

[ EXPERIENCES FROM  
PEOPLE WITH  
DEAFBLINDNESS ]

*- a Nordic project*

**Narratives of everyday life**

Birgitte Ravn Olesen and Kirsten Jansbøl



# Personal accounts about living with acquired deafblindness

A five-year Nordic project  
focusing on the personal experiences of persons  
with acquired deafblindness

*Birgitte Ravn Olesen and Kirsten Jansbøl*

Translation by Ability Top Translations



Information Center for Acquired Deafblindness, 2005

## **The Nordic Project**

### **Six booklets**

- Theory and methods
- Receiving a diagnosis
- Getting support
- Being active
- Getting an education and work
- Narratives of everyday life

© The Information Center for Acquired Deafblindness 2005  
Generatorvej 2 A, 2730 Herlev, Denmark  
Tlf. 0045 4485 6030  
[www.dbcent.dk](http://www.dbcent.dk)

ISBN 87-990212-5-0

### **Many warm thanks to:**

The 20 informants and their  
willingness to share their experiences.

The interviewers and all the work,  
they put into the project.

The Oticon Foundation, who made this  
project possible by their financial support.

# Contents

About deafblindness .....	6
Peter Villadsen.....	8
Søren Mortensen.....	12
Per Nielsen .....	15
Majbritt Højbjerg .....	19
Agnete Hansen .....	23
Torben Nielsen .....	27
Merete Jacobsen .....	30
Monica Larsen.....	34

This topical booklet is the last of a total of six booklets, the result of the Nordic project collecting the personal experiences of living with a progressive disability from people with acquired deaf-blindness. 20 people with acquired deaf-blindness from Norway, Sweden, Iceland and Denmark have over a five year period, from 2000 to 2004, participated every year in interviews about the practical, emotional and social consequences of having a progressive hearing and visual disability, amongst others because of changing conditions of communicating.

The 20 participants have all wanted the project to clarify how people with acquired deaf-blindness are ordinary people with special needs and it was as a result of this that we developed the eight cases. In the cases, we have asked eight fictitious people with acquired deaf-blindness to talk about typical difficulties they come up against and how they cope with these.

In this way, the eight cases represent different people with acquired deaf-blindness and the ways in which they cope with the physical, psychological and social obstacles in their everyday existence.

## **About deafblindness**

All the persons in this study have all become deafblindness as a consequence of Ushers syndrome, which appears as a combination of hearing loss – which can vary from moderate to total deafness – and the eye disease, retinitis pigmentosa, also known as RP, which gradually destroys the retina. Please refer to theme booklet No. 1 to learn more about Ushers syndrome, hearing loss and RP.

Persons with Ushers syndrome are either deaf and have sign language as their native language or are moderately to severely hearing impaired and have Danish, Swedish, Norwegian or Icelandic as their native language. At the same time they have an ophthalmic disease that progressively restricts their vision over a period of several years. Some become blind, but many preserve some residual vision into advanced age.

Some of the participating deafblind persons understand and define themselves as deafblind, but others understand and define themselves as deaf persons with a serious

visual disorder, hearing impaired with a serious visual disorder or severely visually impaired with a serious hearing disorder.

They all have considerable difficulties in communicating, acquiring information and being independently active due to the dual sensory impairment, even though the majority have some degree of vision and even though the participants with moderate to severe hearing impairment all speak the national language.

For the sake of clarity, this study refers to the participants as “persons with acquired deafblindness or the “deafblind”.

**The titles of the theme booklets from the project are:**

1. Theory and methods – Project outline, theory, methods and empirical data
2. Receiving a diagnosis – Experiences of having a disability and being diagnosed
3. Getting support – The significance of support and advice for self-sufficiency
4. Being active – To be participatory despite a progressive disability
5. Getting an education and work – Getting an education, holding a job and being organised
6. Narratives of everyday life – Narratives about living with deafblindness

## Peter Villadsen

*Peter Villadsen aged 20 is born deaf and has Usher syndrome type I. He has two elder brothers and sisters who are both hearing and seeing. He went to schools for the deaf, which he left at the age of 18 with a part 9th and part 10th grade final exam. He now lives in his own apartment outside a larger city and works as a practical helper in a kindergarden with deaf children. He is severely hit by night-blindness and has a visual field of 20 degrees.*

### **Why can't I do what others do?**

You are asking me how it has been to grow up with a visual disability and to reach the acknowledgement of my disability that I have today. It has been hard, and it has been a long and tough journey even though I am only twenty years old.

My parents discovered that I had sight problems when I was eight. My mother took me to an eye specialist and until I reached the age of 18 I went for a check-up every other year with my mother. At that point I had no understanding of what the eye condition was or what problems it would give me. But when I was in the fifth or sixth grade I became aware of the fact that there were certain things I couldn't do, but that others were able to do. It was in football which I loved to play and which I was good at. Sometimes the ball simply disappeared for me. I couldn't keep up. And the others shouted and would point out to me that it was on my right, for instance, and when I turned to the right I would be able to see it. But the opponents would already be by the ball by then. Sooner or later this meant that I was the last one to be picked for a team. I used to be the first one to be picked when I was younger. It was very painful for me.

During my primary school years I got very sad when a teacher would tell me that I was unable to this or that because of my poor vision. I would be close to tears, why couldn't I see as well as everybody else? Why?

When I was at the eye specialist my mother used to speak to the doctor. She would tell me about their conversation afterwards. Over time, my mother has told me a lot about Usher, and I believe that I was about 14 when she told me that the eye specialist was hoping that a treatment to stop the degradation of the retina would be found within the next five to ten years,

I was fine on a day-to-day basis, and I was very active, especially in the summer during the bright season I was actively involved in many different kinds of sport. So I wasn't thinking about my disability on a daily basis. I suppose I perceived myself as a boy who was deaf.

My parents, my mother that is, started taking part in events for parents with deaf-blind children and once a year there was a weekend event for parents and children. My mother thought I should participate in this as well. There were all sorts of fun things going on, but I felt that I was very different from the other children.

### **My sight got worse and a lot of things became more difficult**

At the age of 15 I left primary school for a boarding school for the deaf. In a lot of ways this became a very exciting time, but it was also a time when my visual disability was becoming more and more prominent as my visual field was getting narrower. I started having problems keeping up in class because the teachers weren't prepared to pay special attention to my visual disability. And I didn't feel like pointing out that I couldn't follow the sign language of the teacher say when he was walking around in the class room, or tell a female teacher that she had to wear a dark top rather than a bright one because I was unable to see her hands and sign language on the top's light background. And I was completely unable to follow group conversations.

I also got problems at the house meetings. I find it hard to follow who is talking when people are sitting around a table. Sometimes it just goes too quickly across the table. And then sometimes when one person is talking I will look at him and when he stops talking I will start looking around to find out who has taken over. It then turns out that the person who was talking just stopped to reflect before continuing. Some of them were paying me attention and would for instance say that now it was my turn to talk, but most people would just continue talking and would forget that I was there. At the time, I was thinking that it was my fault, that it was my problem and that I didn't want to be difficult so I withdrew.

However, I don't have any problems if two people are sitting next to each other so that I can see them both and see that they take it in turn to talk.

