

Beyond Eden, but this side of Paradise

By Karl-Heinz Pantke

Ines Böhme, who is now 47, suffered a stroke with Locked-in Syndrome in 1988. She has been completely paralysed ever since. There is no remaining motor function whatsoever. Ines Böhme communicates with the help of a letter board and an 'eye-gaze' system. However, the necessary mobility of the eyes is limited. Ines is fed partly by mouth and partly via an intravenous tube. Ines has an 8-hour assistance on weekdays. She lives with her mother, Christa, in Magdeburg. The interview is conducted by Dr. Karl-Heinz Pantke. (Chairman of LiS e.v. and the Christine Kühn Foundation)

Karl-Heinz Pantke (addressing Christa Böhme):
Can you please describe Ines' current state of health?

Christa:

About Ines' general condition:

Ines is completely paralysed, including her head. Her eyes can only be opened and closed. She cannot look to the side. Her mouth only opens a little, so that a straw fits through. She is also fed with this syringe and straw system. Her tongue still falls back from time to time. That's why Ines still has the Tracheal Cannula. She also has a stomach tube. The swallowing reflex is only triggered when there is something on the base of the tongue. This is why saliva often runs down the "wrong" pipe. This in turn leads to coughing, which causes the head to fall forward vehemently. This entraps a nerve in the neck from time to time, which in turn leads to severe migraines. As a result, she has pain, dizziness, and also nausea, vomiting and suffocation. In addition, there are very strong spasms. The head is drawn strongly to the right or left. The spasms in turn affect the act of swallowing, the tongue and mouth and the entire body. Then there are the "running days". The nose runs continuously, like in the case of a severe cold. This fluid also runs uncontrollably down the back of the throat.

But it can also get worse. If at the same time it gushes out of the Cannula, the head is drawn strongly to one side, and she has entrapped this nerve by coughing. At the moment, her scalp is also very badly inflamed, bleeding, dry, festering, painful and itching like crazy. Ines has been in bed for years and only gets into her wheelchair when the hairdresser comes.



About the diet:

The individual ingredients are blended smoothly. A straw is put onto a syringe, which is carefully pushed to the base of the tongue. Ines lets you know when the tongue and straw are in a good position. Now you have to slowly inject the food in portions with sensitivity and under a careful supervision. You must make sure that the straw does not disappear in the mouth, because Ines cannot open her mouth. Early in the morning, she also gets a cup of coffee this way. In the evening, she is connected to the feeding pump via the stomach tube and gets tea.

About the wheelchair transfer:

We have a lift with a sling with which to lift Ines from the bed to the wheelchair and vice versa.

With a little practice, she can do it on her own. I've been doing it like that all these years. When the current carers have become properly trained, they will take over.

Leisure time:

The morning is filled with personal hygiene and therapies, followed by lunch. Then Ines watches two programmes on TV. The rest of the afternoon is spent either reading aloud or playing computer games. The computer game also requires a person to sit in front of the laptop. Ines has a monitor in front of her eyes and tells her what to do. In the evening, there is a film and the day is over.

Karl-Heinz Pantke (addressing Christa Böhme):

After describing Ines' state of health, one concludes that Ines' care is a 24-hour job, with a 7-day week. How much help do you get? Where do you get the strength from?

Have you ever thought of giving up? An outsider could judge the situation as stressful. How do you see it?

Christa:

Taking care of Ines is more than a 24-hour job if you want to give Ines a "life". As long as she does not fall into depression, I try everything in my power to make this possible for her. This is one of my main drivers. It goes beyond a normal burden. I seriously thought about giving up 10 or 20 years ago and was on the verge of doing so. Then I imagined how Ines would cope in an Institution. And by that I mean the "good" care Institutions. Even if everything is done right when it comes to care, it's a matter of time before Ines either suffocates or goes mad.

Now I have help from an intensive care service from Monday to Friday 10 am - 6 pm. But that only applies if no stand-in shows up here. If we didn't have our trained nursing assistant, it would be bad. She sometimes comes on her day off to make sure that no stand-in is sent. I have rarely seen such an attitude in nursing staff in the last 28 years. Until February 2016, we only had one home care service. This meant that I received help for a maximum of 2 to 3 hours a day. In the last 6 years, someone also came 3 times a week for 3 hours in the afternoon. Since 2016 we already have the third intensive care service, which is a disaster. Now the second nurse has also quit here again, and so at the moment we are only supported by our nursing assistant. I actually wanted to get help at the weekends, too, but we have to have a team in place first, otherwise it's too much of an emotional burden and we can't cope with it anymore.

