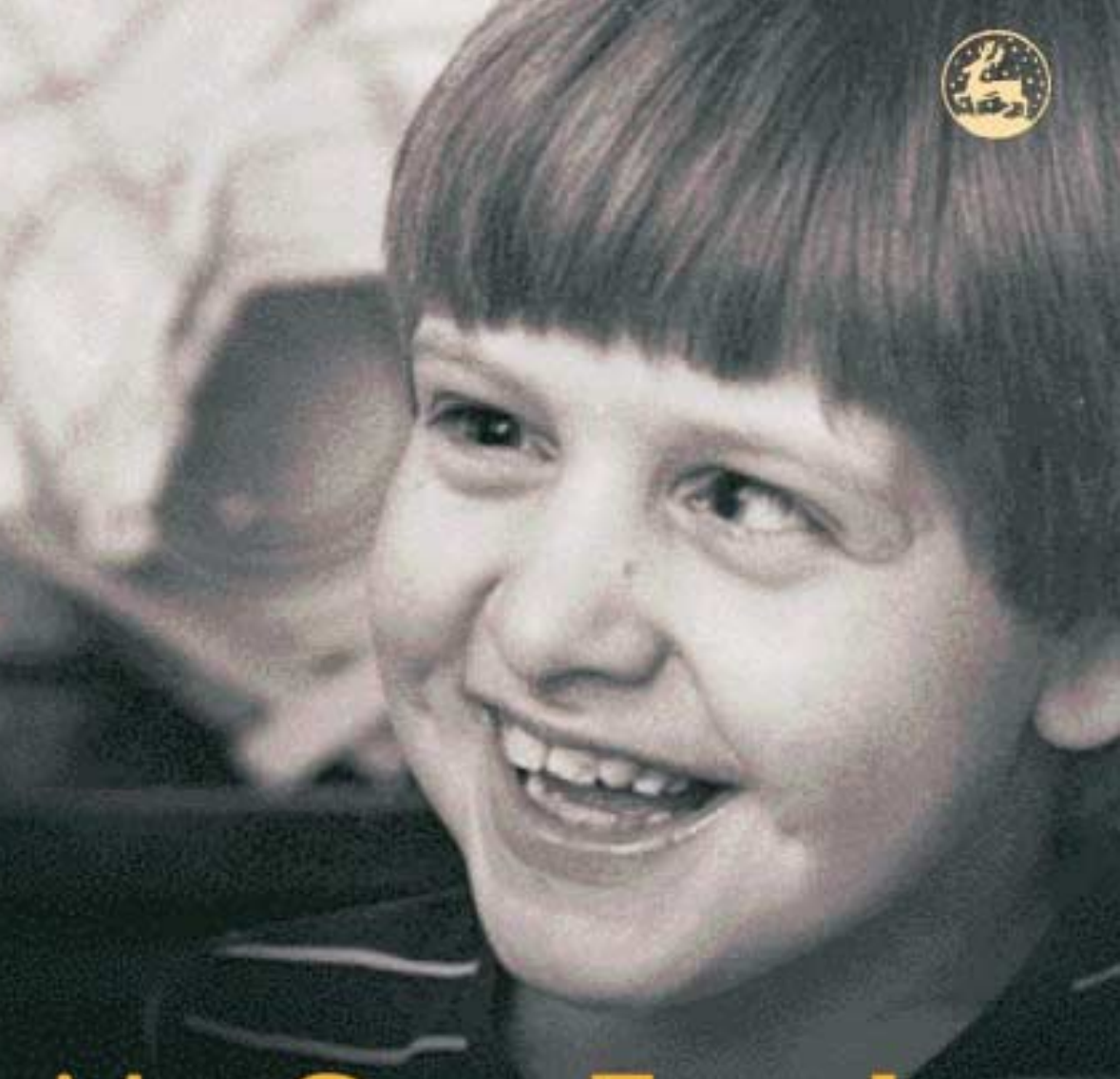

My Son Fred
– Living with Autism

How Could You Manage? I Couldn't. I Did It Anyway

Maud Deckmar

Translated by Ewa Wulkan

My Son Fred – Living with Autism

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I couldn't.
I did it anyway

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To my beloved son

If your work and mine
can give comfort to one single person
or help just one person a step along the way
the pain has not been in vain
With my deepest love and respect
Mummy

To my family with love

Contents

Dear Readers

It has taken me a long time to write this book. I have asked myself why, but I realized that writing a book like this leaves you open to other people's ideas and opinions. That is not a prospect to take on lightly. It involves intense sorrow and pain and I needed time to work through these feelings.

I have also deliberated long and hard on the ethics and morals of putting my son's life on display. After all, he is not in a position to either agree or disagree to this. Still, I have held long talks with him about the book and how he plays the main role. He just flashes his wide smile at me as if wanting to say:

- Oh Mummy, you do go on! Just do it!

In the end, I decided to write the book and to write very intimately about his life and mine. I did it because I feel that the message is important. Writing this book fills me with a great sense of purpose. It gives me a chance to convey my thoughts and feelings. I hope that it will make more people ready to listen, understand and have more respect for people whose lives are affected by these and similar problems.

I have involved Fred's father and sister in the decision to write the book in this personal way. They have chosen more anonymous roles for themselves, which is why I describe experiences and events from my specific point of view. However, they do share my experiences and have always been there, in good and bad times and, of course, while I wrote this book, with support and encouragement. Thank you to my beloved family. I also want to send special thanks to Ingegerd Bäckström, my friend and mentor during the writing process.

When I was young, I never really understood the words to the song by A. Storm:

> Thank you for the roses along the road
> Thank you for the thorns amongst them.

Now, after all of these years, the words have come so clearly to me. Everything in life has its season; sorrow and difficulty, hardships and pain, joy and simple times, happiness and light, healing and a deeper meaning. Why should I not be thankful for the difficult times? I have finally realized that if life is to be complete and totally understood, then the opposites must come together. There must be light to light the darkness, and darkness so we can see the light. I have received many letters, telephone calls and e-mails from people who have read about Fred's and my lives. Some have known themselves in us; they have cried, but many have also found comfort in what they have read. All have thanked me for writing Fred's book and many have even been inspired to share their own stories with me. There have been times while reading, when I have been deeply touched myself, but I have also felt joy when reading about the small world in the big scheme of things, about the meaningful little smile, the hand that suddenly moved or a look of satisfaction.

Most lives are lived quietly, day to day, through work and strife. I am so thankful for all these meetings with my readers and for the opportunities of participating in the joy and love that in some way always find their way past the darkness.

My family and I have sometimes contemplated the meaning of life, like so many others before us. I have met a few people who have openly questioned the purpose of a life like Fred's. My answer must be love. To be able to really see another person while meeting him. No other person in the world has taught me so much about love. He gives love. And keeps on giving…

He restores my soul.

Backtorpet, Sweden
Maud
Fred's mummy

CHAPTER 1

Unto us a child is born…

Can you remember that sense of longing?

The time was filled with longing. I put my hand over my enormous belly, the protecting cover for our beloved child. No other couple had ever been more in love than we and no child had ever been conceived from a greater love than ours. This child, growing inside me, would feel our endless love and his or her life would be permeated with joy and togetherness. How we waited for this child. The Moses basket was draped in a floral fabric and I had put out all the clothes which I had sewn and knitted. I put out the tiny cap, then the jacket, sleep suit and, finally, the baby socks. Now, all it took was the baby to fill all these warm and soft baby clothes. Our baby, our prince or princess, who, with our help and the help of Love, would one day break boundaries and make the world a better place to live in.

What image does the word *longing* give? Are there pictures of longing? Is an image of that word at all possible? You long for this special day to come, you know it will happen and the anticipation gives your eyes a gleam and your body fills with giddy, happy sensations. Soon, you keep on thinking, soon…

The September morning was magic. The autumn leaves glowed in all their colours and the sun blazed against an intense and free and blue-blue sky. The mountain air was light and easy to breathe. My

whole body buzzed with a sense of anticipation and at the same time of solemnity; a feeling I thought lost in the memory of childhood Christmases. My husband and I strolled towards our car, hand in hand and filled with excitement. We giggled, almost as if intoxicated as he helped me into the cramped car and fastened the seat belt around my enormous belly. A very proud belly.

