

THE LIFE-ALTERING BURDEN OF KERATOCONUS



Early intervention and thoughtful surgical planning can restore functional vision, increase independence, and improve quality of life in patients with keratoconus.

BY BROOKE MESSER, OD, FAAO, FSLs

Keratoconus is the most common type of primary corneal ectasia. It has a multifactorial etiology, with genetic and environmental factors contributing to weakening of the corneal collagen fibers and the development of a cone-shaped cornea. Keratoconus is associated with a wide range of systemic conditions, including atopy, connective tissue disorders, obstructive sleep apnea, and Down syndrome.¹

Eye care providers are well acquainted with the visual consequences of keratoconus, but we typically see these patients only once or twice a year, which makes it easy for us to underestimate the profound effect the disease can have on their lives.

THE QUALITY-OF-LIFE BURDEN OF KERATOCONUS

A recent study identified seven quality-of-life (QOL) domains affected by keratoconus, including driving, finances, career, and personal relationships (Table).² The study authors noted that patients with keratoconus often felt guilt or shame about relying on others, which could contribute to those patients' withdrawal from social activities. Patients also worried that they were perceived as a liability at work or unable to keep up in school. Even when they could achieve good visual acuity with contact lenses, patients with keratoconus reported a reduced QOL and lower mental health scores.

One of the most difficult aspects of keratoconus is that it typically emerges, and can progress rapidly,³ as children are maturing. The disease can profoundly affect their future

plans and aspirations.⁴ In a Save Sight Keratoconus Registry study, about 28% of patients with keratoconus reported that the diagnosis compromised their career choice.⁵

TABLE. EXAMPLES OF THE QUALITY OF LIFE BURDEN OF KERATOCONUS²

Thematic Area	Examples of Impact on Patients
Health care	Treatment inconvenience Fear of treatment
Symptoms	Blurred vision Photophobia Poor depth perception
Education and career	Schoolwork disrupted or delayed Inability to meet visual requirements for a desired career Difficulty with screen use or visually demanding tasks Reluctance to request workplace accommodations
Daily life and enjoyment	Reduced independence Reduced enjoyment of daily life Limited participation in sports, reading, and creative activities Loss of confidence
Relationships	Feelings that they are misunderstood and/or isolated Strain on friendships and romantic relationships Concerns about self-image Frustration leading to interpersonal conflict Guilt and shame
Driving	Difficulty driving at night, in rain, or in unfamiliar settings Difficulty reading signs or coping with glare Fear of accidents Inability to obtain a driver's license
Finances	Cost of surgery and/or specialty lenses Ongoing expenses for lens care, office visits, and visual aids Reduced earning potential related to career limitations Guilt about the financial burden on family

POTENTIAL ADVANTAGES OF CORNEAL TISSUE ADDITION KERATOPLASTY FOR KERATOCONUS

Corneal tissue addition keratoplasty has been described as a minimally invasive form of intrastromal anterior lamellar keratoplasty.¹ In select patients with keratoconus, the procedure may represent a useful midpoint between contact lens failure and corneal transplantation. By adding customized donor tissue to regularize the corneal surface, the procedure can help normalize corneal shape and reduce irregular astigmatism.

Corneal tissue addition keratoplasty may offer several advantages over other surgical options for keratoconus:

- ▶ The shape of the donor tissue can be customized to the eye to improve the corneal shape and the manifest refraction.
- ▶ Because the tissue is irradiated, the immune response may be reduced. Patients therefore may not require long-term topical steroid therapy and may face lower risks of graft rejection and failure.
- ▶ Because the implant consists of human donor tissue, it may be more biocompatible and less likely to provoke an inflammatory response compared to a PMMA intrastromal implant. Additional benefits may include lower risks of corneal neovascularization, haze, and stromal melt.

1. Greenstein SA, Yu AS, Gelles JD, et al. Corneal tissue addition keratoplasty: new intrastromal inlay procedure for keratoconus using femtosecond laser-shaped preserved corneal tissue. *J Cataract Refract Surg.* 2024;49(7):740-746.

A STRUGGLING YOUNG PATIENT

A recent case example illustrates the potential long-term impact of keratoconus.

A 23-year-old man was referred to my practice for a cornea consultation. He had been struggling with decreased visual acuity for some time.

The patient's BSCVA was 20/50 OD and 20/200 OS with significant distortion. He had been unable to obtain a driver's license and had withdrawn from college because of his visual limitations. He was diagnosed with progressive keratoconus (Figure 1), and CXL was recommended.

Stabilization Without Functional Success

The patient underwent bilateral CXL with the iLink platform (Glaukos). Once healing was complete, he was fit with scleral lenses, which improved his BCVA to 20/20 OD and 20/30 OS.

He had persistent difficulty with lens insertion and removal. We met for multiple training sessions during the following year, but efforts to help him master scleral lens handling were ultimately unsuccessful. It became clear he was experiencing symptoms of depression and profound frustration.

