Finnish Amyloidosis Association

# Guide for eyecare

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## Foreword

This eye care guide is intended to help with the treatment, self-care and prevention of eye symptoms for people with Meretoja disease and similar eye conditions. The main focus of the guide is on self-care and prevention of symptoms, but we will also briefly introduce other non-self-care methods. The eye health guide can be used by people with Meretoja disease, other people with similar symptoms and health care professionals.

The treatment guide is part of our optometry thesis on the effects of Meretoja disease on the eyes and their treatment. The aim of the thesis was to increase knowledge about Meretoja disease and its effects on the eyes. The eye care guide has been produced in collaboration with the Finnish Amyloidosis Association. The thesis and the guide is published in Autumn 2021.


We would like to thank the Finnish Amyloidosis Association for their cooperation!



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## Introduction

Meretoja disease is a hereditary gelsolin amyloidosis of Finnish origin. Systemic disease causes symptoms in a fairly comprehensive way. The disease particularly affects the eyes, skin and nervous system and is most commonly seen first in the eyes. There is no cure or medication for Meretoja disease, but the symptoms are treated with symptomatic care. The progress of the disease is also monitored through regular visits to the doctor.

This guide focuses on eye health and how to treat eye symptoms. The guide is intended to be a support for self-care of eye symptoms in addition to the treatment instructions given by the ophthalmologist. The guide is part of a thesis published in 2021 and the aim of the project was to create a clear and universal guide for self-care of eye symptoms.

The sources used in the guide can be found in the thesis report, published in autumn 2021 in the Theseus database.



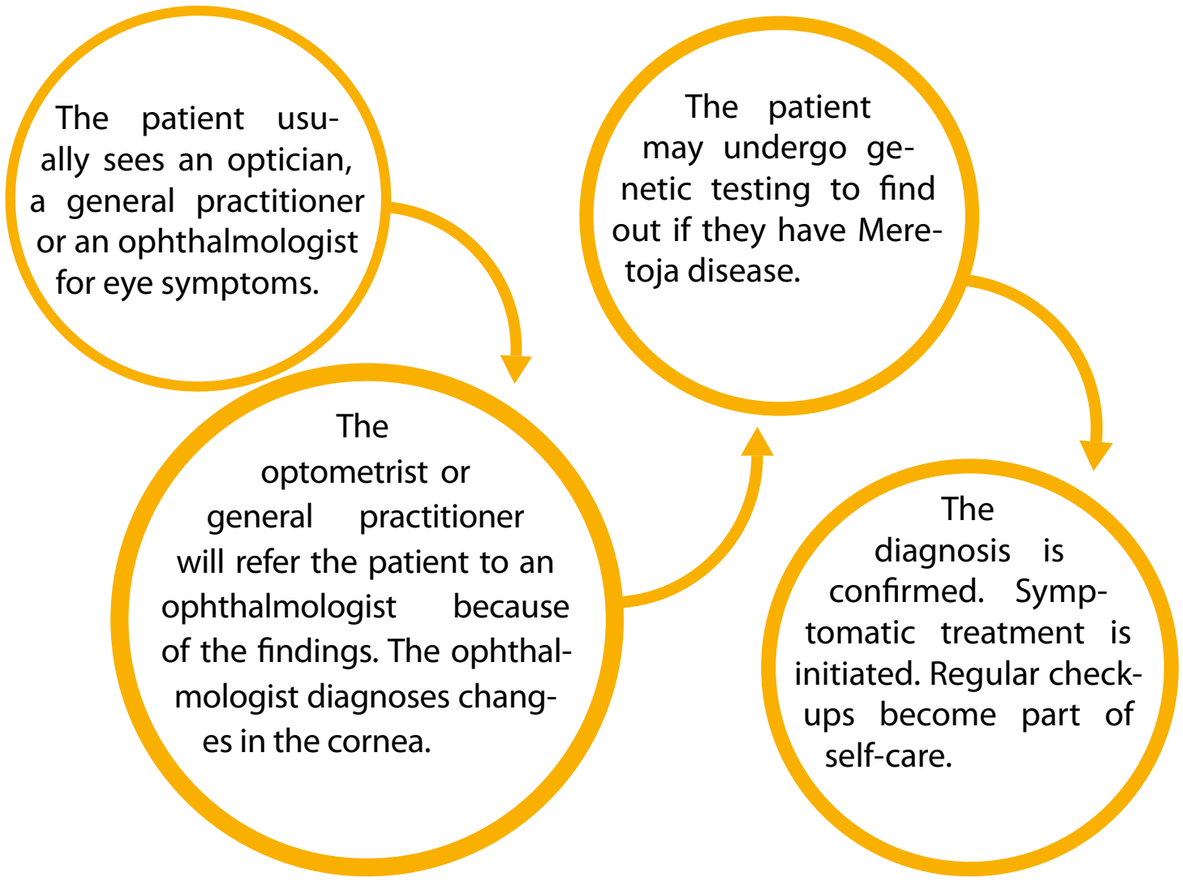
## How does Meretoja disease appear in the eyes?