The expectant father drove slowly through town. We didn't have far to go and we weren't in a hurry. I could see the sun flashing in the chrome of cars passing by. It was a lovely day. We felt as if we were alone in the world. No one else mattered. Everyday life felt very distant. How come the world didn't stop turning in pure amazement?

Waiting felt long.

- You could have stayed at home a long while yet, the nurse said, but if you stay on your feet and walk around things should start to happen pretty soon. She was all dressed in white and so calm and collected.

I was a good girl so I started walking. Back and forth in the corridor, contractions coming in waves until nightfall. I rested for a while and walked for a while. When dawn arrived it was Saturday. The sun was shining.

Soon it will be over, I thought, as the pains clashed over my head. It will get worse, much worse, I thought as the pains made life almost unbearable. I tried to lift myself out of my body so I would be able to leave the pain behind.

The sun set. And the evening was the second day. White-dressed women gathered around my bed.

- You don't have to wait long now, a young blonde told me, wiping my face with cold damp towels. When the contractions carried him into the world, no pain could have been more welcome. There he was… This wonder! Our son. OUR SON! Thank God and HOORAY! HOORAY! HOORAY!

What a baby! What beautiful long black hair! Look at those eyes, big and blue and that beautiful howling mouth. I had to smile. A miracle had happened. Real hands. Real feet. Chin, ears, nose. Look! Toes and fingers. Navel. They were all there.

- Am I really allowed to be this happy? I asked the new father who lay prostrate over my body, gently weeping.

- Just accept it and be thankful, he said. He knew my fear of being too happy, for I have always known that any joy in life has to be paid back in sorrow. Later perhaps, but still. Our son was wonderful, small and perfect and a miracle created from our love.

Everything was PEACE.

The following week The Tears started coming. The Tears were bitter, angry and constant. The doctor suspected colic. It took over our lives. The days became a long, black tunnel to pass through. I carried my little boy through days and nights, rocked him and cried myself. When my husband came home from work I walked straight out of our apartment and slammed the door behind me. I wandered around for a while, but restlessness drove me home again. On my way home I prayed:

- Dear, dear, dear God. Help us. Please help us. Help dear God; make him quiet when I get home. Make him sleep. Dear God, listen to my prayer. Please make it so that he is not crying when I come up the stairs. Dear God. Amen. Dear God. Help!

As I came up the stairs I heard the screams again. There were times when I secretly hated him. There were times when I screamed at him to shut up.

After four months The Tears left us. They just disappeared. I spent the first day waiting for them to start again. The second day passed. And the third. I allowed myself some hope. I even sang an old song that my mother had taught me about every cloud having a silver lining and every hardship having its limits. Life slowly regained its silver lining.

Then a children's nurse came to visit, from the health care centre.

- Does his tongue often stick out like that? she asked.

- And his arms, does he always keep them straight like that?

- He does have a bad squint, but it doesn't necessarily mean anything…

- What do you mean by that? I said, what?

- It doesn't necessarily mean anything, she said and went back to her life.

One night I sat in the kitchen with my son. He was about five months old and lying on my lap. Then SUSPICION suddenly hit me. That horrible, dark, dead dangerous Suspicion.

HE IS INTELLECTUALLY DISABLED.

Go away! I thought. I must be crazy. Ugh! I'm mad. Get a hold of yourself! HE IS INTELLECTUALLY DISABLED. HE IS INTELLECTUALLY DISABLED.

NO! These things happen to other people, people whom I don't know. It doesn't happen to me. To us. God, I'm stupid. I think I'll put some coffee on for my husband. Just look at the baby; he is so gorgeous!

HE IS INTELLECTUALLY DISABLED. HE IS INTELLECTUALLY DISABLED. HE IS INTELLECTUALLY DISABLED.

Help! Where do these thoughts come from? Go away, horrible Suspicion!

Suspicion stayed with me, though. I could forget it for a while but it always came back. I woke up every morning with a sinking feeling that something was wrong, even before any conscious thoughts had started to form in my mind. There is something awful I have to remember, what is it? I wondered. Then it hit me. The Menacing, Ugly Suspicion. He is INTELLECTUALLY DISABLED. THIS SON, BORN OF ME, IS INTELLECTUALLY DISABLED. Suspicion would knock me hard in the head every morning. It haunted me. All day. All my waking hours. When I couldn't ignore it any more, I told the baby's father.

- Stop it! he said. Why do you think that, why do you do this to yourself?

So, what had started it? Our son was five months old and didn't roll over from his back to his tummy. He didn't even try. Well, all babies are different and some may be slower than others. He had a weak grasp. He couldn't really grip the mobile that hung over his cot. Well, some babies develop this ability later than others. This is a fact and very important to remember.

There was something else, though, something even more important. There was something about his eyes. I couldn't really make eye contact with him. He didn't really see me. Sometimes he would gaze straight through me.

When I talked to him, he didn't prattle back. Our contact was one-sided. And it stayed that way. He would laugh and smile at times, but sometimes I felt that he had locked the door to his inner self and thrown away the key.

He was eight months old when I first raised the question with our doctor. I told her about my fear and suspicions. She didn't examine him further, just looked at me reprovingly and said:

- Just go back home with your baby and put those thoughts aside. Make up your mind to just enjoy him; spend quality time with him instead of indulging in these fantasies.

- Fine, I said, thank you. I went back out, tucked my baby into his carriage and started to walk back home.

- Okay, my little baby, let's enjoy ourselves and forget all these stupid fantasies.

Hope stirred inside. The doctor hadn't noticed anything amiss. She even thought me stupid to worry. Lovely! It felt so good to be able to see things positively. OF COURSE there is nothing wrong with my son. He is completely normal. I looked around. People. Cars. Birches starting to sprout. My heart was bursting with joy. Life was wonderful. And all around me, other young mothers out walking their babies in carriages.

A few minutes passed. I looked down at my baby, my beautiful son. He was mine. He was wonderful. But there was something though…and Suspicion returned. My heart sank. Despair crashed down on me like a wave. Why couldn't the doctor see what I saw?

Whatever it was, there was something very wrong with my baby.

How could I just go home, enjoy my baby and forget my suspicions when I could see that something was wrong? How could I be happy when Fear and Despair pushed Hope out of the way all the time?

My mother, having eight children herself and with vast experience, gave me comfort and hope. One of my brothers had not said a word until he was two and a half, but then he was able to talk fluently straight away. See there! These things happen.

I started to hope, at least for the time being. I was happy. Now and then. But my suspicions also grew from time to time. My son and I were close and I already knew him well. But he kept secrets from me. In him there were depths and heights where I couldn't reach. I couldn't fight my way in there. He hid from me. I asked him so many questions when we were alone:

- What secrets do you hide from me, my son? What sources has your mysteriousness? You puzzle me, why? What emotions stir inside your body? What kind of life is there within you? Is it dark anguish? Do you feel joy? Can you see my reality or is everything just chaos within you?

But I knew, deep down I knew. Other people could believe what they wanted. But I discovered my new companions, Pain and Despair. They moved into my heart; they took my hands and guided me through the days and nights ahead.

My son was adorable. Chubby and cute, with light-brown curls and three dimples on each cheek. He would play with his feet. At times, his big, blue eyes would beam at me through his squint. He could laugh. He could cry. He loved lying on his play mat tearing paper to shreds. I guess it made a soothing noise. He didn't care for toys. We became travellers exploring the world together, searching for things to recognize and like. We discovered a love for music. Soft, plain music was soothing. We would listen to the music and we could smile together and relax in each other's arms. At these times he didn't feel the need to cry or hide so much. He would hide just a little, just enough that the big person who called herself Mummy would not be able to force her way into his world. We conducted long, one-sided conversations where I would do the talking and wait for answers. Our eyes met in silent communication. His eyes would tell me that he wanted to be left alone in himself. I would hold his head between my hands and tell

him that I loved him so much and that I didn't want to leave him alone. I let him know my secrets and wanted to know his.

