not implanting a lens is that the lens capsule may not be strong enough to hold the implant in the correct position in the eye. In addition, it has been found that young babies often require extra operations after implants which is not recommended.

What happens after the operation?

All types of eye surgery carry risks and it is extremely important that after the operation, you should keep checking your baby's eyes and follow instructions you are given. You will be given drops and ointment to use and shown how to put them in. These need to be used several times throughout the day. If you notice that your baby reacts badly (e.g. more redness of the eyes) or you are worried about anything, please telephone us. If you run out of drops or ointment between visits, ask for a prescription from your child's GP.

Your baby may be given a pair of glasses to wear after the operation. These are temporary glasses and they will have their own pair ordered later. If your child needs contact lenses, they are usually fitted within two weeks of the operation if the eyes have settled sufficiently. If contact lenses are not fitted, babies can continue wearing glasses and have lenses fitted later.

For more information, please see our leaflet *After your child has had an eye operation* available in the ophthalmology department or on our website www.gosh.nhs.uk

Cataracts in both eyes

If your child needs surgery in both eyes, the operations may be done on the same day or may be done on different days but usually within one week of each other.





Section 2: Focusing the vision

Will my child need glasses or contact lenses after the operation?

In order to replace the focus of the natural lens after cataract removal, an artificial means of focusing is needed. This is provided with glasses, contact lenses or intraocular lenses. Where an intraocular lens has not been inserted, glasses with thick lenses will be needed. If *implants* have been inserted, glasses will still be necessary because a baby's eye needs a much stronger lens than that of a child or adult, so the difference is made up with glasses or contact lenses to wear as well. These spectacles are much thinner than if there is no *implant*.

Because a baby has a small head and small bridge to the nose, it may be difficult to wear spectacles for any length of time, so where possible we try to fit contact lenses. As the baby gets older, we often change to glasses for a time. Vision in the thick spectacles is magnified and therefore the central vision is actually better than in contact lenses (see below "Are contact lenses better than spectacles?") but the field of vision is reduced although this is not usually a problem for a toddler. It doesn't cause any long-term problems and vision can develop just as well in glasses as in contact lenses or with implants.

Unlike a normal eye, contact lenses and implants cannot change focus from near to far so we have to choose where to focus the vision. A baby spends very little time looking in the distance. Most waking hours are spent looking at objects that are nearby – parents' faces, food, toys etc. Therefore we provide contact lenses or glasses that focus close up, within a metre. This doesn't mean that your baby can't see anything beyond a metre but objects in the distance won't be as sharp as those that are nearby. When your child is older and needs distance vision to be clear as well as near vision, we change the focus of the contact lenses to distance and give a pair of *bifocal spectacles* to wear over the contact lenses for reading (see Figure 11). We may not do this until your child starts school. If the child is not wearing contact lenses, we simply change the glasses to bifocal ones. (*Varifocal spectacles* and bifocal or multifocal contact lenses do not work well for young children).





What contact lenses are fitted and how should they be used?

In babies' eyes, all types of contact lenses quickly become comfortable as they seem to adapt to them more easily than adults.

There are different types and materials of contact lenses. The first lenses we try are usually soft lenses but we may fit one of the other types if we feel the eyes will do better with a different material. Soft lenses contain water; if they are allowed to dry out they become brittle and shrivelled, but they will return to normal if they are replaced in saline (see below "How do I clean and disinfect the contact lenses?"). The lenses are made of a special material that can remain in the eyes during sleep. However, there is a risk of infection or soreness if the lenses are slept in every day without removing them for cleaning and to give the eyes a rest. That is why you will be encouraged from the beginning to remove the lenses every night. It is not necessary to remove the lenses whilst the baby sleeps during the day.

If at any time, an eye looks red, watery, half-closed or just 'not right', the lens must be removed as soon as possible as sight may be lost if the lens is left in.

How do I insert and remove the contact lenses?

These instructions are for soft lenses in babies and are to remind you what you will be taught in the clinic.

Instructions for inserting and removing the lenses in older children or for other types of lenses are different and you or your child will be taught what to do when attending the clinic.

- Almost all parents are scared of hurting their child's eyes and may find it difficult to deal with the lenses at first. With time, handling the lenses becomes easier and you will become more confident.
- When dealing with your baby's eyes always ensure that your nails are short and smooth.
- Wash your hands before touching the eyes or the lenses. Any soap can be used but preferably not a highly scented one. It does not need to be anti-bacterial.
- Dry your hands on a lint-free towel or a paper towel.
- The lenses should not be painful but a baby may cry in the same way as some babies cry when they are bathed.



