

Disabled persons can also lead a life of high quality

Henn Kungla

In my youth, I was also healthy and full of ebullient *joie de vivre*. I got married. Great kids were born to me. I had a nice profession as a driver. Life resembled paradise.

Things started to go downhill at the age of 30, when my field of vision began to become severely narrower. Diagnosis – *retinitis pigmentosa*. My visual acuity was very good, but it was as if looking through a tube. I had to give up driving automatic machines. It was a great shock, but I did not give up. I quickly re-oriented myself towards other fields of work, where I could manage with what residual vision I had left. This lasted until the age of 50.

I became blind. As if that was not enough, it was accompanied by a hearing loss. I hear speech only with the help of a hearing aid. It turned out that I have the hereditary USHER syndrome that causes deafblindness. That was a real catastrophe for me. I am a technocrat, but very fond of literature and history. I could no longer read. My life seemed empty and meaningless. I was in a deep depression.

Braille helps

I did not throw in the towel yet. Ms Olga Ilgina, a special education teacher of the blind and a fantastic and learned woman, made me see a ray of hope. She lives in the capital herself, nevertheless she found me in the backwoods and dragged me by the hand to the table and made me learn. She taught me Braille in no time. Now I am very happy about it – I can read and write once again. I wrote memories of my studies and other “adventures”, in Braille of course, in order to master it quicker. These have now been published in the book “Student Henn from under the big fir tree”. Since I know Braille, I am much more independent in my everyday life. I have my own phone book and files with headings such as “Info”, “Books”, “Recipes”, etc. in Braille. This way, I can quickly find the necessary piece of information. I also don't mix up jars of jam with those of mushrooms any more, since these now have labels in Braille.

Support from our organisation

I also participate in the activities of the Estonian Support Union of the Deafblind; I am a member of the board. The organisation offers a lot of support. Adaptation courses are organised, people are taught how to cope in everyday life as a deafblind persons. Aid devices are introduced. Psychologists and doctors from the relevant specialities come to talk to us. Government officials explain social legislation. We can share our experiences and give each other good advice. Such meetings are unforgettable and extremely necessary.

Braille and typewriting courses are offered as well. I have learned to use the white cane. My next objective is to learn typewriting so I could also write for the sighted. After that, I'll take on computers. I feel that otherwise I'm going to hopelessly miss out on life. It is possible to learn everything, even when you are blind. All you need is to have a desire to do it and not be afraid of anything.

Worries and joys

Since I have the hereditary USHER syndrome, I worry about my three children and their children. This is why I take part in the Genome Project. There is nothing that could save me, but it will be to the advantage of future generations. Successful research results from various countries of the world confirm that. I believe in it, because microscience is developing at a great speed.

There are many worries, but I am keeping my spirits up. Every little improvement and achievement brings me joy. This is how I defeat my deafblindness. Living an active life among understanding people, life does not seem so dark and bleak. Constant learning makes it possible for disabled persons to lead a life of high quality as well.