Early keratoconus clinic

What is keratoconus?
Keratoconus is a non-inflammatory eye condition in which the normally round dome-shaped clear window of the eye (cornea) progressively thins, causing a cone-like bulge to develop. This impairs the ability of the eye to focus properly, potentially causing poor vision.

Who gets keratoconus?
Depending on ethnicity, keratoconus affects up to 1 in 450 people. It is more common in non-Caucasians and is usually diagnosed in young people at puberty, in their late teens or early twenties.

What causes keratoconus?
The exact cause is unknown. It is believed that genetics and environmental factors play a role. It is not generally considered an inherited disease, although rarely in some families more than one individual can be affected.

What treatment is available?
In the early stages, spectacles or soft contact lenses may be used to correct vision. As the cornea becomes thinner and steeper, rigid gas permeable (RGPs) contact lenses are often required to adequately correct vision. In very advanced cases, where contact lenses fail to improve vision, a corneal transplant may be needed. Corneal cross-linking (CXL) is a relatively new treatment that can stop the disease getting worse. It is effective in over 94% of patients with a single 30 minute outpatient procedure.

Why do you need to monitor my eyes?
CXL is only suitable where the corneal shape is continuing to deteriorate. 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 disease progression (and worsening vision) is more likely to occur. During monitoring, if we detect any deterioration in your eyes we may recommend that you have CXL.
What happens in this clinic?
Each time you attend this clinic, we will perform the same tests;
1. Vision test
2. Refraction (spectacle test)
3. Corneal scans
We will compare these results with those from your previous visits. If any of the results show deterioration, we will discuss with you whether CXL is required.

Preparing for your visit
In order to obtain the most accurate scans, we ask that you remove your contact lenses prior to your appointment (2 weeks for hard lenses and 1 week for soft lenses). This is because contact lenses distort the corneal shape, which affects the accuracy of our scans. If you are unable to remove your lenses, please discuss this with the clinician at your appointment. Please note that if you are unable to manage without your lenses, it is often not possible to accurately monitor your keratoconus using the above tests. CXL treatment may still be available and so long as the cornea is not too thin, may be offered based on the likelihood that your keratoconus will progress. Age is the most important factor in determining this risk: because of natural cross-linking as you get older, keratoconus usually stops getting worse mid/late 30s, so CXL is not normally required in this group of patients.

How long will I have to attend this clinic?
Changes caused by keratoconus can take many years to develop. For this reason we will invite you back for repeat assessments for up to 5 years from your initial visit.

What don’t we do in this clinic?
This clinic is solely to diagnose keratoconus and to monitor the disease. It is important to stress that no extended eye examinations will be performed. We will not be checking your eyes for other problems (e.g. glaucoma, diabetes). This clinic is not a substitute for regular eye screening with your local optician or other eye healthcare providers.

What if I have further questions?
If you have further questions or would like to understand keratoconus better, please ask the optometrist you see in the clinic. Information on CXL, including a video, can be found on our website: www.moorfields.nhs.uk/conditions/keratoconus

Further information about the condition can also be sought from the UK Keratoconus Self Help and Support Association www.keratoconus-group.org.uk

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Moorfields Direct telephone helpline
Phone: 020 7566 2345
Monday-Friday, 8.30am-9pm
Saturday, 9am-5pm
Information and advice on eye conditions and treatments from experienced ophthalmic-trained nurses.

Patient advice and liaison service (PALS)
Phone: 020 7566 2324/ 020 7566 2325
Email: moorfields.pals@nhs.net
Moorfields’ PALS team provides confidential advice and support to help you with any concerns you may have about the care we provide, guiding you through the different services available at Moorfields. The PALS team can also advise you on how to make a complaint.

Your right to treatment within 18 weeks
Under the NHS constitution, all patients have the right to begin consultant-led treatment within 18 weeks of being referred by their GP. Moorfields is committed to fulfilling this right, but if you feel that we have failed to do so, please contact our patient advice and liaison service (PALS) who will be able to advise you further (see above). For more information about your rights under the NHS constitution, visit www.nhs.uk/choiceinthenhs