

## **Epidermolysis Bullosa as a mental problem**

I have the Simplex form which is not very obvious to others. I have developed the philosophy that everyone has a handicap, and the handicaps that are less visible may be more devastating than the visible ones. Since I look normal, the system does not provide the special attention that is needed to keep me reasonably healthy. A second issue is that since I feel normal, I sometimes do things that are beyond the injury threshold. If I can solve both these issues, then the EB symptoms do not occur. Preventing EB symptoms takes preparation and discipline. Knowing this, I am getting better over time in controlling my environment. Some experiences:

### **Educational System**

Elementary school was not too bad since all classes were in one room with one teacher. The exercise classes on the black playground had to be avoided. Junior and Senior High had foot issues since classes were all over the campus with a limited time to transit between classrooms. I should have gone to the registrar and gotten a specially planned schedule with minimum distance between classes. Physical Education classes just do not work; the expectation is that everyone should participate all the time, not just when they feel like it or it is cold outside. Activities that are on grass are good; sports on hard surfaces are bad. I play softball. Since I got blisters on my hands when I attempted to write long essays, I took the junior high typing class. This was the best class EVER; my fingers did not get blistered and--- with the advent of computers, I had great keyboard skills.

By the time I got to college, I had learned. I selected a college with a small campus; demanded the residence room that was closest to classes; convinced the registrar to give me my selected class arrangement each quarter; and rode my bicycle to class/activities anyway. When I had a car at college, I finally had a discussion with the medical department to get the type of parking permit that allowed me to park in any area, including faculty only. The rules about wearing shoes did not make any sense; there was 100% chance on some days of getting injured because of the shoes, but only a less than 0.1% chance of injury without them.

### **Work Environment**

I was told by my dermatologist when I was 10 years old that I was exempt from the military draft and I should get an education so I could get sit-down job in an air conditioned office. Any job where I was on my feet was clearly out, but even sit jobs have problems. Working at a large work campus with meetings in other buildings is hazardous. I turned down some job offers at locations where the handicapped parking was too far from the work location. Fortunately, over time, Email and call-in discussions became more common. Going out for lunch with the work group was generally not good unless there was special accommodation like pick-up and delivery at the door on both sides. Walking through asphalt parking lots during mid-day is a foot disaster. Of course, the handicapped parking permit is absolutely mandatory for anyone with EB. Buses are impossible.

### **Social Interactions**

“Let’s go for a walk!” “Let’s go for an outing!” Parking is close. Horrors! Decline these best intentions offers politely. Activities such as alcohol, dog walking, tennis, running events, and hiking on warm days must be avoided. Sunburn has two penalties: the burn and the blisters that come with it. Going to any large attendance event is bad due to parking lot distance. I had to get rid of my pride and get a wheelchair at airports and ship terminals, mainly to avoid the long lines. When traveling, there are unanticipated hazards such as distance from the transit stop to the entrance. Beware of the following statement: “It is not far!”. I always ask for actual distances both horizontally and vertically. My worst hazard has been beaches with hot sand. Second worst hazard is going on a walking tour where I am expected to go with a group and keep up with them. I have to live with the embarrassment of parking in a handicapped space and then running to my destination.

### **Medical Treatment**

Prevention of blisters is the best option. EB people should know their limits, especially when the weather is hot or humid. Personal discipline is essential to avoid the blister problems. Naturally, sometimes people want to go on adventures to unknown locations. It is important to plan carefully, and have a backup plan to avoid bad situations. Sometimes, there will be mistakes made. I always have the bottle of antibiotics available for eventual infections. In my case, only a couple of days of pills will stop the infection. Extra padded socks, Neosporin, and bandages are my friends and come with me everywhere. I have learned to soak my feet in cold water (hydrogen peroxide is helpful), change socks, and take off shoes in planes, trains, and cars. With the near-impossible correct mental discipline and preparation, blisters will not occur; hence my comment is that suffering from EB is a mental defect. However, I am still hoping for a cure!