

Keratoconus Group

Information Sheet 5 June 2023

Keratoconus Self Help and Support Association
P.O. Box 26251, London W3 9WQ
Tel 020-8993 4759
www.keratoconus-group.org.uk



Has your child been just diagnosed with keratoconus?
This leaflet is an introduction to what you need to know.

Information for Parents

What is keratoconus?

Keratoconus (KC) is an eye condition affecting the cornea (the transparent front of the eye) and usually develops in the teens or early twenties. It is not very common, so most people have never heard of it.

It is easy to miss the early signs of KC (they can even be missed by optometrists). It usually only affects one eye initially, and the brain is very good at compensating and shutting out the picture from that eye, so young people may only realise vision has changed if they cover the 'good' eye. They may find their vision gets worse later in the day, when the brain is tired, or in low light conditions, or they may complain of headaches. Or, in typical teenager fashion, they may not say anything and hope it will just go away. In most cases, KC will eventually affect the other eye, but this may take a number of years and it may stay very mild in the second eye.

"It's easy to miss the early signs of KC"

Although KC is a progressive condition, how much and at what rate it progresses varies greatly from one individual to another. The good news is that there is now a treatment - corneal collagen cross-linking (CXL) - which can often stop KC progressing.

What causes KC?

Research into the causes of KC continues, but it is likely to be a combination of genetic and environmental factors. It seems to need a lot of different genes to come together for a person to have a predisposition for KC. So although KC can run in families (and if one child has been diagnosed, it is worth checking siblings for KC), most KC is 'random' and no other family members are affected. People with KC are more likely to have allergies such as asthma, eczema and hay fever which make the eyes more sensitive. This means they are more likely to rub their eyes and vigorous eye-rubbing can trigger KC or make it worse.

KC is more common in people from some ethnic backgrounds. For example, in the UK, people with a South Asian heritage are four times more likely to develop KC than the general population. It is also more common in people of African or Afro-Caribbean and Middle East heritage. It affects up to 1 in 10 people with Down's Syndrome.

Effects of KC

KC is often diagnosed in the teens at a critical time for education, with GCSEs, A levels and other exams deciding a young person's future. It is important to inform the school so that teachers have some understanding of the condition and can make any adjustments needed for the student. Our leaflet 'Supporting Students with Keratoconus' <https://www.keratoconus-group.org.uk/index.php/supporting-students-with-keratoconus/> explains the condition and suggests what help schools, colleges or universities can offer.

It can be downloaded and given to the relevant staff. For older teenagers who are already entering the world of work, there are similar leaflets on KC at work and on the help available <https://www.keratoconus-group.org.uk/index.php/access-to-work/>

The effect of KC on vision depends on the severity of the condition and it may change over time. Possible effects are:- ghosting (a faint second image behind the first), multiple images, blurred vision, sensitivity to bright light **but** also worse vision when the light is low,

increased short sightedness, headaches and tiredness (because everything takes a bit longer with focusing being more difficult). KC can also affect a young person's self-confidence and lead to them withdrawing into themselves, so relationships with friends and family may be affected.

Treatment

If keratoconus is picked up by a High Street optometrist or optician, it is important to get a referral to a corneal specialist in a hospital eye clinic. As mentioned above, Corneal Cross-linking (CXL) is a treatment that can help to reduce the progress of the condition. It is available on the NHS and given if the condition is shown to have worsened. The rate of progression varies a lot and is assessed by scanning the shape of the surface of the cornea. Some eyes show only small changes over months or years, while others may have more rapid changes, so regular scans of the eye are important. Not all hospitals in the UK have the equipment for cross-linking, but should refer to a hospital that does if the young person becomes eligible for the procedure. CXL is not a cure for KC; it does not restore vision to what it was before KC developed. But it can stop the vision deteriorating. As sight in the treated eye may be blurry for some weeks after the procedure, timing of the treatment should be discussed for young people about to sit GCSEs or A levels, to minimise any disruption to their education.

In the early stages, glasses or soft contact lenses may correct the vision. As the KC progresses, specialist contact lenses (usually rigid gas permeable lenses) may be needed.

For young people up to 19 in full time education, contact lenses are free if they are fitted in a hospital eye department. If the hospital does not have its own contact lens department but has a contract with a community optometrist to provide contact lenses, they should issue an NHS voucher for the lenses, known as HES(P).

"For young people up to 19 in full time education, contact lenses are free"

If the young person has finished education, contact lenses will be issued at the NHS rate of around £60 per lens (2023 prices with adjustments each year).

In a few cases, if it hasn't been possible to offer CXL, people with KC may eventually need a corneal transplant, but need for these has halved since introduction of CXL. The success rate with transplants carried out for keratoconus is over 90%.

With current treatment options, while there is always a period of adjustment to the diagnosis of an unfamiliar eye condition, and times when the young person may find it harder to cope, KC should not limit their educational opportunities or their career options (with a very few exceptions).

You will find a fuller explanation of KC and the treatment options for the condition in the booklet written for us by specialists at Moorfields Eye Hospital, Keratoconus- Some Questions Answered at: <https://www.keratoconus-group.org.uk/wp-content/uploads/2023/06/KC-Booklet.pdf>

Moorfields has also produced an excellent leaflet about corneal crosslinking which can be found here: <https://www.keratoconus-group.org.uk/wp-content/uploads/2023/06/Corneal-cross-linking.pdf>

**THANK YOU FOR TAKING THE TIME TO READ
THIS LEAFLET, AND FOR YOUR SUPPORT.**

**Further information can be found at:
www.keratoconus-group.org.uk**