Fred contracted asthma at around 12 months of age. The doctor said it could be a case of childhood asthma and that there was every chance that he would grow out of it. He was often sick, especially during autumn, winter and spring. He would be short of breath, would pant and try to climb on us in his panic to get air. So many times we had to rush him into hospital or to whichever doctor was on call. There were times when we had only just got back home when we had to rush back again. We sometimes felt as if we lived at the hospital. And in a way we did. Twice, he was actually so bad that I asked the doctor whether my son was going to die.

- I can't answer that, he said.

How scared I was! I would pray:

- God, make him live. Please God.

My Little Man was lying there on the hospital bed with the tubes and drip connected to his small hand. He looked so tiny in the little, white bed, so pale that his lips looked almost blue. I picked him up and put him on my chest and fell asleep, together with him, heart to heart. I wanted so badly to give of myself, of my life, my strength. He survived.

Every time we turned up at the hospital a new team of doctors would meet us. Our visits started to follow a certain pattern. The doctor would examine our son's body, listen to his heart and prescribe a course of treatment. They also started asking an increasing number of questions as time went by:

- How long has he had this squint? Has he started imitating sounds and gestures yet? Are you sure that his hearing is okay? Has anyone checked his eyesight?

We had our own questions to ask:

- Why do you ask all these questions?

- Yes, he is two years old and he doesn't speak at all.

- Yes, he did say "Mummy" and "Daddy" when he was 18 months' old but he has stopped now. Why do you ask? Is there something you want to tell us?

Silence. BIG SILENCE. LONG SILENCE. One doctor blushed and said:

- Oh dear. I didn't handle this well at all. Do try talking to the hospital paediatrician about your son's development.

He didn't want to answer our questions. We went home with some asthma medicine and still more anxiety.

We were well known at the hospital's paediatric ward by now. After a while we were assigned "our own" special doctor. I kept pestering him with my questions but I didn't receive any answers. Just more questions back. Tests were performed and it was confirmed that my son's sight and hearing were okay. It was confirmed that my claims that he had used the words "Mummy" and "Daddy" and even imitated a couple of other sounds were the result of wishful thinking. I can tell you it wasn't. It was TRUE! There was nothing wrong with my hearing nor my intelligence!

In the spring when my son was two and a half, I was again seated in the doctor's office. My bump was enormous; I was soon to give birth to our second child. The snow was melting away outside and I can remember being dressed in a tartan dress. My son was sitting on the floor playing with some big, red blocks. The doctor was twirling a pen in his hand when I asked him for the thousandth time:

- What are we going to do? What is wrong?

- Well, what do YOU think? he said.

- I think that he is intellectually disabled, I said. I've said it before. You must see it yourself and be able to tell me what you think. After all, you are the doctor.

And finally, after all this time spent in the company of Hope and Despair, the doctor gave me his diagnosis. Intellectually disabled with autistic traits. I remember smiling at the doctor. He said:

- How can you smile when you've just had this tragic information?

I didn't give him an answer. I thought that he would understand that I had to smile in order not to cry. He asked whether we wanted to be registered with something he called Community Care.

- I don't know, I said. I don't think so. I don't even know what that is!

He explained the Community Care programme to me and that we were eligible for extra child-care allowance.

- But, I said incredulously, we don't want any money for taking care of our own child! I kept smiling that constrained smile that just wouldn't leave my face.

The doctor asked again:

- How can you smile like that?

I lifted my child from the floor, held him to my breast and went out the door. I hadn't really had a shock; I had seen it clearly for such a long time. In a way, I had forced the doctor to give me an answer. Still – my fears had been confirmed. I was no longer the only one who knew that I was right about my son. It was there. Written in black on white. In white on black. Anyway, my suspicions had been confirmed. I went right through the waiting room where other mothers sat with their children. I went through the entrance hall to the bus stop. The smile still on my lips. All the way home. I smiled and cooed at my child. I climbed off the bus and walked the short distance to our house, through the slush of melting snow, up the stairs, unlocked the apartment door and closed it behind me. Imagine the doctor not understanding that I had to smile in order not to scream aloud!

Hope went away to its own home, it went back to where it came from. Despair demanded a big place and Grief an even bigger. But in fact, my heart had already grown used to the weight of Grief. Among all these feelings I now felt something new knocking on the door of my heart. Relief arrived. Grief remained strong but knowing what we had to deal with gave a sense of Relief. We had been told. Now we knew. Now we had things to learn. Now we had to live a totally different life to the one we had envisaged and had to find new paths forward for our son and ourselves.

Dark and desperate thoughts found their way into my soul. What had I done to make this happen? Had I eaten too many strawberries during pregnancy? I had eaten at least two pounds a day that summer. Too many peaches? And that time when I fell over while running for the bus. Did I fall on my belly? Other thoughts appeared. Hadn't I

been kind enough, good enough? Was this in any way God's punishment?

Sometimes his eyes would follow me when he thought I didn't notice. Whenever I tried to catch his eye he turned his gaze away or the Shield came up and his eyes went blank. Why did he shut a door to the outside world? I desperately wanted to gain entrance to the cage in which my son lived his life. I wanted to share his confinement to force him to give up his secrets. Was he really from this world? Perhaps he came from another time, another planet? Maybe the birds singing made more sense to him than my language? He did pay much more attention to them than he did to me. Maybe I was the one who couldn't understand. Maybe I was the one who was different in some way. Was I the one who did something wrong? When would he let me have a piece of his secret?

I wasn't to know. Not yet anyway. At least, I now harboured both Grief and Relief inside. They were my companions. We were still together and we would fight from now on. It was a good thing that we didn't know how long and hard that fight would be.

Not always the way you expected

My son and I were close
I already knew him well
He kept secrets from me
in dark depths
or on clear and shining heights
where I couldn't reach
That's where he hid from me.

Questions without answers
What secrets do you harbour
my son
What life is there within
Maybe dark anguish
or do you feel joy
Do you see my reality
or is there only chaos within
What do you like

His big blue eyes beamed
straight in and straight through
my eyes
He could smile
and yet, mostly cry

We became explorers
together on a journey looking for
things to enjoy
things to recognize
We discovered music
Soft, plain music was soothing
Then we could smile together
and relax in that soft embrace
He didn't have to hide
then

My conversation was long and one-sided
I kept talking, waiting for answers
Long and silent communication
between our eyes
when his eyes said
I want to be left alone
inside myself
Then I took his face in my hands
and told him
that I loved him, loved him so much

and didn't want to leave him alone
I told him my secrets
and said that I
wanted to know his

The diagnosis was autism.

CHAPTER 2

People around us

Some people really hurt us. Some left. Some people held on and still some tried to help. Some were simply there for us. That's not bad. I know exactly what it feels like when someone close to you has died. The same thing happened to us when we found out that our son Fred was intellectually disabled. Phone calls from friends became increasingly rare. Some friends neither phoned nor came around to visit. Some tried frantically to keep the jokes and laughter going. Otherwise there was nothing to talk about. Not many people had the courage to ask:

- How do you feel? How are you?

But there were some.

Our telephone used to be a friend; now it became our enemy. It almost stopped ringing altogether. Some said:

- We don't want to intrude.

So that's it, is it? I did wonder what their real reasons were for not getting in touch. Perhaps they didn't want to intrude. For it's hard to know what to say when other people have difficulties. Sometimes it's easier not to get in touch at all. The terrible truth, of course, is that people have to fend for themselves in difficult times.

We lived in a new block of flats. Surrounded by other young families with babies and toddlers. The communal garden made up a

natural meeting place for all the young mothers and their offspring. All day long a parade of carriages, buckets, spades and picnic baskets would pass by.

