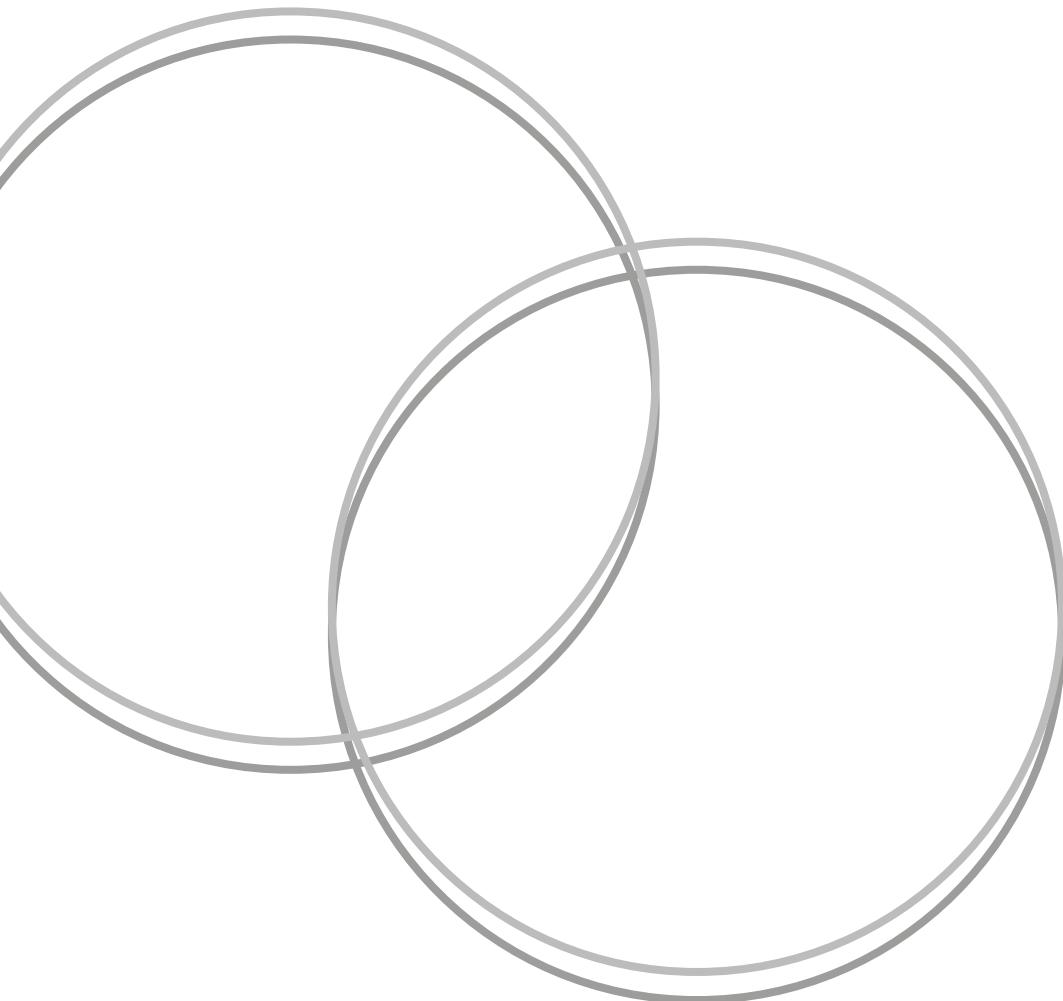


Keratoconus and the Keratoconus Monitoring Clinic

Information for patients



The aim of this leaflet is to:

Tell you about keratoconus, a condition that can affect the front of the eye (the 'Cornea').

Outline why we may need to see you in the Keratoconus Monitoring Clinic for some years after you have been diagnosed with Keratoconus.

What is Keratoconus?

Keratoconus is a problem with the eye that affects the cornea. The cornea is the clear curved window on the front of your eye. When you have keratoconus, the cornea becomes thinner and it can become misshapen. This can make it difficult to focus your vision properly and can cause poor vision even when wearing glasses.

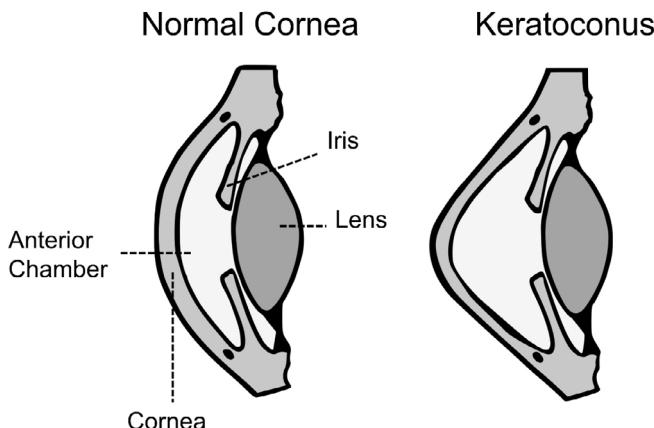


Image adapted from <https://commons.wikimedia.org/wiki/File:Keratoconus.svg>

Credit to: Madhero88

Who gets Keratoconus?

