

Condition Insight Report (CIR)

Keratoconus

Version 1.0

[Slide 2 – Overview](#)

[Slide 3 – Tell me more](#)

[Slide 4 – Fluctuations and Reliability](#)

[Slide 5 – Sensitivities and customer care](#)

Slide 6 – Functional impact 1-3

Slide 7 – Functional impact 4-6

Slide 8 – Functional impact 7-9

Slide 9 – Functional impact 10-12

Slide 10-Additional reading and resources

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Overview

Brief overview of the condition.

Keratoconus (pronounced keh-rah-toe-cone-us) is an eye condition that affects the cornea on the front of your eye. It usually starts in your teens or 20s and generally worsens over time. However, it is important to remember that this not always the case and symptoms can continue to progress into older adults. Furthermore, there are also increasing numbers of cases of 'late onset' keratoconus, with the condition first developing after the age of 40.

As the condition progresses, it causes changes in the regular shape, strength, and thickness of the cornea. The way this affects your sight will depend on the severity of these corneal changes, so that some people experience fewer sight problems than others. It is usually present in both eyes, although one eye may be more affected than the other.



Presenting Symptoms

Keratoconus can affect different people to different extents, but it does not cause blindness. It tends to progress more quickly when it starts at a younger age, and it can continue to worsen until a person is in their mid-30s when it should begin to stabilise.

- As keratoconus progresses and the cornea changes its shape, vision will become more blurred because light entering the eye isn't focused as accurately on the retina as it needs to be to give clear vision.
- Some of the blur from keratoconus is due to a focusing problem called 'irregular astigmatism', which cannot be corrected with spectacles, and which results from the irregular and uneven corneal shape.
- The corneal bulging of keratoconus can also make the eye become more short-sighted (myopic). Being myopic means that distant objects will appear more blurred, whilst objects nearer may be clearer.
- Depending on the degree of keratoconus, someone may be more sensitive to light (photophobic) and experience glare, leading to discomfort and difficulty seeing things in brightly lit conditions.
- Similarly, someone may also experience ghosting (a secondary image around what they see) and see halos around lights, which may make it more difficult to see clearly; for example, when driving at night facing oncoming headlights and street lighting.
- As well as difficulties with glare in brightly lit conditions, vision can also be very poor in low light conditions.

However, everyone is different, and some people will experience these symptoms to a greater extent than others.

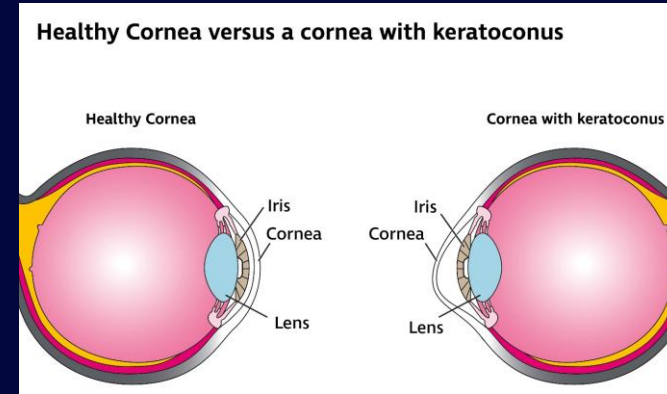
Tell me more.....

If you have keratoconus, the collagen bundles are affected within your cornea, so that the cornea becomes weaker and thinner nearer its centre, or just off centre. These changes in corneal thickness lead to an outward bulging (distension), causing an irregular cone-like corneal shape to develop. This process of corneal thinning and distension is called corneal ectasia.

The diagram shows a healthy cornea and a cornea with moderate keratoconus. The cornea, iris and lens are labelled within each eye. The healthy cornea has a regular shape, thickness and curvature, whereas the cornea with keratoconus has an irregular, outwardly cone-like shape where the corneal thickness is reduced.

Treatment & management

- **Glasses and contact lenses**-where keratoconus is mild, someone may achieve a good level of vision just by wearing glasses. However, if the cornea continues to become steeper and more cone-shaped they will need more powerful lenses to correct their sight. Stronger, more powerful lenses can make glasses thicker and heavier and they can also cause vision to be distorted, making ghosting more obvious.
- **Contact lenses** sit on the front of your eye, providing a regular front surface on the cornea and masking the irregularities due to keratoconus. A thin layer of your tears, known as the tear film, remains between the lens and the corneal surface, and this helps to keep the lens in place. Contact lens wearers with keratoconus usually wear rigid gas permeable (RGP) lenses. However, there are various types of specialised contact lenses that can be fitted.
- **Corneal crosslinking (CXL)**-Corneal crosslinking is the only clinically proven treatment that can stop keratoconus from getting worse by stabilising the shape of the cornea, and it is available on the NHS. This treatment is most effective in treating keratoconus in its early stages, as it will be more likely to stabilise someone's corneal shape, providing a better level of vision for the longer term.
- **Intracorneal ring segments (ICRS)**-ICRS are thin plastic semi-circular rings which are implanted into the corneal stroma. The aim of this treatment is to flatten the central cornea and give it a more regular shape. For some people, this can allow for a better contact lens fit or better vision with glasses.
- **Corneal transplant (keratoplasty)** -A corneal transplant is surgery to remove all or part of a damaged cornea and replace it with healthy, clear corneal tissue



A very small number of people (around 3%, or 3 in 100) experience complications after their CXL treatment that makes their vision worse.