I joined them with Fred in tow. I talked incessantly. I talked and talked. About my concerns, over and over again. About what the doctor had said at our latest visit. About my private theories, that, whatever the doctor said, my son was intellectually disabled. It was painfully obvious that I became a nuisance for those around me. There was only one thought on my mind at this time - what if my baby was intellectually disabled? I was so AFRAID! I think I was even more scared than I realized. I had to turn this reality into something I could grasp, could survive. Maybe it wasn't such a catastrophe to have an intellectually disabled son. These things happen. I tried to make it normal. These things happen.

My friend Inga came over for a cup of coffee one day. After a while she stood up and pushed the chair under the table. She carried her coffee cup over to the sink and asked:

- Is this really all you can talk about? Don't you have any other subject in your head?

- No, I said, I can think of nothing else right now.

- Then I'll leave. I'll see you when you can talk about something else.

My mother had a saying about small wounds and poor relatives and that neither of them should be despised. I think she knew what she was talking about. Small wounds can ooze pus and matter and hurt for a long time. Eventually the wound will heal but the scar will remain as a small unevenness in the skin that you feel when you touch it. And sometimes you can feel the scars on your soul as well. When you touch them. When something reminds you.

I realized that I mustn't talk too much. It was hard not to. At first, I didn't know it, but it was essential not to complain. I thought that our relatives would understand, even if they didn't have the possibility or strength to help in action, then at least in words of comfort. I was wrong. Not about all of them, of course; but attitudes varied even among our closest relatives.

One day I told one of them how tired I was.

- So, why don't you send him away? she said, she with whom I got quite used to avoiding personal issues when chatting.

- Our society has built institutions where they often take care of children like him. Why should you ruin your youth and your life like this? If you can't think of anything but your child and yourself, at least spare a thought for that poor husband of yours. Do it for his sake; can't you see how he is suffering?

All I had wanted was someone to talk to. Someone who cared and had my best interests at heart. I desperately needed someone. I needed some solace, to be able to feel small and needy for a little while. I would never want to send my baby away. Neither would his daddy. That's not what we wanted. All we wanted was to be able to talk about our situation.

Parents of disabled children are never allowed to complain. I learned this the hard way. But how was I supposed to know in those early days? Parents of so-called normal children always have the right to say:

- I'm so fed up with the children; I don't know what to do. They'll be the death of me one of these days. If I don't get a day off soon I will…, etc.

But not us. When I even breathed a word about it, I would always get the same answer:

- Don't complain. There's help available. Send him away.

We never dreamed of sending our son away. Why should we? To make life more comfortable for those around us? To avoid misspending our youth? What kind of life would that be, giving up before we even had tried caring for our own child? The wounds grew worse. They wouldn't heal because the crusts were scratched off repeatedly. The very people that I had expected to be on our side were not. Well some of them, many of them, but not all of them.

It really hurt, but these people stood there stripped bare in front of our eyes. Both those who stayed friends with us and those who didn't have the strength.

We even ended up having rows and fights with people about this issue. We were invited to a relative's birthday party. I asked my

husband to take our little baby girl and go while I stayed at home with Fred. He was at a stage where he would put his hand in his mouth and throw up all the time. We were used to it but other people weren't and there was always a possibility that he would make a mess. My husband arrived at the party and when he explained about my absence, he was brought to book.

- When are you going to understand that you need help?

They even raised their voices and tried to convince him.

- You can't live like this! You're letting Fred ruin the whole family!

Fred's father told me everything about it when he got back home. He was sad, but he hadn't said much in response to the onslaught.

I grieved then. I cried for days and nights. I kept dwelling on how they could be so cruel to us. Didn't we have enough to deal with? I asked myself repeatedly why they couldn't understand. Why didn't they even try to understand? People hurt us so much, for such a long time. Words stung like daggers being thrust into our bodies. We felt that everything that had happened was our own fault. According to these people Fred was just a spoiled brat whom we obviously couldn't discipline the right way.

- Give him a slap on the fingers! some would tell us. Send him away!

Myself, I couldn't see why we weren't allowed to talk about our weariness without being met by these attitudes. It would have been enough had they only listened for a little while. Couldn't they see that our son mattered as much to us as their sons to them? Didn't they understand that we loved our son just as much as they loved their children?

I said to one woman:

- Would you be able to send your son away?

She answered:

- Why should I? There's nothing wrong with him.

Did she totally lack the ability to understand or was it just a question of not wanting to? I don't know. There were others like her. People were not evil, just totally without or with very little under-

standing. They were people who, from sheer stupidity or lack of empathy, hurt us badly.

Some people thought that we didn't discipline Fred. Once upon a time there was a man who wanted to give us a pair of second-hand car speakers. He had bought a couple of new ones.

We gratefully accepted the gift.

- But I will give them to you on one condition, he said. That you won't let Fred play with them or break them.

Of course, the joy of receiving that gift disappeared completely. The sun hid behind a cloud again. We tried to explain that we never actually *let* Fred break things. That he was intellectually disabled and it was *hard* to keep one step ahead of him.

- He *shouldn't be allowed* to break things. You have to discipline him. He is just ill mannered! Well, how about those speakers?

My heart ached. My whole body ached. My soul cried. WHY couldn't they understand? Why did we conceal our feelings, why did we accept the gift and say nothing? We told ourselves that they didn't understand that we had to be tolerant that they didn't have the ability to give love and compassion.

- Those poor people don't know what they are missing, I said. But I cried inside.

I should have cried aloud. There are no excuses for their behaviour. I should have kicked and screamed. I should have told our so-called friends what I thought of their attitudes and behaviour. They turned the knife around in my wounds and I now feel that I should have stood up for myself and told them how I felt. Maybe I could have avoided much agony later when the Pond of Pain inside overflowed. For if you fill up with pain you can only keep it locked up for so long. The walls can be built rather high and able to hold a lot of misery, but when finally the special drop comes – the drop that the pond can't take – the walls burst and – I can tell you – there is a spring flood!

Many years later we moved Fred into sheltered accommodation and I met the relative who had told us to "send him away".

- So you've finally realized what I've tried to tell you all these years. You're sending him away. At last you finally have understood that you have to send him away! You followed my advice after all!

There was no point in trying to explain that we had to live through all the agony and hard work first in order to reach that final decision.

Our isolation grew. It was so painful trying to talk to people that we withdrew from company, to a certain degree. It was easier with just the family around. We could avoid the added pain of listening to opinions and meeting all this lack of empathy. Some people just disappeared and some we stopped calling.

Inviting people to our home became a big strategic operation. Shopping and preparing everything was fine, but when the event itself approached the problems got worse. I would lay the table as close to dinner as possible and still the pork chops would inevitably end up on the floor at some stage. The table had to be re-laid after glass explosions had precluded a safe meal. These incidents may seem banal and some may say:

- Well, these things happen when there are small children around.

I agree, but in our house these things happened ALL THE TIME. Only one of us parents at a time could sit down trying to keep up some sort of interaction with our guests. The other would be running around working to save whatever clothes, purses and decorations there were.

People would invite us to their homes. One night our old friends Bertil and Barbro invited us to a dinner party. Two other couples would be coming as well.

- We're sorry, we said, we have failed to find anyone who can baby-sit for us, we can't come.

- Why don't you bring him, there will be lots of adults who can help, they said.

We demurred, trying to explain the dilemma of the boisterous little chap who made a habit of tearing down anything loose and not so loose.

- I won't hear of it, Barbro said, you have to come. We'll all take turns helping.

We reluctantly agreed to come.

The night of the party arrived and we put on our finery. Our friends had a lovely home and had arranged everything beautifully. The stereo, as was the custom during the 1970s, was placed close to the floor. You had to crouch down in order to put on a record. They had a TV, a glass cabinet and books. Plus a lot of other paraphernalia. Purses belonging to other guests were placed within reach. We moved things onto shelves and out of reach; we checked that the most expensive decorations were placed out of the reach of our son. Then the party got off to a start. For us it was a sweaty time. One of us would always sit down at the table during the whole evening, but never the same parent. We took turns, rushed around, saved the stereo, books, china, garbage, food…

AND NO ONE HELPED AT ALL. Parties are very enjoyable; you forget that you promised to help; besides, they couldn't see the need.

