Expulsion from Paradise

Sonja Ufer (aged 65) suffered a stroke with Locked-in Syndrome (LiS) 38 years ago in the former GDR. In an interview with Dr. Karl-Heinz Pantke (Chairman of the LIS e.V. Association and the Christine Kühn Foundation) she reports on the death of her husband Wolfgang, the accommodation in a care home and the new reality of her life.

How you you communicate through the computer, given your paralysis?

I am completely paralyzed and can barely speak. Nevertheless, it is possible to write on the laptop. Many years ago (in 2007) Dr. Deutsch from the friendly association kommhelp e.V. did support work at the LIS e.V. This association helps disabled people with computers. A new writing system was introduced to our members who were interested. Initially there were some teething problems. Unfortunately, I'm the only one in our self-help group who was "on the ball". Dr Deutsch intensively looked after me all through the years. The writing system is called 'Dasher', and I wouldn't be without it at all. Before, I had to type letter by letter, but I am now able to write much more fluently. Since I'm able to move my head, I use the head control. It even works by eye control. Still, I need someone to put the laptop in front of me and turn it on. Then I can communicate with friends, family, and the association.

I remember that your late husband understood your quiet and indistinct voice. Is there is no one in the care home who communicates with you verbally?

As time goes by, some of the people in the home understand me very well. However, as in hospitals or rehabilitation facilities, there is not enough time. I also miss my husband as an "interpreter", as everyone relied on him. Now people have to try and communicate with me, and I have to try to speak loudly and clearly.

What do you do when your voice is not understood and your voice computer is not at hand?

I try repeatedly to formulate the words louder and more clearly, but some people just don't understand me. Somebody who is familiar with people from LIS e.V. has no such difficulty. You can get some sense from spelling and nods. I remember a situation in hospital years ago. I was able to make myself known with a cheek bell. A nurse from another ward was checking on me. Since I wasn't able to speak to tell her what I needed, she commented succinctly: "If you're not telling me what you need, I can't help you at all" - and with a loud slam, the door was closed again. I sometimes despair like this even today. However, on the one hand it is rare to have total strangers in here, and on the other hand I try to remember that for these people the situation also feels helpless for them.

Wolfgang´s death was traumic.
Photo: private

You had a stroke with locked-in Syndrome back in 1992. In the years that followed, your husband was your caregiver. He passed away in 2019. The current care home placement was the result. Which of these events - the stroke, or the death of your husband - was the deeper turning point in your life?

The stroke was a bad event. Since my husband stood by me and the family supported me a lot, I was able to lead a great life with LiS. We did a lot with the children - we even went abroad! Of course it was a hard time but all in all we had a great time. The death of my husband was painful, but I look back on the good times.

Your husband had your back with the disease and was a support for you. Where has it shifted to?

With the death of my husband everything suddenly changed. I had to deal with a lot of losses. Not only was

Trip of LIS association.
Photo: private

my partner gone, he was also my support in all situations. I had also lost my loving caregiver, my mouthpiece, my travel companion, my househusband. We just did everything together. After his death I have coped with it all, with help from my family (my sisters, for example, went on LIS association trips), my friends and from the LIS association. Then the Corona pandemic came along. But yet again, it is mainly the family and my work for the association that has helped me. Doing something meaningful just helps me get through the day.

Do you worry about being a burden to your children?

I don't think I would have made it without my boys. My family gave me something to hold onto, as well as moral support and with practical matters. When they were children, the boys were my source of strength through their very existence. But today I wouldn't be able to cope without them. Of course, the boys have their own families and I try not to be an unnecessary burden on them, but they let me be part of their lives and that's great. And that is true for the entire family. So I went to all the family celebrations with the driver service. By "Being a burden" you probably refer to the financial aspects which burden me very much. It's sad when, as an old person, you can only live if you burden your children. That alone is degrading.

I gather from your answer that without your family, you probably would not have found your way to a second life?

Yes, the family was very important, but the association is just as crucial to me. It's not only that I have a meaningful task with my work on the board. I have also made many friends over the years. We have travelled together, spent leisure time together and attended meetings and so much more. A small delegation attended Wolfgang's funeral, and many have already visited me in the care home. I correspond with a lot of people, which will surely supplant many social relations. There are also a few long -time friends with whom I write.

Who finances your care home accommodation?

The place in the care home is partly financed by the health insurance and partly by my own contribution. Since the personal contribution is greater than the pension, the savings are gradually getting used up. You can then submit an application to the social welfare office. Then they turn to the children later, and I find that totally repugnant. Parents should be there for their children, and not the other way around. For me, that is a fundamental question.

The family gives me power and energy.
Photo: private

That means you're sitting on such a ticking time bomb! What does the accommodation in the care home cost?

I am aware that I will soon need help from the social welfare office. The home place costs 4,347 Euro monthly of which the nursing care fund covers 2,005 Euro in my case. The remainder of 2,342 Euro is my own contribution. Assisted living would be much more expensive. Back when my husband died, I might have imagined assisted living, but that wasn't possible. I wasn't allowed to be alone at night. Setting up my own team would have taken at least a quarter of a year. Our apartment was no longer affordable even by me. Nice to look at, but mould on the walls. When I was still with my husband, I had already been registered for the annual short-term care, I so was only placed there temporarily. Since then, I have been there for many years, and they found me a long term place in the home. The nursing home is situated in the same building, and I knew many people there, Somehow I felt at home right from the start. Everybody is very nice. I am well looked after with medical issues and therapeutically. So I don't really want to leave.

What is your everyday life in the care home like?

As with everyone, some of the procedures follow a daily routine. This includes personal hygiene as well as meals. I am grateful that I don't have to go to the dining room to eat. It would be much more strenuous in the wheelchair, and the confused state of some residents makes me rather sad. So I do something that parents often forbid their children - watch TV while eating. The TV is on quite often. Less for the entertainment, more that it is my window to the world. Not only because of the news. On the RBB (local broadcasting) channel I see what is going on in Berlin. I see more of the animals in zoo films than when I actually go to the zoo, and take (virtual) cruises on a regular basis, and a lot more besides. In the morning, there are various individual therapies. I do physiotherapy twice a week, plus occupational therapy once a week. In the afternoon I spend most of my time on my laptop. I am constantly in contact via email with my family, friends and acquaintances including the association. Everything was different before Corona. I used the car service to go to family celebrations or association events.

When do you have to get up or go to sleep? What happens if you want to sleep longer or watch a movie in the evening?

In the evening I watch as long as I want to. I use a bell to make my needs known. I never want to sleep longer in the morning. However, I have heard from others that this is possible. All this used to be different in the past.

If I interpret you correctly, is the home not in a position to provide you with the technical possibilities that would enable you to operate the television independently?! What do you do when the bell hits the floor?

I used to be able to switch TV channels from my electric wheelchair. I've had to give up so many things since my husband passed away! For example the apartment, the wheelchair, and a lot of independence..

What advice would you give to other people in a situation like yours?

I can only say “Never give up!" Early rehabilitation and rehabilitation in general are important. But you can still make progress years later. Never let yourself be persuaded otherwise. Never let yourself be told otherwise, even if some doctors say differently. The experiences in our association, with the experts and my own experience tell a different story.

Sonja und Wolfgang Ufer.
Photo: Mechthild Katzorke und Volker Schöwerling

Translated by Gundula Butthoff, Eva Carter and Yair Meshoulam..