Ines is a very life-affirming person and that gives me additional strength. To keep her that way, it is

absolutely necessary that her hobbies are being addressed.

Karl-Heinz Pantke (addressed to Ines Böhme):

Does Ines sometimes fall into depression? And apart from that, do you think that Ines leads a happy and contented life? You also write that Ines is a life-affirming person. What do you base that on?

Christa:

Ines has never had any clinical depression. She cried a lot in the first months, but never expressed the wish that she wanted to die. We laugh a lot, despite anger and adversity, and try to make the best of every day. I don't think she is happy with her situation. But she accepts it and lives with it. She just wants to live. Otherwise, she would voluntarily go into a home and let everything happen to her without a sound. Ines also still actively participates in the therapies.

Karl-Heinz Pantke (addressed to Ines Böhme):

Your mother has described your life in detail. Despite all this, she sees you as a "life-affirming person". How do you see yourself?

Ines:

I am of the same opinion as my mum, I am a very joyful and life-affirming woman. Unfortunately, I only have one carer at the moment, so my leisure activities (being read to, playing computer games) come up a bit short. But as long as I am well looked after, I am fine.

Karl-Heinz Pantke (addressing Ines Böhme):

Do I understand correctly that your greatest adversity is the lack of support, so that you cannot lead the life you would like to lead? Can you confirm that?

Ines:

Quite right. Since my eye computer and also the laptop have to be set up first, I am always dependent on support. So that someone operates the devices and maybe holds my head. Quite right, I have far too few carers since I changed to intensive care. That's why my leisure time falls by the wayside. My care (basic care) has to be taken over by my mum at the weekends, for example, because there are not enough staff. If my current carer falls ill, she also has to cover for her. So it's natural that she wants to have her rest in the afternoon.

Karl-Heinz Pantke (addressing Ines Böhme):

What did you value before the stroke, if you can still remember, and what do you value now?

Ines:

You can't compare. Nowadays, it is important for me to be cared for by reliable people.

Karl-Heinz Pantke (addressing Christa Böhme):
Your whole life has also been turned upside down. Do you see certain things differently after Ines' stroke than before?

Christa:

My current life cannot be compared to a "normal life". I have lost all my "supposed friends". But I have made a few new ones in the care environment. In the past, I often missed out on life and lost valuable time with so-called problems in my family, friends, relationships, work, etc... I was chasing after dreams. This taught me something about life, but a lot of it was unnecessary and time-consuming. Today I am a realist. It is important to me now that Ines and I experience something positive every day; for example, a cute look from our cat, a kind word from neighbours or even strangers on the street. A smile from oncoming people, small chats on the way, an interesting book or computer game. The smaller the radius one has at one's disposal, the smaller the needs become.

Karl-Heinz Pantke (addressed to Ines Böhme):
Do you grieve for your old, lost life?

Christa:

No. You can't change the past, but you can change the present.

Karl-Heinz Pantke (addressing Christa Böhme):
So, nothing can be changed about Ines' illness. Ines and you have to live with it. But what bothers you most today? What should change?

Christa and Ines:

We are bothered by the insincerity of the intensive care companies. They shoot up like mushrooms on the market, promise you the moon and once you're on the hook, you get nothing. These complaints are always played out through the shortage of nurses. We believe that we have a contract and that it must be fulfilled. If you set up a care company, you can't build it up at someone else's expense, especially if the patients can't defend themselves and can't get justice anywhere. It also happens that one is dismissed, or presented as no longer tenable, if one opens one's mouth too wide. So that one becomes afraid of being labeled as insane. To all those who are in the same situation as us, we don't need to say anything more. The "non-involved" people only see the media reports, that everything is great and only a few troublemakers are not satisfied. It is not asking

too much to be looked after by a team of capable people; that should change !!!

Karl-Heinz Pantke (addressing both):

Fate has not been so kind to you. But you had to make the best of it. Actually, we have only two possibilities to react to such blows of fate: Either we drown in them, or we somehow manage to come to terms with the new reality. You give the impression that you have managed to come to terms with the situation. I am interested in what you would advise other people in a similar situation. What was helpful to you?

Ines:

My therapists were helpful to me. I could find out from them where and what therapies I should apply for. My nurse and my mum looked after me and also found out where we could get what. Somehow it went on and on. Heads down and through it all !

Christa:

By all means, keep going. Every day is a gift. You can give up anytime. I have also gone through everything that many relatives go through in such a situation. It took years to accept a new life like this. But it can be done if you want to. Don't grieve over the past, but live in the present. Ines wants to live, and that gives me the strength every day to carry on.

Translated by Gundula Butthoff, Eva Carter and Yair Meshoulam.

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