The party ended. We were the first to take our leave. The hosts followed us out on the front porch. Then they said THE WORDS that we later have heard, and have smiled about, so many times:

- I don't know what you worried about. He's not at all as wild as you claim. We didn't notice anything at all. Did you have a nice time?

It seems my husband and I had been successful in filling in for each other at the table. No one had noticed our rushing around. NO ONE HAD NOTICED ANYTHING. No one had paid any attention to the fact that we had not attended a party but had been sitting there holding our breath.

And all the outings! We went on outings. I couldn't tell you how many! Fred's energy level was so extreme and his hyperactivity so intense that it would bring him out of bed in the middle of the night, craving activity. This made for long and arduous days. Exhausting days. Bad days, tough days. Dark and everlasting days with many hours until evening.

On days like that we had to get out. Come sunshine or rain, come frost or darkness. We had to get out in order to make it through the day. Saturday morning: pack a thermos of coffee, something warm to drink for the children, some sandwiches and a couple of bananas. Get into

the car and off to find a meadow or maybe a clearing in the woods where we could sit down and let Fred roam around working off some of that excess energy. We could honestly say that we knew most meadows and woods in our county. For it was easier going into the woods where we could be on our own and did not have to protect other people's picnic-baskets, food and other property. Sunday mornings would follow the same pattern. Pack a picnic and off we would go. These excursions were important because Fred could run around; he had space and laughter without me chasing after him. And I could have some breathing space. We all felt better during these excursions. Life was easier to live for a while.

I had come up with a standard answer whenever I was asked how we were doing:

- Everything is fine.

Outward appearances became important. The picture of a perfect family who can deal with life's little difficulties.

- Of course we're fine.

I had to say it. If I didn't someone was bound to say something about sending Fred away, or:

- You can't live like this. You have to…

Showing a carefree façade was much easier. It meant fewer arguments with people who had a need to express their opinions.

- Of course. Yes, but you see, everything is just fine.

Then, on top of all this, I was nominated Super Mum! I went to the children's clinic with Fred for a general check-up and heard a nurse say to the doctor:

- Come and meet Maud, doctor. This, you see, is a real, genuine Super Mum.

It's hard being a Super Mum. I've had to live up to that epithet ever since I heard those words. Once you've been nominated Super Mum you have to go on being one, don't you think?

Reaching for the stars.

Or rather, drinking that thousandth cup of coffee, in that thousandth clearing, in the thousandth forest, letting Fred run around carrying his banana, shouting with laughter.

We didn't attend big family get-togethers. Why should we? Though I would have liked to. We attended funerals, weddings or people coming for a visit on their holidays; that is to say, we went there, said hello, and left again. We did have a baby-sitter who would help us from time to time, but we didn't want to exhaust her by using her services too often. There was always the risk that she wouldn't want to come any more.

I often felt deprived. The child in me craved its space. I wasn't allowed to join the other adults. Fred didn't usually fit in with other people's rules and often his father and I would take turns taking him out for walks. It never felt like quality time. Instead it was a question of keeping him away from others. He became the obstacle keeping me from doing things I would really have enjoyed. After all, I sometimes wanted to spend my time indoors, having my coffee and talking to the other grown-ups. Instead I spent my time in the garden, looking after a child, on my own. All alone, sometimes this would go on for hours. Fred's dad would come out to take his turn. He must have felt just as lonely. We were always left out of things. It was always us who didn't fit in. I was so angry. I cursed silently inside me. Long, dirty sentences. Fucking hell, shit, I hate all this fucking shit! Fuck! Hell! Over and over and over again. So, why did we visit other people? It should have been so much easier to just stay at home?

To be honest, had we been fair to Fred we wouldn't have subjected him to places and situations where he inevitably became "the difficult one". Of course. But, apart from being a mother, I was also an adult. I was on maternity leave, spending most of my time at home, but I needed to see other adults, needed some time off, needed to have some fun. My husband needed it too, but at least he spent time with other adults at work every day. We didn't often go over to other people's homes and only kept in contact with a few. Of course we held on to our respective families.

People like my mother. She is the only person apart from ourselves who always, from the start, showed Fred that she loved him for the person he is. She showed both Fred and us, in words and deeds, that he was worth all her love. My mother's name was Astrid. She was 45

when Fred was born. I'm the oldest of her eight children. Some of my brothers and sisters had moved away from home but the youngest ones were still children living at home. My mother worked full-time at a nursing home and ran a livestock farm. In many ways she had a hard life. Even so, her *joie de vivre* was infectious. She was radiant. She became our firmest friend. Her experience with children was extensive but she would say:

- Giving birth to, and raising, eight healthy children is nothing compared to giving birth to, living with and trying to raise Fred.

She didn't have much time to spare in her busy schedule but was still the one person who gave us most help and support. People who have gone through much in their lives are often much more ready to give practical help in times of need. I wonder why? Sometimes she would watch Fred, for a day, a night and even a whole weekend.

She understood. She loved him. She could tell us how hard it was to look after him. She'd had to wake up at three in the morning and supervise him in a way that she had never experienced with her own children. She found the lack of contact and interaction hard to bear. You yourself turn silent when you don't get any feedback in a conversation. And the silence can get hard to bear.

It was good that she shared her experiences from caring for Fred with us. And bad. Of course, it hurt when she thought that he was a handful. Even so, we needed to hear it. We weren't the only ones who found it hard to cope. She did as well. The biggest difference between my mother and other people was that she always added words and gestures of love. She would give Fred a hug, buy him a bar of chocolate and say:

- Granny loves you, Fred.

She thought he was beautiful. Most beautiful of all. Her first grandchild. She was proud of him. She would show him off. She would sew clothes for him to wear. If a solution was possible, she would find it. She was the Mother of Solutions. When my youngest sister Maria was a baby and my mother had to go out for a little while, she turned an ordinary Windsor-style chair upside down on the floor.

She placed the baby inside with her back resting on a pillow. And Maria sat there until my mother came back.

Once, my mother had looked after Fred for a night, and I came to the farm to pick him up. She had tied one end of a long rope around his tummy and the other end round the trunk of a big tree. She had a lot to do, hanging laundry and couldn't stop doing all the chores around the place. The first thing I saw was my little four-year-old. My baby. A captive. Tied down with a rope. He was pulling at the rope that restrained him. I saw red. He wasn't an idiot whom you had to tie down as if in a strait-jacket. I was used to not showing my anger and quietly went over to the tree and turned him loose.

- Are you upset? my mother asked.

- Yes, I damn well am, I said indignantly. Do you have any idea how awful it seems, his being tied up like that?

- Yes, she answered quietly. But it was the only way for me to do anything but watch over him, and I don't honestly think it harmed him one little bit.

She reminded me of all the makeshift solutions which she had to devise while raising her own children.

I stayed angry for a long time. I felt as if she had shown disrespect towards Fred. And it hurt. Deep down. Next summer we went for a picnic on Midsummer's Eve. We went to a derelict farm which lay close to a main road and a rapid brook. I was rushing around constantly trying to keep Fred out of a harm's way. He ran towards the main road where cars sped by. I laid out the blanket. Ran. Pulled the corners of the blanket. Ran. Took out the picnic hamper. Ran. Ran. Unpacked the bread. Tossed it away and ran. Pulled him back. Held onto his arm. Threw out some food in a jumble all over the blanket. I had packed everything with love and care, including napkins, a small Swedish flag and tablecloth. All to no use. Why did I even try to make things nice and keep up a semblance of a festive mood? A dark rage came over me again. Fuck! He got hold of an egg and smashed it in his hand, threw himself over the rest of the food to find something else to smash. I helped him, threw an egg at a tree. It smashed. I didn't give a damn. His father said calmly:

- I've got a 30-foot rope in the car…

- Get it! I said.

