

## **Rehabilitation as seen from the patient's point of view**

*By: Torstein Lerhol, Norway*

I will divide my presentation into 3 parts. First I will speak about myself and my basic needs, secondly about my practical rehabilitation and thirdly about my views on travelling as a way of rehabilitation.

I am a 20 year old student from a small village in Norway called Vang. My disorder is spinal muscular atrophy. This disorder makes my muscles disappear gradually. Fortunately the disease has stagnated, and I have now reached a point where I feel stronger than ever before.

I've had, what you can call a very happy childhood. My parents are farmers, and my dad also runs a hardwarestore. I have three siblings. The oldest, is my brother Knut. He's a professional soldier based in Afghanistan. My little sister, Synne, is 15 years old, and has the same disorder as me. My little brother Sondre, is 12 years old, and has in some ways functioned as my personal butler during the years.

When I was 16 years old, I had to leave home to start my further education. When I started secondary school, I had to begin a whole new regime of care. This included everything from 24-hour assistance to physiotherapy. At the new school I made many good friends, that I keep very much in touch with today. Having good friends means a great deal. People that take me for what I am, that accepts me even though I look different, and that make me part of their world, is invaluable. Fortunately, I have been granted such friends.

I have a positive outlook on life, and like to take part in many different activities. I was a football coach for a kid's team, and a member of the board of a local political youth organization. Personally, I think that having a positive

outlook on life has helped me a lot in my rehabilitation. As has filling my life with something meaningful. I don't lie down to contemplate the pain, if you know what I mean. Right now I'm in the middle of my exams in social science, in my first year of a Bachelor. My goal for the future, is to become a teacher.

My life consists of help 24 hours a day. Both the local council and the state contributes to my daily care and rehabilitation. I have physiotherapy twice a week. The treatment consists of stretching and exercises that helps me maintain the muscles I've got left. Most of the daily care comes from my assistants. I am totally dependant on their help for most things.

To function on a day to day basis, I use a respirator that expands my lungs. This has been the single most important change in my life and has greatly improved my quality of life. Before I acquired the respirator, my body had a constant co2 surplus. This meant it was really difficult to get me out of bed in the morning, and I fell asleep during class. I feel I owe my life to the respirator. It gave me my life back, both physically and socially. I remember my fiends were shocked to see me awake in all the classes, they couldn't believe the change in me.

The care and the equipment is what keeps me alive, but the thing that really makes my life worth living, is travelling. Travelling gives me a feeling of mastering and a life experience that is useful in our welfare society. I have seen rich parts of the world, and poor. My most memorable experience with poverty happened during my journeys to Estonia and Poland. Seeing with my own eyes that people hadn't been able to afford new clothes in decades, that their houses and cars were falling apart and the general lack of hygiene, made a great impression. The two countries were still marked by the Soviet communist era,

and had little access for and accept of the disabled. But with the help of good friends and carers, the trips became highly enjoyable.

The next year I travelled to Paris and Edinburgh. These countries were totally different. They were very accessible for the disabled, and the public transport was even better than in Norway. The highlight from the journey to Paris was to be carried by my dad to the top of the Eiffel Tower. This gave me butterflies in my belly, and the feeling of being different disappeared. When I was in Edinburgh, a friend carried me up a spiral staircase in an old tower. This was incredible, but the best was knowing that I have friends that are willing to do such things.

Two years after this, I went back to Estonia. A lot had changed from the last time I was there. The society was much more open, and ramps for wheelchairs was to be seen at several places. It meant a lot to me to see that changes took place in a country that hasn't always looked after its disabled citizens. Last year I went to the USA with my mother and aunt. I have very active parents, that like to participate in many different activities. We went to visit our family in Minneapolis. We were a bit nervous about the ten hour journey and the transport facilities in the US. When both worked out perfectly, I felt that nothing was impossible. And this is my point. Rehabilitation for me, is the feeling of being able to master a lot of the things that "normal" people do. Rehabilitation isn't just physiotherapy and good eating habits, but also the psychological condition of the mind. As long as I can match these things, I can have a good quality of life.

I'm a prime example of a sunshine story from the Norwegian welfare state.