

Corneal cross-linking

Information for patients, relatives and carers

Introduction

This leaflet explains what corneal cross-linking is and what the operation involves. We hope it answers any questions you or those who care for you may have. If you have any further questions, please contact us using the details on page 4.

What is corneal cross-linking (CXL)?

Corneal cross-linking (CXL) is a treatment designed to prevent progression of corneal weakness. Keratoconus is the most common condition that needs this treatment. Keratoconus is a condition where the cornea weakens, becomes thinner and changes shape. CXL is successful in 9 out of 10 cases.

How does CXL work?

Keratoconus gets worse because the cornea weakens. With CXL, ultraviolet light and riboflavin (vitamin B2) eye drops are used to stiffen, or 'cross-link', the protein fibres in the cornea. CXL mimics the natural corneal stiffening that occurs with ageing. This is why keratoconus rarely progresses in people aged 30 and over, and why CXL is not normally needed for older patients.

Who can have CXL?

Corneal cross-linking is usually only recommended for patients whose glasses test and corneal shape scans show that their keratoconus is getting worse, providing the cornea is not too thin. Cross-linking is not recommended if the cornea is too thin. This could damage the endothelial cells, which pump fluid out and keep the cornea clear.

To get the most accurate shape scans, it is best to stop wearing contact lenses before your scan:

- Two weeks for rigid gas permeable (RGPs) lenses
- One week for soft contact lenses

If you cannot manage without your contact lenses, treatment may still be available, depending on the likelihood of disease progression, which partly depends on age. Corneal cross-linking may also be recommended for weakening and thinning of the cornea after LASIK (refractive surgery), which is a very rare complication.

The benefits of CXL

CXL is the only treatment currently available that appears to stop keratoconus from getting worse. Evidence from four randomised clinical trials, one year after CXL treatment, showed:

- success in stopping keratoconus from getting worse in more than 9 out of 10 treated eyes (90 per cent).
- improved corneal shape in over 9 out of 20 treated eyes (45 per cent).

Longer term data (up to 5 years) shows continued success in preventing keratoconus progression.

Risks of having CXL?

Generally, CXL is very safe but, like all operations, there are risks.

About 3 out of every 100 patients (3 per cent) might have reduced vision in the treated eye, because of infection, scarring and corneal haze. In most cases, this visual loss is potentially reversible with a corneal transplant.

Some patients experience glare, halos and mild blurriness in dim light due to corneal haze after CXL. This usually disappears within 12 months, without permanently affecting vision.

Cross-linking might not be advisable if the cornea is too thin.

You will still have to wear spectacles or contact lenses after CXL treatment as it does not correct your eyesight.

Alternatives to CXL

At the moment, (as of August 2023), there are no alternatives to CXL that stop the progression of keratoconus. If your keratoconus is worsening and you do not have CXL treatment, there is at least a 1 in five (20 per cent) chance that you will eventually need a corneal transplant.

What you should do to prepare for CXL

- Eat and drink as normal before the treatment.
- Wear comfortable, loose-fitting clothing.
- You must ensure you have someone to collect you after surgery if you are having the procedure to your only good seeing eye or both eyes

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- Remove your contact lenses one day before surgery unless requested to remove earlier
 - Ask someone to help you put in your eye drops after surgery if you are having the procedure to your only good seeing eye or both eyes. For the first three days after treatment, your eyesight will be very blurry in the treated eye(s) and likely to be painful and uncomfortable.
 - Plan to take at least one week (ideally two weeks) off work after surgery. If possible, remain in the UK for the first two weeks in case of any complications.

Tests before your corneal cross-linking operation

You do not need to take tests before surgery. This is a day-case procedure, and no further tests or investigations are required apart from the tests carried when you attended the outpatients appointment.

What happens on the day of your corneal cross-linking operation?

CXL is a day-case procedure, performed by a clinician or n/practitioner. Following your arrival to the department, your eye will be examined to ensure that the procedure can proceed. Your written consent will be confirmed following discussion of the risks and benefits of the procedure.