During my last year at the school for the deaf, the final year students had to move to a student hall in town and had to manage the cooking, laundry and cleaning on our own.

At the monthly house meeting I managed to implement that you had to stand up when you were talking. It helped. But I had also realised that it was necessary to say that I had a poor vision, although I was feeling very sad inside every time I was saying it.

Otherwise, I was managing well at the student hall. I had no problems in daylight. I cycled to school and went shopping in town and I suppose I also managed to keep my room reasonably clean. I never got the moped that my father had promised me when I turned 16. My parents were unable to believe that I would only use it during the day. I was very disappointed as I was really looking forward to it!

At the school's own student hall I had really good lighting in my room, really proper lighting. But at the room in the student hall in town I would get dim lighting as everyone else. I did know where my things were so I managed to find my way around. Today I realise it was stupid. But we were having a good time in the rooms and you had to have dimmed lights. Quite often I couldn't see anything at all and was unable to see the sign language so I was not part of the conversation. It didn't matter so much as the most important was just being together.

It was also hard at the disco parties – I could hardly see anything at all. One evening there was a girl that I really wanted to get in touch with. We were talking but I was unable to see her signs. So I reached for her hand to be able to communicate with her in a tactile way, but instead I touched her breast. She got furious. I later explained to her how it happened and we are in fact good friends now.

### **There are so many things I would like to do**

You are asking me what kind of education I would like to do? I have been thinking about a lot of things. Most of all I would like to build bridges. I am deeply fascinated by bridges. But I think I need to be better at maths. And I believe it is a long education. I was a trainee at a garage when I was at the school for the deaf. I had been looking forward to it. But I got quite disappointed, as my main task was to put the things that arrived daily away in the storage space. I also had to do the cleaning and fetch things for the mechanics from the storage. This had little to do with the mechanics of a car. It turned out that I wasn't as good at lip reading as I thought. I am using this at home, you see, as it is only my mother and one of my elder brothers who understand sign language. So there wasn't much talking going on with the people at the garage.

When I applied for the job that I have now as an assistant nursery teacher they asked me during the interview if there was anything else I wanted to add about myself. I said no and didn't tell them about my vision difficulties. I am employed on a part-time basis, 30 hours a week, and when autumn arrived I had to speak to the manager about placing my working hours during the bright time of the day. I can't afford to go by taxi every day. I like my job. It is good fun being with the children and I have a strength that only a few of the other teachers have. I understand sign language. I book an interpreter when we have internal meetings. But whether or not I want to become a nursery teacher, I am not sure. I don't want to continue being an assistant. It is too badly paid.

I have a girl friend now. We are talking about moving in together and she would like to have children. I think I would like that too, but imagine if they also get Usher? It would be awful. I wouldn't want to pass that pain onto them. And imagine if I go blind. How will I be able to feed and raise them? No, it will have to wait. On the other hand, I would really like to see my children grow up.

### **I will talk about my vision problems, but not flag it**

But to go back to your initial question, then my conversations with you have been very important for me. Previously, I found it very hard and it was hurting inside of me when having to tell people that I had a poor vision. I have become much better at this. It is perhaps because I have a better understanding of myself now. Three years ago I preferred to deny that I had any problems and now I speak about it openly. However, I am not flagging it.

## Søren Mortensen

*Soren Mortensen is 30 years old. He was born with a moderate hearing impairment and has Usher syndrome type II. He is married to Birthe and now has two children aged 1 and 3. They live in a house on the outskirts of a medium sized town. He is trained as a social adviser and has been employed by the social service department for 5 years. His vision field is now < 20, and he has 6/12 vision.*

### **Loss of freedom**

It is 1st October just before one o'clock. The new social service manager is starting today. All the employees are due to meet her at one. I don't feel particularly comfortable about the situation. I wonder if she will accept the alteration made to my job description as a result of losing my driving licence? Will she accept that I have to use taxis every time I, as a child and youth consultant, have a house visit? Or public transport that I can manage, but it will take much longer and this is time that goes from my working hours? I have to admit that I am quite worried.

During my annual check-up, about a year ago, when the eye specialist told me that I had to drop my driving licence I got very upset and angry. He had pulled the carpet from underneath me. I went home to recover, but called him and told him off. It couldn't be true? My vision was fine during the day and I was responsible. I didn't drive when it was dark. I had adjusted my life to the situation. If for instance I had a house visit during the winter, I would do it on the weekend and during the day. Of course this had an effect on my family, but my wife accepted it. To lose my licence could ruin everything; did the doctor realise that I could risk losing my job? I was furious and got into such a state that I could hardly recognise myself.

Having said this, I have now managed without a driving licence for two years and although I feel my life has changed a lot, it is ok. The worst thing about it is that you are so dependent on other people and that you no longer can be spontaneous – e.g. I can't just decide to drive to the forest with my kids when the weather is nice. I now have handicap transport in the winter to and from the bus terminal to catch the bus to work. If my working hours change, it has to be agreed well in advance, and you can no longer be spontaneous and stay in the office to discuss a case. It feels as if something outside of me is controlling my life. I find this very hard. I have lost some of my freedom. I can't bring or pick up my children from the crèche or nursery school anymore either. That's my wife's task alone now.

## **Anger and bad conscience**

But to take my driving licence away was the right decision. My sight has deteriorated. I feel this at work as well as at home. I have had difficulties reading things on my screen for a long time, but not had the courage to draw attention to it. Fortunately, we have all had new computers, so it is fine now. When I walk from my office out into the corridor, I always stop in the doorway, look to both sides before entering the corridor to prevent bumping into someone. Such precautionary rules are easy to make. It becomes a lot more complicated when there are other people involved.

Last Christmas I had a daft experience. When I walked into the canteen at our Christmas party, all lights were off and there were only candles on the tables. So I automatically put on the lights and straight away there were people shouting that I should turn it off. "It is so nice and cosy with candles", they said. But I responded in a slightly angry tone "then I can't see anything" and then I left. I got angry with myself afterwards for having reacted in such a strong way. Later on, a couple of colleagues came to my office and apologised, said that they had forgotten that I have a poor vision when it is dark. As they said: "You seem so normal".

My sight is also giving me problems at home. I can feel it with my youngest son, Ole, in particular, who is now crawling. I have stepped on him twice by accident. This never happened with Kasper. Initially I get irritated with Ole and then I get a bad conscience. It isn't his fault and I cannot explain this to him.

Sometimes when I am wiping the table after dinner, it happens that I overlook a glass or something like that, so it hits the floor and usually breaks. My wife will get annoyed with me and tell me that I am becoming too expensive to have around. But I am not doing it on purpose. It is just that I don't see the glass.

## **A lot of things are possible when you are open about your problems**

Otherwise, I think that I am quite good at finding ways of coping. When it is dark and I have to get off the bus I walk to the exit and stand behind the last person that's leaving the bus and I walk very close to this person. I am using him as a kind of companion or guide dog. After this I am guided by the streetlights because I know the route, like I know the way to my work. I am unable to cope in unknown territory when it is dark. At my last visit to the vision agency, I decided to get a white cane. I keep it in my backpack, but so far I have only used it twice. It was discovered that I have RP ten years ago. At the time, my doctor told me he thought something that could stop RP developing would

be discovered within the next ten years. He also told me that according to him I only had a mild form of RP. I hope my doctor is right, as I was quite shocked when I went to a meeting for people with Usher syndrome about three months ago. Several were only about five to ten years older than me and were already using the long white cane and had an escort!

