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Parent perspective

# Childhood Cancer—a Mother's Story

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In March 1994, when our son Stefan was 13 years of age, he was diagnosed with acute lymphoblastic leukaemia (ALL). He was treated with chemotherapy according to the BFM-92 protocol in the Children's University Hospital in Bonn, Germany, followed by brain irradiation and maintenance therapy. He recovered slowly from the side-effects of the disease and its treatment and life seemed to be "normal" again, when in November 1997, we were shocked again by the news that our son Martin, then aged 18, was diagnosed with osteosarcoma of the pelvis. He too received chemotherapy, was operated upon and received further courses of chemotherapy according to the COSS96 Protocol. One half of his pelvis and one hip joint had to be removed. As a result, he is now handicapped, walks with a severe limp, cannot run or cycle and needs special cushions for sitting. However, he has learned to cope with the deficiencies relatively well.

Only a year later, in December 1998, Stefan, then 18 years old, had a relapse of his ALL, which was treated with more intensive relapse therapy and more brain irradiation and maintenance therapy.

Today, both our sons are well integrated in their social environment and are presently attending university: one is at medical school, while the other is studying computer science. You can imagine that we all hope that cancer is now a part of our past. It is not very common that two children in a family—we also have a daughter who is now 20 years old—are affected by this dreadful disease and our experience should not panic other parents. We would like to illustrate herein our personal experiences and how we learnt to cope.

At the end of Stefan's first treatment episode, I started to get involved in the local parent initiative for children with cancer at the University Hospital in Bonn, as well as in the national organisation of all parent initiatives in Germany, which shares its office with the local group. Today, I coordinate a school project designed and sponsored by the local parent initiative that links the patients with their home school via a specific 'Intranet'. School-aged patients, when they come to the ward, are equipped with a laptop with Internet access which enables them to participate in their individual classroom teaching. We also provide the server and a camera in the classrooms of the home school, instruct the teachers and the other classmates who are generally very enthusiastic about this way of being able to communicate with the student in hospital. Thus, the patients are closely connected to their classmates and teachers, keep up with their curriculum and are informed about all school events.

The diagnosis, childhood cancer, was a great shock for us, especially as it hit our family three times. Retrospectively, we can say we were lucky to live in a town with a qualified paediatric cancer Unit, where we got the proper treatment and excellent care. We were thoroughly informed about all aspects of the disease and its treatment. We got answers to almost all our questions—of course not the one "why us?", which is still on our minds, even though we, the parents, underwent genetic counselling. During the treatment period, doctors and nurses always found the time to talk to us, explained each new step in the treatment and all of the medications involved. Most of the time, we were prepared for all of the expected side-effects and the reasons why these or those measures had to be taken. Our sons were also well informed, which certainly increased their compliance. Both had a port-a-cath implanted which eased the application of the necessary infusions. They always knew the doses of each medication and were able to control the infusion pumps themselves which gave them independence and a sense of responsibility.

When I met with parents from other hospitals, I was amazed how much I knew about the diseases of my sons compared with these other parents. Of course, some medical background—my husband is a general practitioner—helped. But frankly, most of the knowledge I acquired about the disease I got on the ward and from my work with the 'parent initiative'. We felt that this knowledge und understanding helped us in any decision-making and in the support of our sons as patients. We also realised that honest information was very important for our sons—and any other patient—to be

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able to endure the treatment procedures, with all their implications.

When we were in the hospital for the first time, we were appalled about the situation on the ward. It needed renovation badly: there were only two bathrooms for 16 beds, large rooms with four or more beds, no privacy—especially uncomfortable for teenage patients. The University budget had no finances for extensive renovations. So the 'parent initiative' took actions and raised enough money for the renovation of the old ward and the building of a new annexe which added double the space to the Unit. Now, we can proudly present a modern set-up equipped for all necessary treatment modalities: comfortable single or double bedrooms with private bathrooms, isolation rooms for stem cell transplantation, a spacious playroom which at night is also a meeting room for teenagers, a meeting room with a kitchenette for parents, two modern treatment rooms, a fully equipped outpatient unit with day beds and the stem cell separation equipment, rooms for the psychosocial staff and much more. In short, the situation has changed very much for the better.

In spite of the outward appearance of the Unit, we experienced very professional medical care from the very beginning, and this gave us confidence in all the decisions that had to be made. The well-trained nurses on the ward are an essential part of the team. They are the first ones to notice any changes in the patients' behaviour or appearance and are able to react in a considerate way. They are not only involved in their medical routine, but also in comforting patients, taking their fears seriously, yielding to their likes and dislikes as much as possible and helping them in so many other ways.

