

Your child's corneal cross-linking procedure for the eye condition keratoconus

This leaflet is about your child's procedure to treat an eye condition called keratoconus. If your child has keratoconus, the clear window at the front of their eye called the cornea gets thinner. It gradually bulges outward into a cone shape. The leaflet explains what you should do before your child's procedure, on the day of the procedure and when you return home.

Your child's condition and procedure

What is keratoconus?

Keratoconus is a condition that makes the clear dome at the front of the eye called the cornea get thinner. The cornea then slowly changes shape. This can affect your child's eyesight. Keratoconus can cause blurred vision and sensitivity to light and glare.

The condition usually appears during puberty when your child starts to develop into an adult. It can get worse with time.

Keratoconus affects about 1 in 1,000 people. It can happen in males and females equally, and in all ethnic groups. About 1 in 5 people with keratoconus eventually need a cornea transplant. This is when we replace a damaged cornea with healthy tissue that someone else has donated.

What is corneal cross-linking?

Corneal cross-linking is a procedure to stop your child's eyesight getting worse. This treatment makes the cornea stronger using vitamin B2 (riboflavin) drops and ultraviolet (UV) light.

The procedure is called cross-linking because it adds links between fibres made from a substance called collagen in the eye. They work like support beams to help the cornea stay stable.

Research shows that corneal cross-linking stops keratoconus getting worse in about 3 out of 4 people. It can also improve the shape of the cornea.

Why does my child need a corneal cross-linking procedure?

Your child is having this procedure because their cornea shows signs of getting thinner and changing shape. The aim of the procedure is to strengthen the cornea and stop your child's eyesight getting worse.

Are there any other treatment options to this procedure?

There are no other treatments that stop keratoconus progressing. Without the treatment, your child's condition and eyesight might get worse.

Before your child's procedure

What needs to happen before my child's procedure?

Most children have the treatment under a local anaesthetic. This means that they are awake for the procedure but do not feel pain when it takes place. We give them numbing eye drops for pain relief. Other children prefer to have a general anaesthetic. This is a medicine to make them sleep during the procedure.

If your child has the treatment under a general anaesthetic, we need to see them at a pre-admission clinic. This clinic may take place face to face or online. We make sure that your child is ready for a general anaesthetic and surgery.

Our admissions team contacts you by letter, text message or phone. We offer you a date for your child's procedure. We also explain when your child should stop eating and drinking (fast) before their procedure.

Do I need to get pain medicine ready for my child?

Please make sure that you have a week's supply of paracetamol (a painkiller) and ibuprofen (an anti-inflammatory medicine) at home before the procedure. We do not routinely give these medicines to take home for your child after day surgery.

You can buy paracetamol and ibuprofen from a pharmacy, supermarket or shop. Paracetamol for children may also be called Calpol[®]. Ibuprofen for children may also be called Calprofen[®] or Nurofen[®]. You need the type of medicine that you would give your child if they were unwell with a cold or ear ache. If your child cannot take paracetamol or ibuprofen for any reason, please speak to their healthcare team about other options.

On the day of the procedure

When you arrive at the children's day surgery unit

We give you a time to arrive at the Evelina London children's day surgery unit. It is important that you arrive at the correct time and have followed the fasting instructions for your child. If you arrive late or have not followed the fasting instructions, we may not be able to do the procedure.

You and your child meet the surgical and anaesthetic teams on the admissions ward before the procedure. We confirm that you have given your permission (consent) for the procedure. You can ask us any questions that you may have.

During the procedure

If your child has a local anaesthetic, we put numbing drops in their eye.

A general anaesthetic is a medicine that makes your child sleep and stops them feeling pain during the procedure. If your child has a general anaesthetic, you can stay with them until they are asleep. Please see our separate leaflet called "Your child's general anaesthetic" for details. When your child is asleep, we put anaesthetic drops in their eye.

During the procedure, the surgeon:

- gently removes the surface skin of the eye (the epithelium)
- puts vitamin B2 drops into the eye (this takes about 10 minutes)
- waits until the vitamin B2 drops have soaked into the middle layer of the cornea (stroma)
- directs the UV light from a special machine onto the cornea for about 30 minutes

The whole treatment for each eye takes about 1 hour. Usually, we only treat 1 eye at a time. We treat your child's other eye a few months later.

Are there any risks to my child's procedure?

Every procedure has some risks of complications. To reduce these risks, we make sure that your child is well at the time of the procedure. We talk to you about the risks in the clinic and before the procedure when we confirm that we have your consent.

The specific risks of the corneal cross-linking procedure are as follows:

- **Infection and scarring**
This happens in about 1 out of 250 cases. Infection and scarring can reduce your child's eyesight in the long term and might mean that they need a cornea transplant.
- **Treatment not working**
This can happen in about 1 out of 4 cases. Keratoconus usually progresses slowly and it can be 1 year before we know if the treatment has worked. Your child's eyesight and the shape of their cornea do not usually improve until at least 6 months after the treatment.

After your child's procedure

How will my child look and feel after their procedure?

Your child may feel drowsy after their surgery and sleep for a while. They may be restless (agitated) and upset for up to an hour after waking up from the procedure. Some children may have mild discomfort and feel or be sick (vomit), but this is not common.

At the end of the procedure, we might use a contact lens to protect your child's eye. This also eases pain and helps with healing. After a few hours, your child should not be able to feel the contact lens. The doctor removes it at a follow-up appointment 2 to 7 days after treatment.

You and your child should not need to handle the contact lens at all. It stays in overnight. Sometimes, the contact lens falls out. If this happens, do not try to put it back in your child's eye. Please throw away the contact lens.

