

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 treatment to prevent the progression of keratoconus. Keratoconus is a condition where the cornea weakens, becomes thinner and changes shape. CXL is successful in over 90 per cent of cases.

How does CXL work?

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

Who can have CXL?

CXL 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. CXL is not recommended if the cornea is too thin as it 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 (2 weeks for rigid gas permeable (RGPs) lenses and 1 week for soft contact lenses). If you cannot manage without contact lenses, treatment may still be available, depending on the likelihood of disease progression, which partly depends on age. CXL may also be recommended for weakening and thinning of the cornea after LASIK (refractive surgery) which is a very rare complication.

What are the benefits of CXL?

CXL is the only treatment currently available which appears to stop keratoconus from getting worse. Evidence from 4 randomised clinical trials one year after CXL, showed success in stopping keratoconus progression in over 90 per cent of treated eyes, with improved corneal shape in over 45 per cent of treated eyes. Longer-term data (up to 5 years) shows continued success in stopping keratoconus progression. ¹

What are the risks of having CXL?

Generally, CXL is very safe but, like all operations, there are risks. About 3 per cent of patients might have reduced vision in the treated eye as a result 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 the vision. CXL might not be advisable if the cornea is too thin. After CXL treatment, you will still have to wear spectacles or contact lenses as it does not correct your eyesight.

Are there any alternatives to CXL?

There are currently (as of November 2018) no alternatives which stop the progression of keratoconus. If your keratoconus is worsening and you don't have CXL treatment, there is at least a 20 per cent chance that you will eventually need a corneal transplant.

Is there anything I should do to prepare for CXL?

You can eat as normal before the treatment, preferably only a light meal. Wear comfortable, loose fitting clothing. It helps to have someone accompany you home afterwards, to listen to the post-operative instructions with you.

For the first 3 days after treatment, your eyesight will be very blurry in the treated eye. If the surgery has been carried out on your best seeing eye, ask someone to help you put in your eye drops.

You should plan to take at least 1, ideally 2, weeks off work and, if possible, remain in the UK for the first 2 weeks in case of any complications.

Will I need to have any tests before my CXL operation?

You will have a standard pre-operative assessment with a nurse before eye surgery. This will be arranged by the hospital admissions team.

What happens on the day of my CXL operation?

CXL is a day case procedure, performed by a senior ophthalmic nurse or doctor. After you have been admitted to the ward and your eye has been marked, the ward nurse will prepare you for theatre.

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 8 minutes of ultraviolet (UV) light whilst the riboflavin eye drops continue to be applied. A soft 'bandage' contact lens is placed in your eye at the end of the procedure. Usually only one eye is treated at a time.

What happens after the operation?

After the operation, we will give you a discharge pack of antibiotic drops and steroid eye drops, as well as painkiller tablets. The soft contact lens will remain in your eye until the surface of the eye is healed (usually 3 to 7 days). If the bandage lens falls out during this time, please throw it away – do not attempt to reinsert it.

After the anaesthetic eye drops wear off, your eye 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 3 days as very painful. The following can help during the first few days:

- taking regular 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 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 7-14 days for vision to return to how it was before your operation.

Will I feel any pain?

It is normal to experience pain in the first 3 days after surgery. Taking regular painkillers will help. If you experience worsening pain in the first 4 days or more after the procedure, this could be due to infection and you should visit the Western Eye Hospital's A&E. Infection is rare, affecting less than 1 per cent of patients.

When can I go home?

Although the procedure itself takes approximately 50 minutes, there is usually some waiting time before treatment and you will also need to stay for a short while afterwards, so that we can check you have everything you need to go home. Please be prepared to spend half a day or more in hospital.

Is there anything I need to watch out for at home?

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

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 don't, 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 2 weeks). Do not rub your eyes after the procedure as this may make keratoconus worse.

When can I get back to my normal routine?

You should have at least 1 week off work while most of the surface healing occurs, or 2 weeks if your job involves a lot of computer work, and the treatment is being done on your best eye. You will be putting eye drops in every 4 hours initially, then 3 times a day for 1 month and 2 times a day for another month.

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

We will check your vision in clinic the week after the procedure, to confirm whether or not it is good enough for you to drive.

It is safe to start wearing RGP contact lenses once the epithelium has healed, usually after 2 weeks. We will confirm this at the first visit after the surgery.

If you wear glasses, it is best to wait at least 3 months after treatment, to see if your prescription needs updating.

Will I need any follow-up appointments?

We will see you 3 to 7 days after surgery to remove the bandage contact lens and check that your eye is healing properly. If your eye looks like it is healing well, your next eye clinic appointment will be 6 months after that, for a corneal shape scan and glasses test.

Contact details

If you have any questions, please contact the secretary at either Western Eye Hospital (020 3312 3258) or Charing Cross Hospital (020 3311 1498).

Further resources

Further information on corneal cross-linking is available from:

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

References

¹ Wittig-Silva C, Whiting M, Lamoureux E et al. (2008) *Journal of Refractive Surgery* 24:S720-S725.

¹ O'Brart DPS, Chan E, Samaras K et al (2011). *BJO* 2011;95(11):1519 – 1524.

¹ Hersh PS, Greenstein SA, Fry KL. *J Cataract Refract Surg* 2011;37(1):149-160.

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 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). 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