

Keratoconus Group

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



Supporting Students Information for Schools and Colleges

WHAT IS KERATOCONUS?

Keratoconus is an eye condition, where the cornea, the front surface of the eye, thins and becomes distorted, often forming a cone shape. This affects the refraction of light into the eye and if the condition progresses, can affect visual ability to see clearly.

"If the condition advances, it may become increasingly difficult to fit normal hard lenses due to the cone shape of the cornea"

WHAT IS THE TREATMENT FOR KERATOCONUS?

Every case of keratoconus is different, but a few generalisations can be made. Some people with keratoconus get good correction of their sight with glasses. However hard contact lenses of various types are usually required. Often good correction is achieved for many years with lenses. If the condition advances, it may become increasingly difficult to fit normal hard lenses due to the cone shape of the cornea. Another option for some are scleral lenses. These are large conical lenses, which cover most of the front of the eye.

In addition, many keratoconus patients may experience atopic conditions, such as eczema, asthma, hay fever and chronic allergic conjunctivitis, which can make lens wear difficult and painful. Dust, wind, pollen, smoke and air conditioning can also create problems. All these things can reduce daily lens wearing time and consequently the time available with good vision. Some people with keratoconus juggle a variety of different lenses and glasses over the day in order to manage work and studies. This takes time and effort, maintaining cleaning routines and hygiene during removal and insertion.

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If diagnosed early corneal cross linking may be used to stiffen the cornea and slow progression. Sometimes surgery becomes necessary and corneal transplants are carried out. The recovery process from this takes time, as stitches remain in place for about a year and new lenses cannot be fitted immediately.

Hydrops is a rare, but possible, complication of keratoconus. This is where the inner surface of the cornea breaks down, allowing aqueous fluid from the inner eye to flood the cornea. This results in blurred vision. Treatment is simply to wait for it to heal, which can take several months. The condition can be painful and at the acute stage contact lenses cannot be worn. Infections and abrasions (damage to the surface) of the cornea are more common, and again mean that a contact lens cannot be worn for a week or two resulting in very poor vision.

WHAT ARE THE EMOTIONAL AND PSYCHOLOGICAL EFFECTS?

When you cannot see properly you miss out on the visual cues that sighted people take for granted; facial expression, body language, gestures. Simple activities like crossing a road, making a hot drink or inserting an electrical plug require concentration and

take much longer. Trying to keep up with lessons or lectures with visual presentation is exhausting. These experiences often result in a loss of confidence, frustration and irritability. It is easy to feel excluded and to turn in on oneself. Some people with keratoconus get depressed with the constant daily struggle.

HOW DOES IT AFFECT PEOPLE AT SCHOOL AND COLLEGE?

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Keratoconus is not a visible condition, so there are no cues for others to pick up on. It is important to remember that when someone with keratoconus is wearing glasses, they may not be getting 'good' vision. Equally they may have had to remove their contact lenses and without them may be partially sighted. So a student, who can cope well in lessons/lectures in the morning, may be struggling come the afternoon. Allergies, poor contact lens tolerance and corneal abrasions may also affect the pattern of contact lens use.

By the evening, the time for private study, eyes may be sore and strained, making it hard to keep up with assignments.

WHAT KIND OF SUPPORT IS NEEDED?

It is important to consult the individual student with keratoconus to establish their precise needs at different times of day and in different situations and to make all the teaching staff aware of these. With school students it would be helpful to involve their parents.

It is very hard to have to ask for what you need in every lesson/lecture.

To establish good practice as a routine is very helpful.

Suggestions for support, which will vary with the individual:-

- Provide enlarged handouts (A3 from A4)
- Use black markers on whiteboards, rather than red or green.
- Write large and legibly on boards.
- Provide sight of hard copy of slides during sessions, e.g. the originals.
- Ensure that student has good lighting. A small reading lamp may be helpful. Glare from sunlight can be problematic.
- Obtain advice from the Local Authority Special Needs Adviser (in the case of schools) on other measures such as software packages for computers and for specialist equipment.
- Where a student is taught IT or regularly uses a computer, arrange that one computer has a large screen, a minimum of 19" or larger set with large font text; funding for which may be available through your Local Authority and the guidance offered in the new Code of Practice for Special Educational Needs. For example you must make reasonable adjustments to auxiliary aids and services (SEND Code of Practice: 0 to 25 years, January 2015 p17).
- Avoid embarrassing students (such as requesting reading aloud from normal text, without checking first, whether they can see the text).
- Accept homework/assignments in printed form. (This allows a large font to be used and then reduced.)
- Alternatively allow students to use black felt tip pen for assignments, when necessary.
- Allow extra time in exams, especially open book exams.
- Enlarge exam papers.
- Ensure that the edges of stairs have a contrasting colour, otherwise they may look like a long ramp!
- Allow more time, where necessary, for moving around the building. Crowds can be disconcerting.
- Consult on ability to take part in sports.
- Provide a clean place with running water and sink plug for inserting/cleaning contact lenses. Student communal facilities may not be adequate.

"There is plenty of evidence on our website of students achieving good academic results and of people with keratoconus holding down responsible jobs"

Students with keratoconus want to do well in their studies. With support and understanding from their schools and colleges, particularly when they are going through a difficult time, there is no reason why they cannot succeed.

There is plenty of evidence on our website of students achieving good academic results and of people with keratoconus holding down responsible jobs.

A little understanding and consideration go a long way to making this possible.

Students with keratoconus are not looking for constant sympathy. What they do need is practical support to allow them to access the curriculum like anyone else and to fulfil their learning potential.

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

Registered charity in England and Wales (1057629) and in Scotland (SC039552)