Early signs of Meretoja disease start to appear around the age of twenty. If you have eye symptoms, such as dry eyes, you go directly to an ophthalmologist or optometrist, who will refer you to an ophthalmologist. Examination of the eyes reveals degenerative changes in the cornea typical of Meretoja disease. After the detection of corneal abnormalities, patients can be subjected to genetic testing to confirm the diagnosis. For people with a close family history of Meretoja disease, genetic testing can be done proactively.

There are many typical eye symptoms of Meretoja disease, as well as symptoms affecting the eyes. Corneal degenerative changes cause irritation and dryness of the eyes and blurred vision. Deficiencies have also been found in the corneal sensory nerves, which can reduce the sensitivity of the cornea. With a decrease in corneal sensitivity, you may not feel the need to use eye drops because you will not notice the drying sensation in your eyes. This can further predispose to dry eyes and eye infections. Indeed, dry eyes are the most commonly experienced problem, especially in the early stages of the disease.

In Meretoja disease, the eyes become dry because not enough tear fluid is secreted, and it evaporates excessively. With age, dryness is an even bigger problem, as the eyelids may droop or turn inwards or outwards due to sagging of the skin. As the disease progresses, the eyelids may no longer close properly all the way. The role of the eyelids is to spread the tear fluid over the entire surface of the eye, and improper positioning prevents this from happening normally. An open eyelid due to drooping eyelids and eyelid dysfunction also predispose to dryness, as tear fluid can evaporate too quickly. Meretoja disease is associated with an increased risk of glaucoma and cataracts.

## Treatment pathway




■ The law prohibits an optometrist or optician from independently prescribing spectacles to a person who has been diagnosed as having an eye disease, is suspected of having an eye disease or has had an eye operation. If the optometrist or optician finds anything abnormal during the examination, he or she will send the person to an ophthalmologist for tests. The ophthalmologist's job is to examine your eye health and make a diagnosis. In the future, if an eye disease is diagnosed, it will be up to the ophthalmologist to monitor the health and changes in the eye. In some cases, however, an optician may be authorised by an ophthalmologist to prescribe glasses.

## Regular Doctor´s follow-up examinations as part of self-care

***Follow-ups play an important role in supporting self-care. The symptoms of Meretoja disease are progressive and increase with age. People with the disease also have an increased risk of developing certain eye diseases.***

■ People with Meretoja disease benefit from regular examinations by an ophthalmologist. Regular follow-up of eye symptoms improves the prognosis for vision preservation, as corneal changes and eye diseases can be treated early enough. It is typical, for example, to develop asymptomatic glaucoma, which, if left untreated, causes detoriation of vision or even loss of sight.