This can be due to:

- **Corneal scarring**
- **Corneal haze**
- **Increase in corneal irregularity**
- **Infection**

Other complications may occur with corneal rings (which may have to be removed) and to corneal transplants (which may be rejected).

REMEMBER: People may have specific difficulties with lens wearing.

This may include;

- ❖ Difficulties obtaining the correct lens.
- ❖ Regular eye infections impacting ability to wear contact lenses.
- ❖ Cost of lens fluid and having to consistently maintain this
- ❖ Lots of people utilising the lenses report them to spontaneously pop out

Fluctuations



- ❖ People who have Keratoconus will often have fluctuating vision dependant on levels of light.
- ❖ You must consider how their vision is impacted in different lighting, or at night, especially when out of the home
- ❖ If they have eye infections, consider if this impacts their ability to wear lenses. If so, how often do they have infections and how long do they last for? What is their level of vision without lenses?
- ❖ Some people develop intolerance to contact lenses after many years of wear. Also a condition called 'dry eye' can make contact lens wear difficult, as can air conditioning. So the number of hours per day that someone can wear their lenses can be limited.
- ❖ A period of adaptability also needs to be considered. Someone who loses vision later in life may need time to adapt to managing certain activities.

REMEMER: Just because someone uses the term 'stable', this does not mean there is no functional restriction. It simply means the deterioration has stopped for that period of time.

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY



TIMELY



ACCCEPTABLE
STANDARD



REPEATEDLY



Do they have any symptoms which could cause a safety consideration?

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Are they able to repeat a task as often as required? Is this the same every day?

If someone has impaired vision, this is likely to impact their ability to safely complete activities such as cook and complete journeys. You must explore if they have had any incidents secondary to their condition. How do they overcome their restrictions? Do they use aids or do they require assistance?

Someone with a visual impairment may require extensive focus to complete activities that someone without a visual impairment could do without issue. This may impact how long it takes them to do things. You must explore if their condition means they take more than double the amount of time to complete activities than someone without a disabling condition.

If someone has a longstanding visual impairment, they may report they are completing activities as this is how they have adapted. We must consider, if they are completing activities so an acceptable standard. Just because they are completing activities independently, it does not mean it is acceptable.

Consider if someone can complete an activity, can they complete it as many times as is reasonably expected? Does their vision worsen throughout the day?

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Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

People with sight loss often go through a type of grieving process and this can include stages of anger, depression and denial. Depending on their stage in the process they may underplay the difficulties that are caused by their sight loss or they may be at a stage where they blame spectacles or other causes for their difficulties

Customer Care



How is it best to ask about any sensitive topics and what are the common courtesies?

During face-to-face interactions

- Introduce yourself and what you do
- Always talk to the person directly, rather than their companion
- In a group conversation, always make it clear who you are and who you are speaking to
- Use verbal responses, avoid nods and head shakes
- Verbalise your actions
- Inform people when you are moving away from them or leaving the room
- Remember if someone has a visual impairment, it doesn't always mean they have no sight at all
- Ask if they would like you to 'guide' them or whether they would like any other support
- Provide information in the person's preferred format so that it is accessible to them - audio, large print or braille
- Be aware of where you are seated. Many people report having a window or extensive light behind the person addressing them, makes it extremely difficult to see them.

The areas where assistance might be required would be:

- Navigating around an unfamiliar place (trip hazards, food and drink, toilets etc).
- Controlling the light levels in the room.
- Accessibility of documents, computer forms and correspondence. These should be offered in the persons preferred format so ensure that you ask what they prefer and don't assume what format you think is best for them.
- Introduce anyone in the room and inform the person if someone leaves the room.



Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Blurred vision and difficulties focusing are likely to impact someone's ability to safely cook. They may be at risk around knives or flames which must be considered.

Remember in PIP...

Can they safely complete this activity? Have they attempted to use aids before? Can they cut vegetables or see a flame on the hob? Have they had any incidents in the kitchen? Do they require assistance?

Activity 2: Taking nutrition

Many are likely to be independent with this task but this will depend on how they are/have adapted to their sensory changes.

Remember in PIP...

As keratoconus can cause blurred vision, they may drop food. You must establish if this does happen, how often? How do they mitigate this?

Activity 3: Managing therapy and monitoring a health condition

Consider if the claimant has medication for other conditions, the keratoconus may impact their ability to manage this.

Remember in PIP...