When the anaesthetic wears off, your child's eye will be gritty, red and sensitive to light for several days. Their sight in the treated eye will be blurred at first.

Will my child be in pain after their procedure?

Your child does not feel any pain during the treatment because of the anaesthetic. Their eye will be painful when the anaesthetic wears off. The pain is worse for 12 to 18 hours after treatment, but slowly gets better.

To help with the pain, we give your child anaesthetic eye drops. Your child may also have paracetamol, ibuprofen or both medicines while they are with us. You can continue to give your child these medicines as needed when they are at home. The nurses can guide you when the next amount (dose) of pain medicine is due.

When can my child eat and drink after their procedure?

Your child should be able to eat and drink as usual within 1 to 2 hours of the procedure.

Do we see the surgeon after my child's procedure?

Yes, the surgeon comes to check your child after their procedure. They update you about the surgery and answer any questions that you may have.

When can my child go home?

Your child can go home on the same day as their procedure when they:

- feel comfortable
- can manage (tolerate) their usual food and drink
- are not feeling sick (nausea) or being sick (vomiting)
- are behaving as they usually do

Please supervise your child carefully on the journey home. According to the sudden infant death syndrome (SIDS) guidelines, it is best to avoid long car journeys for babies under 1 year of age. If you travel home by car, it is important that:

- you stop for frequent breaks to feed your baby and change their position
- an adult sits with the baby in the back of the car

After you go home

How do I care for my child's eyes after the procedure?

After treatment, your child's eye will be painful and they need to rest. It is best that someone stays at home with them for at least 3 days after the treatment. Their eyesight will be blurred for 1 to 2 weeks. Here is some guidance on how to care for your child's eyes:

- **Antibiotic drops and other eye drops**
We give you antibiotic drops or ointment and other eye drops that your child needs to use for 2 weeks after the treatment. This is to lower the risk of infection, and reduce redness and inflammation in the eye. It is important to put the drops in your child's eye regularly, as prescribed.
- **Protecting the eyes**
During the first week while your child's eye is healing, try to discourage them from touching or rubbing their eyes.
- **Sensitivity to light**
Your child's eyes will be more sensitive to light after the procedure. It can be helpful for them to wear sunglasses in bright light for the first few days. If your child watches television or uses a computer, this will not harm their eyes. However, they may find it more comfortable to rest in a dark room with their eyes closed at first.
- **Keeping the eyes comfortable**
To help keep your child's eyes comfortable and reduce swelling, you can put cool cloths (compresses) or ice packs over the eyelids.
- **Bathing**
Your child can have a bath or shower as usual and you can wash their hair. Try to avoid getting soap or shampoo in their eyes, as you would normally do.

- **School or nursery**
Your child needs to take 1 to 2 weeks off school or nursery after the procedure.
- **Sports and swimming**
Your child should not do any sporting activities for 2 weeks. Similarly, it is best not to take your child swimming for at least 2 weeks until the surface of their eye has healed. If your child does swim before then, they need to wear watertight goggles.
- **Contact lenses or glasses**
Your child cannot wear their usual contact lenses for 2 to 3 weeks after the procedure.

How can I manage my child's pain after their procedure?

Your child's eye is likely to be sore and painful after the procedure, especially for the first 2 days. These symptoms gradually improve. We give you all the eye drops needed to ease the pain.

We also recommend giving your child paracetamol and ibuprofen regularly for 1 to 2 weeks after the procedure. Please remember to buy these medicines before the day of your child's operation. It is also important to make sure that your child drinks plenty of fluids.

It is safe to give the 2 medicines at the same time, ideally with food. This is easier to plan and the medicines work in different ways. You can give your child:

- 1 recommended amount (dose) of paracetamol every 4 to 6 hours and no more than 4 doses in 24 hours
- 1 dose of ibuprofen every 6 to 8 hours and no more than 3 doses in 24 hours

You may find the following chart helpful to keep track of your child's medicines.

Home medicine chart for parents

Medicine	Time to give	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Paracetamol								
Ibuprofen								

Do I need to look for any symptoms after my child's procedure?

You need to get urgent medical help if your child has any of the following symptoms 12 to 18 hours after treatment:

- Their eye feels more painful.
- Their eyesight becomes worse.
- Their eye becomes redder, or you notice a yellow-green liquid (pus) or leaking fluid (discharge) from the eye.

These can be signs of infection. Call our eye casualty on 020 7188 4336 (Monday to Friday, 8.30am to 4pm). Outside these hours, call 999 or go to your nearest emergency department (A&E) immediately.

Do you see my child again after their procedure?

Your child has a follow-up appointment 2 to 7 days after their treatment. We usually book this appointment for you before you leave the Evelina London children's day surgery unit. It takes place in the children's eye clinic at St Thomas' Hospital.

Contact us

If you **cannot keep your appointment**, contact our admissions team, **phone** 020 7188 9098, **email** gst-tr.paediatricadmissions@nhs.net

If your child has a **cough, cold or high temperature** in the 2 weeks before the procedure, contact our pre-assessment team, **phone** 020 7188 7188 extension 58209

If you have any **concerns about your child's procedure but it is not an emergency**, contact our eye department, **phone** 020 7188 4299 (please leave a message on the answerphone and we will call you back within 3 working days), **email** gst-tr.paediatricophthalmologyenquiries@nhs.net (we reply to emails within 3 working days)

If you are concerned that your child is **seriously unwell during working hours**, contact our eye casualty, **phone** 020 7188 4336 (Monday to Friday, 8.30am to 4pm)

If you are concerned that your child is **seriously unwell outside working hours**, go to your nearest A&E or **phone** 999

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, **phone** 020 7188 3003, Monday to Friday, 10am to 5pm **email** letstalkmedicines@gstt.nhs.uk



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