A Tissue-Based Option

At the time we concluded scleral lenses were no longer an option, Steven Greenstein, MD, and colleagues described a new refractive procedure for ectatic corneas: corneal tissue addition keratoplasty (CTAK).⁶ The procedure places donor corneal tissue in a laser-created channel in the corneal stroma to normalize its shape and decrease irregular astigmatism (see the sidebar).

Michael Greenwood, MD, the comanaging surgeon on this case, and I felt that the patient was a good candidate for CTAK given his failure in handling scleral lenses and that his other options were limited to penetrating keratoplasties. The patient subsequently underwent bilateral CTAK (Figure 2).

(Continued on page 20)

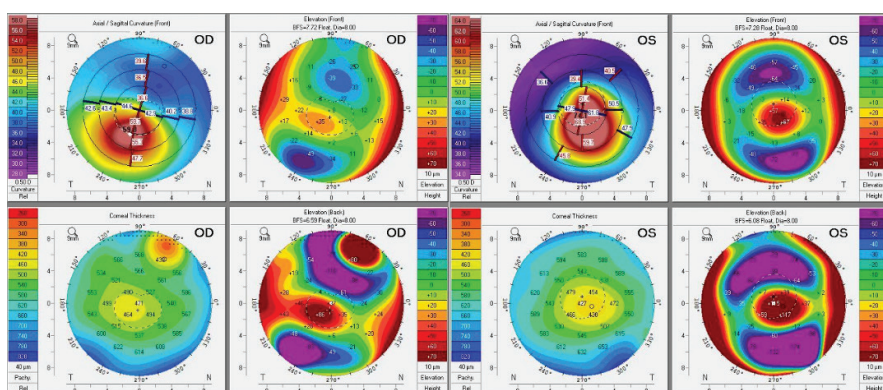


Figure 1. Baseline corneal tomography shows progressive keratoconus, with greater involvement in the left eye than the right eye.

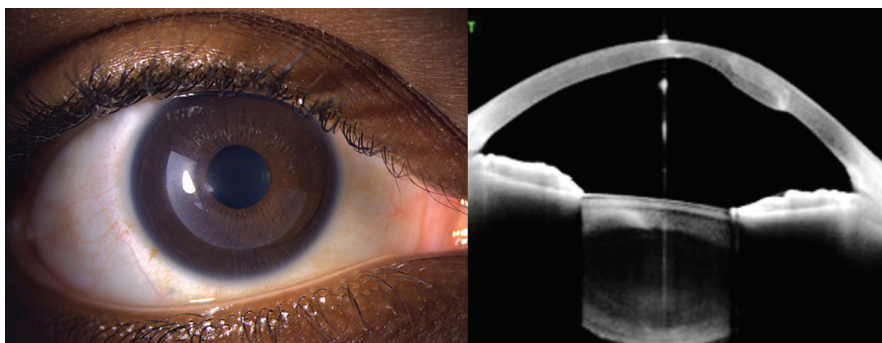


Figure 2. Corneal images obtained 1-month after CTAK.

(The Life-Altering Burden of Keratoconus, continued from page 17)

Restored Function, Renewed Independence

The patient is now 27 years old, and it has been 4 years since his CXL procedures. Since his CTAK was performed 6 months ago, the transformation and improvement in his QOL has been remarkable.

His UCVA improved from 20/600 OS preoperatively to 20/80 OS on postoperative day 1, and his BCVA continued to improve over the following weeks. His BCVA is currently 20/25 OD and 20/40 OS, and his BSCVA is close to 20/20 binocularly.

It would be difficult to overstate the impact that CXL and CTAK had on this patient's life. He is in the process of obtaining his driver's license and is looking for his own apartment. At his appointments, the patient demonstrates greater engagement, seems happier, and carries himself with greater confidence. His mother

tears up every time he reads the visual acuity chart. As a mother myself, I can only imagine how difficult it has been for her to watch him struggle with his visual limitations.

AN INTERVENTIONAL MINDSET FOR KERATOCONUS

In an ideal world, my patient would have undergone CXL before his visual acuity became so impaired. The successful management of keratoconus requires eye care providers to have an interventional mindset and treat patients at the time of diagnosis instead of waiting for their visual acuity to decline.

When speaking with primary eye care providers, I encourage them to suspect keratoconus in young patients whose vision cannot be corrected to a crisp 20/20, those who report difficulty with nighttime driving, and those who demonstrate rapid changes in their myopia or astigmatism. Another clue is inconsistency between autorefraction and manifest refraction.

In rural states such as North Dakota, where I practice, even traveling a considerable distance for specialist care can be worthwhile for these patients. The lifetime out-of-pocket expenses of keratoconus can be substantial. Early CXL can reduce those costs and lessen the associated QOL burden. ■

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