- In the operating room, the surface of your eye is first cleaned with antiseptic solution and then numbed with anaesthetic eye drops.
- A small eyelid clip is used to keep your eyelids open.
- The surface skin of the cornea (epithelium) is gently wiped away after using a solution which will help loosen the surface of the cornea. This allows the riboflavin (vitamin B) drops to absorb into the cornea.
- Additional topical anaesthetic drops are used throughout the operation to ensure your eye remains numb.
- Riboflavin eye drops are applied frequently to your cornea for at least 10 minutes. Then the cornea is exposed to up to eight minutes of ultraviolet (UV) light while the riboflavin eye drops continue to be applied.
- A soft 'bandage' contact lens is placed in your eye at the end of the procedure.

What happens after the operation?

After the operation, we will give you a discharge pack to use afterwards. This will contain:

- antibiotic drops
- steroid eye drops
- lubricants

The soft contact lens will remain in your eye until the surface of the eye is healed (usually three to seven days). If the bandage lens falls out during this time, please throw it away – do not attempt to reinsert it.

- After the numbing eye drops wear off, your eye(s) will feel gritty, red and sensitive to light and glare for several days.

Everyone's experience of pain is different, with some patients reporting mild discomfort and others describing the first three days as very painful.

The following can help during the first few days:

- taking regular oral painkillers
- wearing sunglasses in bright light
- resting or sleeping in between the doses of eye drops
- using cool compresses over the eyes.
- Vision in the operated eye(s) will be quite blurry initially but will gradually become clear as the surface cells of the eye heal over and smooth out. It can take 7 to 14 days for vision to return to how it was before your operation.

When you can go home

Please be prepared to spend half a day or more in hospital.

The procedure itself takes about 30 minutes for one eye or 50 minutes if both eyes are done on the same day.

There is usually some waiting time before treatment. You will also need to stay for a short while afterwards, so that we can check you have everything you need to go home.

Taking care at home

Your eye will be sore for the first three days and your vision will be blurry for up to 14 days.

Taking regular painkillers will help with the pain. If your pain gets worse in the first 4 days or more after the procedure, this could be due to infection, and you should call the Western Eye Hospital Emergency department. Infection is rare, affecting less than 1 in 100 patients (1 per cent).

It is important to put the eye drops in regularly as prescribed. Make sure that you have enough eye medication until your next appointment at the hospital. If you do not, your GP will be able to prescribe this.

~~You can wash and shower normally but try to avoid getting water in your eyes.~~

You can exercise but should not swim before the surface of your eye has healed (usually after two weeks).

Do not rub your eyes after the procedure as this may make the keratoconus worse.

When you can get back to normal life, driving and working

You should have at least one week off work while most of the surface healing occurs. You should aim for two weeks if your job involves a lot of computer work, and the treatment is being done on your best or both eyes. You will be putting eye drops in every four hours until we see you in the clinic

Watching TV or using the computer will not damage your eyes but you might find it more comfortable to rest with your eyes closed early on.

Your vision will be checked in clinic about two weeks following procedure, to confirm whether your vision is good enough to drive.

It is safe to start wearing RGP contact lenses once the epithelium has healed, usually after two weeks. This will be confirmed at the first visit after the surgery.

If you wear spectacles, it is best to wait at least three months after treatment to see if your prescription needs updating.

Follow-up appointments

We will see you 10 to 14 days after surgery to remove the bandage contact lens and check that your eye(s) is healing properly. If your eye looks like it is healing well, your next eye clinic appointment will be 6 months after the procedure, for a corneal shape scan and glasses test.

Who you can contact for more information

- Emergency Department at Western Eye Hospital – 020 3312 3245
- Outpatients at Western Eye Hospital – 020 3312 3236
- Outpatients at Charing Cross Hospital - 020 3311 1109/ 1233/ 0137

Further resources

Further information on collagen cross-linking is available from:

UK keratoconus Self-Help and support Association: www.keratoconus-group.org.uk

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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