

## TEETH

### EBS generalized severe

#### 1. Introduction

Dental problems can occur with different frequencies and different degrees of severity in many forms of EB. In some (not many!) forms of EB tooth damage is hard to avoid, since genetic enamel defects exist. But even with forms of EB where there are no enamel defects, normal dental condition often leads to tooth decay, because oral hygiene can be difficult due to blister formation or difficulty in opening the mouth.

With [appropriate care](#), a [dental healthy diet](#), [regular dental check-ups](#) and [professional oral hygiene](#), damage to the baby teeth as well as the permanent teeth due to caries in many cases is preventable. It is worthwhile in any case - despite all the other worries and problems caused by EB - to pay regular attention to your teeth and their care. When parents and children are well informed and from the beginning a good working relationship exists between the family, the supervising dentist and EB-specialists, the condition of the teeth can generally be positively influenced.



#### Important points in a nutshell

- **Dental care starting with the first tooth is important in EB to avoid many subsequent problems.**
- **It is based on regular teeth cleaning at home, at best twice daily with a soft toothbrush, with a small brush head and age-appropriate fluoride toothpaste.**
- **Find a good dentist as early possible, because professional cleaning and rapid intervention when problems arise is necessary.**

## 2. General Information

In epidermolysis bullosa dental and oral hygiene may be difficult due to blistering of the mouth. The best possible dental and oral hygiene is necessary, despite the risk of blistering, to avoid developing dental caries. A healthy and functional set of teeth is very important for eating and nutrition.

In [Epidermolysis bullosa simplex generalized severe](#) you often have blistering of the [mouth](#). As a result, there can be problems when biting and chewing. The dental hygiene can thus be difficult, and it may lead to secondary damages.

## 3. Options for Prevention of Dental Caries

With appropriate dental [care](#) at home, [a healthy dental diet](#), [regular dental check-ups](#) and [professional oral hygiene](#), the destruction of the milk teeth as well as the permanent teeth due to caries in many cases is preventable.

### **Special Measures:**

Consistent daily teeth brushing/oral care

Regular professional cleaning by a dentist/dental hygienist

Fluoride prophylaxis

The classical [pillars of prevention](#) include "[diet](#)", "[oral hygiene](#)", "[Fluoride](#)" and "[fissure sealing](#)". Fluoride tablets now play a secondary role. More important is the topical [fluoride treatment](#). This includes child fluoridated toothpastes and fluoridation with coatings or gels applied by the dentist. Mouthwashes are only useful if the children have learned to spit the mouthwash back out properly. The nature and frequency of the respective fluoride treatment should be discussed with your dentist. Professional oral hygiene in a dental office, in conjunction with the examination of all teeth should be done at least 4x annually, in severe forms of EB more frequently.

When special requirements are needed, oral hygiene can be supplemented by special mouthwashes such as chlorhexidine. There are chlorhexidine rinses as well as gels; the mode of administration should always be discussed with a dentist. This treatment usually takes place as a short-term treatment for about one to two weeks, which may be repeated periodically as needed. Prolonged use will lead to discoloration of the teeth and an irritating taste left in the mouth. The repeated use

of chlorhexidine about every 2-3 months for a period of 1 week has been proven to be effective in children with EB. A more recent approach is the use of pastes made from a calcium and phosphate base. This has to be used in addition to fluoride toothpaste and is well accepted by most children because these pastes do not irritate the mucous membrane and have a pleasant taste. These pastes (e.g. GC tooth mousse) are only available from dentists or from the Internet.

In addition to the above-mentioned fundamentals of prevention, namely "diet", "oral hygiene" and "fluoridation" is dental sealing of molar fissures. Dental sealing is the only measure which lies solely in the hands of the dentist. For this treatment a plastic coating is applied to the surfaces of the molars (back teeth used for chewing) this can prevent the development of dental caries. The teeth need to be kept completely dry for a short time, which can be difficult when you have a hard time opening your mouth.

## 4. Age Related Information

### 4.1 Infants

For the "primary prevention" of the so-called "[early childhood caries](#)" (formerly called bottle tooth decay) you should pay attention to the spread and [prevention](#) of dental caries. This usually starts with a rapidly progressive destruction of the upper incisors. While it used to be caused by instant baby teas that were offered in the baby bottle, today it is rather caused by supposedly healthier fruit juices. Pure fruit juice also contains fructose which corresponds to approximately a 10% sugar solution. In combination with a very low pH in juices, continuous bottle drinking leads to massive early destruction of the milk teeth. Studies have shown that children with early childhood dental caries that have been treated are still at a higher risk of developing dental carries later in life.