Lens insertion

The instructions are written for right handed people, swap over if you are left handed.

1. If possible, ask someone to help hold your baby, especially the hands, or you can swaddle the baby in a blanket. It may be easier to remove (and insert) the lenses if the baby is asleep.
2. Remove the lens from its container and hold it gently across the middle between your right thumb and index finger (**Figure 4**) (left for left-handed people). There is only one way to hold the lens; it cannot be easily turned inside out nor can it be upside-down.

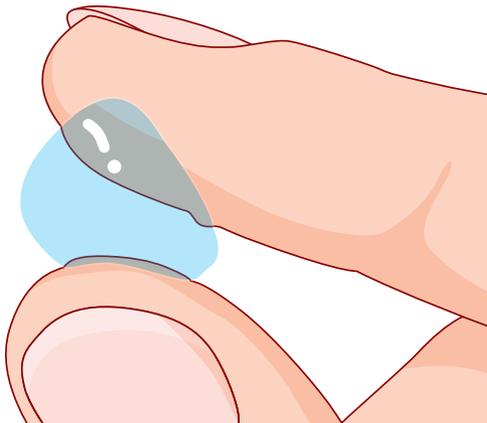


Figure 4:

Holding the lens between finger and thumb

3. Using your left thumb, pull up the top lid (**Figure 5**). It is important to place your thumb as near to the lashes as possible and in order to do so you may need to put your thumb right over the whole closed eyelid. Make sure that the lid is dry and if necessary use a clean tissue to provide a drier contact.

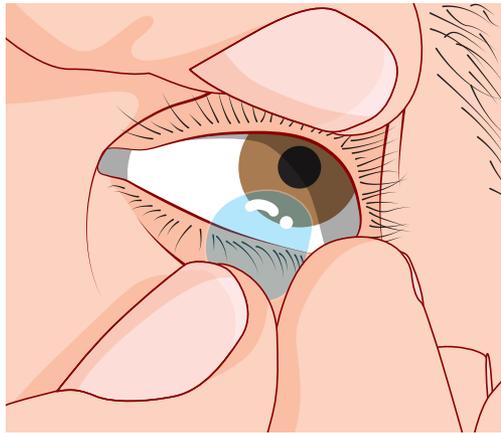


Figure 5: *Pulling up the top eyelid. Note the space underneath the lid to slot the edge of the lens into.*

4. Position the edge of the lens under the top lid in the gap formed underneath the top eyelid (**Figure 6**).
5. Then using your forefinger, or thumb and forefinger, gently push the rest of the lens up under the lid until it sits on the eye (**Figure 7**).



Figure 6:

Positioning the lens in the gap under the top lid



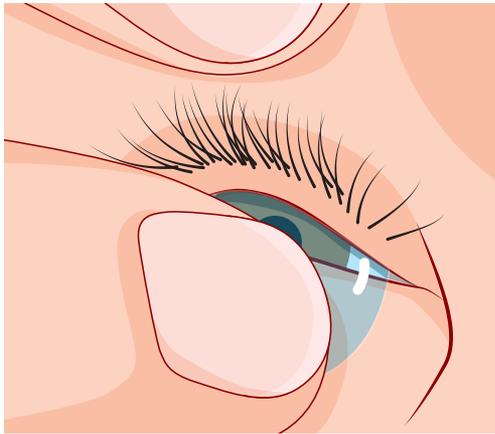


Figure 7:
Pushing the lens into position on the eye

6. When the lens is in place, pull down the lower lid to make sure that the lens is sitting on the eye correctly (**Figure 8**).

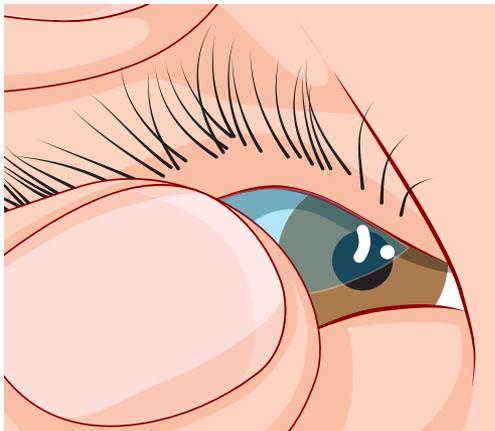


Figure 8: Pulling down the bottom lid and make sure the lens is in place.

