

EB AND SPORT/PHYSICAL ACTIVITY

1. Introduction/General Information

Children and adults with EB will encounter many restrictions in their everyday life. Due to the vulnerability of their skin care it is natural and also required to be more cautious, especially during physical activity. Those affected by EB often express great uncertainty regarding the selection of appropriate types of sport and exercise. It is not very productive, to give up physical activity. Our experience shows that often a lot more activities are possible; more than parents, carers, physicians and the victims themselves initially think, although still not everything is appropriate.

Sports and exercise are generally healthy and are intended to prevent secondary diseases in an existing, underlying condition. This is also true for people with EB. We would like to convince all people of all age groups affected with EB and encourage them to participate in some form of regular sport or activity. Yes you need a lot of will power to extend your own borders, even with your vulnerable skin. It is definitely worth it as you can improve your physical and psychological state both subjectively and objectively.

We cannot give you general advice, as children and adults who live with EB have too many differences. There is an advantage in slowly trying out the possibilities. The individual's interests and capabilities of the affected differentiate in most cases, what is necessary is some assistance, guidance and bravery in order to create a feasible sports program.



Important points in a nutshell

- **Exercise and sport are also possible with EB and an important part of health.**
- **Not all types of sport are suitable for some forms of EB. With a little patience, a way can be found to participate in sport and exercise for each individual that is affected with EB.**
- **It is worth searching for a suitable type of sport.**
- **Exercise and sport are important at any age; however you should start as soon as possible.**

2. Why is exercise so important?

Sufficient exercise is a crucial prerequisite for [good motor development](#), but also for many other processes in our body. An example would be bone growth, which depends strongly on movement capabilities. One's psychological state is also associated with exercise. We now know that the lack of exercise may be the cause of many diseases. This of course generally applies as well for people living with EB.

How the development of an individual occurs depends on its "genetic framework". This framework, within which a person can develop, also contains a certain schedule. It stipulates when and at what speed for example, muscles and bones mature, but also included are the phases of growth and development of the nervous system. In addition to the genetic plan it also depends on the manner of support for a person and the extent to which development options given are actually utilized. This requires sufficiently strong development stimuli to stimulate the maturation processes. Such stimuli are visual, acoustic or tactile sensory stimuli. Also, exercise is a very important development stimulus for the development of e.g. the bones, the muscles, the nerve cells, the cardiovascular system, metabolism, immune system and other organ systems.

For these reasons, it is important to begin a sport and/or exercising as young as possible. The time span between childhood and adolescence is the time period in which increased bone growth and increased bone density formation is carried out. A lack of stimuli due to the lack of exercise programs in these crucial years may lead adolescents with EB (among other causes) to lag behind, which may not or only with difficulty be compensated for. If these problems are then combined with problems of nutrition, growth can actually be reduced and the bones do not obtain a solid matrix. Since our internal development plan is present during a limited time window for certain stages of development, such development phases are very difficult or impossible to catch up too later on. Therefore, exercise and sport especially in children and adolescence is very important and should not be a topic that is always shifted to "later".

Regular exercise supports the structure of the muscles and bones not only in youth but also in adults. This is important for all people, yet for those who already suffer

from a serious underlying disease, lack of exercise can even cause additional problems.

In addition to improving physical fitness, exercise naturally contributes towards an improvement of your emotional well being, for example, in the form of stress reduction, strengthening of self-confidence and it promotes social contacts. In this way exercise and sport also contributes to the overall improvement of your quality of life and is very important, especially in a life with EB.

3. Physical Activity and Sport in EB

In addition to nutrition and good health care, a crucial pillar in the treatment of many chronic diseases is physical activity. Children and adults with all forms of EB tend (understandably so!) to protect their bodies against injuries and blisters, by limiting physical activity. This applies to all types of movement, but especially physical training and sports. Both can certainly pose a hazard, therefore those affected by EB and their parents express a great uncertainty regarding the actual possibilities available. It is not only the parents and those affected by EB, it is naturally the doctors who are also repeatedly uncertain, because vulnerable skin and sports seem to obviously contradict one another. Therefore, from our side we would like to repeat the advice to proceed with caution. All too often for "safety's sake" any physical activity is immediately discouraged. This is partly understandable yet on the other hand the resulting lack of movement during the searching period for a suitable activity can lead to subsequent problems that may be more burdensome than a few additional blisters and sores.

It is clear that it strongly depends on the EB-form, as to what options are now actually available. The heavier pronounced the blister formation is, the more limited you are. In addition, the daily condition of the individual concerned repeatedly changes. Of course you have to be realistic; there are certainly sports that are virtually impossible with EB. With a good companion, a little courage and a few precautions, the boundaries that are often developed with EB can often be set much further than one might initially believe. Horseback riding, cycling, dancing, table tennis and swimming would be good examples of such realistic possibilities. We will review the individual sports and physical activities further on in this section.

In our view physical activity has a growing importance for pain therapy in EB. Of course, it is less about acute pain and more about a preventative lifestyle. If bone can grow well, if the joints remain flexible, the muscles are strengthened and the body generally feels better, then in the long term there is also the "side effect" that less pain may occur.

For example bone pain and joint pain may therefore be reduced in advance. No one can promise you that pain can be completely prevented by sufficient exercise alone. However, if care is taken from the beginning of life on, the resulting pain can probably be avoided by a far greater extent than is imaginable for you today.

In EB House Austria we therefore support our patients from the outset in exploring their own abilities and limitations. Children with EB cannot and must not be overly restricted in their freedom of physical activities, so that they can get to know their limits and develop and improve their body awareness. Exercise and sport should also be a part of life in adulthood for people with EB. Both children and adults suffer from a bad body image which leads to uncertainty and thus reduced mobility and increased risk of injury.

Of course not everything is possible, but too much anxiety is also not appropriate. By being well prepared and taking appropriate precautions such as protective dressings or using special equipment many things are possible. By providing specific advice, uncertainties can be generally eliminated and good options for those affected can be found.

Which physical activity types are suitable, depends of course as mentioned above on the particular form of EB - of the person concerned. Suitable in most cases is any kind of gymnastics, cycling (also on a home trainer), light- weight training, therapeutic horseback riding and vaulting, dancing, swimming and table tennis. Of course, other sports can be practiced.

Each individual should be allowed to try out for themselves what is possible and what their own personal limits are. Depending on the severity of the disorder an individual consultation is necessary, among our patients we even have – though only sporadically - snowboarders and climbers.

Certainly there are limits, and with increasing severity of the disease, the options are very limited. Also the risk of injury can be significant in some sports. In a good context, it is possible to take one or the other risks. Our goal in the EB House Austria is to give people with all forms of EB, in all age groups, courage to participate in more physical activities.

An objective and subjective improvement in physical and mental constitution, more self-confidence and overall improved quality of life are, in our experience, is the best reward for the courage to break new ground and to extend your limits!