

**Dr. Claus Brüstle:**

**Disability and Death in the Family and at Work.  
Personal thoughts after the death of the disabled daughter**

**Drübeck, 13 August 2004**

There can be no topic that is more personal for me than talking to you here about the life and death of our daughter, with respect to everyday life at home and at work. About 15 months have passed since Magdalena died, on 20 May 2003, at the age of just under 19.

Magdalena had a serious mental and physical disability; she had been deaf from birth and grew only upwards. So she was unusually slim and even at the end of her life weighed only 15 kilograms, although she had a good appetite and ate well. So she had to be fed all her life, and of course also wore diapers. For my wife, in particular, that was a major *task*. I would not say it was a *burden* - it was a *responsibility*, which she took on with joy, readiness and great love for Magdalena.

Everyone in our family loved her, particularly her two sisters, one of whom was four years older and the other four years younger. Not to forget our brothers and sisters and her grandparents – many of you will know the parents of my wife, I'm sure. We have many friends who have shared in our lives in spite of, or indeed because, of Magdalena. Our two children Catharina and Theresa always observed visitors and guests in our home to see whether they greeted and took notice of Magdalena – first in her basket and later in her wheelchair.

I will now describe five experiences and what an effect they had on me.

The first experience was a striking everyday experience affecting both our private and professional lives. About 15 years ago we were sitting on the terrace with Magdalena and our other children. Magdalena was about three metres away from the table in her wheelchair and was therefore quite visible, when a business friend dropped in and stayed for coffee, as arranged. We talked for about an hour about all kinds of things and there was a pleasant, friendly atmosphere. Walter, himself the father of two children, omitted Magdalena when saying hello, did not look at her for a second, did not ask about her, say anything to her or look at her when saying goodbye. She was apparently non-existent in his eyes. How exhausting it must have been for him to “overlook” someone, or even some object, during a whole visit? What would his reaction have been if, instead of Magdalena, there had been a wounded dog, a sick cat or a broken garden hose in front of us? I could not understand then, and cannot even now, how someone could look so unmoved and at the same time do his best not to take any notice of a disabled child.

That was one side of things that I noticed, and that was *his* side. Today I can also see the other, i.e. *my* side of this encounter. It was also up to me to lead Walter more or less carefully to Magdalena, or simply to introduce him to her. "That is Magdalena," I would probably say today, "she is disabled and can't hear us, she is six years old." I would take her by the hand and stroke her head, thereby making the connection to the visitor. The situation would have taken a quite different turn. Walter and I would have probably been more relaxed, our situation less awkward, and our conversation could have deepened into an encounter between two fathers, neither of whom could cope appropriately with this situation. Sooner or later we would have gone over to the comfortable, relaxed part of the afternoon. Having been annoyed with him, primarily, it would have been better to ask myself what I could change about myself the situation. As the parent of a disabled daughter I am, in such a situation, also the stage-manager, or designer of the necessary information that could lead to a successful meeting. Johann Wolfgang Goethe, when in Naples, wrote on this: "Perhaps one would have more thanks and advantage from life if one said frankly what one expected of one another. Then both sides are content and the relaxed part, which is the beginning and end of everything, appears a mere encore." Perhaps we parents are attributed more experience and ability to respond to expectations than to a guest, for whom such an encounter will never happen again. But the parents of disabled children are only human beings, perhaps even more clumsy and vulnerable than parents of healthy children, but both must be able to learn.

Now to the second event. Just as in the garden, the same thing happened at a lunch in a restaurant in our home town. Neither the waitress nor the manager cast a glance at Magdalena, although she and her wheelchair were visibly in the way when they were serving food and drink. It is humiliating for relatives and insulting for the disabled person and his/her worthwhile life to be passed over. The waitress did not have to start a conversation but a glance or a greeting can show: I have seen you and I respect you, or: I was shocked when I saw you, or the child looks pretty, or the "Goodness, this poor child". Then there is at least room for a reaction. The same considerations presented above apply here too.