My current boss knows about my dual hearing and visual disability. My visual disability wasn't bothering me when I was first employed. But I had problems hearing in the big conference room. Initially, I pretended that I understood everything. That didn't last though. I was misunderstanding too many things. So when I had my three months review with my boss I told her about it. I asked to have an inductive coupler with a microphone put up in the big conference room. She was very positive and asked if I also wanted one in my office and I accepted this. It is helping if I have a client who speaks very quietly. There is also an inductive coupler in one of the small meeting rooms now, and I have first priority to this.

## **Recoil**

But then as my sight was deteriorating and I lost my driving licence I recoiled. It does say in my job description that you need a driving licence in order to make the house visits either in your own car or a company car. I called in sick. I didn't know what to do. After a couple of days, my wife told me that I couldn't continue like that. I had to ask for a meeting with my boss in order to find a solution.

A week later, I called my boss and asked for a meeting. I agreed with my wife that she would be my driver for a whole Sunday a month so that I could plan most of my house visit on that day. And my parents who live in the vicinity would look after the children and make Sunday dinner.

The meeting went really well. She liked what my wife and I were offering to do, but thought that I should make as many house visits as possible during the week using taxis or public transport where I was able to. It has been like this for two years now. My wife has not had to be my driver for work and I am actually happy about this. I would hate to be dependent on her. She has enough on her plate as it is.

*P.S. We now know that the new boss has accepted Soren's altered job description. We also know that the new boss has put Soren in a coordinating role for child and youth cases where he has fewer cases. As a result there are fewer house visits, which continue to be made by taxi.*

## **Per Nielsen**

*Per Nielsen is 35 years old, was born deaf and has Usher Syndrome type I. He lives on his own in a flat in the same small town as his parents and two brothers. The syndrome was discovered when he started at the school for the deaf at the age of 6. He was only told about it when he was about 14. He has completed a technical education and been a trainee for various companies however, due to anxiety and his increasing sight problems he has received a pension since he was 22. He now has a visual field of less than 5 degrees and a slightly reduced sight.*

### **My contact person**

It is 4 o'clock in the afternoon and Erik, my contact person has still not arrived. I was sure we had an appointment just after lunch. Maybe he forgot. I know he is busy. I have been allocated a contact person for 25 hours a week, but I often have the feeling that it is becoming less than that. Perhaps I am just comparing it to how it used to be. Only two years ago, Erik spent almost all his time with me. We didn't count the hours then. We went for walks, did the shopping, played chess, went to visit our mutual friends and relaxed in each other's company. Back then I used to think about him as a friend. We were both part of the deaf environment and we had a mutual group of friends. Erik had the eyes to see for both of us.

Erik is now married and has a child. Of course his life has changed.

### **Very few people like using tactile sign language**

My life has changed too. Sometimes I don't see other people for days. I do go to the few events they organise in the local association for the deaf, but it is as if very few people like using tactile sign language. I get too close to them and become too much trouble. Moreover, the majority is older than me.

Then it is much better to go to the association for the deaf in the capital. It has a lot more members and they even have a youth group. I can make my own way from my flat to the bus stop and I am carrying pen and paper to ensure that I get on the right bus. Erik has taught me the way from the bus stop to the association for the deaf. It has however happened that I have taken the wrong bus home, but with pen and paper in my pocket I can write to people and ask for help.

But after Erik stopped going to the association in the capital it is as if my conversation with the others have also stopped. We do say hi and perhaps even slightly more, but then they continue to talk and I cannot keep up, it goes far too quickly. They can't be bothered to use tactile sign language and then I can't cope anymore. They gradually disappear and then I am left there on my own! No, it doesn't work without Erik.

I miss a real friend to talk to!

### **Fed up with the support aid agency**

It is passed 5 o'clock now, and we were supposed to go shopping. I think I will send him another mail. It might be that the first one didn't go through as the mail programme broke down while I was sending the previous one. It seems as if I have a lot of problems with my computer. I am very pleased with it as it gives me contact to the outside world. I can see just about enough to read with the magnification programme so the computer allows me to be on an equal footing with other people.

But there often seems to be something wrong with the computer. I am really fed up with the support aid agency, and they are no doubt very fed up with me too. I often contact them to find the reason why the computer is down so frequently. This has been going on for quite a while. They tell me that they are busy and they will send someone out, that the man cannot find anything wrong, that I have to be patient, that an engineer is expensive to send out, that a new programme is on its way to me etc. etc. But I want it to work properly, and I would really like to play chess on the computer. It is annoying to have to depend on other people's help.

I could email my mother. She must be back from work by now. She could do the shopping for me. I know that she will then invite me home for dinner, but I cannot be bothered. At the age of 35 I wish to be as grown up as my brothers. I don't want to be sitting at home with my parents. And I think it is hard to communicate with them. My father never managed to learn sign language before I couldn't see the signs anymore, while my mother is good at sign language, but has difficulties with tactile sign language. She is really keen to be in touch with me, but we don't have much in common. My mother is mostly talking about the children of my brothers and I am not really that interested in doing that, as I am unable to speak with them.

There is an answer from Erik now. His daughter needed a vaccination so he forgot our appointment. He is going to be here as soon as possible, but it will be hard to find the

time to do the shopping together so if I can send him a note about what I need he will get it on his way here. No shopping trip today then.

Oh well, I am going on a course tomorrow. It is the third year that I am attending this advanced English course together with other deaf people. I would like to improve my English to take more advantage of the internet. And then it is nice to be with others, although I am sometimes worried that I take too much time from them. Even though we are only three people, it is often hard to keep up and then I feel that too much time is taken from the others to explain to me what is going on. I don't suppose you can ask to bring your own interpreter when there are only three students? I do wish that the teacher was provided with information about Usher as the signs he is using often are far too big and he speaks too quickly. I feel that I misunderstand a lot and then I get hurt. It isn't easy to be me. However, I don't think it is easy for the others either.

### **Interpretation support – a matter of principle**

I am going to the doctor the day after tomorrow. I booked an interpreter two weeks ago and asked to have Monica who is the one that I communicate the best with. She is fantastic at tactile sign language and over time we have developed a number of support signs to describe people and the surroundings which make me feel more comfortable and in control of the situation. I really hope that it will be her. I offered to find an appointment with the doctor that suited Monica, but the principle is that they never promise any particular interpreter. Interpretation for the deaf-blind is a support that all interpreters can manage so the administration doesn't need to make any particular considerations to the individual.

Erik arrives at 7 o'clock. He is busy. He is suggesting that we go somewhere soon. Erik's dad has a summerhouse; we can go there just the two of us. I tell him that it is a good idea whilst thinking that he has been talking about this trip for over a year. He mentions this trip every time he feels bad.