Infants are often found to have a greater acceptance of a toothbrush during the so-called "oral phase" because the mouth is the contact element to the outside world. This is just as frequently followed by an absolute "Toothbrush refusal" phase.

Even with "tooth brushing opposition" consistency is important, it often helps to integrate teeth brushing into a ritual. The objectives in this age group are preventing the transmission of germs and making oral hygiene a "[daily habit](#)".

The bottle should be **weaned as soon as possible**, this is usually around the first birthday and the child should then become accustomed to drinking water from a cup.

In the so-called "window of infectivity" (window for infection), which is the phase where the "milk teeth", primary dentition break through the gums. During this period of time, the child can be infected with caries from contact with the saliva of caregivers, usually their mother. The top priority at this time is to keep the milk teeth healthy. Therefore, an **early examination by a dentist** is important. In this way, the visit is experienced in a relaxed atmosphere and time can also be used by the dentist for educating the parents.

## 4.2 Toddlers

Starting between the ages of 2 - 3 years, most children want to try to brush their own teeth. This is important so that they can learn a certain technique and not lose the desire to brush their own teeth. Kindergarten aged children are particularly susceptible to praise and reward, they often live in a fantasy world that can be supported by stories or songs in oral hygiene. Make brushing teeth fun.

The best way is to always clean with the same technique; we recommend the "CEI" system that is - chewing surfaces 1<sup>st</sup>, then Exterior surfaces followed by Interior surfaces. Tooth brushing should be started as soon as the first tooth breaks through the gums. No later than the 1st birthday a tiny bit of fluoridated toothpaste should be used, at least 1 time a day, preferably in the evening. It is particularly important that the parents help with brushing and check for spots that are missed. When the permanent teeth breakthrough the gums, you should change the toothpaste from a child's to a junior type of paste. Tooth paste containing Menthol can cause discomfort for children with EB. In this case a tooth paste without menthol, yet containing fluoride is a good alternative.

Particularly **dangerous are frequent snacks!**

Even seemingly healthy things such as bananas can cause caries due to their stickiness. If you cannot reduce eating snacks due to general medical reasons and teeth cleaning after every meal is not feasible, you can make do with a little compromise: for example a dental chewing gum, which stimulates the flow of saliva and promotes self-cleaning or at least rinsing your mouth with water between meals and snacks.

### 4.3 Children

It is not until [about 10 years of age that the fine motor skills are advanced enough that brushing your own teeth is possible](#). Electric toothbrushes are from about kindergarten age just as suitable for use as manual toothbrushes. Many children find electric toothbrushes simply "exciting" and are therefore more motivated to brush their teeth. Electric tooth brushes are especially helpful with disease-related limitation of fine motor skills in EBS generalized severe. It is also easier for the parents to use an electric tooth brush when helping the child get spots they have missed while brushing.

However, an effective plaque removal by the child himself is not possible until about the age of 10. Until then, the parents really need to check for spots missed. Good teeth brushing technique and [help from the parents is far more important](#) than the frequently asked question about the best toothbrush or toothpaste to use. True to the saying "you cannot teach old dog new tricks" means that behaviors that are practiced in infancy are very resistant to future changes. It does not matter whether these behaviors are positive or negative. In other words, at this age the foundations should be laid for a good dental health-conscious life.

### 4.4 Adolescents

The closer the children get to puberty, the less parents can influence choices in diet and oral hygiene. With pocket money they can buy sweets and oral hygiene is no longer regularly monitored by the parents. Negative motivation along the lines of "if you eat too many sweets and do not brush your teeth, you're going to get bad teeth" is usually unlikely to be successful. It is usually better to use [positive motivation](#), for example, "beautiful teeth look so attractive".

The aim of these measures is to motivate children from the beginning, so that diet, professional prophylaxis and oral hygiene, at home are included in a daily routine so that as adults the risk of caries can be held correspondingly low.

Another topic at this age can be braces. In such cases, a precautionary approach is recommended. Especially important is a good working relationship with the orthodontist.

## 4.5 Adults

In adulthood, the regular daily dental care, professional prophylaxis and dental appointments should be routine. Problems that might arise in EBS generalized severe should be discussed with a dentist. As with other people it can be that you need small fillings for dental caries. Also necessary treatments like crowns and/or implants and root canal are possible under certain circumstances.