And the third incident. An entrepreneur is attributed qualities like courage, boldness, perseverance or fearlessness, but in private dealings they do not necessarily manifest much of that. When a young man became paraplegic after jumping into a swimming-pool containing not enough water his old friend, a business man, did not visit him a single time after that, "because I simply cannot deal with it", he told me. Is it cowardly to try to deal with suffering? Is it fear of strong emotions or having to show your feelings? Even after the death of Magdalena I received no sign of sympathy, although we had known one another for years.

The fourth incident happened to me in the real sense. I was amazed to experience what a person in a wheelchair must suffer. After a serious injury to my leg, a time in hospital and a few weeks confined to my bed I had a several-day appointment in Hamburg. My leg still in plaster, I was pleased to accept the offer of a stewardess at Zurich airport to sit in a wheelchair and be pushed to the plane. I felt like a box of cargo because at the two checkpoints, passport control and luggage, the airport staff no longer spoke *to me*.

The questions were all to the woman behind me. Where does he come from? Where is he going? Where is his passport? What about his luggage? In a wheelchair you are easily overlooked, ignored, made a nobody. Since then I have understood how this impinges on your personality, how you feel worthless, how anger, impatience or aggression well up. What can we learn from this? To take notice of people in wheelchairs, greet them like anyone else, talk to them, not about them, let them use their own skills, not to see them as disabled persons but, first of all, as people, and only then to see their wheelchair and disability.

And, finally, the fifth experience. The special attraction of a disabled person cannot be avoided – otherwise there would not be such strange reactions, which do not happen in our contacts with normal people. Generally animals can also sense that, which can take on valuable therapeutic tasks for people with disabilities, and in particular we experience this with our short-term guest Benny, the dog. Many children, our own and those visiting, were bothered by his frolicking and nipping at them, but he always circled Magdalena cautiously, protected her and sometimes licked one of her hands. Our cat was also more cautious and considerate, never without respect.

I have already mentioned that Magdalena heard nothing and therefore could not speak either. And yet it was remarkable to see the effect on her when we talked. After my wife began telling her – without her understanding, naturally – that we were going on holiday with her, there was absolutely no problem with the preparations and departure for our holiday. We often spent a couple of weeks in a small apartment by the seaside in Tuscany, which she obviously liked and which did her good. Without prior information she evidently sensed our preparations for the departure and the hustle and bustle associated with packing our cases. Perhaps she feared that we would not take her with us. And so she regularly fell ill, and developed a temperature. Twice we had to call the doctor on the day of our departure. When we arrived in Follonica, she beamed with pleasure and the temperature disappeared. The sea air and the shady balcony provided a marvellous holiday for Magdalena too, and we could see from her hearty appetite and peaceful air that she was happy.

Although she did not understand the words she took in what we meant. That is why we know that she grasped everything, and perhaps understood even more about everyday life and the people around than we who can hear and see take in with our customary senses. In a special way she possessed this sixth sense.

“Magdalena notices the energy around her, she feels whether people around her are well-meaning, she is enormously sensitive.” I still remember these words uttered by a psychotherapist and experienced astrologist in July 1997 about Magdalena, without her even knowing Magdalena at the time or being informed about her disability. What she went on to say – here reproduced in note form – was most accurate: she can only feel she is nothing but an impressive mirror; she has given much, she has served others, she has given herself in giving to others, and now, to balance things out, she wants to have other experiences, to try just to get; it is not easy to accompany this child out of her shelteredness, she is Mummy’s baby in the best sense; even if she cannot move herself, she will give much, she is like a big mother and a big child at the same time; people like

her, she is very popular. Magdalena wants to explore things to the full; her optimum is withdrawal; being moved means for her spiritual sustenance; she tends to express what she likes and less what she does not like; her main development lies in gaining more rough edges.

By comparison, and by way of supplement, I will now cite the text we heard at the service before her burial. It was written and read by Werner, who picked Magdalena up from home almost every day, looked after her when she was at the social centre and brought her back late in the afternoon; he was visibly fond of Magdalena and knew her well. These lines are most accurate and touched all of our hearts.

Magdalena  
Silent, but not without sound  
Speaking without talking  
Understanding without hearing  
Frail and slim and yet strong  
Seeing without staring  
Calm without being tired  
Strong will without compromises  
Honest feelings without inhibitions  
Joy in being  
A full, rounded person  
Here and Now.

