Foreningen
Cancerramte Børn

A Danish mother tells about her experience with her son's 1½-year hospitalisation, when he at age 16 was diagnosed with leukaemia.

When the treatment fails

Let's start with the end....

My son Rasmus died in September 2006 less than two months before his 18-year birthday. Prior to this he had fought for nearly 1½ year.

At first he was hospitalised at the ward for adults at Herlev hospital. It came as a shock when I received the message: *"Your son suffers from leukaemia and you ought to know that there's a risk he might die"!*

Tests were taken and after a few days we knew that he was suffering from leukaemia ALL, acute lymphatic leukaemia also called children leukaemia. The physician seemed relieved because there was a good chance he would recover.

They started the treatment. Rasmus was feeling all right. He suffered a lot from headache and was very tired but he ate well and he did not lose his hair. His figures were not alarming, later we came to learn everything about blood figures and high infection figures.

We met the physiotherapists for the first time. It is of vital importance to keep being physical active therefore the physiotherapist asked Rasmus to walk the stairs. They went up and down a couple of floors. Rasmus had been to a physiotherapist before due to pains in his shoulders where he had a massage. He had really been looking forward to it and became rather disappointed when he did not have a massage following the exercise!

After about one month the outlook of Rasmus course changed. We had stayed at home during the day for a period of time and Rasmus spent the nights at the hospital. The physicians gave him medicine with intervals that he should take it morning and night.

One morning we had just returned from the hospital. We had a good time and I had prepared a lovely breakfast. It was very important to me that he ate well and that we had a good time together. The hospital staff had informed that Rasmus would start feeling very sick after 3-4 weeks. A doctor from the hospital called me. We had to return to the ward immediately. Rasmus' father was also encouraged to come. And it could not wait until 2.00 pm it had to be right now!

I was so scared. I had heard about incidents where the physicians had diagnosed wrongly and it turned out that it was not ALL but one of the more dangerous types of leukaemia.

At the hospital

After we had arrived at the hospital we learned that we had been transferred to Rigshospitalet's ward for children with cancer. The chemo Rasmus had been treated with had failed. The tests had been taken the week before and the physicians had known the result for three days. It was devastating for us. There were not any positive announcements the opposite and we were told that we might as well get to know Rigshospitalet because Rasmus would have the transplant here.

In chock we drove directly to Rigshospitalet. Rasmus was taken to a room with extra space for one of the parents to spend the night with him. It was great but actually rather difficult to have to move from one hospital to another. This we only realized again later on.

At this ”new” hospital we had to be responsible for a large part of the care and we were left to ourselves.

Rasmus underwent a new treatment, which made him feel sick, but the bone marrow test showed that it was working well. Another treatment was initialised again; this one was “the recurrence protocol” treatment that was being carried out. Now Rasmus became really sick. For six months we were hospitalised most of the time. Rasmus either had chemotherapy or he had an infection and needed antibiotics. Most of the time he had an IV to relief the discomfort of mouth infection and muscle pains.

Many times he was feeling so sick that he could not go to the toilet adjacent to the room. He had to have a shower on a daily basis. I tried my best to support him but he was very tall and heavy. Sometimes he fell. Occasionally I would get a wheelchair in order for him to go to the bathroom on the same corridor. But it was not a good idea to use the wheelchair. Rasmus was at age 16 a rather lazy boy. If we were not being careful he would end up not trying to walk by himself.

His age taken into consideration he should be in the process of distancing himself from his parents. Now the situation demanded that we stayed there 24 hours a day and we were the ones who took care of him.

Of course he had contact with other people too. Nurses would come and hook up the medicine e.g. IV (a tube inserted into a vein). Once in a while we had time to chat. The schoolroom had a couple of assigned teachers but Rasmus could not stand to sit there. There were different types of entertainment in the kitchen. Sometimes we managed to persuade him to go and see what was happening. Also there were excursions with Children with Cancer among others. Rasmus participated a few times but it was extremely tough and tiring.

