

Book-CD „ Playing with children suffering of cancer
A mother´s diary “
120 sides with photos - German / English

About the autor:

Helma Kustermann, who was born in 1950, has been living in Oberstdorf/Allgäu since 1969, she has been married since 1975, she worked in the profession “housewife an mother” for decades and has been dovoting herself as a journalist to the “investigative journalism”.
Helma Kustermann, who has – since 1981 – been social-critical, involved, succesful and, who has been working only voluntarily, is the founder and chairwoman of the officially registered, charitbable and non-profit making “Patientenhilfeverein” (association to helf patients), called “*Bürgervereinigung Oberstdorfer Krankenhaus e.V.*” and counts – **after the doyens of the German patients´ help, Prof. Dr. med. Julius Hackethal and Dr. jur. Georg Meinecke – to the pioniers oft the patient´s helf in Germany.**

About Isabella and her family :

... Isabella was born on 13 August 1986, grew up as normally as every healthy child and was a very lovely little girl. Her time of suffering began when she was 6 years old, on 14 December 1992, and ended with her excruciating death after one year of "medical therapy" in a German children's hospital on 11 November 1993. ...

Specimen “Playing with children suffering from cancer
A mother´s diary “

"Monday - 28 December 1992

Can the bottom fall so fast out of the world?

I don't understand it...

Why we again?

At the end of October Isabella got a temperature.

Nearly 41°C .

Sometimes it went down, then it increased again - a bit sore throat, a bit earache.

In the middle of November then suddenly suspicion on leukaemia.

We have to wait for the blood test for 2 days.

It's all clear.

No blood disease.

...

On 14 December Dr. R., whom I have known for long, noticed a 12 cm kidney tumour during an ultrasound scan.

The nightmare started.

Afterwards a conversation with assistant medical director H. and another doctor.

I have only understood half of that.

Do the doctors always have to speak in such a complicated way?
Johannes was with me.
He didn't understand much more either.
If it is the tumour, which they thought it to be, it will not be so serious.
A 90% chance.
But there are still 10% left.
And then all this strain.
Nearly one year in hospital.
I shudder at the thought of this.

On Tuesday - 15 December - she had to go to in-patient treatment.

At first we were sitting around for 2 hours before something was happening.

But then came one checkup after another.

And the Christmas time.

Johannes took a holiday.

Otherwise, where should our other 4 children go to?

Thank goodness that Isabella is a lovely, patient child.

She has patiently endured all checkups without any problems.

On 22 December the first CHEMOTHERAPY started.

Is there really any use of pumping poison into a child?

I can't imagine.

...

On Christmas Eve Isabella was allowed to go home for a couple of hours.

She always had to vomit.

Mrs. Dr. Ehrlich is really great.

In that short time, she found an after-school care centre for Thomas - in a children's home just beside this ...clinic.

Johannes or L. can pick him up from there after work.

She is helping a lot in the house and she is taking care of the children.

Despite, I commute back and forth several times.

The doctor does not agree.

But Isabella stays alone for some minutes however, during this time, nobody is allowed to touch her.

He is then supposed to tell me the dates for the checkup before.

On Boxing Day the CHEMOTHERAPY was over.

...

Today it's New Year's Eve - Thursday - 31 December 1992

Isabella is again at ward number "6".

She has still got a temperature and broke out in a rash.

Saturday - 2 January 1993

Isabella has still got a rash.

Go into the room - it's infectious.

Go out of the room - it's not infectious.

What shall we do?

Several doctors of the clinic are coming up to the warrant professor.
Nobody knows what she has.
The one says "an allergy against medicine",
the other says "measles".

...

Thursday - 4 February 1993

On Tuesday Isabella ate quite a lot - 2 schnitzels.
Dr. S. came in the afternoon.
The operation is supposed to be at 8 o'clock in the morning.
I was at the clinic at 5.30 a.m.
Isabella got a tranquillizer at 7 o'clock.
At 7.30 the operation was postponed.
First to 10 o'clock, then to 12 o'clock, then again to 3 o'clock.
She was finally operated at 5 o'clock in the afternoon.
Due to the tranquillizer, she slept until midnight.
The University Clinic is terrible.
They keep little children quiet the whole day without eating
and drinking...
If you were only not so extradited to these white-coated wizards.
She was operated for 5 hours.
At 2.00 p.m. I was going to the clinic.
I was surprised: the door stood open.
Are they not scared of anyone who does not belong here,
roaming around?
Isabella is very bad.
A room in an intensive care unit with a guard.
There are machines everywhere.

...

Monday - 15 February 1993

Today we were in the clinic for outpatient treatment.
We disputed with Dr. B. because of the tablets.
Isabella always has to vomit when she has to swallow these big
ones.
He said to me that Isabella is rather "spoilt".
She is to swallow the tablets *without vomiting*.

