

Tay-Sachs is a terrible anomaly which can affect children as well as adults. I do not know much about children, but in adults it can affect most of the body's systems over time. I have Late Onset Tay-Sachs, whereas an older sister, Ute (two syllables) has it also. Because of her trouble, she was held back a grade in elementary school. I, being one year younger than she, caught up with her in terms of training years and shared with her many of the same experiences going through the first twelve years of learning, especially those in middle school and junior high.

I played with the Balancing Board that our mother hammered together in the basement for Ute. She saw a physical therapist, Dr. Miller, once per week. Also, she had to take the 2nd grade over twice because my parents held her back. They believed this would be the best way to help her. While in school it was very difficult for me because my sister was different but no one knew what she had. It hurt me when other students would make fun of her. I hated it when pupils mocked her because of her lack of coordination but I felt helpless.

During grade school it was very hard for me. I did not understand what was wrong with my sister or how to help her.

As a junior high school student I found out from our parents why my sister was held back a subsequent time in the second grade. Not only was she extremely in coordinated, but she was, also, mildly retarded. Most kids who were at the ages of nine or ten could, understand that she was different for some unknown reason. Children can be very mean and I gave my sister all of the

emotional support that I could.

A good number of the teachers and the staff who dealt with her situation did not know Ute's diagnosis. They really did not understand what Tay-Sachs was. It was a small rural country school in which few had as much education as the workers for the local school system.

I, of course in grade school, did not have the maturity or the education level that many of the adults who had contact with my sister did. She could deal with things such as hall passes on an average teaching day. Like any other pupil she would go to the rest room or any other place in the building where she needed to go. But she was always treated differently and I knew that being made fun of by others hurt her self esteem.

With myself being in the same grade the professional personnel had to keep me separated from my sister. They didn't want us in the same classroom. This was very frustrating for me because I knew my sister needed my help. Therefore, I never saw her except before or after school.

Later when we both were sophomores in high school, the entire family was checked for Tay-Sachs at Cincinnati's Children's Hospital. It was found that Ute had Late Onset Tay-sachs and that I had similar enzyme numbers in my blood, but they did not know why I was so normal. Klutzy but normal when you compared me to my sister, Ute. I was so sad for my sister and equally frightened for myself. Fortunately my symptoms did not emerge until my late 20's. But my sister had

many limitations placed on her because of the illness. This was hard to deal with because I love my sister.

That is how our early life was. Many still do not understand it to this day, especially when Tay-Sachs is mentioned. Yes there are many different symptoms and, depending upon your place in society, you may get the help that you need or you may not. I love my sister very much. Because I too have Tay-Sachs I am very aware of the pain and suffering she has experienced her entire life.