I negotiated with the hospital and the municipality and in a miraculous way; I succeeded in finding a vacancy for Rasmus at “our first hospital” Herlev Sygehus where he participated in rehabilitation in the short periods when we were at home. Perhaps it was because it all started at Herlev Sygehus. Everything was settled at the same time Rasmus should have the transplant. We had the arrangement postponed.

Transplant

The time up until the transplant was critical. Regarding the initialisation of the last treatment the physicians took a bone marrow sample. Immediately afterwards we received a temporary result – it appeared clean. We were informed that a board must approve all the transplants. Meetings are held every Tuesday. Following the meeting I called the ward but there was not any answer. The documents did not make it to the meeting. I could not have a proper answer regarding the bone marrow samples and there still was not made any decision after the next meeting. There were no more treatments in Rasmus' protocol. Finally we received the approval of the transplant.

From the beginning of November Rasmus was hospitalised at Rigshospitalet's transplant ward. This was where he should belong in the future. All contact with the children cancer ward was cut off. It felt very lonely and we had to get used to new rules and methods.

There were several rules but worst of all, we were being treated as if we were newcomers at the hospital. For the last six months we had already got used dealing with a dropper and we knew how to give Rasmus a bath, change bed linen, give him medicine and clean the CVK (a tube inserted in a vein in the neck). We even thought at the time that the CVK which had worked great for six months should stay and that the physicians should put another one in the other side enabling them to have access from two points. The hospital was filling so much in our lives.

Isolation and mobilisation

Most likely it was stated in Rasmus' medical record that he had a tendency to be inactive. They were very focused on him getting up and sit in a chair. Unfortunately, I witnessed that they often were telling him off for not getting up rather than praising him when he actually struggled to get up and sit in a chair.
In the beginning we had an exercise bike in his room. He was using the bike when the physiotherapist came. They should have come every weekday but there were many cancellations.

Rasmus received radiation therapy and in addition he was treated with chemotherapy, he was sick like a dog. As a matter of fact, he was sicker at this time than when he died. Everything had to be sterilized before you could bring it into Rasmus' room. All surfaces were wiped with a rag soaked in alcohol and Rasmus struggled to have a bath. We cleaned our hands with soap and alcohol. Nobody was allowed to visit if they were not feeling well. Not many people dared to visit us anymore, being afraid that they might carry a disease without knowing it.

After some time Rasmus depended 100% on the CVK both for food and medicine. He vomited in spite of this. Just the very thought of getting out of the bed made him vomit. Rasmus was giving up hope. I often thought to myself what could I do to cheer him up or ease his pain. I suppose his pain was eased through the IV but he suffered tremendously even though. It hurt if we just happened to bump into the bed.

New bone marrow

On December 12 Rasmus received his new bone marrow. Christmas eve was horrible while New Years eve was a little bit better. He could not do anything just lay down but he managed to smile to us though.

After New Year Rasmus should get up again. To begin with he would drink 350 ml and eat a cracker during one day. When he came out of isolation he should start to walk again. The physiotherapist took him outside in the corridor. It was very tough.

The new bone marrow did not function properly. We were very much looking forward to the day he could go out in public places and eat regular food again but again and again the day was postponed. Rasmus was released from the hospital in mid January but only at the end of March almost two months later was he allowed spending time with other people. This was also .... a very difficult time. Still nobody dared to visit us and Rasmus was feeling very sick and we had all the responsibility ourselves.

Rasmus could hardly walk from the ward to the car even though I had parked it right outside the entrance. He was out of balance and had no strength left. He had lots of different medicine e.g. prednisolon. We were very limited in our leisure time activities. Once a week we were at the hospital for check up. It would typically last all day because the results of the examinations would determine what would happen that day. Twice a week we went to Herlev Sygehus for rehabilitation. Often Rasmus did not have strength to exercise once we were there. The trip was more than enough. On the way home it was quite common that he would vomit due to exhaustion.