The lens will move to the correct position in the eye unless it has folded in which case it must be removed and replaced. A folded lens may be uncomfortable and the baby may try to rub it out. Only soft lenses can fold, but any lenses can slip underneath the top lid and disappear from view. The lens will not do any damage to the eye if it remains there for some time, even overnight if necessary. **It cannot get lost behind the eye** and will usually move back into place if left for any length of time. If a second lens is inserted into the eye, it will not do any harm and the first one will usually fall out.

If you accidentally drop the lens, rinse it with *saline* before putting it into the baby's eye. It is not necessary to disinfect the lens each time this happens.

If the eye continues to look uncomfortable after a few minutes or if the child won't stop rubbing the eye, remove the lens, check it and rinse it with *saline*, and then reinsert it.





Lens removal

The instructions are written for right handed people, swap over if you are left handed.

1. Wash and dry your hands.
2. Ask someone to help hold your baby (especially their hands) or swaddle them in a blanket.
3. Place one thumb (or finger) over the top lid at the very edge, close to the eyelashes, and pull the lid up high. This is the same as inserting the lens only unlike lens insertion, try to make sure the lid is pressed gently onto the eye so there is no gap. This helps to stop the lens from slipping underneath the top lid.
4. Place the other thumb at the edge of the lower lid and pull it down, again making sure that the lid is turned inwards onto the eye (**Figure 9**). You should not be able to see the inside of the lid.
5. Gently press on the edges of the lens that should now be visible and move your thumbs together to scoop the lens out. Turning the lids slightly clockwise or anti-clockwise at the same time helps to remove the lens (see arrows on **Figure 10**). You can actually touch the lens with your thumbs as you are trying to remove it. You need to put a little bit of pressure on to the eye (this doesn't hurt – try it on yourself!) and the lens will pop out.

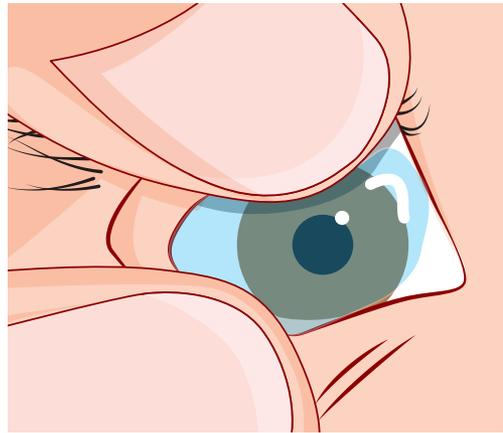


Figure 9: Position the thumbs above and below the eye to remove the lens

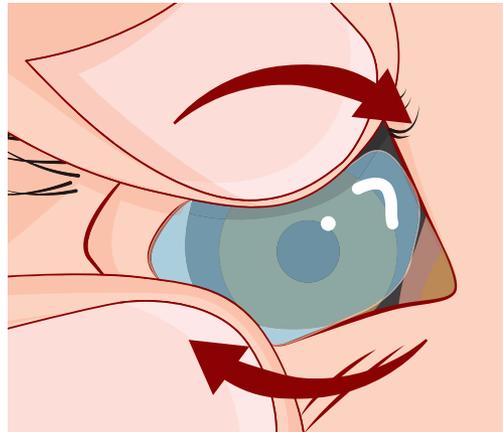


Figure 10: Removing the lens. Arrows show the direction to move the thumbs or fingers to aid lens removal.





How do I clean and disinfect the contact lenses?

Cleaning contact lenses is extremely important. If the lenses are not cleaned properly, infection can occur which can be dangerous to the health of the eyes.

The lenses should be cleaned and disinfected overnight. You will be supplied with the necessary cleaning solutions by the hospital but if you should run out between visits you can buy further supplies from a local optician or pharmacist.

The following cleaning instructions and solutions are an example only and you will be given the correct cleaning instructions when you come to the clinic. From time to time, the method of cleaning the lenses may also be changed.

1. Fill the case three-quarters full of disinfecting solution (such as OPTI-FREE®)
2. Place the lens on the palm of your hand.
3. Put one or two drops of the cleaning solution e.g. Oté Clean onto the lens and rub it with your forefinger or between finger and thumb for about 20-30 seconds.
4. Rinse the cleaning solution off with the saline e.g. Lens Plus Saline.