So we tied one end of the rope around Fred and the other around a fence. It didn't feel at all good. But it was a solution. We were able to eat. Fred moved around freely, albeit within a limited area. What's preferable? Ranting and raving and someone holding on to you by your arms or neck or clothes? Or, being tied to a big birch tree? He didn't scream or anything but he would use the whole length of the rope. Sometimes we would resort to solutions that I still cannot and will not assess. We did those things. Then.

My mother, Astrid, was there for us as often as she could be. She would listen and understand. She was the only person that we couldn't do without. She died of an aneurysm on the brain when Fred was six.

My youngest brothers and sisters were only kids when it happened. Maria, the youngest, was only 13 and moved in with us. Kjell, at 14, still needed lots of hugs and kisses, as did all the others. My oldest brother had married and moved away. It was a relief to me that he had someone to care for and who cared for him. My brothers and sisters found a home with us for many years, until they had homes of their own. I suddenly functioned as a surrogate mother for teenagers and, more or less, the whole grieving family. My own grief was no less than theirs. I just had to put it aside for the time being. These experiences closely united my siblings and me. This has turned out to be a lifelong union and the love I receive from my brothers and sisters carry me through many dark moments.

But I lost my tears. It would be a long time before I cried again.

CHAPTER 3

Another baby – will I dare?

I went back to work part-time when Fred was six months old and it felt good. My maternity leave was over and one of our neighbours, Lilian, a housewife, watched Fred while I was working. She doted on him and even knitted him a new hat. She stayed on as his childminder until he was almost two years old. They enjoyed each other's company and she would take Fred for long walks in the carriage.

It would do me good to get away every morning to my familiar office and meet my colleagues. To be honest though, the first day back at work I couldn't concentrate on anything but Fred's round arms and cuddly body. I was homesick.

After a while I told my colleagues that I suspected that Fred was intellectually disabled in some way, but I didn't elaborate. It was hard to talk about it. Not that I felt embarrassed, but some reactions were hard to take. People were completely taken aback. Some would think it very dramatic and pass it on to other people. Maybe it really *was* dramatic; to me it was everyday life. I can remember once telling a colleague about an incident at home and she exclaimed:

- I feel lousy complaining about my son needing braces. I'll never open my mouth again!

I then decided to keep quiet at work. You don't want people to feel that their problems are any less important, just because your own life

has developed in a certain direction. A person's problem is his or her own and his or her reactions are based on his or her own circumstances. I have the deepest respect for other people's responses to problems.

My husband and I made life hard for each other from time to time. I wept. I worried. As soon as he came through the door, I was all over him, telling him about my misery and my conviction that Fred was disabled. He would be showered with questions.

- What do you think will happen?
- What should we do?
- Will life ever get any easier?
- What do you think will happen in a couple of years?
- Will he ever learn to talk?
- Will he suffer?
- Maybe, just maybe, there's nothing wrong with him after all?
- What should we do?

Over and over. Again and again. This would happen all the time. My husband is my opposite in many ways. He doesn't find it as easy to talk about his problems. He wasn't able to discuss things at all. He wanted to keep all his fears and thoughts inside.

- Nothing will get better because we go on and on about it, he would say.

I hurt him with my constant worrying and my need to talk. He hurt me by not wanting to listen or talk.

One day we were discussing whether we should have any more babies. Did we want any more? Yes, we had always felt that we wanted more than one, but what did we feel now? Would we dare? There was obviously something wrong with our son even though the doctor hadn't given us a diagnosis. If Fred turned out to be disabled, then why had it happened? Was a new baby running the risk of having a similar problem? I asked the doctor about his thoughts on this issue, but he answered that he just didn't know. His response to our having more babies was positive.

I can't honestly say that I worried about having a new baby but then, one day, the question became academic. The new baby would be

born during the spring. Weeks and months went by. My bump grew. I worked part-time at work and full-time at home. I patted and talked to my bump whenever I had the opportunity. I never considered that our next baby could be intellectually disabled. I told myself that it couldn't happen again.

- You never hear about two in the same family, I persisted.

I was hoping for a little girl and searched for Fred's old baby clothes. I sewed and knitted. A few baby hats with floral patterns found their way into the collection.

My husband worried. True to his nature, he didn't say much. But from time to time I had the feeling that he worried in secret about our new baby.

- Well, what if…? he would say.

Now I was the one who didn't take his worries seriously.

Eight months into the pregnancy I attended the antenatal clinic for a few tests. A couple of days later the phone rang. It was my midwife.

- Hello, we've just had your tests back and we would like to take some more, if you don't mind. There's no hurry. You can come in during the week whenever it's convenient.

I took a taxi into the hospital straight away. Bloodwaves from my heart were breaking in a rough swell and thoughts were buzzing behind my eardrums. So, there was something wrong after all…

I jumped out of the taxi when we arrived at the hospital and the driver had to call me back. I had forgotten to pay.

We had only recently had Fred's diagnosis as being intellectually disabled with autistic traits and even then I hadn't worried about the new baby. I hadn't allowed those thoughts into my mind. I had been so sure that everything would be okay.

And now my whole world collapsed.

A volcano started erupting behind my eyes and fire and lava ran down my spine. The midwife noticed that I was shivering so badly I could hardly speak. She comforted me and told me that this was just a precautionary measure. The worst thing that could happen was that they might have to give the baby a blood transfusion after birth and that everything would be fine. She took some more blood samples and

sent me home. I was so scared. How could we ever care for another disabled child?

A few days later the midwife called me at home and told me that the new tests didn't show anything amiss.

- Everything looks just fine, she said.

Those few words took a load off my shoulders. I resumed my earlier attitude: It can't happen again. There won't be anything wrong with this baby. Sometimes people would ask me whether I worried at all and I could truthfully answer:

- No, everything is going to be just fine.

I felt sure. Maybe it was a form of self-preservation. Anything else would be too hard. Where would we ever find the strength to care for another intellectually disabled child?

We longed for the baby to arrive. I hoped for a girl but also felt that it didn't matter what sex it was. I just wanted the baby to be healthy.

One Saturday night I felt the first contractions. I felt warm and happy! I felt joy! A baby. A life created by me, by us. Another soft little being to welcome into the world and to love. At midnight I had the show – the small mucus plug that signalled that something was happening. I didn't recognize this at all from last time. I called the labour ward and told them that we timed three minutes between contractions. Then we were on our way into town and the hospital.

My mother had taken Fred to her home so he was well cared for.

All the stars were out this dark and clear night in the beginning of April. On nights when princesses are born there should be something magic in the air and there certainly was that night. I looked up at the stars and thought:

- The stars are out to welcome my child. This will be a happy baby.

The staff at the labour ward made us feel welcome. There were not many other expectant parents around and I felt increasingly relaxed. The contractions waned and finally I couldn't feel any at all. Help, what was happening now?

- Don't worry, the midwife said, these things happen.

I was past my due date by a fortnight and consequently a doctor came by next morning and kick-started the contractions with a drip.

My delivery was short but very intense. She was born three hours later, Sunshine of Life. A faint wail: "I'm here now". I put her on my breast. Her blue eyes blinked at the stark light. Her face was so small but round and perfect. The eyes were big and dark blue and she had perfectly formed lips. Her black hair formed a shining helmet round her small head with the perfectly rounded neck. I made a point of checking her neck. Fred's neck was flat whereas hers was rounded. It probably didn't mean anything.

The midwife leaned over me after having finished checking me over.

- We'll send for a paediatrician to examine the little one, she said. She knew that my first baby was intellectually disabled.

- Why? I wanted to know.

- I thought you'd worry, she answered.

- There's no need, I said. There's nothing wrong with her!!!

That's what I said. I felt so certain!

So, no paediatrician arrived. Afterwards, I've been amazed many times over my answer. But I felt so sure.

