

Living with Keratoconus as a Student

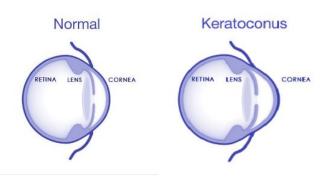
How does keratoconus affect students?

Keratoconus (KC) can cause emotional distress, as it can be very frustrating to not be able to see the classroom board clearly, and contact lenses can cause discomfort when worn for long periods of time. A student, who may be able to cope well in lessons in the morning, may be struggling later in the afternoon. By the evening, the time for homework and private studying, the eyes may be sore and strained, making it difficult to keep up with assignments. Additionally, KC is not a condition that is noticeable to another person. Oftentimes, others assume that because someone is wearing glasses or they don't "look" like they have a disorder, they should have good vision. These misunderstandings can cause a student to feel invalidated in their struggles.

What is keratoconus?

Keratoconus is an eye condition in which the cornea, the front surface of the eye, progressively thins causing a cone-like bulge to develop. This results in significant visual impairment.

The cornea is the clear window of the eye and is responsible for refracting (bending) most of the light coming into the eye. Therefore, abnormalities of the cornea severely affect the way we see the world. This can make otherwise simple tasks, like driving, reading, or using a computer difficult. KC can cause blurring, distortion of images, haloes, eye strain, headaches and light sensitivity. Each eye may be affected differently, and symptoms can progress at different stages.



Who gets keratoconus?

The actual incidence of KC is not known. It has been estimated to occur in 1 out of every 300 persons in the general population. KC is generally first diagnosed in young people at puberty or in their late teen's, but can affect individuals at any age. It is found in all parts of the United States and the rest of the world. It may be more prevalent in certain geographical regions or among certain ethnic groups. KC is caused by a combination of genetic and environmental factors. If you or a family member has KC, your whole family should be screened. Individuals with KC may have more allergies and tend to rub their eyes. Eye-rubbing can cause physical stress and trauma to the cornea, making KC worse. Don't rub your eyes!

Keratoconus Treatments: What can be done about it?



• Eyeglasses and Contact Lenses:

 Every case of keratoconus is different, but typically, in the early stages, eyeglasses or soft contact lenses may be used to correct the mild nearsightedness (myopia) and astigmatism caused by KC. In more severe cases of KC, specialty contact lenses, such as rigid gas permeable (RGP), hybrid, piggyback, scleral, or prosthetic lenses are typically used. While contact lenses are often effective in restoring vision, they are not a cure for keratoconus.

• Gas Permeable Contact Lenses:

 Rigid gas permeable (RGP) or gas permeable (GP) lenses are typically offered for mild-tomoderate cases of KC. These lenses sit atop the irregular cornea and create a smooth surface.
 For some, there is awareness of the lens on the eye that typically goes away within the first few weeks. GP lenses are easy to apply and remove, durable, relatively low cost, and provide optimal eye health and vision correction.

• Hybrid Contact Lenses:

• Hybrids incorporate a GP lens in the center, surrounded by a soft peripheral 'skirt'. These lenses are intended to be replaced every six months. The promise of hybrids is achieving the clear vision of the GP lens with the comfort of a soft lens.

• Piggyback Contact Lenses:

 A tandem or piggyback lens is a technique of putting a soft, disposable lens on the eye and placing a GP lens on top. Some use this technique as they get used to the feel of a rigid lens on their eye.

• Scleral Lenses:

 Scleral lenses are typically used for advanced or severe cases of KC. They are customized largediameter contacts that vault over the cornea and rest on the sclera (the white part of the eye). The cost can be significant, but these lenses are increasingly popular for management of KC. Some find applying and removing the lenses a challenge, but those who receive proper lens handling training report high satisfaction with vision and comfort.

• Prosthetic Shell Contact Lenses:

 For those who experience severe discomfort wearing any type of contact lens, or those with a highly irregular eye surface where traditional lenses fall short, an impression mold of the eye can be taken, and a made-to-order contact lens is manufactured. This is a premium, highly specialized option that offers hope in extreme cases.

• Corneal Crosslinking (CXL):

CXL is the only procedure that will help to stop or slow progression of keratoconus. It utilizes
ultraviolet light and vitamin B2 (riboflavin) to help strengthen collagen fibers within the cornea,
making it less susceptible to warpage. However, CXL does not reverse KC changes that have
already occurred. The hour-long procedure is typically performed once and is relatively painless.
Most patients will still need to wear glasses or contact lenses after treatment.

• Corneal Transplant Surgery:

 Corneal transplantation is a rare procedure that can help in severe cases of keratoconus where vision cannot be corrected with contact lenses. This procedure uses donor tissue to surgically replace the damaged cornea. After a corneal transplant surgery, the corneal surface irregularities may be reduced, but glasses or contact lenses will likely still be necessary. Thanks to CXL, corneal transplants are needed in less than 10% of individuals with keratoconus.

What kind of educational support is needed?

If you are having trouble, it's important to talk with your teachers and counselors about what you may need in order to be successful at school. Explain your condition and symptoms and together you can come up with some solutions to make your learning environment better suited for your needs.

Some suggestions may include:

- Visit the Office of Disabilities to see how they can assist you in receiving the accommodations you may need.
- Request enlarged handouts with good contrasting print or a copy of the lecture slides.
- Ask your teachers to write largely and legibly on boards. You may want to request a seat closer to the board.
- Ask for a seat with good lighting. Request to be seated away from windows to avoid glare. A small reading lamp may be helpful.
- For computer work, ensure that the settings have large fonts and good contrast.
- Ask if you can have extra time in exams, especially open book exams.
- Use a magnification system (i.e. a hand-held magnifier).
- Seek out textbooks on tape (available from Recordings for the Blind).
- Inquire about a clean place with running water and sink plug for inserting/cleaning contact lenses. Student communal facilities may not be adequate.

Advice for students:

Contact your teachers/professors in advance. Talk with them in person, if possible, rather than by phone or email. This will allow you to meet them in person and show your eagerness to succeed. Share a copy of the <u>Keratoconus Guide</u> with them so that they can further understand what KC is. Let them know that while you are excited to learn and aim to do well, you experience vision issues (try to specifically describe your symptoms) and ask them what advice they have for you or what accommodations they can make in their respective classes. For example, they may suggest sitting near the whiteboard or projection screen, or they can assign you a special computer in the computer lab with a large magnification display. They may also grant you extra time on exams or other accommodations.

Try to avoid situations in which you know that you will be having difficulties. For example, if you wear contacts that begin to irritate your eyes in the evening, try to avoid evening classes or schedule in a time to give your eyes a break from your lenses before your evening class starts. Get in the habit of re-wetting your contact lenses before you habitually get dry eyes.

If difficult-to-read handouts are an issue, ask for them to be given to you earlier in the term so that you can spend more time with the material. Come prepared and on-time for class, as it may be difficult to catch up if you fall behind.

Talk with your guidance counselor or disability services center to help you reach your academic goals. Discuss with your eye doctor some of the challenges you may be facing at school so that they can help you to have the most effective and comfortable contact lenses and treatments possible.

While you may be experiencing some set-backs as a result of your vision, you are capable of succeeding in your academics. Don't be afraid to ask for help – your teachers and doctors want what is in your best interest and should be understanding of your situation. You can do it!