5. Do the same with the other lens. Always make sure that you keep the right and left lenses separate, as they are not necessarily the same.
6. Screw the lids on tightly and leave overnight or for at least four hours.
7. Always clean and disinfect the lenses every time they are removed (although it is not necessary if they are only removed for a few minutes) and completely empty and replace the solution in the case every day when the lenses are used.

Clean out and dry the case after you have put the lenses in. Bacteria do not survive as well in dry conditions as in wet ones so once a week, clean the case and the lids, both inside and out, using a baby toothbrush or a cotton bud together with contact lens cleaning solution. Rinse with saline, dry with a clean tissue and then leaving the lids off, turn the case and lids upside down on a clean tissue and allow to dry.

If the lenses are not used for several days or weeks, it is a good idea to replace the disinfecting solution once a fortnight and to clean the lenses as described before inserting them.



What problems can occur with contact lenses?

- Eyes are not created to have foreign objects placed in them. A contact lens is a foreign body and although it is made of a plastic that is safe to wear, it can cause problems to some eyes by increasing the risk of infection and by reducing the amount of oxygen that normally reaches the cornea. The tears of the eye contain a natural antibiotic called lysozyme, which prevents many minor infections from becoming major ones. When a contact lens is placed in the eye it dilutes the effect of lysozyme and so increases the risk of infection. This is especially so when the lenses have not been cleaned adequately so it is extremely important to make sure you handle the lenses with clean hands and clean the lenses carefully every time you remove them.
- Always avoid water when cleaning the contact lenses as there is a risk of infection when water gets onto the lenses. Be sure to wash your hands and dry them properly and only use contact lens solutions for cleaning the lenses.
- The prescription of lens that your baby needs means that the lenses are thick. Even with modern materials, the thick contact lens acts like a polythene bag and reduces the amount of oxygen that normally reaches the cornea. The situation is at its worst when the eyes are closed. A closed eye uses oxygen from the eyelids but the amount of oxygen is much reduced when there is a contact lens in place. Some eyes

react to overnight wear by becoming sore and sensitive to light. That is why you should try to remove the lenses at night when the eyes are closed for the longest time.

- Babies often rub their eyes when they are tired or if their eyes are irritating them. Always check that the lenses are not damaged before inserting them and if the baby continues to rub the eyes, remove the lenses, check them and rinse with saline before reinserting them. If the lenses are frequently rubbed out, it may be an indication that they are no longer fitting properly. You should discuss the problem at your next visit and if necessary make an earlier appointment.

Can lenses be used when swimming, bathing or flying?

- The lenses absorb whatever liquid they are kept in or whatever liquid splashes on them and all types of water carry a risk of infection when wearing contact lenses. Lenses should not be worn for swimming or when washing with tap water when bathing, showering and face washing, in order to avoid any irritation or infection. Leave the lenses out for at least two hours after swimming.
- Prescription swimming goggles can be made for older children but the hospital does not pay for these.
- It is advisable to remove contact lenses before flying as aircraft cabins are usually very dry.





Section 3: Vision after surgery

How well will my child see after surgery?

This is the question that all parents want the answer to, but only time can really tell. We are not being evasive when we say we don't know. What we do know, however, is that it is important to focus the lenses accurately and to stimulate the vision. The focus and size of the contact lenses or glasses will be changed when necessary during your child's visits to the hospital. Children vary in the number of changes that are needed and it is neither a good nor a bad sign if alterations are made. If you think your child's vision seems worse in any way between appointments, contact the hospital to ask for an earlier appointment.

Try to stimulate the vision by having brightly coloured toys and black and white shapes to look at and encourage the baby to follow them: this will be very slow at first but will gradually become quicker. Assemble a mobile above the cot so that it can be seen when the baby is lying awake instead of staring at a blank ceiling. Many babies will stare at lights as they are bright; try to discourage this.

Focusing the images on the retina with contact lenses, glasses or implants does not mean that your baby can see: vision has to be learned and the brain only learns to interpret the messages that it is given repeatedly. It is a bit like presenting an adult with a book in a foreign language and expecting them to read and understand it. The eyes will see the foreign words but the brain will not be able to understand until it has been taught the language. In the same way your baby's eyes may look towards the objects in front of them but the brain has to learn to interpret the messages from the eyes.