Ensure to explore how they manage their medication. Can they reliably establish what their medications are? Can they get it out of the packet and self-administer? If not, why is this and how do they overcome the restriction? Can they administer their own eye drops of utilised?

Functional Impact

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Activity 4: Washing and Bathing

Sight loss in a wet environment can be challenging for many and they will manage this in different ways. Some may rely on aids to guide them and keep them safer in this environment, others may not require this.

Remember in PIP...

We must consider everyone's ability to transfer in and out of an un-adapted bath, even if they only have a shower. As keratoconus may impact depth perception, you must explore how the claimant gets in and out of the bath safely.

Activity 5: Managing toileting needs and incontinence

There is no physical limitation unless there is a co-morbidity, however, many people will have different ways to manage their sight in this environment.

Remember in PIP...

Within the scope of the activity, we must know;

1. How the claimant transfers on and off the toilet.
2. How they manage to clean themselves.
3. If they have any incontinence, if this is majority of days, and if this is self-managed. (Remember if incontinence is self-managed this would still be considered an aid within the scope of the activity.

Activity 6: Dressing and undressing

Sight impairment secondary to keratoconus may impact the claimant's ability to establish if clothes are clean.

Remember in PIP...

If there is evidence of a visual impairment, we must establish how the reported restriction is being overcome, if at all.

For example, it may be that someone with a longstanding visual impairment and no cognitive difficulties, would be able to establish if clothes are clean or dirty.

Have they adapted to their vision loss? Although many will have adapted over time, some may require prompting to support them to manage their reported restrictions.

What, if any techniques do they have to separate clean and dirty clothes? How do they tell when clothes are clean or dirty?

You must consider if they are completing the activity reliably.

Functional Impact

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Activity 7: Communicating Verbally

Comorbidities should be considered as visual loss is unlikely to impact speech.

Remember in PIP...

As Keratoconus is unlikely to directly impact this activity, try and remember the scope of the activity in general.

The claimant needs to be able to both **express** and **understand** complex verbal information. PIPAG would suggest complex verbal information is information conveyed in either more than one sentence or one complicated sentence, for example: "I would like tea please, just a splash of milk and no sugar, as I always have sweeteners with me for when I go out."

Activity 8: Reading and understanding signs and symbols

Typically someone with Keratoconus will have difficulties with reading. They may require specific aids, including their specially made contact lenses, or their visual impairment may be so severe that they require assistance to read normal size font.

Ghosting, doubling and glare can all make reading digital displays particularly difficult - e.g. train indicator boards, ATM machines, digital road signs. A light over a sign can cause glare which completely obliterates the sign below it.

Remember in PIP...

Any visual restriction will need to impact their ability to read on the majority of days. Remember, the PIPAG suggests that the distance between the eyes and written material is not relevant.

However, we need to consider if the claimant has any aids to assist with this activity or if they need assistance. What can they read and how do they overcome their restriction?

If they are holding something close to their face to read, how long does this actually take for them to read? Are they reading to an acceptable standard?

Activity 9: Engaging with others face to face

The condition may make it hard to make eye contact with others, often making social situations awkward for them. It may also impact someone's ability to recognise faces, be them familiar or unfamiliar. Dealing with this element of the condition causes some people to avoid public situations and limit going out or socialising.

Remember in PIP...

Cover where specific restrictions are reported how they manage this. Detail of any support provided and whether this support can be provided by anyone or only specific individuals.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

The ability to manage this will be different for each individual.

Remember in PIP...

Ability to see coins is not considered within the scope of the activity, neither is reading household bills.

Explore their cognitive ability to manage household finances, future purchases and change in a shop.

Activity 11: Planning and following a journey

Keratoconus can cause difficulties with spotting things in a crowded or moving environment and can make judging distances and speed of objects difficult as a result of blurred vision. Some people will suffer from a glare (glare that reduces vision). This will mean that any task that is outdoors will be significantly more difficult to do. Vision often changes in lighting so they will be limited further if going out of the home at night.

Remember in PIP...

Ensure you explore the claimant's ability to safely navigate when out of the home with their visual impairment. Can they navigate curbs? Can they safely cross the road? How would they manage a diversion? Do they have any orientation aids or require assistance to go out of the home? If they have adapted, would this be considered reliable within the scope of PIP?

Activity 12: Moving Around

This will depend on an individual's comorbidities.

Remember in PIP...

Remember that any safety due to their sensory loss will be covered in A11, here you should seek to determine if there are comorbidities which affect their physical ability to move around on flat surfaces and management of kerbs.

Additional reading or other resources

EXTERNAL

[Keratoconus | RNIB](#)

[Keratoconus Overview, Causes, and Treatments | Specsavers UK](#)

[Keratoconus - Moorfields Eye Hospital](#)

Version	Date	Signed off by	Comments
1.0	02/01/2024	Rebecca Sparks, Shah Faisal and Jade Mayfield.	New document