Follow-up examinations by an ophthalmologist can detect changes in the structure of the eye even before the onset of symptoms. In this case, the doctor can give home care instructions to help maintain good vision and eye health. The importance of regular examinations increases with ageing and in severe forms of the disease where eye symptoms are more difficult.

## Eyelid care

***The risk of eyelid inflammation is typical of Meretoja disease, and therefore eyelids should be cleaned regularly every day.***

**What do I need to clean my eyelids?**

- Towels
- Cotton buds
- Eyelid wipes for cleaning eyelids
- Cotton wipes and products for cleaning the eyelids
- Clean water, for example boiled water

### Daily cleaning of the eyelids

1. Always clean your hands thoroughly before touching the eye area.
2. Dampen a towel or cotton pad with clean water or an eyelid cleanser. You can also use the ready-to-use, eyelid-cleaning
3. Carefully wipe the eyelids one eye at a time. First wipe the upper eyelid from the inner corner outwards, then repeat for the lower eyelid. The wipe

should go right over the lash line. You can then close the eye, and wipe the top of the eye again.

4. Replace a new cotton pad or cloth at the other eye. If you wiped the eyelids with a towel, turn the towel over to a clean spot or replace with another towel. Do not wipe both eyes with the same towel or cloth.

5. Soak the eyelids 1-2 times a week in a warm compress.

## Cleaning of inflamed eyelids

***Blepharitis, an inflammation of the eyelids, can be recognised by red, irritated eyelids and crusty eyes. Your eyes may feel even drier and your eyelids may itch. Eyelid cleaning should be intensified during inflammation. The inflammation is two-sided; if you notice inflammation in only one eye, consult a doctor immediately.***

1. Wash your hands thoroughly with soap, and dry them on a clean towel or paper towel.

2. Wet a separate towel with hot, but not scalding water.

3. Bathe the eyelids with a warm damp towel for 5-10 minutes 1-2 times a day.

4. Dampen the cotton swab with water or an eyelid cleaner.

5. Using a moistened cotton swab, rub the entire eyelid area up to the eyelid line, with the upper eyelid from top to bottom towards the eyelid line and the lower eyelid from bottom to top towards the eyelid line. Rubbing helps to clear inflamed and clogged oil-producing glands.

6. Clean your eyelids with a damp cloth, cotton pad or eyelid wipes. First, start on the upper eyelid, on the nose side, wiping the entire eyelid area. Then fold the cloth into a clean area and wipe the lower lid in the same way. Between eyes, replace with a new, clean cloth or towel.

7. Continue until the inflammation is gone. Intensive treatment can last for weeks. In mild cases, self-medication can be continued for longer, but in severe cases of inflammation, it is advisable to consult a doctor as soon as possible. Inflammation of the eyelids may need medical treatment.

## Treatment of dry eyes

***Dry eyes is a very common condition that affects the eyes in many different ways. Dry eyes can cause an uncomfortable feeling of dryness or debris in the eyes, stinging, itching, discharge from the eyes, blurred vision and more. Vague visual symptoms, eye fatigue and fluctuating visual acuity can also be signs of dry eyes.***

When choosing the right product to treat dry eye symptoms, it's a good idea to find out what causes dry eye. The tear system in the eye involves a number of different factors, and a malfunction in any one of these can cause dry eye. Dry eye may be caused by excessive evaporation of tear fluid, insufficient tear fluid secretion, poor tear fluid composition and insufficient tear fluid distribution on the surface of the eye. Often dry eye is also a combination of the above factors. It is a good idea to identify the causes of dry eye together with your ophthalmologist or optometrist, so that the treatment you choose is appropriate to the underlying causes of your symptoms.