That is why it is important, when spectacles or contact lenses are prescribed, that you keep the baby wearing them as much as possible. You may think that the behaviour is the same whether the lenses are in or not. Babies and young children can adapt to their surroundings very easily and will function much better than an adult in similar circumstances, but the vision is not developing and may in fact be getting worse if there is no focus for any length of time (more than a few days).

The vision tests that are carried out at most appointments will give us a clue of how much the baby is seeing. These tests are the same as those used before the operation.





Are contact lenses better than spectacles?

Many parents are worried that if their baby cannot have implants or if they change from contact lenses to spectacles, their vision will be poor. As mentioned earlier, in fact the vision with strong spectacles is magnified and bigger objects are easier to see. That is why many children (and some adults) prefer to wear their glasses for school or work instead of their contact lenses. However, the area that they see (their field of vision) is reduced and their peripheral vision is distorted. This can cause difficulty in some cases.

Note: We will discuss with you what sort of correction is best for your child. Contact lenses are not always preferable to spectacles.

Section 4: Patching

What is patching and why is it done?

Patching is where the stronger eye is covered to make the weaker eye work on its own in order to try to make it stronger (**Figure 11**).

If a cataract has been removed from one eye only (unilateral cataract) and the other eye is normal, you will need to cover the normal eye with a patch to try to encourage the vision in the poorer eye to improve.



Figure 11: Patching the left eye. Note the bifocal line on the spectacle lens.





The length of time that you need to patch varies between individuals, so you will be advised how much patching to do when you attend the clinic. Unfortunately, patching can be difficult, but there is no alternative. The patch is sticky and may irritate, especially in warm weather, and your child's activities may be restricted as they are forced to use the eye with poor vision. As their vision improves, however, they will become more used to the patch but bear in mind that they may still go through difficult phases!

You mustn't over-patch the unoperated ('good') eye by leaving the patch on all day otherwise normal vision cannot develop in that eye.

You may occasionally be told to patch one eye all day for a short period, but this will be explained and discussed with you.

Patching for unilateral cataracts will continue for seven years or more if there is a chance of reasonable vision, so the consultant will discuss this when you are deciding whether to go ahead with surgery in the first place. In spite of all our efforts (both yours and ours), an eye that has had a cataract may not be able to develop much vision. When this happens, we will stop the patching (and possibly also the contact lenses) much earlier. This does not mean that you have 'failed' – your child's eye probably didn't have the necessary eye structures to ever see well.

As parents, you may decide that the routine of patching will be too stressful for your child and family. If you decide not to patch, *don't feel guilty about the decision*. Whether it is because we stop the patching or you decide against it, the vision in the better eye should, in most cases, develop well and allow him or her to live a normal life, including driving.

Note: Patching does not make eyes straight if they are squinting (not pointing in the same direction).

Why do I need to patch if my child had cataracts removed from both eyes?

If cataracts have been removed from both eyes but the vision is not equal, some patching of the stronger eye may be necessary. In these cases, you will be told to patch for short periods, as both eyes need as much visual stimulation as possible.

Where there is *nystagmus*, the patching times may be different.





What are patches made of?

The patches used are sticky ones (like a sticky plaster) put directly onto the skin. If the patch is stuck to glasses, your child is likely to look over the top of the frame and use their better eye. Black 'pirates' patches' are not used as the elastic can be dangerous, and children also try to peep around the patch!

It is unlikely that the patches used nowadays will cause an allergic reaction but the skin can become irritated especially if sticky patches are pulled off quickly. It can help if you stick the patch to your hand first and peel it off before sticking it over your baby's eye. It also helps to put a little face or baby cream onto the area after the patch is removed. If an allergic reaction does occur, tell the clinic, as a different type of patch can be tried.

It can be very difficult to stop your child from pulling off the patches. Putting a little Vaseline around the edge and across the middle of the patch can help but do discuss the problems when you come to the clinic; there may be ways around them.

You should be supplied with enough patches to last until your next appointment. If you run out in between, ring up and ask for more.

Section 5: Follow up

How often will my child need to visit the hospital?

We would like to see your child straight after surgery and then a few days or a week after that. This is followed by appointments a few weeks later. Appointments depend on how well the eyes are settling after surgery, whether contact lenses are fitted and whether we have the correct lenses available at the first fitting appointment. You will also need to learn how to insert, remove and clean the lenses.

Once the eyes have settled down, we will generally see you every three months until your child is 2-3 years old when the appointment intervals will be increased.