After dinner, I sit down at the computer to chat. Other grown-ups have come back from work now, so there should be a chance to have a sensible conversation. I would like to be in a news group with people who are interested in chess, philosophy and psychology, but most of them are in English, unfortunately, and my English is still not good enough. I really hope that Soren, my best friend from the school for the deaf, will be online

this evening. I need to speak with someone. Just before going to bed there is an email from my mother reminding me that it is my brother's birthday tomorrow. So I need to remember to send him a greeting if the computer will allow me...

## Majbritt Højbjerg

*Majbritt Højbjerg aged 42 is born deaf and has Usher syndrome type I. She is a sign language user. She went to a school for the deaf and has a degree in commerce & office administration. She has been employed on a part time basis as an accounts clerk at an institution for the deaf for a number of years. Majbritt currently has a visual field of app. 5 degrees and 2/60 vision. She lives on her own in a flat in a big city.*

For my 18th birthday my parents gave me money for a driving licence and when I turned 21 they bought me a second hand car. At the age of 25 I hit a cyclist as I was doing a right turn. Luckily, the cyclist only ended up with superficial injuries. But I was horrified. How could I possibly overlook a cyclist? I was so worried that I decided to see an eye specialist. The first one I saw couldn't answer my questions sufficiently and ended up referring me to an ophthalmologist. He examined me very carefully and subsequently told me that I had the eye condition Retinitis Pigmentosa that means that my peripheral sight would become more and more restricted. This could be the reason why I did not see the cyclist. When I asked to what extent the visual fields could be restricted, he replied that they could be reduced until there was no vision left, but that it is hard to predict how each individual case develops.

### **The diagnosis represented shock and grief**

The doctor then asked me if I had trouble seeing things in the dark, but I didn't respond to this question. I was totally shocked that I had an eye disorder with consequences like the ones he had described. I left the eye clinic, went down to my car and decided to leave it there and walked all the way home. I was all on my own when I got home and didn't know how to handle the information I had just been given. So I called my mother on the text phone. She became just as upset as I was and we both cried. Neither of us knew anything about Usher syndrome type I.

I called in sick and wandered around restlessly for several days, altering between crying and being angry that something like this had to happen to me. I slowly started to think about the eye specialist's question about my ability to do anything when it was dark. Yet I was unable to find an answer. I was thinking about my life so far. It was true that it was only in the summer that I was out till late, while in the autumn, winter and spring I was always inside when it was dark. When I went to the school for the deaf and later at the business school I had been out in the evening in the summer, but when it turned dark, I

had to do my home work and study, so I didn't have time to go out in the evening. Then I suddenly remembered something from when I was a child, maybe four or five years old. I was sitting on a bench outside our house. My mother came out and called me from the top of the stairs and asked me to come in. But I wasn't able to because between me and my mother who was standing under the front door light, there was nothing, only darkness and I couldn't enter this. My mother called me several times, but I couldn't move. Eventually, she came and picked me up, took my hand and together it was so easy to walk into the nothingness.

At that time, at the age of 25, I was wondering why I hadn't seen the pattern in my behaviour earlier. Upon reflection, I realised that I had always managed to arrange for someone to pick me up when I was going out after dark. A strategy I had adopted subconsciously. I found the telephone number for the association for the deaf-blind but didn't use it.

### **I prefer the company of other deaf-blind people now**

I only called the association for the deaf-blind several weeks later, and even though it was awful to acknowledge that my sight progressively would become poorer, it was also a positive experience to get to talk with other deaf people who had sight problems. In the first couple of years I was using the association for the deaf-blind a lot, or rather two of its members, two women a bit older than I. We got on very well.

But I continued to go to the events organised by the association for the deaf as it was where I belonged at that point. I don't go to the association for the deaf anymore I go to the association for the deaf-blind because I can no longer follow a conversation in the association for the deaf. They speak far too quickly and I can't manage to see who is talking, and then they use such big signs which I can't see in my restriction visual field anymore. It was also hard to see the facial expressions. No, I now prefer to sit quietly at home with a friend.

### **My mother's death resulted in poor contact to my family**

My mother died a year ago after being ill for a short period. It was terrible! My mother and I were so close. And it was through my mother that I had any contact with the rest of the family, especially my two sisters. It was my mother who understood sign language. My two elder sisters never really learned it. And no one else in the family understands. So it was not only my beloved mother that I had lost, I had also lost contact to the whole family. It was a hard blow and a grief that I am still recovering from.

My flat has been redecorated in the last six months. Light walls and proper lighting in all the rooms. The vision agency has been a great help in this instance despite my previous bad experience with them. I fell out with them the last time, I needed my magnifier exchanged, my CCTV. They didn't want me to have the best CCTV, the one that allowed me to see the most, only a cheaper one, which I had trouble using. As I use CCTV both at home and at work it needs to be the one that gives me the best vision. I insisted on wanting the one that allowed me the best vision. And I got it. It was unpleasant to have to fight with them though.

My contact person whose name is Grete has helped me buy new furniture. I inherited quite a lot of money from my mother. Grete is really good. She understands that she needs to be my eyes and ears. She tells me what she sees and is good at asking what is on my mind when we are out shopping for instance. She is neutral and unlike my previous contact person, she is not trying to influence or control me. It has been really good buying the new furniture with Grete, but she is also really good when I need new clothes. She asks me what I want and then she finds the various things, e.g. a skirt, and then describes the colour and the cut. I would never use an interpreter in a situation like that. An interpreter is only there to translate not to find different things and describe them.

I use an interpreter when I have to go to the bank, the post office, the doctor, the dentist, to the vision or hearing agency – or otherwise when I have to communicate with hearing people. I don't use one at work as there is always someone there who can interpret for me. But you have to make plans, and plan well in advance as there is a shortage of interpreters so you have to book one several days in advance. Unfortunately, you cannot be spontaneous.

### **My job means a lot to me**

I have always been good with numbers and when I was studying commerce and office administration it was the accounts side I was focusing on. I was a trainee at Sofiegaarden, an institution for the deaf, and was later offered employment as an accounts clerk. In the administration, where I am working there is only a few who understand sign language, but I did go to an oral school for the deaf. This is a school where you learn to speak Danish, so my Danish is ok, and I was particularly good at lip reading. So for many years everything was going well and at lunch in the canteen there were lots of other deaf people that I used to be able to talk to.

But with my vision getting progressively worse, it became more and more difficult to maintain an overview of the accounts. Fortunately, the technological development has been on my side. So as my vision deteriorated I was offered CCTV, a PC with a magnification programme and much more. But it was hard to work eight hours a day under such circumstances and at some point I asked for my working hours to be cut down. I succeeded in doing this and for several years now, I have worked three days a week from 10.00 to 15.00. And in addition I have handicap transport to and from work.

Three years ago, Sofiegaarden's budget was cut dramatically and at the same time, my vision had been severely reduced. I was working far slower than previously. They asked me if I wanted to be transferred from normal employment to a role where I would be better looked after. Initially, I felt really sad, but after a while I was relieved as I was aware that I was starting to work very slowly. I can only see two numbers at a time now, so it takes an awful long time to get an overview of any accounts. Still, I am very pleased with my job, It means a lot to me that I have to work three days a week on something that I am good at although I am a lot slower now. There aren't many people left at work that I can talk with as I now use tactile sign language and I don't have eyes to lip read anymore. But there is someone there that I always have lunch with.

