

EYES

1. Introduction

Eye problems can occur with varying frequency in most forms of EB. The eyelids, the conjunctiva and the cornea can all be affected. Problems involving the eye and the area around the eye are particularly unpleasant and are often quite painful. This section shows you ways in which the incidence of eye problems can be reduced and what to do if they occur. There are also some points to consider when preparing to purchase eye glasses.



Important points in a nutshell

- **Blisters and wounds can occur around the eyes on the eyelids, conjunctiva and cornea.**
- **Occurrence is common in RDEB, time and again in DDEB, regularly with JEB and sometimes even with generalized EBS.**
- **Immobilization and pain relief are the most important initial measures.**
- **Prevention through regular use of artificial tears and eye ointments can reduce the incidence of problems developing.**
- **All measures must be accompanied by visits to the eye doctor!**

2. General Information

Eye problems are possible at any age even in infants and young children. It is often seen in recessive dystrophic EB and junctional EB; it sometimes occurs in DDEB and generalized EBS. It is important that you are prepared and know what to do in such a case, therefore it is advisable that you seek an eye doctor as early as possible in your neighbourhood, so that you can talk about EB and the problems which can occur. The treatment is the same for both adults and children.

EB can cause blistering and formation of small wounds on and around the eyes. Blisters can be caused by rubbing or scratching the eye, by irritations such as heat, wind or dust, or by dryness of the eye. They also often occur spontaneously, i.e. without known cause. The eyelids, the conjunctiva and the cornea may be affected. Blisters in these areas can subsequently lead to erosions (superficial injuries) to scarring and to adhesions. This may lead to conjunctivitis, inflammation of the eyelids, an outward expression of the lower lid (e.g. by the drag from scars in this area) and corneal inflammation. One must also pay attention to whether the eyes are completely closed. With an incomplete eyelid closure you have increased ocular dryness, which can lead to increased formation of blisters.

Particularly unpleasant are injuries to the eye and gluing between the eyelid and conjunctiva that can occur during sleep. On opening the eyes after sleep these adhesions can tear and lead to further injury.

Of course, eye problems can also occur that are not directly related to EB. Examples include strabismus, myopia and hyperopia or cataracts and glaucoma. When eye glasses or eye surgery are necessary, it is very important that the treating ophthalmologist is informed that you have EB.

Blisters and injuries to the eye can be very painful. It may also be, that vision is temporarily impaired. This can have serious consequences in everyday life when you cannot attend school or go to work. Therefore, one must try to reduce or avoid these eye problems as best as possible.

There are a few things that you can do to prevent these problems. The important aspect is to ensure, that the eye does not dry out by constantly wetting the cornea

with artificial tear drops. With each blink ("eye blink"), the tears evenly distribute over the eyeball. The formation of tears can also be reduced, or the tear duct is narrowed so that the eye is not kept moisturized properly. There are also other reasons for dry eyes. For instance air conditioners, visits to a particularly dry climate or even prolonged computer work. Concentrated work on the computer reduces the frequency of blinking, so that the eye is less frequently wetted with liquid.

Even an incomplete lid closure may cause a portion of the eyeball to not be moistened regularly. If there is improper lid closure, surgical correction of the eye lid is recommended but must be discussed with an eye specialist.

Wearing a pair of sunglasses (protective glasses) can also be helpful to protect the eyes from external influences such as wind and increased solar radiation. A humidifier can be useful during the winter season when the heat is on and the air in the room is dry.

Smoke, excessive air pollution as well as sprays of all kinds (e.g. hair sprays, deodorants and perfumes) can also contribute to the increased sensitivity of the eyes and should be avoided if possible.

If for some reason you are having problems with dry eyes, then you need to take action. Regular moistening of the eyes with moisturizing eye drops (sometimes called "artificial tears") and eye ointments can significantly reduce the occurrence of blisters and injuries. Since eye ointments lead to a slightly hazy vision, ointments should be used at night. During the day you can use the artificial tears, yet remember they should be applied several times. In general, use of artificial tears and ointments are not a problem, but sometimes can cause hypersensitivity reactions. It has been proven that the use of products with only a few preservatives works best. Because there are so many different products available you should consult your ophthalmologist (eye doctor).