Psychosocial support is an integral part of the treatment. Two psychologists, a social worker and a childcare worker take care of the entire family from day one. They may help extensively in all legal and financial aspects, or support the family only when needed. We—apparently—had a well-functioning family and needed only very sporadic support, but we know of many families or especially single parents who fortunately got a lot of help throughout the course of intensive treatment and even later on. Today, the Unit also has a homecare team: four nurses who visit the families at home for applying care that would have to be done in the clinic. This kind of help is invaluable, especially for terminally-ill children, who can be treated in the home situation.

With each new period of hospitalisation, our family had to yield to the unexpected situation. The third time around, we were already experienced, though the treatment was much more intensive and our fears—realistically—much more profound. As we live not far from the hospital, we were able to take 'shifts' in visiting the patient— we, the parents, but also siblings, school friends and girlfriends. Often the whole family gathered around the bed, but we also felt it very important to leave the siblings and friends alone with each other at times. Thus, they could communicate with each other about worries they may have wanted to hide from us, their parents. However, most importantly, all of them were well informed at all times.

We are grateful for the recent developments in the treatment of childhood cancer. The therapies, although more intensive these days, are more tolerable with more effective supportive care, especially the effective control of nausea and vomiting. We know from former patients how much more difficult the therapy would have been without these advances.

For Stefan, the irradiation and maintenance therapy was a frustrating burden. Both times, he experienced severe side-effects which hampered him as he wanted to get back to a 'normal' life as quickly as possible. Instead he felt very tired and often dizzy and sick. But his social surroundings—friends and family—supported him as much as possible and he finished school with good grades. It hurt him very much when he realised that he could not continue with his favourite sport, tennis, as his backbone was damaged by the disease. He started to invest his energy in music instead and is now a very passionate drummer, plays in different bands—for fun and for money!

Martin's therapy was different, especially with the invasive operation—which was done in another city—followed by courses of chemotherapy involving one week in hospital and two weeks at home. In between another operation, lung metastases had to be removed. He needed much more physical care as he was in a cast from the waist down for most of the treatment time. When the cast was removed, he had to learn walking with part of his hip missing and one leg shorter than the other—a young adult who needed help like a baby. It was not easy for him to accept this help from any of us, let alone the nurses. Driven by his deep desire to become independent again as quickly as possible, he trained his body mercilessly. As soon as possible, he took driving lessons and got his driver's licence. We bought him a small car and thus helped him take another step towards independence. Nowadays, he lives in another city, has a girlfriend and, hopefully, will finish his studies soon.

Both our sons were teenagers, almost young adults, when they were diagnosed with cancer. Nevertheless, they were treated on a paediatric ward, which was good. We felt that the care and treatment for these kinds of diseases were in the 'best hands' on this ward. The boys were always respected as individuals with rights of their own in the decision-making process. Throughout the treatment, they were often dependent on help from others—nurses, parents, siblings. In turn, we all respected their needs and wishes in order to give them back part of their lost independence and a sense of responsibility for their own fate. We are grateful to the entire team for whom this philosophy was self-evident.

In Germany, the family of a child with cancer is entitled to a four week long rehabilitation period, paid by the general health insurance, in specially qualified centres. We decided not to take advantage of this possibility, but took an extended vacation instead.

## Wishes for the future

All parents and patients would like to see survival rates increase to 100%. It would be great if every child with cancer had the chance to survive. Meanwhile, the fear of a possible relapse is hovering over us all like a Damocles sword.

In the time that we were actively involved as parents of patients much has changed for the better in the treatment procedures. To give a few examples, there is better supportive care and pain control, control of nausea and vomiting has improved and anaesthesia is now applied for painful procedures. It is our wish that the quality of care will not suffer from the expected budget cuts in our health system. We would also suggest a better coordination among all of the clinics involved in the treatment. This would cut down on frustrating waiting times and would certainly enhance the efficiency.

Our sons would have liked a set-up that was more suitable for teenagers or young adults. Although they preferred the treatment in the paediatric Unit with the expertise of the paediatric oncologists, they would have liked to have a place of their own on the ward, a room just for teenagers, a retreat where patients of their age group could gather and maybe listen to ‘their’ music or play ‘their’ games or just talk. Of course they would have preferred shorter periods in hospital and, if possible, a shorter treatment time overall—and, most of all, no pain. They still hope for more understanding among their peers or in their social environment for the disease and its long-term effects.

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