We were equally moved by the wonderful essay by our daughter Catharina, written at school at the age of twelve.

My sister Magdalena is eight and mentally and physically disabled. We do not know why.

But Magdalena also has hobbies and does sport. When she lies near the radio and rock music comes on she creeps into a corner- As soon as it is classical music though, she is happy.

Every Wednesday she goes swimming with her school class, which only has five children, and two teachers. In the water she feels really good.

On Fridays she goes riding, which she loves. Last Friday she imitated the movements of the horse afterwards.

When Magdalena is away for a while I really miss her, as if there were something wrong with me.

When we go out for a walk with Magdalena and people turn round and look at her I glare at them.

My other, three-year-old sister often says to Magdalena: "Don't be sad, you will soon be able to walk!"

Magdalena senses it when Mummy is going away and she cannot go too. Then she immediately gets sick.

Magdalena has often been in hospital and does not like thinking about it as she had to stay for a few days. Whenever we go to a hospital, not just because of her, she starts to kick and scream.

Magdalena has a good friend who is not disabled. When she comes, Magdalena always laughs. They do fantastic things, and once they even flew to the Grand Canaries, for two weeks.

Magdalena is a sleepy head and even falls asleep at breakfast when she has to go to school.

My mother does not have so much time for me now, but I do not mind.

Often I have thought about what it would be like if Magdalene were not disabled. I would certainly grow up quite differently.

Much later, when Catharina was already twenty, she met a friend with the same birthday as Magdalena, i.e. 30 June 1984. Excited, she said “Here I can see what Magdalena might have been like.” Today Catharina is completing a degree in psychology, a subject she is most interested in.

I received these lines of my father with respect. On his 76<sup>th</sup> birthday he wrote the following to try to console her and us – they reflect his religious attitude.

„14 March 1998. I am really sad to see how disabled you are. I would like to comfort you with the Sermon on the Mount. Jesus said: ‘Rejoice and be glad for great is your reward in Heaven.’ On my birthday I send you a special greeting. Your Grandad.” I could not say I felt sad about Magdalena’s disability but found his view of things thought-provoking. And four years later my father wrote to his granddaughter Magdalena: “On my 80th birthday I naturally think of you, too. I am truly sorry that you have to bear this heavy cross. In heaven we will be able to talk to one another.”

How near the other grandfather, the father of my wife Maria, was to our Magdalena, and fond of her he was, is shown in a poem that he especially wrote for her at New Year 1985, when Magdalena was just 18 months old.

Your eyes seek our gaze,  
Your mouth moves slightly,  
Silently.  
Fingers move.  
Take hold,  
Let go.

Quite lost in yourself  
You reflect,  
Closed to us,  
Mute shock of curly hair.

Sometimes you feel in your throat  
Well-being:  
A soft sound.

Living means becoming, growing and changing. Through the birth, life and death of our Magdalena we – all the closer and more distant members of the family – went through a process of growth and change only through a stubborn disregard for the actual circumstances, with constant counter-pressure, and thus combating a weight of suffering. Yet many people, regardless of their extraordinary fate, stroll through their boring walk of life, or even just to stand around, without spiritual growth – they cannot help growing physically. Each crisis that leaves us the freedom to let it make us physically and/or mentally ill, or to be healed by it, calls those so chosen to tread the path of change, transformation and a new beginning. I do not doubt that at the start the rougher, steeper, more rocky or shadowy path must be trod without any assistance, security, signposts and sight of the goal. But with great probability there will be a plateau with a lot of fresh air, a deep blue sky, bright sunshine, a splendid view, clear water, fruitful fields, juicy fruit, wonderful flowers, friendly people – and many colourful butterflies.

Our big, little Magdalena led us to this height, without even asking whether we wanted to go. But she knew about the land of our dreams and so we had to take this route, and we did so gladly. Magdalena gave us almost twenty years, which were among the toughest, most challenging but also the happiest times of our lives, and always will be. Our life took a good turn and will continue to do so.

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