Sunday afternoon we were wheeled up to the ward. I felt fine and not particularly tired. I was just so happy. The staff seemed to think that I needed sleep and rest and took care of the new little person. My baby. My princess.

Five hours later they wheeled her in to me in one of those see-through cots, carrying a pink label with her birth weight, length and mother's name.

- She is very calm and aware; the nurse's assistant said. She hasn't slept yet. She's been quiet and keeps looking around.

In the evening we had a visit from Fred and his father. Fred didn't look us in the eye, didn't in any way show us that he had understood what was going on. But when I told him about his little baby sister, he slowly and carefully put his cheek against hers. He was two and a half and we had just had his diagnosis.

During the following week the doctors duly examined Princess in every possible way. She was so beautiful and completely normal, but of course I knew that already. Then we gave her a name.

Seeing her develop was a completely new experience to me. The first smile came early. Eyes that smiled and followed us around, hands that grasped. Contact. Contact. She would gurgle and say "dada", "mama", and "papa".

Fred also developed. He started to walk. Of course it was wonderful, magnificent – but it also meant that the baby needed to be protected. I had to lock her in a room in order for her to get some sleep. Getting out was difficult but I bought an extra seat for the pram and we went out for walks. Endless walks.

Three months later we moved from the flat and the neighbours whom we knew so well and who knew all about our situation. I missed them. I missed the natural way in which they related to us, to Fred. They would yell "Hi, Fred" when we came into the yard. Someone's dad would throw him in the air. Someone's mum would put Fred in the swing next to her own child. Everyone knew that Fred was intellectually disabled. That was a pretty natural state of affairs to the people in our yard.

We bought a small house in another part of town, a small house with a small garden. We thought that having a garden would give more freedom to our little boy. Around the garden my husband built a low fence.

There were to be no more children. I may be the one who really made that decision. I believe that the children's father would have liked more but I had grown wary. Somewhere inside, I had reached the insight that it could happen again. There was no saying that the next baby would be so perfectly created that it also would be perfectly healthy.

After all, did anyone ever claim that I should have happiness and sunshine all along my life's road?

Every child is unique, and the child who comes into your life at birth is the very child that you are supposed to share your life with. I wanted nothing more than to spend my life with my children. But I'm not at all sure that we could have lived through having another disabled child. A child with intellectual disability or autism. Would we have had the strength? And if we didn't? I could never send Fred away

for someone else to care for so how would I have been able to do that with a new baby?

I found it hard to contemplate amniocentesis. My outlook on life doesn't allow me the right to discard a baby just because it doesn't suit me, or because there is something wrong with her. If I went through amniocentesis and something turned out to be wrong, what choices would I make?

I sometimes have the feeling that all this scientific development is a curse. Not knowing is not having to choose. But I also do know that a lot of people need this kind of help in their difficult decisions. I don't judge or condemn. Never.

And still…

What if…

This time it was about me, about us. A nurse told me that only certain defects such as Down's syndrome, can be detected with amniocentesis. Not autism. And not neurological damage that can cause intellectual disability.

No, I didn't want that.

So many thoughts went through my mind, and meanwhile time passed. We didn't have any more children. But, the children we had were the most beautiful in the world.

CHAPTER 4

"Just for today" is all I can handle

And it happened in those days, when we had moved into our small house and his baby sister had been born, that Fred started to walk. He started to climb. He climbed the bookcase and threw everything on the floor. He would then sit or lie on the topmost shelf and peek over the edge. It looked dangerous. The stereo would go on the floor even though it had been put on the topmost shelf to prevent him from reaching it. Once. Twice. Several times. It made big dents in the floor. The stereo was never itself after that, even though Fred's father fixed it to the bookcase. Fred would climb the bookcase and throw all the books on the floor. He would tear the books to shreds. I loved my books. In fact, I had always loved books. But there was no way I had the strength to protect them. In the end, I would let him tear them to pieces for at least that gave me a minute of peace. The floor, indeed the whole house was covered in book pages. Shredded book covers were everywhere. When Fred's father came home he said accusingly:

- Why in the world have you let him tear the books apart?

My anger was such that I would often answer him in a nasty voice.

- Well, hasn't he done a good job of ruining them? I just thought that he should be allowed to, that's all.

Fred would climb to the top of the swing frame in the garden. He would lie on his stomach on the top horizontal bar. We realized that his balance was perfect, even if it looked a bit unsteady and we knew where to say stop. He never fell from the swing frame, but the neighbours contacted us. They couldn't stand sitting in their garden with their coffee watching Fred. His climbing adventures looked too dangerous. I watched him all the time, and didn't take my eyes off him one second while he was out playing.

He would pull down everything he could reach and ruin everything that got within his grasp. He climbed on the table, threw china on the floor. Paintings. Furniture. Tablecloths. The ornaments had been reduced to a mere memory. One morning I was awoken by a noise. I found him sitting on the table having opened the glass showcase. We had had some beautiful cups as an engagement present, and a few still remained intact. The sound that had wakened me was the crashes as he threw cup after cup and saucer after saucer on the floor. I was in time to save a few. Life was reduced to running around trying to retain something that at least could be said to resemble a home.

Fred started to make sounds. He would scream and laugh. His laughter was furious and his crying was violent. When I expected him to laugh he would cry, and when by all accounts he should have been crying, he would laugh. When he got his fingers caught and hurt himself, he laughed. Standing on a climbing frame three metres up in the air leaning out, he would laugh. But, having to step over a one-inch threshold was enough to make him cry and refuse to step down from it.

Our home turned into chaos. There were always torn book pages scattered on the floor. Curtains were being torn down, paintings thrown on the floor and ornaments disappearing into oblivion. Was Fred's inner chaos so profound that he needed his outer surroundings to match it? Every day he would climb, rush around, tear down and ruin things that I had acquired and loved. I was sad. I was angry. I

almost turned into a child abuser. He would put his fingers down his throat and throw up everywhere. Over the newly re-upholstered sofa. Over himself. Outside or indoors. He toppled the heavy chest of drawers over himself. Only his small head stuck out from underneath it.

- Is he badly hurt? I roared through the chaos and confusion.

He got some scratches.

- Is he badly hurt? I roared after he had toppled the cooker on top of himself and was lying under it.

He got some scratches.

Fred's father bolted everything to the walls, the furniture, the mirror, the cooker, sofas, the bookcase and the chest of drawers. Almost everything except the chairs.

He was in me
and around me
Over me and under
He surrounded my whole body

He ran, he climbed
he screamed, he laughed
and cried
Great Big Chaos in Big Black Hole

Finally, he had ruined everything
The angel in the window
The candle on the table
and the engagement china

He had torn all the books
slaughtered all the flowers
thrown all the paintings on the floor
until their frames cracked.

Until the whole framework cracked.

I heard, through the grapevine, that some people talked about me not cleaning my house.

- Listen, an acquaintance said to me one day, I've heard a lot of crap from a woman living on my street. She claimed that your place is so messy that some of your relatives won't even come to your house any more. They say that you never vacuum your floors!

I didn't even know the woman in question. I guess she needed to find something interesting to talk about. I never went to see that particular acquaintance again. Being honest is a good thing but I don't know whether being the bearer of malicious gossip is. It hurt me a lot.

There were forever more book pages, flowerpots and compost on the floor, so why should I even try to clean the house again? Fred had torn down the curtains for the 200th time so why should I put them up again? I had had the strength to do it 199 times. I might even have the strength to do it the 201st time but not today, not this time.

The opinions about our unruly son were not only conveyed to me in underhand ways but often straight to my face. People who claimed to be close to us accused us of not being able to discipline our son.

- There's nothing very wrong with him, he is just bad mannered, they said.

Sometimes I would try to explain to them that we couldn't come to visit since there was so much going on with Fred. Their answer would be:

- He SHOULD NOT touch the stereo. You will just have to teach him that. He SHOULD be able to sit still in the car. You will just have to teach him that. He SHOULD NOT pull down the tablecloth and the whole coffee table. You will just have to teach him that. He SHOULD NOT put his hand in his mouth and throw up over the sofa. You will have to spank him. You let him get away with everything. You have to discipline him.