On average, it is estimated that keratoconus affects 1 in 725 people around the world, but can be more common in certain ethnic groups, such as those from Asian backgrounds. It is usually diagnosed in young people in their teens or early twenties when changes to the cornea are more likely. If keratoconus is first noticed when a person is in their 30s or older, then the condition is more likely to be mild.

What causes Keratoconus?

We don't know exactly what causes keratoconus. It is thought that genetics may play a role, along with certain other factors which have been shown to increase the risk of developing the condition. We know that keratoconus occurs more frequently in people who have rubbed their eyes from a young age.

This tends to happen more often in people with allergic conditions such as hay fever or in those with asthma or eczema. It is important to always try and avoid rubbing your eyes, particularly if you are diagnosed with keratoconus, as it could make your condition worse.

What treatment is available?

The best way to improve your vision depends on the how much your cornea is misshapen. If it is only slightly misshapen, vision can be managed with glasses or soft contact lenses. If the cornea becomes thinner and more misshapen, modern hard contact lenses called rigid gas permeable contact lenses (RGPs) are often required to be worn to give good vision. If your keratoconus is severe, you may be fitted with specialist, larger contact lenses called scleral lenses. In very severe cases, where contact lenses do not improve the vision, surgery such as a corneal transplant may be needed. Most people with keratoconus do not require a corneal transplant.

Why do you need to monitor my eyes?

If you have a new diagnosis of keratoconus, it is important for us to monitor your eyes regularly to see if your condition is changing. If there are signs that your keratoconus is progressing (getting worse), we might suggest a treatment called corneal cross-linking (CXL) to slow or stop these changes.

What is corneal cross-linking (CXL)?

CXL is a treatment that can help to prevent keratoconus getting worse. Keratoconus gets worse because the cornea, as it becomes thinner, can weaken. CXL uses a special lamp with ultraviolet light and vitamin B2 (riboflavin) drops to stiffen the cornea. Used together, they cause fibres within the cornea to 'cross-link' or bond together more tightly.

Research has shown that CXL will stop over 90% of patients getting worse with a single outpatient procedure.

When might we consider suggesting CXL?

CXL is only suitable when we can see signs that the corneal shape is continuing to change. Once you are past your mid/late 30s, the cornea often naturally stiffens and CXL is generally not required. Below this age, the cornea is more flexible and changes to the shape of your eye may carry on during this time. It is therefore important that we look for change in the eye shape. We do this in the Keratoconus Monitoring Clinic.

Preparing for your visit in the keratoconus monitoring clinic

In order to take the most reliable measurements of your cornea in the Keratoconus Monitoring Clinic, we ask that you remove your contact lenses at least 1 week before your appointment. This is important as contact lenses can temporarily affect the shape of the cornea and may hide or mask signs that your keratoconus is getting worse.

What happens in the Keratoconus Monitoring Clinic?

In this clinic we are measuring your eye regularly (usually, every 6 months) to see if corneal cross-linking (CXL) is indicated for you.

You will be seen by a specialist member of the Optometry Team. We will examine your eyes and repeat the scans of your cornea. We will compare these results with those from your previous visits.

During monitoring, if any of the results show change, we will discuss the results with the Corneal Consultant. We may then discuss with you the option to be considered for CXL under the NHS at the nearest available provider.

If your condition is deemed to be at low risk of changing (for example if you are over 30 years old or the keratoconus is very mild), you may be monitored in our Virtual Keratoconus Monitoring Clinic. These visits are similar to the face-to-face clinic, however your results are reviewed after you leave, and you are contacted by letter afterwards with the outcome of the appointment and the plan for follow-up.

How long will I have to attend this clinic?

Changes to your eyes caused by Keratoconus can take many years to develop. Age is an important factor in determining the risk for change because of the natural cross-linking and corneal stiffening that occurs as you get older, therefore we monitor for stability until around 30-35 years of age.

IMPORTANT: Please ensure that you do not miss these clinic appointments. If you need to rearrange your appointment please email optometry.secretary@ouh.nhs.uk to make sure your appointment is rescheduled to a time you can attend.

If you have been advised that you still need ongoing monitoring, do make a note in your diary/phone to ensure that you always have a planned appointment.

What don't we do in this clinic?

This clinic is solely to monitor Keratoconus and we will not be specifically checking for other eye problems. It is important to stress that no extended eye examinations such as sight tests for new glasses or contact lens fitting will be performed.

Further information

www.keratoconus-group.org.uk

www.moorfields.nhs.uk/eye-conditions/keratoconus

If you have any questions please email the Optometry Department optometry.secretary@ouh.nhs.uk or ring **01865 234567** then select 'Optometry' Monday to Friday between 8.30am and 1.00pm.

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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January 2025

Review: January 2028

Oxford University Hospitals NHS Foundation Trust

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