

Chapter 2

April 29, 2002

This was the day I started to write what would become this book. Why exactly this day? Luise's consultation with her psychiatrist had more or less the same result as always.

I can see from your journal how you have insisted over the years that you cannot tolerate the medication and have requested a lower dose. The psychiatrist always answered that you were very ill and would get even worse if you didn't go along with his treatment. It's clear you were never taken seriously, and since you didn't want to defy authority you always complied. Nothing new there.

I know I have said over the years that the strong doses of medication were making you ill. You got anxiety attacks, had hallucinations, became distraught. The higher the dose, the worse your torment. I often said that if the dose wasn't reduced, things would end badly. I've also learned that my 'intervention' in your treatment in several cases led to even higher doses. Anyway, the consultation with your psychiatrist on April 29 2002 was just like almost all previous sessions. But this was the first time I saw you after the consult. It struck me hard to see how badly it had affected you.

We were at Sundbygård, Luise's residence. We sat in the hallway waiting for her to talk to Sofus, her psychiatrist. Afterwards we were going to Holbæk to celebrate grandma's 89th birthday.

We sat and chatted. Luise said: 'I'm looking forward to our coffee break in Roskilde.' Then her gurgling laughter. The coffee break in Roskilde was our standing joke about DSB, the Danish rail system. DSB operation was often erratic, so we sometimes had to change in Roskilde to a Holbæk train. We would have coffee in Roskilde while waiting for a connection. When the train went according to plan, directly to Holbæk, Luise often said with a wry smile: 'Arrgh! There goes our coffee break.'

Normally you wanted me to talk to your psychiatrist on your behalf. You knew from bitter experience that you always fell short. The psychiatrist did not listen to what you said, and he did not accept your request for a lower dose of the medication.

Today, for once, you dared to have the consult with Sofus yourself, because the outcome was

inevitable. You should be given a lower dose of the antipsychotic drug Orap. You believed the conversation was just a formality.

After three weeks at Amager Hospital Luise was discharged on April 10, 2002. During the hospitalization it was decided that she would slowly be taken off Orap.

Extract from the April 8 chart note from Amager Hospital: ‘The patient is advised that dosage reduction will take place at Sundbygård. For a start I am complying with her wish to lower Orap dosage, and she is reduced to 12 mg.’

Your contact from the living center and your psychiatrist had participated in the conference at Amager Hospital on April 9, when a further decrease in the Orap dose was confirmed.

So everybody knew that treatment with this drug was being phased out.

We sat and waited outside the meeting room. Luise sparkled.

She was wearing her beautiful eggplant-colored silk pants and a loose silk blouse that matched the pants. It was Luise’s favorite outfit, which she had bought the year before in Portland, Oregon. The clothes brought out the colors of her beaming face.

In her hands she had a bouquet of red roses. ‘Grandmother must have red roses because I love her.’

You were looking forward to a psychiatric consultation where your request for less medication would for once be honored. A conversation where you would be heard and taken seriously.

You walked into the room with head held high and came out shortly afterwards stiff and gray.

Excerpts of chart notes for the April 29 consult: ‘Conversation with patient. She expresses a desire to reduce the Orap dose ... In the session I recommend she continue with Orap unchanged, which she seems to accept ... ’

Your expression and slumping posture as you came out of the consultation did not indicate that you had voluntarily accepted.

You told me, ‘Sofus will not let me reduce the Orap. You must go and talk to him, Mom.’

I went in and asked Sofus why he would not reduce Luise’s Orap dosage, as had been decided a few weeks earlier while she was being treated at Amager Hospital. The result of my efforts was that, instead of coming off the medication, her dosage was to be increased.

I was cold and stiff as I walked out of the consulting room. My legs barely functioned – I could hardly put one foot in front of the other. I walked with head erect, my forehead so upright that my whole body was bent backwards. This was the only way I could get my reluctant limbs to work.

I felt the urge to scream and lash out wildly around me. But a calm mother doesn't do that kind of thing.