When we finally were allowed to mingle with other people Rasmus wanted to go window shopping. We would go as close to the shopping centre as possible. Rasmus was unable to pass around other people. He could stop but he could not change direction without losing his balance. Many people turned around and stared. I apologised and tried to explain that he was very sick. Indeed it was not easy to be Rasmus.

Special occasions

We held a ”I am well party” for the closest friends and family. I gave him my word while he was very sick. He wanted to be celebrated and show the world that he could overcome it. I did not want to wait for his 18-year birthday .... I am happy I did not, when looking back today.

During the month of July Rasmus was starting to feel better. He could walk around at his own pace. We found an old bicycle that was too little for him in order for him to have support with both his feet. He could drive around for a little bit. It was a lovely time. He also started visiting some friends once in a while. He went to the cinema once.

Recurrence

The physicians were not totally satisfied. The liver was not functioning right. They treated him for GvH (a reaction where the transplanted bone marrow expels parts of the patients body). Starts up treatment with prednisolon and sandimmun again in the end of July. Rasmus was starting to feel better. In August the physicians changed the medication a bit. Something happened to the blood figures. We were happy because Rasmus was feeling better than he had been for more than 1½ year. Then the worst thing happened .... We were at a check up when the doctor said: ”I am sure that the medicine is playing a trick but…. we need to take a bone marrow sample”!
On our way home in the car Rasmus said to me: ”When the doctor mentioned the bone marrow sample, all I could think about was recurrence”: He was not the only one who thought about that and unfortunately it turned out to be true.

When we received the result Rasmus commented: ”I have always said that I am going to make it if I do not suffer a recurrence *What am I going to do now?” ....!*

We were admitted to the children ward, I simply could not think about going back to the 4th ward again.

Rasmus was given the choice whether he wanted to take pills and wait and see how long they would help or if he wanted to start up the recurrence treatment again. Rasmus chose to fight it. *He lived 16 days more after we received the result.* The night before he passed away he gave his younger sister an iPod. I am sure it was her confirmation present. It was important that we all were there the whole family and it was very solemn. Rasmus had a visit of his cousin later that night. When it was time to leave Rasmus said: ”I want you to take good care of my sister when I am not around any more”. Other than that Rasmus never mentioned that he was going to die.

Rasmus died of the side effects of the treatment.

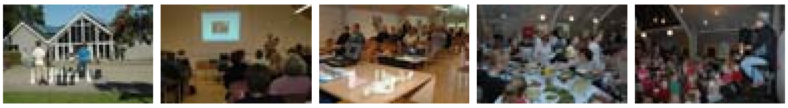
The family weekend

One year after Rasmus’ death I was at the annual weekend event in our association for Children with Cancer (FCB). This is an event for families with children undergoing treatment and families who have lost a child within one year. Rasmus and I had participated the year before. It was a great experience.

This time I went alone but accompanied by Rasmus’ sister. One of the letters this weekend was about reflexology. Many thoughts went through my mind. The information from Leila Eriksen about reflexology, how it is being practised and how people are working tirelessly both on a national and international basis wanting to document the results, made me realize that reflexology very well could have been something very positive for Rasmus. Something he could have benefited from in the tough periods he had to go through. Following a treatment this weekend and having experienced myself what reflexology did to me I decided to write this article.

Could reflexology have made a difference?
I do not know. What I do know is that the experience from the family weekend where everybody children and adults alike had the opportunity to try reflexology was very positive. Imagine if Rasmus had been given the opportunity during his long hospitalisation to enjoy the positive attention and physical contact offered to him just for his own well being. Pure enjoyment that perhaps even could have eased his muscle pains, nausea, stomach problems and other side effects. An opportunity all children with cancer should be offered.

I am convinced that everybody did his or her best to save Rasmus’ life but it was a tough and merciless time.



Lena mother to Rasmus
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