### **Leisure activities**

I don't have a lot of leisure activities. The days when I am working I come home very tired. I cook, read the paper and respond to emails. Once a week I will clean or do the laundry. When your vision is as poor as mine, everything takes an awful long time. Twice a week I will do the shopping with my contact person. When I return from my shopping I have to touch all the groceries and put them away in their appropriate places in order to find them again, I also like going for a walk and to have a little exercise. This I do with my contact person. I spend a lot of time on the computer. I write a lot of letters and have many email contacts. I invite a friend for dinner about every other Saturday and I often have visitors for coffee on Sunday afternoon. And then I spend a lot of time planning. Planning transport to and from work, planning a visit to the bank etc., book my interpreter, make arrangements with my contact person to do this and that. So my spare time I spend on the computer and doing the planning.

But I miss the contact to my mother and miss hearing how everyone else in the family is.

## Agnete Hansen

*Agnete Hansen is 49 years old. She has Usher syndrome type II which was discovered when she was 45. She lives in a flat on her own in a small town that she only moved to a couple of years after her husband died seven years ago. Agnete was born with a severe hearing impairment which meant that after three years at a normal school she had to be moved to a school for the deaf and severely hearing impaired. She has no further education. Agnete married young and has two children, Lisa and Jan. For a time, she worked as a child minder. Today she has a visual field of less than 10 degrees and a vision of 6/36.*

### **Once I walked off the problems**

It is autumn. I woke up early, but stayed in bed enjoying the warmth. Why get up when there is nothing I have to do? Today is a peaceful day. There are many of those. Sometimes I feel lonely, but then I call my mother. We speak every day. Fortunately, I have an amplifier on my phone without which I could not use a telephone at all. It also happens that I call my sister, Inge, with whom I still have good contact, or maybe Aase, my good friend from where I used to live. Sometimes I get really sad. Sad because I live alone and am so far away from my children and family in general, and because I can no longer walk off the sadness in me.

Previously, when I got angry, irritated or sad, I would go for a long walk and it felt as if things sorted themselves out as I was walking. It was probably because I had time to reflect and look at things in a different perspective. But now I cannot just put on my coat and go for a long walk. Well yes, there are two small routes that I can do on my own. But that is not enough. Sometimes, I feel imprisoned. Perhaps I should say yes to a contact person so that I could get some exercise and be physically active a couple of times a week.

Life has become quiet. I rarely go out and hardly have any contact with other people. Yes, I am in good contact with Birgit who lives on the third floor, but then when she takes me to an event in the community centre, I can't really follow the conversation if there are several people talking at the same time. And they do. It is much better one-to-one and by telephone.

## **I felt stupid**

I recall when I was a child minder, surrounded by small children I was constantly feeling tired and irritable as I couldn't quite hear or see what was going on. I am glad it isn't like that anymore. Often I just felt stupid – and Bjarne, my husband got annoyed. He often said that when he asked me a question then I would answer something totally different or not at all. Also, I was clumsy, stumbled over toys on the floor or Bjarne's shoes if he hadn't put them away. I still remember with horror a barbeque given by one of Bjarne's colleagues. Because I was so keen in my attempt to hear what people were talking about I ended up putting all my food on the table cloth next to my plate. On our way home, Bjarne told me off and I felt so stupid, so very stupid. Not until much later did I discover that my vision was restricted – especially in the dark.

Today I am happy that I know my diagnosis so that I can tell others and ask for help when I need it. It sounds easy, but I am still practising. Asking for help or asking others to pay special attention is very hard. When is it reasonable to do so? When am I causing trouble? When am I allowed to cause trouble?

When I am with other people, I am constantly considering if, for instance, I can ask for strong lights to be on during dinner when the others are enjoying the candle light? I am also considering if I have the courage to ask Lisa not to bring her children when she comes here, at least sometimes. I can't hear properly when the little ones are running around. Should I ask for a contact person although I can usually cope without? It would give me the opportunity to shop in other places than the mini market and to go for long walks and perhaps even go to the bingo again. On the other hand, I can manage without the bingo and the mini market has most of what I need. But can I live without exercise?

## **It is easier when you only have yourself to take care of**

I have been on quite a few courses for the blind over the years, and it was on one of those that I met Jens. It was so lovely to have someone who understood my vision difficulties, and Jens and I became very fond of each other. I was on my own, you know, a widow, so I moved in with him. Unfortunately, it only lasted for a couple of years. However, I was lucky to get this nice flat, and then I am thinking that things are so much easier when you only have yourself to take care of.

When I first moved into this flat, I also tried to get onto the labour market in a town

close by. However, that trial was unsuccessful as the company wasn't able to accommodate my special needs. I so wanted to get out and be active, now that I was on my own again. But it required too much of me. There was quite a lot of noise in the work place and it was very tiring not to be able to pick up the words and having to ask for things to be repeated. And the lighting was poor. I became more and more tense and started having back pain and pain in my legs. It often made me irritable, tired and impatient. No, I think it was probably a good idea to give up wanting to go back to work.

After having had breakfast, I enjoy being on my own. Everything is where I put it and I have good lighting now which allows me to do everything in the kitchen. I had very good support at the vision and hearing institute with decorating the flat and getting proper lighting. But I miss my analogue hearing aids. It is incredible that you can't get them anymore. That you can only get digital hearing aids now a days and I find it very difficult to get used to them.

When I don't have any particular plans I usually go online after breakfast. I just want to check if any of my friends, also from the courses for the blind and deaf-blind have written to me.

### **I met an internet shark**

Initially I didn't want a PC or learn how to use one. But then 3 years ago I took a course for the blind. This was how I met Karin who despite being older than I was a real internet shark. I noticed how Karin was writing and receiving emails, and how easy it was to read the text on the screen as everything could be enlarged. Arriving back home, I applied for a PC and for some lessons in how to use it. This is almost three years ago now. Still it took me over a year to really get to use the pc. It took a while for the application to go through and then when it was delivered it was not installed. A man from the support aid agency had to come and do this. It took a long time for him to come, and when he finally arrived it turned out that the magnification programme was missing. So I had to ask for this and eventually got it.

I was then offered a course in learning how to use the computer, a course specially made for people with acquired deaf-blindness. Yet at that point, I found that it was too far away. So I was offered a tutor to come to my home instead. I was very happy about this until it turned out that this man also was hearing and visually disabled, which meant

that it became very difficult for us to communicate. But then about a year and a half ago, I accepted a course for the deaf-blind and since then the computer has been of great importance to me.

### **Insecurity is my true companion**

The door rings and the bell flashes – it is the housemaid who comes flying through the door. She has been allocated to me for 45 minutes every two weeks to take care of all the cleaning that I can't manage to do myself. It is so little that it hardly seems worth it however; I use her for the things that I can't see myself. I want my home to be clean and to look immaculate myself. That is why I change clothes every day to ensure that it is spotless. It is difficult to distinguish colours, but on a course I attended, I was taught how to put my clothes together so that it matches and so that I can find it again. Nonetheless, insecurity is my true companion.