At every appointment, both you and your child should ask all the questions that you want: it is better to ask about something that you think is silly than to go home and worry about it; and remember, what sounds trivial to you may actually turn out to be important. And don't worry about contacting the department between appointments if you are concerned.





Who will my child be seen by in the clinic?

On your visits to the clinic, you may see one or several of the following people:

- The **ORTHOPTIST** will check the vision in the eyes of young children and advise on any necessary patching. They will also check for a squint and discuss if surgery is needed.
- The **OPTOMETRIST** tests the eyes for glasses and measures and fits the contact lenses. They also check the health of the eyes before discussing treatment with the ophthalmologist.
- The **OPHTHALMOLOGIST** (eye doctor) carries out the surgery, checks the health of the eyes and decides on the treatment your child requires.
- The **DISPENSING OPTICIAN** will measure your child's face in order to fit the best size and type of spectacles if glasses are ordered for them.
- The **EYE CLINIC LIAISON OFFICER (ECLO)** will speak to you if we feel that your child's eyesight is not developing well. They will discuss sight registration and liaise with your local authority to advise when extra help is like to be needed at nursery or school.

Your child may need other tests:

- **ELECTRODIAGNOSTICS TESTING EDTs** is a test that assesses how well both the eyes and the vision pathway in the brain are working.
- **FUNDUS PHOTOGRAPHS** to record the appearance of the retina

- **OPTICAL COHERENCE TOMOGRAPHY (OCT)** is a painless test that uses light to take a cross sectional image of the different layers of the retina or other areas of the eyes.

Your child may also be referred to other people or departments.

- The **DEVELOPMENTAL VISION CLINIC** if we feel they have very poor vision and are behind in their development.
- **LOW VISUAL AID (LVA)** clinic if the vision is poor, where they may be prescribed magnifying glasses or binoculars and advice is given regarding your child in the classroom.
- If your child has problems other than just with their eyes, then they will need to see a **PAEDIATRICIAN** who can assess the whole child and advise on their health and development.
- We may recommend that you and your child are seen by a **GENETICIST**. If you are worried that your child's eye problems are inherited – 'run in the family' – or about future children being affected, you can ask for a referral to a geneticist and if we feel it is appropriate, we can refer you. This can also be done locally and you can be referred by your GP or paediatrician.





Will my child need any more operations?

Listed below are the main reasons why further operations are sometimes necessary:

- **LOOSE STITCH:** Most stitches dissolve after a few weeks, but they can occasionally cause problems and need to be removed.
- **THICKENED CAPSULE:** If a lens implant is used, the capsule that holds it may become opaque and have to surgically removed or cut with a laser.
- **REMOVAL OF REMAINING LENS MATTER:** After a cataract has been removed, the vision may deteriorate again because a few cells from the original cataract have regrown and need to be removed surgically.
- **AN UNUSUAL SHAPED PUPIL:** Instead of being round, the pupil may become oval or move off-centre. This does not usually cause problems unless the pupil becomes too decentred in which case your child may need another operation.
- **GLAUCOMA** (raised pressure in the eye) can occur after cataract removal. The pressure is checked at each clinic visit. If it is found to be high over two or more appointments, it is likely to need treatment with eye drops. If drops don't work, surgery may be needed. This will be discussed with you if the need arises.
- **SQUINT OR STRABISMUS** (when the eyes are not pointing in the same direction) is present in many children after surgery for cataract, although the squint may be slight and not need any treatment. If the squint is very noticeable, an operation may help the eyes work better together or simply improve the appearance of the eyes. The timing for the operation varies and the orthoptist and ophthalmologist will discuss with you when is the best time to have the surgery.
- **EXAMINATION UNDER ANAESTHETIC (EUA):** Sometimes it is not possible to examine your child's eyes thoroughly enough without giving them a short anaesthetic. Your child will need to come into the hospital for a day for an **EUA**.

If your child wears contact lenses, they will need to be left out after surgery for some days or weeks; glasses should be worn during this period. Check with the doctor or optometrist when contact lens wear can be resumed.