## Treatments for dry eye symptoms

***There are many different treatment options for dry eye symptoms. Some options are suitable for self-care at home and some treatments need to be carried out by a professional.***

- Different types of humidification
- Eyelid hygiene
- Thermal decompression of the eyelids
- Proper nutrition and supplements
- Goggles to prevent evaporation of tear fluid
- Warm steam goggles or mask
- Tear plugs
- Special contact lenses for dry eyes



## Dry eye products

***The most common and first-line treatment for dry eye symptoms is the use of artificial tears, or moisturising eye drops. The use of moisturising drops often relieves the symptoms, but they do not address the causes or causes of dry eye. In addition to eye drops, other products available on the market include thermal steam goggles, humidifiers and goggles.***

### Moisturising eye drops
### Dosage and use

When applying eye drops, hygiene is of paramount importance. Before applying eye drops, wash your hands thoroughly with soap and dry them well. Care should be taken with products that are administered into the eye, taking care not to let the mouth of the bottle or pipette touch anything, including the eye or hands. The moisturising eye drop is applied to the eye by opening the lower lid with one hand and dropping the drop into the lower lid pocket. The surface of the eye can only hold a limited amount of liquid at a time, so one drop in each eye is enough. Depending on the product and your needs, you can drip the moisturising drops into the eye up to 4-6 times a day or more. However, you should check this with the product label, your doctor or pharmacist.

Sometimes it can be difficult to dispense eye drops and drop them into the eyes, in which case a spray-on lubricant may be a good choice. It is sprayed onto the surface of the closed eye, allowing the appropriate amount of fluid to enter the eye. An additional benefit of the eye drop in spray form is its moisturising effect on the eyelids.

### Product free of preservatives

Because of the typical symptoms of Meretoja disease, eye drops used to treat dry eyes should be preservative-free, as preservatives may expose the eyes to sensitisation with continued use. In the worst case, preservatives can cause allergic reactions,

Preservatives can also dry out the eyes, so using eye moisturising eye drops may not have the desired effect. If you are also using a medical eye drop, for example for glaucoma, it is particularly important that the moisturising drops are preservative-free.

### Composition

Moisturising eye drops come in different formulations. In general, more fluid and liquid drops are good for daytime use, as they do not blur vision. Gel moisturisers, on the other hand, provide longer-lasting relief as they evaporate more slowly from the surface of the eye. However, thicker and gel-like drops will temporarily blur vision after application, which should be taken into account when using them. Thicker drops and creams are especially suitable for night time use.

### Active substance

There are many moisturising eyes drops on the market and a wide variety of active ingredients. Suitable preparations include hypromellose, carbomer, carmellose and povidone drops. Different substances affect different layers of the tear fluid. You should talk to a professional to find the right product for you.

| Active substance | Example | Effect of preparations |
|---|---|---|
| **Hypromellos** | Hyprosan eye drops<br>Artelac eye drops | Affects the aqueous layer of the tear fluid,<br>Moisturizes and lubricates the eye,<br>relieves eye irritation |
| **Carbomer** | Oftagel<br>Viscotears gel<br>Thealoz gel<br>BioDrop MD plus | Affects the musin layer of the tear fluid,<br>forms a protective film on the surface<br>of the eye and forms a lubricatingn film<br>that delays the evaporation of the tear fluid |
| **Karmellos** | Celluvisc eye drops | Affects the aqueous layer of the tear fluid,<br>which forms a moisturizing layer<br>on the surface of the eye. |
| **Povidoni** | Oculac Eye Drops | Acts on the aqueous layer of the tear fluid,<br>preventing the evaporation of moisture from<br>the surface and the conjunctiva in dry eyes |
| **White Vaseline Vitamin A** | Vitamin A (Bevita Eye A, VitA-POS) | Acts on the lipid layer of the tear fluid and forms<br>a protective film on the surface of the eye |

### Moisturising eye drops checklist

- **Artificial tears should be preservative-free.**
- **Be sure to use moisturising eye drops often enough, the feeling of dryness may not be noticeable due to the reduced sensitivity of the eye.**
- **The gel-like moisturising drops stay on the surface of the eye for longer.**
- **Ask a professional for help in finding the right moisturising product and try different options.**

### Tips to prevent dry eyes

- Remember to blink your eyes at regular intervals.
- Take several breaks when working on your computer or other work that strains your near vision. Every 15-30 minutes or so, look into the far distance.
- Use moisturising eye drops regularly to prevent dry eyes.
- Remember to drink enough water and eat a varied diet.
- Sea buckthorn oil capsules available on the market as part of a varied diet have been shown in some studies to help with the symptoms of dry eye, including reducing redness and itching.