Waiting outside the consulting room, you looked expectantly at me.

'What did Sofus say?' you asked.

My small voice uttered soothing words: 'Sofus thinks it's best for you if you take more medicine.'

You got angry and shouted: 'Get out of here. I don't want to see you anymore. You're not helping me. You've never helped me. You always say the same as them. They're killing me with their drugs, and you just don't care. Get out!'

Your anger was understandably directed against me. The red roses for Grandmother were thrown on the floor.

You did not come to grandma's 89th birthday.

Instead, you spent the rest of the day in bed under heavy sedation.

I didn't get to grandma's birthday either. I tried to make myself go, but I was heartbroken.

It was neither the first nor the last time we would be in a situation where you had blind faith in my ability to help you, only to make your situation turn out even worse.

I was crushed. I could not bear the thought that I had again disappointed Luise.

I came home crying. I wrote and wrote. My desperation made the words incoherent. The expression on Luise's face when she came out of the consult with Sofus was etched in my mind. It took over my entire body like a big painful boil. To think that in a five-minute consultation a psychiatrist could transform a bright, erect woman into a pale-gray girl with dead eyes and the characteristic drug-induced stoop.

I had done everything in my power. At the same time I got a nasty feeling that Sofus's 'show of force' with the increased medication dose had nothing to do with Luise's welfare, but rather was intended to demonstrate who makes the decisions. I must sadly relate that it was not the first time I experienced such a power play in the psychiatric treatment system.

Over the years I contacted I don't know how many experts in hopes of meeting someone who could come up with the right kind of support for Luise. I tried to get help through the social system. For

several years I tried the dialog approach (family consultations with the treating psychiatrists). Since the talks changed nothing – and even made things worse – I started to write letters to air my concerns over Luise’s medical treatment, which I thought was reckless and consistently made her worse.

I began to see a psychiatrist myself, wondering whether it was perhaps my fault that everything went wrong, that it was my personal input that caused my relationship with psychiatrists to fall apart, so that Luise’s treatment never got on the right track. I hoped that the therapy sessions might get me better prepared, so I could communicate with Luise’s psychiatrists.

Nothing helped.

As time passed I was consumed by sorrow. I felt inept, incompetent and paralyzed.

It pained me endlessly to feel like a passive spectator watching Luise’s mistreatment in a mental health system that was unaccountable, rigid and aloof.

But it pained me even more that Luise thought I didn’t want to help her.

April 29, 2002

Dear Luise

I understand that you felt that I did not help you today with Sofus.

I want you to see that I tried.

I can see why you often get angry at me and accuse me of never wanting to help you. But I can’t understand why so soon after your accusations you apologize. Your anger is justified. I have not always helped you well enough.

But, dear Luise, it’s important that you realize I’m doing my best, that through the years I’ve desperately tried everything in my power to help you.

Unfortunately, everything in my power is not always enough. And I’m very sorry about that.

But you don’t need a mother who’s sad, you need a mother you can have good and happy experiences with. And we’ve had many wonderful experiences together.

Do you remember our trips to New Zealand, USA, Palestine, Spain, Greece and especially our

annual trips to London and Cornwall? Haven't we been to many wonderful places and met many nice people?

Yes, we have done many things together, enjoyed ourselves and laughed. We have a special connection, you and I – all we have to do is just look at each other to know what the other person is thinking or laughing about.

Luise, I want to tell you about all your incredible abilities (everything you can't do has been firmly nailed down with six-inch nails).

You have marvelous inner strength. You don't give up. You have a great appetite for life and a desire to experience the world. I think your humor, your strength and your thirst for experience make your life a good one. In spite of everything.

I don't understand where you get your strength from, and I am full of admiration for your enthusiasm. You know how hard it is to be constantly misunderstood. You have experienced firsthand how bad things can get when you don't fit into society's little boxes. You've often said you wanted to tell about your experiences in the hope that it would help.