After lunch I often go to the little mini market, which is, 200 metres left of my front door. I always do this in the early afternoon when there is less people in the shop. I know where to find things in the mini market and how to find my way around on my own. Normally I manage to find everything quite well, but sometimes they move things around and I have to go and ask for help at the till. It almost went wrong once. I had asked for cooking oil and arrived home with lamp oil, which I was just about to put on the pan when I suddenly realised by smelling once more that something was wrong. Usually they are very helpful.

When I get back I have a coffee and listen to an audiotape. I read a lot of books this way. And then there is the television. I follow many series and programmes, but they have to be in Danish, as I cannot read the subtitles. Yet with the inductive coupler I manage to hear and the screen magnifier allows me to get the main picture.

I usually don't make a fuss about dinner. In the evening, I might watch some more TV, the news at least, or might read some more in my audio book and then it is almost bedtime and another day has come to an end.

# Torben Nielsen

*Torben Nielsen is 53. He has Usher syndrome Type II and was born with a severe hearing impairment. Torben and his three brothers were all technically trained, Torben trained as an electrician. He worked in his field for 20 years after which he was forced to stop due to his progressive loss of sight. At that point he was already a member of the association for the blind. He used to have a car when he was younger, at the age of 35 he started using a walking stick and at 40 he got a guide dog. His field of vision is less than 5 degrees on one eye now, and he is blind on the other.*

At one of the weekend courses for the newly blind he participated in, just before he had to stop working for his company, they presented the latest computer for the blind and partially sighted. He got excited about this and Torben now sees the computer as his saviour.

When his job as an electrician came to an end, Torben fell into an existentialist crisis. He is telling how he worked himself through this by committing himself to learning and researching the possibilities the computer was offering to the blind and visually impaired. Two years later, the institute for the blind employed him as a computer instructor. His is still employed by them, but for the last two years, he has been preparing himself to stop working there and to retire.

## Family life

I am married to Inger who has a part-time job as a legal secretary. Together we have three children aged 28, 25 and 16 – the youngest is still at home. Inger also has a hearing impairment and we met each other through the association for the hearing impaired. Like everyone else we have had our ups and downs, but all in all we have a good life together. In the association for the hearing impaired, I also met Soren, and he probably means as much to me as Inger does. Soren's wife and Inger are fortunately also good friends so we have been sharing good and bad times for many years. Soren is also my contact person. It works well.

We have a house and live in walking distance from my parents. It has been very valuable to have my parents close by. My poor reading sight has meant that I haven't been able to help the kids with their homework so this has become my father's job. A job that I think both he and the children have enjoyed.

Although I have been unable to help the children with their homework, I have always made an effort to keep up with their schooling. I have attended parents' evenings and at the time when my youngest son was mocked by his mates because they thought I looked strange, was unsteady in my step and didn't react when they said hello to me, I called the teacher and asked if I could come for a visit to talk about my hearing and visual disability and show them my support aids. This stopped all the mocking.

Both Inger and I are social people so we have many friends, both individually and together, that we see on a regular basis. I think it is true to say that we have a good network of family and friends.

### **Work life**

Initially Inger had a full-time job so we were sharing the practical chores in the house. At the time when we had our last child my eyesight had become so bad that I could no longer handle my share of the housework. Inger had to take on more and more things so in the end we decided that she should ask to have her working hours reduced at the solicitor's. This was accepted which is good, however, I do miss the days when we did the shopping etc. together. Inger does this on her own now, she thinks it goes too slowly when I am with her. I am still in charge of a lot of the cooking, though, and I am enjoying it.

Outside of the direct work with blind and visually impaired users, my job involves a lot of travel to provide tuition to the individual blind and visually impaired people in their homes and lots of meetings in other agencies. Previously, when my sight was better I managed without any problems – 'ish – the daily commute and also travelling to certain towns I knew already. I only use Soren as a companion when travelling to unknown places.

I feel that I am still coping well with the direct client work. And the actual meetings at the agencies also used to be fine. I have always prepared myself well for the meetings, partly to be able to cope with the unexpected, and partly to have the concentration required with my impaired vision and hearing. I was good at lip reading and this got me far in official meeting. There was an agenda and usually also someone to chair the meetings to prevent people from speaking all at the same time.

At some point I thought that my hearing had deteriorated as well because I was finding

it more and more difficult to hear anything in the meetings. I had my hearing checked and it turned out that the hearing impairment was unchanged. The eye specialist did however discover that apart from a further reduction of my visual field, I also had the initial stages of cataract. This was the reason for the decreased 'hearing' as I was unable to lip read as well as I used to.

As a result I decided to bring a voice interpreter to important meetings.

On the other hand, it is many years ago since I gave up following the conversation at lunch or during coffee breaks. So I haven't really been able to keep up with all the gossip at work. I miss this. It is becoming harder to have a real sense of belonging.

As my vision has decreased, it has become harder and much more tiring to cope with the travel. I no longer go to unknown places on my own, but will use Soren every time. The daily commute has also become exhausting. I get a stiff neck and shoulders in my attempt to find out if there are any changes or dangers in my surroundings and as a result I get bad headaches and ringing in the ears. I have talked to my doctor about it. He thought that I was stressed and offered me some tranquilisers. I am scared of taking anything like that as I wouldn't want my senses to be affected. I need optimal use of my senses in order to cope and need to be able to concentrate on my work.

The doctor also said that I ought to retire, so I am considering this. The alternative would be to have a contact person all the time, but I find it hard to image being so dependent on other people on a daily basis.

And I guess no one believes that you can stay in employment until the age of 65 if you are deaf-blind or have a severe hearing or visual disability?

## Merete Jacobsen

*Merete Jacobsen is 57 years old. She has Usher syndrome type II and a severe hearing impairment. She is married and has three children living outside the home. She and her husband live in their own house in a suburb to a large city. They also have a summer house. Since her first year in primary school she has received special tuition in lip reading to compensate for her impaired hearing. She has a degree in commerce & office administration and was in employment until she had her children. She was a house wife for 14 years and then had another couple of years of employment. She has a 6/24 vision and a visual field of 2 degrees.*

### **My freedom is being restricted as the years go by**

Since I was young it has always been of great significance to me to be able to decide to do or not to do something. I remember that when my husband said that he thought we should get married – yes he was indeed proposing properly – I wasn't sure although I did love him. To get married meant a restriction on my personal freedom, I thought. Was I prepared for this?

We got married and have been for 32 years. We have three children and that part of my life has been good. No doubt about that!

### **I fight to keep my independence**

I managed well at school. I became incredibly good at lip reading so when I could see the person who was talking my hearing disability was of no significance. But I wasn't doing very well in ball games. As a child I went to see an eye specialist regularly as it felt as if there was something wrong with my eyes. But the eye specialist didn't discover anything. I got reading glasses at the age of 30, which didn't really help me. Only about 10 years later did I watch a TV programme about Retinitis Pigmentosa, during which the doctor invited anyone who had the symptoms he was talking about to get in touch with him. I did and it was made clear to me that I had Usher syndrome type II. It was actually a relief to be diagnosed and to better understand the problems I was experiencing on a daily basis.