...

Thursday - 4 March 1993

Today she was allowed to go home again.
We brought a school-bag today.
She is bad.
She doesn't want to eat or drink and she cries permanently because
she feels sick.
She has **7 ray treatments** and the last one will be tomorrow - then
only ray treatment where the lymph nodes were.

...

Thursday - 11 March 1993

Isabella is in a bad way.

However, the ray treatment goes on.
I've got a strange feeling about it.
Doctor B. has informed me now.
It's another sort of cells than they had thought, so she gets a stronger **ray treatment** and another **CHEMOTHERAPY** that can only **be made outpatient**.
He thought that she, however, has a **good chance to survive** - at least, that's something...
I hope that this nightmare will end soon.
Dr. H. came into the room for a short moment and he said that the doctor had already explained everything to me.
The CHEMOTHERAPY has to be made a bit stronger and a bit longer but that would **not be a problem**.

...

Thursday - 25 March 1993

I'm absolutely angry.
This Dr. B. is an terrible human-being and doctor.
This evening I was going along the corridor and suddenly he screamed at me like an idiot:
*"It's about time that she eats - he is tired of this fuss.
She lies in bed and pretends to have stomach-ache because she doesn't want to go home due to the TV. Because she is not allowed to watch at home, she wants to stay in clinic..."*

...

This morning, Dr. B. told me that she has so **heavy burns in the whole stomach**.

...

Friday - 9 April 1993

There is again CHAOS today -
She has been crying the whole night because of pain.

...

Friday - 7 May 1993

She has been getting medicine against "fungus" for the whole week.
Although she feels good we had to stay in clinic today.
Politics for having a lot of beds occupied.
Because nearly all beds are empty.

...

Thursday - 3 June 1993

Once again in-patient treatment.
She doesn't like to eat or drink, either.
She permanently complains of stomach-ache.
The doctor doesn't take it seriously anymore.
She has got nothing...

...

Thursday - 1 July 1993

Today I had a heavy row with Dr. B.
Isabella wanted some cake and I was standing in the kitchen.
Then he entered and shouted at me:
*"...If I don't mind I should see that my daughter eats.
Otherwise he would refuse any further therapy.
He is so sick and tired of the child's permanent malingering
and acting.
She is not so sick and only gets half of the CHEMOTHERAPY
doses and then this permanent fuss because of eating.
He insists on the fact that she increases 300 gram on weight..."*

...

Saturday - 28 August 1993
Sherry died yesterday.

...

Monday - 30 August 1993
Isabella has been crying with pain the whole week.
The doctor gave her **intestine suppository**.
However, it doesn't help.
She absolutely doesn't feel good.
Chris is also in a bad way.

...

Monday - 20 September 1993
Isabella has been crying with pain the whole weekend.

...

Tuesday - 21 September 1993
Last week André was buried.

It was horrible.

...

Friday - 24 September 1993
Today I have been at Mrs. Dr. Ehrlich`s.
She inquired about Isabella at assistant medical director Dr. H.
He told her,
*"Isabella is fine, she is merry and jumps across the ward
and her blood counts are super."*
All lies.
**She has been lying in bed for 5 days with terrible stomach-
ache and she has 0 leukocytes.**

...

Thursday - 21 October 1993
I have been realising the whole week that the doctors
get out of my way.
As soon as they see me, they turn round and walk
in the other direction.

...

Friday - 22 October 1993

...

In the afternoon I tucked Dr. B.

Then he granted me and Johannes an audience

*If she has an intestine and lung tumour then we will make a
"bone marrow transplantation."*

He told us all that in details.

...

Tuesday - 26 October 1993

Today we have been at the computer tomography.

It's over.

...

**If that is true the ray treatment and the
CHEMOTHERAPY wouldn't have been necessary.**

Anyway, Isabella has only still 3 to 6 weeks to live.

...

Tuesday - 2 November 1993

...

**D. told me today that Isabella had told A., the teacher,
already over a month ago that she will die soon,
namely as a child angel.**

...

Isabella has been feeling for long that she will die soon.

...

Thursday - 4 November 1993

**Yesterday Isabella talked with me about her death
for the first time.**

...

Sunday - 21 November 1993

**Isabella died on Thursday, 11 November
at 20.20 o'clock.**

It was horrible.

On Tuesday, 16 November 1993 she was buried.

We couldn't have managed it without Mrs. Dr. Ehrlich.

I wouldn't have gone to the clinic once again.

After her funeral some mothers and nurses went back to the ward.

Dr. B. said really sarcastically:

"Well, heavy grieving finished?"

This man is really terrible...

..."

Appendix

Epilogue