### Vitamin A eye cream

Those with severe dry eye symptoms may also benefit from using a preservative-free vitamin A eye cream. The purpose of the cream is to provide long-lasting relief of dry eye symptoms by restoring the normal physiological state of the tear film and protecting the surface of the eye. Apply the ointment to the inner surface of the lower eyelid for about 1cm overnight. Always put eye drops or other preparations on first and only then the cream.

### Blephasteam thermal glasses

Patented thermal glasses are available on the market to treat the glands in the eyelids responsible for producing tear fluid. The moisture and heat released from the glasses help to dissolve blockages formed by glandular secretions, which also improves tear production.

### Special contact lenses

The symptoms of dry eye can also be relieved with special contact lenses. Hard scleral contact lenses are placed in the eye with preservative-free saline solution. The preservative-free saline solution stays between the contact lens and the surface of the eye, forming a liquid layer. The lens protects the eye and the liquid keeps the eye moist. Scleral contact lenses can also be used to protect the eye in cases of corneal degeneration. With hard contact lenses, it may be possible to achieve better visual acuity than with spectacles. Special contact lenses are fitted in some opticians' shops and in specialised hospitals. If you have a diagnosed eye condition, such as corneal degeneration, the use and suitability of special contact lenses should be discussed with your eye doctor first.

### Nutrition and supplements

Among the vitamins, vitamin A and the antioxidant beta-carotene have been shown to be important for eye health. In addition, sea buckthorn seed oil products have been shown to have positive effects in supporting the treatment of dry eye. It's also good to remember to eat a healthy, varied diet and drink enough water.



## Protecting dry eyes from external irritation

### Protective glasses

Various external stimuli, such as wind or debris, can make your eyes feel even drier. However, dryness can be prevented and treated with protective goggles or glasses or sunglasses that go with the skin. The best protection against the wind is to wear glasses that are as close as possible to the skin on your face. The above-mentioned glasses or sunglasses prevent tears from evaporating from the surface of the eye, even in normal weather conditions. You should ask opticians for alternatives, as they can help you find the right products for the right purpose.

### Warm Mist Humidifier

Often the air indoors is dry, which irritates the mucous membranes and thus dries the surface of the eye. The dryness of indoor air is particularly pronounced in winter, when humidity levels decrease in cold weather. Dry room air can

be improved with a humidifier. The Allergy and Asthma Association recommends using a hot-air humidifier, which prevents microbes from multiplying and improves indoor air quality.

### Increasing pausing and blinking in precision work and working on the computer

Working at close distances for long periods of time, for example on a computer or tablet, increases the symptoms of dry eye. Breaks should be frequent, especially when working on computer, about every 15-30 minutes. During the pause, the gaze should be directed as far away as possible, for example out of the window, to give the eyes a break from close observation. When working close up, it is easy to forget to blink, which prevents the tear fluid from spreading to the surface of the eye. So remember to blink at regular intervals while you work. Also pay attention to the location of the screen in computer work. When the gaze is upwards, reflexive blinking is further reduced. So, point the screen downwards from the viewing line, the top of the screen should be below the eyes.

### Eye care routine

- Wash and dry your hands thoroughly
- Clean your eyelids according to the instructions
- Bathe the eyelids with a warm moist compress
- After cleaning and incubation, it's time for eye drops*
- Finally, apply eye creams*

*The dosing order for eye drops and various eye medications may differ from the above. For some products, you have to wait a certain amount of time before dispensing the next product. Always check the product label for the dosage regimen and any withdrawal period associated with the use of the product.