After finishing my degree I got a job as an office clerk in a large company and I was doing well. Then after I had my children, three with a two year gap, I was a house wife until the youngest was eight years old. I was offered a refresher course through rehabilitation

and went back to my former job on a part time basis. Shortly afterwards, unemployment came inevitable and the company asked all the people with disabilities to apply for early retirement. I had no choice but to do this, but was sad about it as I was still good at my job and I was enjoying being with other people and to get away from home.

Practically coinciding with ceasing my employment, my vision deteriorated significantly and since then - that is over the last ten years - is has become progressively worse. I am able to see very little now, but I am fighting and fighting to keep my independence as much as possible.

### **Everything takes longer**

I get up early to make the most of my day and to avoid getting stressed. All practical tasks take much longer when your vision is poor and I often don't feel I have the time to do all the things that I need to do. It takes a lot longer to do the dishes and especially to put everything away. It takes longer to find out what is missing in the fridge and the kitchen cupboards. It takes much longer to cook and to make sure you are using the right ingredients. It takes much longer to do the cleaning as I have to clean all over. I cannot see the places where I might not need to go. I have almost removed all ornaments from our home. They are only trouble, not purely because they have to be dusted, but also because I can easily stumble into them. More and more we only have exactly what we need. Everything else has been ditched.

We have lived in the same house for 30 years so I am very familiar with the area and have always enjoyed going for walks in Vestskoven (the forest), which is just behind the house. I know all the paths in and out, so I am still able to go for walks on my own. But if I meet a neighbour in the forest I have to be careful not to turn around to better hear them because then I might lose my sense of direction. I have done it a couple of times and I get so miserable and angry with myself.

If I focus I can still manage to walk to the subway station, but it is the same here. If I meet someone who wants to talk, I really must look carefully how I am moving my feet around in order to hear so that I can find the right direction afterwards.

### **Rather go home hungry than have a contact person**

I use the subway to go the vision institute where I go once a week to attend a class on Braille, and then I use the subway when meeting up with my rambling group. We meet

every Thursday at 11 at the central station, and from there we go to a place where we then walk for two or three hours. They are very good at picking me up from the platform and to give me a hand. During our walks, I walk by myself just behind the others. But lately it has become more difficult and I have been thinking about stopping in the rambling club. However, I would prefer to stay otherwise this becomes yet another thing that I can no longer manage and I have been part of it for nine years.

Adjacent to the vision institute there is a nice café, which I have been told, have good food. But I am unable to cope on my own with such things, so I always leave hungry. In a case like that it might be good to have a contact person. But no, rather go home hungry.

My husband and I have both always been physically active. We go skiing every winter and during the summer we go for long walks. We also used to go skating at the ice rink in the neighbourhood. But this I can't do anymore due to my sight. Once a month we meet with some good friends of ours. We go for a long walk together and then we go to a nice restaurant for a late lunch. I enjoy eating out.

No matter where and who I walk with, I always use walking sticks. It is a good support when you don't see that well.

### **Social gatherings can be a trial**

We frequently see two couples from my husband's previous job. I think it is demanding, but I am doing it for my husband's sake. When you meet for a dinner like that, then the lights will be dimmed so I can't see very much and I am scared about bumping into things and even break them. I always bring a small table lamp so that I can see what I am eating, but I can't hear any of the conversation at all. Well yes, one of the men has a voice so I do understand what he is saying. But otherwise everything just happens over my head. It is no pleasure at all, and I am always happy when it is over.

My husband and I used to go to events in the skating club together. But these days I get nothing from it. There are too many people so my husband goes by himself now.

I prefer to have guests when we are at our summerhouse. We will sit on the terrace where the light is good or walk down to have a swim. There are so many other things to do there than talking. I like that. One of my sayings is that I hear a lot better in daylight.

But now it often happens that I can't even hear in daylight, as I can't see enough to lip-read. This was the way I used to hear. There are very few people left whose speech I can hear and understand. It is awful. Fortunately I have a neighbour whose voice I do understand and we enjoy each other's company. We take it in turns to meet at each other's house for a nice cup of coffee once a week.

### **Life is shrinking all the time**

I used to spend a lot of time reading the paper. I liked keeping up on what was going on in the world. Now I can only read the head lines with a magnifying glass. I will get a magnification tool, a CCTV, next time at the vision institute, but even with that it takes an awful long time to read. I am not as knowledgeable at all as I used to be. I have an inductive coupler for the TV so I can hear the news, but I don't get all the background information that I used to read about anymore.

And my husband now does the shopping that I was in charge of before. He thinks it takes too long when I am with him. Still, I will insist on coming with him sometimes.

My visual impairment is frustrating. There are a few surprises now and then when I suddenly can't do things that I used to be able to do. Not so much at home as I know where everything is. But when I go to town or walk around in the area then there are sometimes surprises dependent on where the sun is and whether it is overcast or raining. So one day is not like the other as my vision varies according to the weather. As a result, I feel more or less anxious depending on where I am going. Little anxiety if I am going somewhere locally, and lots of it when going to town.

I have to remember very careful to bring all the necessary support aids in my handbag. That is two kinds of glasses, a magnifying glass and batteries. My sunglasses hang in a string around my neck so that I can quickly put them on if blinded which often happens. And then my white walking cane in my hand and my wide-shadowed cap on my head.

No, life is shrinking all the time. I used to be able to do so many things on my own. It is becoming less and less now. Being dependent affects me in a negative way. I get depressed and in a bad mood, and I get angry easily. And that always feels very sad!

## Monica Larsen

*Monica Larsen is 61 years old. She was born deaf and has Usher syndrome type I. She is a sign language user. She lives on her own in a three bedroom flat in a small provincial town. After she finished at the school for the deaf, she moved back to the town where she was born and where her parents were still living. She got a job in a factory. Monica was married at the age of 24 and had her first child, Kasper, two years later. At this point, she stopped working. With a gap of three years, she had another two children, Ilse and Grete. App. 13 years ago, her husband died after a short period of illness. Monica Larsen's field of vision is now approx. 5 degrees and she has 6/60 vision.*

I am feeling a little sad as I have just said goodbye to Lene Høst who has been my interviewer in a Nordic project that has been collating the personal experiences living with a progressive disability from people with acquired deaf-blindness. I have taken part in six interviews for this project over the last five years.

Initially I was reluctant to participate. What would it mean to be interviewed once a year for five years? Did I feel like it? What would it involve? And how could I contribute to such a project?

Today I am happy that I agreed to take part because I have had the opportunity to look at my life in a larger perspective through the interviews, notice how I reacted in different situations and how I wish I could have reacted knowing what I know now.

The first interview was very frustrating. Lene Høst had brought a professional interpreter with her while I – to be on the safe side - had asked my daughter, Ilse, to be an interpreter. Lene Høst insisted that we used the professional interpreter so Ilse was let off. Ilse and I have developed many support signs, though, which give me information about the environment and the environment's reactions in the meeting. But during the course of the interview I found the communication with the interpreter satisfactory. She was good.

