

6th European seminar of the acquired deaf blindness network 1.-5.november 2006

The art of communication – creating solutions on the individual, social and organisational level in the world of acquired deafblindness

QUALITY OF LIFE

PRESENTATION

It's really nice to be back in the Netherlands. Eight years ago I stayed some months nearby the Hague with my husband who worked for a Norwegian company. We had just got our first baby.

My name is Nina Helene Skorge. I'm 40 years old and with my husband we have three daughters; one is 8 and the two youngest are twins of 6 years old. When I was 21 years old I got the diagnosis Usher syndrome. I am born hard of hearing and I combine using hearing aids and lip reading. My side view is between 10 and 20 degrees.

THE WORK

I started to work as a doctor 27 years old and have worked as a GP most of the time.

I stopped working 4 years ago even though my work was adjusted for me in all possible ways. At home my husband contributed and helped me in all different ways to get things done. Nevertheless I became incredible exhausted. After the three children had been put in bed at the end of the day, I ended up sleeping on the sofa the rest of the evening.

To be both hard of hearing and visually impaired, caring for three small children and work as a doctor at the same time was simply too much for me.

It wasn't poor sharp vision that would stop my working career. It was exhaustion and lack of energy that would be decisive to what I had to do. I chose caring for my family and took a break from working life.

FILLING THE EMPTINESS OF WORKING

Much of my identity was connected to having a job and working as a doctor. Making a contribution and being part of the society.

How could I fill the emptiness after not working anymore?

After I stopped working, the energy slowly returned. Gradually I got time and energy enough to be more social with family and friends. I was able to do sports and workout. I could participate in organisation life in my local society. I am very active there. Finally I got enough energy to continue my own rehabilitation, both mentally and physically. This has become the content of my new life.

THE LIFE IN MY FAMILY

I have always thought that our children should not suffer just because I am too exhausted. My portion of energy, however poor, I consider important to save for them and my husband. Having kids require much attention and caring, but at the same time it is good for me to be busy with something beyond myself.

How to deal with the everyday challenge with my limitations?

The practical tasks take more and more time to carry out. It is always a challenge to cover everything.

My daily life happiness is when things run smoothly without me getting too exhausted.

To achieve this, I have learned some survival mechanisms in daily life:

I have to be up to date

We try to keep our house tidy and the children have to take their part. To search for lost things is terrible exhausting. We have a cleaner helping us on a weekly basis. She is our weekly deadline and before she arrives the house has to be tidied and made ready for washing.

I have to be ahead

To save time and energy I have to plan the shopping. There are lots of clothes, shoes and birthday presents to be bought. In our basement I have stored different birthday presents ready for wrapping to all the birthday parties my children join.

HOW CAN I PARTICIPATE IN SOCIETY?

When I find myself in new social settings and surroundings like in a kindergarten, a new school or in a meeting where people are new to me, I use to present myself and tell shortly about my handicaps. I tell that I am hard of hearing and that my side view is poor.

As an example I say: "When you try to give me the biscuits, I will probably not see them immediately. Please instead tap my shoulder first to make me aware of it." I also tell about my need for much light.

I never look forward to telling this because then I ask for attention and I expose myself. But it makes it much easier for people to relate to me afterwards. This openness and information in advance has been a condition for me to participate with people in a social context in my community.

Friends

All my friends are of course informed about my needs so they put on their flood lighting when I arrive. When they redecorate their houses they think of me and say they choose bright colours and more light sources just for me. It's really touching...

Keeping physically fit:

Training is very important to me. It gives me endorphins and energy. I need a lot of that to cope with the never ending pile of new challenges in my life.

Once a week I go to a gym and usually together with one of my friends. I let them pick me up at home and since I have an accompany card they can train with me for free. That is a good deal for all of us. I also meet my best friends once a week to play bandy. I can still hit the ball, and now and then I even manage to score a goal. But of course, that won't last forever.

However the social meeting is the most important part of it, so now I try to figure out what to do when I can't play anymore.

NEW CHALLENGES

About a year ago I discovered I couldn't use my right eye for reading. My hearing is also reduced over the last decades. Then I asked myself new questions. How will it influence my reading and communication skills? Should I consider a cochlea implant operation? What about learning sign language or Braille?

I realised that to find out the answers on this was too big for me alone. I knew I needed help to sort out my worries and find out what to do.

My contact person:

In Norway we have one national centre, Eikholt, and four regional centres working on deafblindness. I called Gunilla, my contact person at the nearest centre. She's an experienced professional and has worked in this field for years. She is very empathic, an essential quality for me. I asked her: "What is wise to do now?"

We met and set up a plan. The plan is a summary of all challenges we could foresee and my wishes. It was a relief to see it on a piece of paper what to do about it and who was responsible for doing the next step.

TO COPE WITH USHER

Living with Usher has been a constant mental pressure because I can't hold on to today's situation. I never know how the progression is tomorrow. It has not been easy and I have had my sorry days.

There are always new challenges waiting for me around the corner. That is how it will be and I expect them to be bigger in the years to come. This requires that I am able to readjust to the new situation, again and again. How can I do that in a good way?

Working with myself I must all the time try to reduce the demands to myself and be realistic to what I can expect from life. I have to focus on what I am capable of and put aside the things I am not capable of.

When I loose one skill it always takes some time until I have found a way to deal with it. Maybe I can still do the same thing but in another way or with some help? My experience is

that the time I use for finding a new strategy should be as **short** as possible. That will take away most of my thinking and worries about the future.

Motivation for change

What has inspired and motivated me to find out how to cope? -

First of all it is meeting other people in the same situation as me. Starting to use the mobility stock was some time a barrier for me. Then one of the guys said: "Using it makes it a whole lot easier to go window shopping." That made sense to me and it was a good excuse for me to start using the stock.

What gives me hope

One expert said to me that "Very few people with Usher become totally blind." Another one said: "A cochlea implant can perhaps make you independent of lip reading."

After being told about the diagnosis in the early years I asked an eye specialist if he thought I could continue my education and he said: "You couldn't have chosen a better education because as a doctor you have so many opportunities."

These are words I can never forget. They are important facts that I can hold on to and that give me hope.

The balance of knowledge

I have realized how important it is to seek information and have the knowledge about what to do. In that way my freedom has increased.

On the other hand it has been a challenge for me to protect me against knowing too much about what is coming. I think it is not necessary for me to face in detail what may possibly happen ten or twenty years into the future. I have stopped asking my eye specialist about my future prognosis; I don't want to know. I am just trying to prepare for the next move.....

My quality of life begins when I am occupied with my daily activities, family and friends. When things pass by smoothly and I am not reminded about my diagnosis. Then it's OK to just be myself.

Thank you very much!