Unfortunately, the preventive measures are limited. Sometimes reasons for the development of these wounds is often difficult to understand and difficult to avoid. We can only do so much to protect against wind, cold and rubbing the eyes when tired or sleepy, as the use of safety glasses is not always sufficient or practical.

It is important that you are prepared for problems that can occur in the eye area, despite all preventive measures against blisters and/or injuries. We recommend that

you visit an eye doctor in your neighborhood, even if no eye problems have occurred. Briefly describe your condition or that of your family member or child, and let them prescribe a first-aid package for eyes. This should include the already mentioned artificial tears, nourishing eye ointments, and sometimes antibiotic eye drops or ointments. Eye drops that contain steroids (e.g. cortisone) should be avoided. Steroid preparations for the eyes should only be used in exceptional cases and under close medical supervision

How do blisters in the eye area appear? On the skin of the eyelids, they are easy to see, they should be treated like all other blisters on the skin. Blisters in the conjunctiva and cornea appear the same and are similar to care for. They are usually less painful on the conjunctiva. Signs and symptoms may be a "red eye", increased sensitivity to light, decreased visual acuity, tearing and especially pain.

In this case pain relief is of course particularly important. The best analgesic that can be swallowed (as tablets, juice or drops) should be given. If possible, no analgesic eye drops should be used, as this can delay the healing process. The anesthetic eye drops do not succeed very well in keeping the eye quiet, which can lead to further injury. Moisturizing eye drops and eye ointments are important, yet sometimes this is not possible, as you are unable to open your eyes in the initial phase. Then it must be omitted, but you should at least apply some ointment into the corner of the eye and also the gap between the eyelids. To reduce the risk of infection, you can also consider whether antibiotic eye drops and ointments should be used for several days when there is an occurrence of blisters and erosions.

A respite for the eyes is necessary in most cases. It is enough for most affected to keep their eyes closed, the eyelids then work as a dressing and lead to a natural healing of the blisters and sores. When your eyes are closed, movements are also limited, which reduces the friction on the affected area. Some sufferers find it enjoyable to put a cool damp cloth over their closed eyes. If a dressing is deemed necessary, then the same rules apply as with the other EB dressings. However, it can be difficult to fix such a bandage over the eye. Is it best to practice this at a time where there are no eye problems, so in an "emergency" you will be ready!

Most blisters of this type heal relatively quickly. Blisters on the cornea that are the most painful, usually heal within one to three days. The period of healing appears

brief at first, but if you have to spend it with closed eyes, then this time can seem very long. Distraction with music or audio books can somewhat shorten the time. If it is possible, to open the eyes a bit, or at least open one eye, then television is also fine, but working or playing on the computer is not a good idea. When watching television, the movement of the eyeball is very limited, thus in this case it supports the immobilization of the eye. In contrast, playing on the computer and also with reading, the eyeball is constantly in motion, and this is really bad for the healing of blisters and injuries that involve the eye.

If healing is delayed then be sure to consult a doctor who will then examine whether there is an actual inflammation or some other problem going on.

Rarely some injuries, scars and adhesions due to blisters develop in the eye area, which are not so easily cured. If the eye movement or visibility is severely limited, surgery should be considered.

[Special Topic Refractive Error:](#)

Even people living with EB may suffer from different levels of defective vision. This should be evaluated by an optometrist and treated with a pair of glasses or contact lenses.

If you wear glasses, unpleasant pressure points and thus blisters and sores on the nose and behind the ears may arise. If possible, the glasses should be made of very light material to avoid this. Plastic glasses are preferable because they have significantly less weight. Additionally, it may be helpful to choose a model with a silicone nose bridge, thus the pressure on the bridge of the nose is distributed a little better. The spectacle arms should have a good fit and this should not be overlooked. They should be adjusted repeatedly in children when their head shape changes due to growth. It usually works out well, finding suitable glasses. When blisters and sores develop behind the ear, a narrow strip of adhesive foam dressing material often provides good protection.

The use of contact lenses is also possible when your cornea does not tend to blister. Under certain circumstances, cases of severe defective vision can be treated with surgery. In each case the ophthalmologist must decide which solution is realistic and appropriate for the person in question.