### **It isn't easy to use your family as interpreters**

My daughters, especially Grete have been my contact to the hearing world for many years. But all three of them, Kasper also, have been happy to turn up whenever I needed an interpreter. When the children were young, my mother was the interpreter. Initially,

it was fine, but she gradually wanted too much control. I had to use her as an interpreter and companion when I went to parents' evening at the children's school for instance. The meetings took place in the evening when I couldn't go out on my own because of my night blindness, and even though I was good at lip reading, I was unable to discuss things in depth with the teachers without an interpreter.

When my mother was interpreting, she often ended up talking much more to the teachers than she was translating for me. When I asked her what was going on, she would tell me that it wasn't important. Then at other times when she wanted to make decisions about the children's education, she would refer to something that the teachers had said at the meeting which of course I didn't know anything about. I often felt both anger and despair, but I had no idea what to do. I needed my mother as an interpreter. I was really keen to meet other deaf people with hearing children to talk about how to manage education for your hearing children when you are deaf yourself.

Furthermore, I need help to say no to my mother without hurting her. For several years I felt very desperate. My husband didn't want to get involved. He insisted that while he was making the money I had to take care of home and children. Just imagine that I had to reach 50 almost before my mother's criticism no longer had an impact on me. But at that point, my children had taken over the interpreter role; I wasn't dependent on her anymore.

### **My vision difficulties have had consequences**

When the children were small, my vision difficulties weren't that big, however, it did have an impact on our lives. Because of my restricted peripheral sight I had to look down all the time to avoid stumbling over things lying on the ground. Still, I often stumble. And I have been night blind since I was a child, which meant that at dusk I could no longer be out on my own.

As a result of my night blindness, it was always my mother who accompanied the children when they were young to leisure activities during the winter. This was yet another area in which I was dependent on my mother. I have often been unhappy and felt that I wasn't good enough. Everyone else – perhaps my mother in particular – knew better. But what option did I have but to persevere?

When Grete moved out, it was probably a bit in protest or as an escape, as Grete became the one I could talk to when my husband died. Sometimes she would take me to events for the deaf, but it wasn't nearly as often as when my husband was alive, and it turned out that most of our friends were my husband's friends. At that point, Grete became my anchor. At the same time, my peripheral sight was getting smaller and smaller and my tunnel vision was also getting worse. This meant that I couldn't understand normal sign language with big signs, and that the sign language had to be done with smaller signs and movements. I told my children, but they almost always forgot about it. Time after time I had to ask them to repeat themselves and to use small signs.

I really wished that there would have been information about the effects of my vision problems then, which my children could have had to improve their understanding of my situation.

### **It is a gift to have a contact person**

I had an acquaintance, Irene, who was also deaf, and who supported me as much as she could. She told me that I needed outside help. She made some enquires in the association for the deaf and told me about a deaf-blind consultant that I should get in touch with. Irene came with me for the interview and it was nice to talk with someone who was familiar with my problems. The deaf-blind consultant wanted to apply for a contact person on my behalf for five hours a week. This was granted and it was Irene who became my contact person. Then when Grete moved out, the hours were increased to ten hours a week. In fact, we actually spent more time together than the ten hours as we became really good friends.

When the deaf-blind consultant came again, I asked if I could have a better screen for my text telephone as my tunnel vision was now so bad that I could hardly read anything on the screen. She suggested that I should have a PC and learn how to use email. But I didn't want any of that. All I wanted was a better colour screen. I ended up getting a PC and after considering it for a while, I accepted to learn how to use email etc. at a course for the deaf-blind.

This definitely is one of the highlights in the last couple of years. I couldn't live without a computer anymore. I am using it every day and since then I have participated in more course for the deaf-blind. In addition to this, I have met quite a few deaf-blind people who I correspond with via email. I am really enjoying that. It makes a difference to

the loneliness that I feel more and more often. This is also one of the reasons why I am taking part in the monthly meeting for the deaf-blind which is held in this region despite the fact that it takes two hours to get there. It feels good to be with other deaf-blind people who are familiar with your situation and who pays attention to this. I relax when I am in their company.

### **I can see a little now**

But the very best thing that has happened to me in later years is that I had a cataract operation on my right eye. When I was at the eye clinic a couple of years ago the doctor suggested the operation to me. He didn't do a very good job at explaining it, though, and as I had none of my children with me to interpret, I was too scared to do it. Less than a year ago, before going to see the eye specialist I booked an interpreter and the doctor made time to explain everything. I had the operation three months ago, and I can now see the difference between gravel and stones which I haven't been able to for many years. I can now go out on my own as I can see the surface clearly that I am walking on. It is lovely!

Almost coinciding with the operation, Irene decided to move away. It was very sad for me because although we are emailing each other almost on a daily basis, it isn't the same as spending time together. I now have another contact person who is good, but not a friend and who spends exactly 10 hours a week with me. That is why I am enjoying being able to go for walks by myself. Hopefully my sight will last!

When I turned 60 last year, my children thought I should have a big party. Due to my good experience with a professional interpreter through the Nordic project, I decided to book an interpreter for the party. We were 30. My children, their spouses, and grand children, two of the in-laws' parents, my two sisters and their husbands, some neighbours and friends from the world of the deaf and the deaf-blind. This was the first time I could speak with everyone without having my children as interpreters. It was such a great party, and it was so lovely to be free to speak with everyone.

Now I book an interpreter when I have to go to the doctor, the dentist, to the bank or otherwise need to communicate with the hearing world. I only use my children as interpreters when there are no professional interpreters available. Unfortunately, there are not enough interpreters to cover the needs of the deaf and deaf-blind. My children are also busy. They have a job and now they also have children themselves. However, we

do see each other on weekends. I much prefer to have my children one-on-one. Then we are able to talk. When they are all there with their families or just a few of them together, then of course sign language will be used a lot, and although I had the cataract operation I still cannot see enough to lip read and I simply cannot follow who is saying what. It is all going much too fast for my narrow visual field.

There is not much happening in my life, but I think that I am quite good at adapting to the situation.



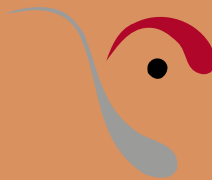
# EXPERIENCES FROM PEOPLE WITH DEAFBLINDNESS

*- a Nordic project*

The Nordic Project is a joint cooperation between the Nordic countries. 20 people with acquired deafblindness from Norway, Sweden, Iceland and Denmark have every year over a 5-year period, participated in interviews about the practical, emotional and social consequences of having a progressive hearing and visual disability.

The result is 6 booklets covering different subjects and containing very personal narratives and experiences of life, which gives the professional world a possibility of discovering or re-discovering the people, that the professional work is pointed at. The booklets talk about what is good – and what does not work. About being in the centre of a rehabilitation process or about the feeling of loosing control over ones own life, and where the strengths and weaknesses lie.

The booklets can be used as a source of inspiration for adapting or developing the work and the services offered people with deafblindness. The 6 booklets can create a deeper understanding of the individual perspective and the necessity of maintaining a focus on each individual person. Finally, the booklets can be seen as a historical cut in time, a documentation of the lives of 20 people.



Information Center for Acquired Deafblindness