Some important points

- The **GOLDEN RULE**: If at any time an eye looks red, watery, sticky or half-closed or just "not right", **contact lenses must be removed within 6 hours** as there is a danger of loss of sight if the lens is left in. **IF IN DOUBT LEAVE THE LENSES OUT.**
- If you see anything unusual or anything that appears to have changed in your child's eyes, let us know **straight away** and if necessary make an early appointment.
- Where possible, always remove contact lenses first before seeking medical advice. Most doctors and hospital staff do not know how to remove babies' contact lenses so it is better, if possible, that you remove the lenses first yourself before seeking medical advice. Once the lens is removed, the eye may start to heal itself, but you should still discuss the situation with the clinic doctors and should not reinsert the lens(es) without checking first. If the eye does not appear to improve after a few hours, take the baby to the eye doctor at your local hospital for treatment.
- If at any time the eyes look uncomfortable, don't insert the lenses
- When your child is unwell, the lenses should not be worn.
- If your baby normally wears contact lenses in both eyes and develops a problem in one eye, remove **both** lenses and then contact the hospital.
- If the lenses need to be removed for more than a couple of days, ensure that the baby wears back-up glasses. You may already have these but if not, the hospital should be able to lend you a pair. During the time when the baby is wearing neither contact lenses nor spectacles the sight does not develop and can get worse if left for too long.
- Always ask questions if you have any and be sure you understand the answers. If not ask again; we don't mind!
- In most cases, your child's vision should develop just as well whether they have glasses or contact lenses.
- In an emergency or if there are urgent questions please phone the hospital between 9am and 4.30pm on weekdays. If your child needs to be seen urgently at night or weekends go to the Accident & Emergency Department of your local hospital or Moorfields Eye Hospital.
- It is important that you keep your appointments at the hospital and if you are unable to do so that you make another appointment in order that we can check for any early signs of problems before they need urgent attention.





Useful numbers and addresses

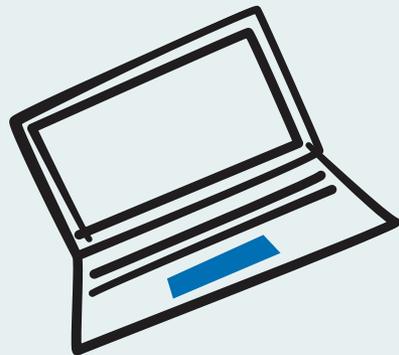
- **Great Ormond Street Hospital Eye Department: 020 7405 9200**
Ophthalmology department or secretary during the day
or to leave a message out of hours if you have urgent questions
- **Moorfields Eye Hospital 020 7253 3411**
Accident and Emergency Department, City Road, London EC1V 2PD
(nearest tube – Old Street) if your child needs to be seen urgently
at night or weekends
- **Your local Accident and Emergency Department**





Glossary

- **Bifocal spectacles** – Glasses with a line across where above the line is focused for distance and below the line is focused for close up (see Figure 11).
- **Bilateral cataracts** – cataracts in both eyes
- **Capsule** – clear membrane that holds the lens (or cataract) a bit like the egg shell is in relation to the egg). Where possible, this is left in place when the cataract is removed.
- **Dense cataract** – a cataract that is completely opaque so almost no vision is possible.
- **Implant** – the plastic lens that is inserted into the capsule when the cataract is removed (see Figure 3).
- **Intraocular lens (IOL)** – see Implant
- **Lens capsule** – see Capsule
- **Nystagmus** – where the eyes make constant rapid involuntary movements.
- **Partial cataract** – a cataract that is not completely opaque so some vision is possible.
- **Peripheral vision** – vision at the outer parts of the field of view as opposed to central vision which is used for reading, looking at faces, pictures etc.
- **Saline** – slightly salty water. Used for cleaning contact lenses and lubricating the eyes. **NB Never use saline for the eyes that is not made and labelled especially for eye use.**
- **Sight registration** – Being put on the Register at your local social services to give the degree of lack of vision. There are two levels, Sight impaired (SI) or Severe sight impaired (SSI)
- **Squint** – where the eyes do not look in the same direction (sometimes called strabismus)
- **Syndrome** – a number of symptoms that occur together e.g. Down syndrome
- **Unilateral cataract** – cataract in one eye only.
- **Varifocal spectacles** – Glasses where the focus changes gradually from distance (upper part of lenses) to near (lower part of lenses) so unlike bifocal spectacles, there is no visible line.





NHS

**Great Ormond Street
Hospital for Children**

NHS Foundation Trust

Children with cataracts

Information for families

This leaflet from Great Ormond Street Hospital explains cataracts (cloudy lens) in children and how they can be treated. It also gives a reminder about contact lens use after surgery. This booklet has been produced to help parents and carers of all children with cataracts. As each child is different, not all sections will be relevant.

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Compiled by the Ophthalmology department
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