## Protection against glare

***Changes in the cornea and dry eyes make the surface of the eye uneven, altering the way light enters the eye and causing glare sensitivity. Some eye diseases, such as cataracts, also cause glare due to changes in the structure of the eye. These changes can cause glare even in normal daylight.***

Glare can be prevented by sunglasses that come as close to the face as possible, and also have thicker temples to block light from entering the eyes from different directions. Highly protective sunglasses have 100% UV protection. The darkness of the sunglasses does not in itself indicate the UV protection of the sunglasses, but dark lenses in sunglasses help reduce glare.

### Tips for the buyer of sunglasses

- Try on different models, well-fitting sunglasses offer the best protection and are the most comfortable to wear on your face.
- Make sure your sunglasses have 100% UV protection and CE marking.
- Lenses with a large surface area and darker lenses provide the best protection against glare.
- Different lens colours do not in themselves provide different levels of glare protection, but they can improve vision in other ways. For example, a brown lens tint enhances contrasts and brightens colours.
- If you spend a lot of time by the water or driving a car, polarised lenses may be best for you. Polarisation reduces reflections from horizontal surfaces such as water or wet road surfaces. This means that glare is significantly reduced.

A subtle tint can also be added to glasses to reduce glare indoors. It is also possible to wear lenses that darken in the sun. However, it is also a good idea to have separate sunglasses alongside your glasses.

## Surgical treatment

In patients with Meretoja disease, a typical symptom is drooping eyelids caused by skin laxity and nervous changes. Sagging bones are often a cosmetic burden, but they can also cause functional problems. Changes in the structure of the cornea are also part of the picture, causing blurred vision and dry eyes.

### Eyelid surgery

Drooping of the upper eyelid can impair vision, causing visual field defects. The lower eyelid drooping and turning outwards, on the other hand, causes dry eye. Day surgery is often used to correct these vision problems. Excess skin can be removed by upper eyelid surgery and sagging caused by the levator muscle can be corrected by shortening or tightening the levator muscle. Drooping and outward turning of the lower eyelid can be corrected by lower eyelid surgery.

### Corneal surgery

In cases where reticular corneal degeneration and recurrent corneal erosions cause corneal clouding and consequent vision loss, corneal brightening surgery can be performed. The cloudy surface layer of the cornea can be removed by phototherapeutic keratectomy, or PTK, using a laser. The treatment brightens the cornea and can improve visual acuity.

Corneal clouding that significantly reduces vision may require a corneal transplant. This treatment is a last resort when other treatments do not work. A corneal transplant can make the cornea clearer and improve vision, but corneal degeneration can easily reoccur with a new transplant and the transplant may need to be redone.

### Tear plugs for the treatment of dry eyes

In severe dry eye disease, one treatment may be tear plugs. They are placed in the tear ducts during a polyclinic procedure to prevent tear fluid from draining away from the surface of the eye into the tear ducts. Tear plugs are available in temporary and permanent versions. Temporary tear plugs are usually made of collagen and melt away on their own in about 2-3 months. If tear plugs are found to be useful, permanent silicone plugs can be fitted in the tear ducts. Even permanent tear plugs can be removed if necessary. You can ask your ophthalmologist for more information about tear plugs.



# Conclusions

In addition to the self-care methods described in this guide, you should always follow the treatment instructions given by your ophthalmologist. When new symptoms appear, you should first consult your own doctor or ophthalmologist to identify the symptoms and their causes and begin the right treatment to relieve them. You can also discuss the need for non-self medication methods with your doctor and make a treatment plan. More information about Meretoja disease and its symptoms can be found on the website of the Finnish Amyloidosis Association, where other guides and other material related to the disease are also published

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