

# How to prepare for an adult life with a neuromuscular disorder

*By Evald Krog, National Chairman of the Danish Muscular Dystrophy Association at Vingsted on 18 May 2006*

Good afternoon etc.

I am now 62 years old and I can honestly say that I was well prepared for an adult life with SMA.

How and why, you may ask.

You grew up at a time when independent living was not at all common.

You grew up at a time when the usual procedure was to lock disabled people up in institutions?

And you grew up at a time when there was no tradition for asking questions like “How to prepare for an adult life with a neuromuscular disorder?”

In reply I can only say: I **was** well prepared and I think much of it had to do with the way people looked at me. I grew up in a so-called ordinary family with my mother, my father and my older brother Henning. Looking back now, I can see that perhaps my family was not so ordinary after all. They acknowledged that I was not physically strong - but apart from not asking me to carry pianos and play football - they demanded exactly the same from me, as they did from my brother.

More than anything else they expected me to behave well - irrespective of my handicap. My handicap was never an excuse for not treating other people with respect. My parents had ambitions on my behalf. Like all parents they wanted me to do well and get a better – or at least easier – life than they had had. They worked very hard in their shop and never had much time for anything else. They never focused on my handicap, and therefore I did not either.

Unfortunately, there are in this world a few – and I hope it is only a few – disabled people who are professional disabled. A strange profession when you think of it! They only want to talk about their disability, how difficult life is and how awful the world is to them. It is very sad.

I think that one of the keys to preparing yourself or your child for an adult life with a neuromuscular disorder is attitude. Your attitude determines it all.

Instead of spending time talking about your disability and feeling sorry for yourself, I recommend that you try:

- Smiling instead of complaining
- Being positive and happy, not always dissatisfied with things.
- In an interview in a Danish radio programme I was once asked: What is the biggest handicap? I answered: In my opinion, it is to be a person who is constantly complaining.
- Try humour instead of grumpiness

I know it is a delicate balance. It is not a matter of saying: “We are like everybody else”, because we are not. There are things we cannot do and places we cannot go, but we are human beings with charm, humour, self-irony and a lot to offer. A positive attitude takes you a long way.

So far I have had a wonderful life – despite the odds, you could say. There has never been a lot of horsepower in me, but I have always enjoyed living. I try to focus on what is possible instead of what is impossible. I prefer possibilities to limitations. However, that does not mean that I do not acknowledge that there are limitations – also in my life.

The technological developments have also helped me along the way. Three years ago I got my home respirator and one year ago I got my stomach tube. These are invaluable aids in my life and have both increased my quality of life.

There is no recipe for a good life. A good life for me is among other things jazz music, lovely food and beautiful women. For others it is jogging, raw vegetables and water. It all depends on who you ask and that is the way it should be.

When you have a handicap of some sort, you experience peculiar and funny things which I am sure do not occur to the rest of the world. I would like to give you a couple of examples:

- ◆ Mrs Wiese taught my class German when I went the Danish equivalent to high school. She was a little too concerned about my health, though I am sure she meant well. She started every lesson by saying: “Sit down! And please, Sonja, close the window - Evald is freezing”.

At the final oral exam while I was in the middle of my presentation of Goethe’s Faust, Mrs Wiese suddenly interrupted the examination and exclaimed: “Please, stop immediately, Evald is thirsty!” The external examiner was a bit puzzled, but I dutifully drank half a liter of water...

- ◆ When I turned 21 I spent 2 years in a sort of a nursing home – at that time there was no personal assistance scheme in existence – and always when my parents came to collect me for a weekend at home, they were very surprised to see the collection of people with all sorts of disabilities. One day while going back in the car my father said to me: “Thank God, you are in such a perfect health”. My father had a fantastic sense of humour!
- ◆ While I was still fairly young I shared a house with a group of people. Among them was Poul Lüneborg. He was blind. When the antenna on the roof had to be fixed, we sent Poul up there. While I was busy giving him directions from the garden, a neighbor came running up to me. She was shocked and really told me off. “What are you thinking of – sending a blind man to the roof?” When she finally stopped to breathe, my answer was: “Well, Poul is the only one of us who doesn’t become dizzy!”

Everybody has potential, not necessarily the same potential, but potential. If you are able to use it, depends partly on the effort you make yourself, but also on the framework of society.

This framework should include the possibility for a disabled person to employ personal assistants. When you have a handicap it is an important step on the way to a good life to have personal assistants. Denmark was the first country to introduce the system, but hopefully there will soon be more countries, Iceland for instance.

Speaking of Iceland, I have to mention that I have visited that beautiful country twice during the last 6 months. The purpose was to help the Icelandic Association of NMDs persuade national politicians that they must introduce both home respirators AND a scheme for personal assistants. I spoke to many people, among others the ministers of health and social affairs and, reportedly, things are now moving in the right direction.

It is not enough that the doctors can put you on a respirator. If you have to stay in hospital afterwards, it is worth nothing. Therefore, I cannot stress enough how important a public arrangement for allocation of personal assistants. Personal assistants enable people with a handicap to live an independent life on equal terms and to join the rest of society without being dependent on their family and friends. With personal assistants you are suddenly mobile and can contribute to society, for example by studying and taking a job. By the way, it is an interesting fact that the personal assistance system is less expensive for society than to have disabled people in institutions.

Personally, I have had helpers since 1969, but the official scheme was not introduced until 1981. The scheme has made it possible for me to do my job in Muskelsvindfonden, to travel the world, and to have a normal life - with girl friends, music, art and all the things that I appreciate.

So if the system is not yet in existence in your country, a way to prepare for adult life is to work for it.

I want to stress that my mission is not to picture to you that life with a neuromuscular disorder is a bed of roses. Far from it! It takes a lot of effort. And no matter how much you try to prepare yourself or your child, there will be disappointments and frustrations.

As I said in my introduction I was well-prepared for an adult life with a neuromuscular disorder. My family was fantastic. They had the right attitude and created an environment for me, where it was natural that I went to an ordinary school and had an education. They did not for a second doubt that my life should be like everybody else's life including girl friends, wife and possibly children.

And nevertheless, I experienced that it was not quite enough: Because some things are more difficult when you have a severe physical disability. For instance, like all teenagers, I desperately wanted to have a girlfriend. I wanted to have sex. I wanted to be confirmed in my belief that I had something to offer. And it took years before I succeeded.

However, my father kept on encouraging me: "Try again! Have you realized how many girls there are in Denmark? Some time it is bound to happen".

So part of the preparation for adult life is to build a considerable sense of own worth and self-confidence. If you have that, you will be able to handle the unavoidable disappointments and defeats of life.

In Muskelsvindfonden we have worked at this, and at the same time we try to give our members a realistic idea about their future life.

Another good thing when you prepare for adult life is to take an interest in things. I have been politically active and have worked for the rights of the disabled for as long as I can remember. I am proud of the results Muskelsvindfonden have obtained. Results that make it easier to live with a neuromuscular disorder.

Finally, when asked the question "How to prepare for an adult life with a neuromuscular disorder" I cannot help saying that a good quality to have or develop is patience. Not one of my own best points, I must admit. However, it does help to be patient. Here I think of the lifelong training of helpers, the everlasting waiting for doctors at hospitals and the repeated proving to authorities that: Yes, I still have a neuromuscular disorder!

I hope that my speech may serve as a sort of eye opener. My message is that life with a neuromuscular disorder is not necessarily a catastrophe. There will be ups and downs, and you have

to make an extra effort, but if you do, adult life with a neuromuscular disorder can be a wonderful life. I can prove it!

Thank you. Questions?