

Epidermolysis Bullosa (EB) – Complications

Eye problems

In some kinds of EB, the outer layers of the eye can be affected.

- The outer layer covering the eyeball (cornea) can get scratched, torn, or scarred. This can be very painful and may take several days to heal.
- The eyes may be very sensitive to light, watery, or have other discharge (including pus and mucus).
- Children may also have trouble closing their eyelids which can cause dryness during sleep. Eye ointment or drops can help keep the eye wet and prevent more damage.

How to help

- Use an antibiotic eye ointment prescribed by your child's doctor.
- If your child's eye has been injured, using a patch will help the eye heal and prevent more damage.
- Your child may need to have check-ups every year with an eye doctor (ophthalmologist or optometrist).

Dental Problems

Children with EB can often have problems with their teeth and have more cavities than usual.

- In some of the severe forms of EB the tongue may be scarred which can make it hard for your child to eat and swallow and can affect their speech
- Some children may also have scarring around the mouth, which can make it hard to open the mouth wide enough to get a toothbrush inside.
- Not being able to brush the teeth can cause cavities and other problems with the teeth and gums. Children with EB can also have very sensitive mouths and get sores, which can make it hard to keep the mouth, and teeth clean.

How to Help

- Make sure to get a toothbrush with very soft bristles and to brush gently around the gums and tongue to prevent damage.
- It's important to find a dentist who is familiar with EB. Talk with your child's EB doctor for recommendations if you can't find a dentist.
- Tooth sealants, water with fluoride, or fluoride supplements can also help prevent cavities.

Contractures

A contracture is a shortened, tight area of the skin, ligament, or tendon that can make it hard for your child to move. If your child isn't moving these areas, they may have more weakness than usual.

- Helping your child be active keeps the muscles strong.
- Physical therapy and/or occupational therapy (PT/OT) may be needed to help reduce any problems from contractures and to make sure the muscles and ligaments work as they should.

- Swimming is a great sport for children with EB and a good form of exercise. It's ok for your child to swim with their bandages on and may help make it easier to change them. Chlorine is also an antiseptic, which means it can help fight infections and keep infections from starting.
- Playtime and other activities will help improve your child's mental health. Be sure to use bandages with extra padding to protect your child from injury while playing.

Do contractures cause deformities?

Sometimes, children who have severe EB may experience fusing/webbing in their fingers and/or toes. This can happen because of repeated injuries that cause blisters or sores. This fusing/webbing can make the fingers and/or toes "curl down" or look like claws. In more severe cases, the webbing can completely cover the hands and feet and make them hard for your child to use.

How can I lower the risk of contractures and deformities?

If your child starts to have injuries, blisters, and sores to their hands and/or feet, there are things you can do to lower the risk of fusing/webbing.

Helpful tips when wrapping hands and fingers:

- Always wrap up the fingers from the back of the hand and to try to keep the fingers as straight as possible when wrapping. This helps support the fingers and keeps them from curling down into the palm.
- Use a 1-inch gauze to wrap fingers.
- It is best to start the hand wrapping at an early age in severe or scarring forms of EB. This helps make hand wrapping a regular part of your child's routine and may help slow or stop the webbing before it starts.
- Sometimes your child could need surgery to release the thumbs and fingers. Only a hand or plastic surgeon who works with children who have EB should perform this surgery.
- An occupational therapist (OT) can offer hand exercises, gloves, or adaptive devices to help your child maintain hand function.

There is no recommendation to wrap the feet/toes.