The people who said these things never listened to us. Therefore, after some time, I stopped trying to explain. It all just made me so very sad, sad, sad. The very people who could have supported us didn't understand and that made our burden even heavier. They put stones in our hearts. I cried many a night over people's accusations and lack of understanding.

The accusations would sometimes be veiled in an air of jocularity:

- Look at this place, there's no way I can come in for a cup of coffee. Ha, ha, ha. No, I think I'll come back another day when you've had time to do some cleaning. Ha, ha. Bye.

And with that they went home. I was left in my prison. A day and night consist of 24 hours. An hour of 60 minutes. An hour can pass quickly when you are happy. When you only have an hour to spend with the one you love it passes in seconds. On days when I couldn't even contemplate "tomorrow', these 60 minutes were mountains to climb, mountains where I couldn't even see the peak and I didn't even have rope and axe to help me. I would cry from despair. I had no one. There was no one who could help me. No one. Alone. Alone. Alone. Well, I still had my mother then. But the few hours of relief she could give me weren't enough to banish the sense of loneliness. This innermost lonely responsibility that I carried alone. The hours that Fred spent with my mother were restful, but then it would all start again. Sometimes I would get a call from an old friend and I would tell her some of my woes. After we had hung up I felt even lonelier. No matter how understanding and sympathetic she had been during our conversation she would then be able to go back to her own settled life after hanging up. But I…I was left in my despair. My life was my own. No one could live it for me.

Fred's father worked while I had left my job. I could see no other solution. He usually came home at six. I told him that I could only cope until six o'clock.

- Try and come a bit earlier if that's possible.

Six o'clock was my salvation. The rock ledge where I could rest. SIX O'CLOCK became magic. I had to cope until six o'clock. Then he would come home, he who knows my reality. The only one in the whole world with whom I share this reality. He who also understands. He who is also trying to cope. He who also loves this child, who knows it's not just a question of discipline. He with whom I can grieve. He who doesn't judge me when I don't have the strength to clean the house. He who doesn't have the strength either. He who shares my Loneliness.

Nothing in particular happened after six o'clock. I didn't need to go out or anything. But there were two of us. We could divide the children between us, have one each to cuddle, give a bath, read to and put to bed. We could be together all four of us and I had a grown person on whom to rely and with whom I could share some time. I didn't have to cope all the time, then.

He would sometimes come home at ten past six. By then I didn't exist any more. I didn't have a spare battery on which to run when my power was worn out. All spare supplies had run out long since. When it happened he would often find me lying on the floor, with a crying child on each side. The baby girl so scared and upset because Mummy was so upset and the little boy scratching, screaming and trying to tear himself loose. I would sometimes scream as well, from fury, anger and despair. The more I screamed, the more the children would scream.

There is a period in every person's life when you build up that life. I wanted us to build our lives together and I felt the need to create a beautiful home according to my own taste. I love colours and shapes and wanted to create our own personal setting. I didn't stand a chance. Everything I tried to do disappeared in chaos. Everything was ruined.

I used to have a pink ceramic lamp. I loved lighting the candles in it. Even though I tried to protect it and put it out of harm's way, I found it one day shattered on the floor. What was the use of even trying?

Our home was turned into an empty room. Nothing even remotely like a home. We had no pictures on the walls, having put away the ones that Fred had already ruined. Nothing was put on display, no ornaments, no photos, no books and no tablecloths. We had nailed our few remaining pieces of furniture to the walls. Our home was reduced to an empty space. My life was a prison. In my mind I was a child abuser and, almost, in my actions as well. My mind was black. I was filled with an impotent rage. I felt evil.

I said:

- He has ruined everything that I have tried to build. Everything. This is not a home. It's nothing. I intend to keep the few flowers that are still standing in the windows. I intend for them to stay there. I will fight to keep them.

The flowers turned into symbols of the home I wanted. They were an image of something "normal". My son pulled them down. He tore them from their pots. He threw them across the room and scattered the compost. He tore off the leaves. After having swept up the potsherds I bought plastic pots instead. They were unbreakable. I swept everything up from the floor. I had made a decision. I will sweep. The flowers are staying. I kept on sweeping, once, twice, five times 25 times, 40 times. Every day. Every day. EVERY DAY.

One day I was seized by Madness. I shook all over and while screaming on the top of my voice I grabbed hold of him. I felt ready to hit, and hit and hit again…

Then I didn't exist any more.
I wanted to hit, and hit and hit again.
when a red haze came before my eyes
and I was No One.
So easy to be seduced, and
flee into solitary Madness.

Thank you, God, for the line I didn't cross, for the insight of what I was about to do. Thank you for the small light that made me see again. I sat down on the floor and stared into nothing. Was that really me, the woman who had seen red, who had wanted to hit, and hit and hit again? Was that I? I? I, who was a loving person, who had always been praised for my sweet nature, I, who was always, nearly always happy? Had I been driven this far? Had I let myself be driven this far? I tried to hold the little savage that I loved so much. I wanted to cry with him, make him understand, but instead he just laughed and looked around him in a friendly way. How was I to survive this madness, these awful situations which didn't play a part of a normal life? HOW?

I didn't really want to hit him. I didn't want to hurt him. I loved him. I hated him. I hated the life I led. I hated life, I who used to love

life. I didn't exist any more. Desperate thoughts flew through my head. HOW can I live through this? How can I survive today without hitting him? I never want to feel this way again. I stood up, raised my right hand as if swearing an oath and said out loud:

- I hereby solemnly swear that I will always, every time something happens, count to ten. Every time he tears something down, ruins something or wreaks havoc, I will count to ten. Then I will sweep things up, care for him in a calm way and try to explain.

I didn't always succeed. I didn't always manage to keep my calm, but I have always kept the promise to count to ten and by giving me those few seconds I've managed to keep madness at bay. Of course I've felt despair, anger and sorrow many times, but that awful, red haze has never taken hold of me again.

Small child who didn't know
Maybe he had to try
to make the outer chaos
– the inconceivable –
resemble the chaos inside?

Small child with angel's face
velvety skin and curly hair
doesn't sleep, only minutes
But I love little angel
though I hate him who destroys

God and devil
Oh so small
He now runs our entire life
Empty spaces in our house
since that morning
he tore down the last curtain

and I didn't make any new
just left things as they were

Fred didn't need much sleep. He would wake up between three and four thirty every morning. Every morning. Every morning. Every morning. Every week. Every week. Every week. Every month. Every month. Every month. Every month. Every year. Every year. Month after month, year after year. Morning after morning. I would be given hundreds of different hints on what to do to make him fall back asleep. Pin him down! (As if I hadn't tried that one already!) Let him play for a while and try again. (Yeah, right!) Talk to a doctor! Give him sedatives! Keep him up at night! Go and see a homeopath! Write to a faith healer! Do something!

Yes, we did everything that we could possibly imagine.

I would be wakened by him crawling up to me carrying a defoliated weeping fig, including dirty roots, at three in the morning. Many a time. At four in the morning by china being broken. Many a time. Fred pouring fruit drink on my bed wakened me at five in the morning. Many a time.

I would wake up to the sound of him throwing eggs on the kitchen floor, of him thrashing through the garbage bin. Or having smeared faeces all over himself or eaten soap. Many a time. Many mornings. Many weeks. Many months. Many years.

I got used to hurling myself out of bed before really having had the chance to wake up. Everything went black before my eyes, but sometimes I would be in time to save something. Fred taught us that he never needed to be saved from anything. He never hurt himself even if it sometimes looked bad. Catastrophes would always happen around him but he was a survivor.

I became an expert in keeping one step ahead. I bought a twin carriage in order for us to be able to take walks. On the days when he refused to sit still in the carriage, he would run away and I couldn't very well leave his little sister alone in order to rush after him. If, on the other hand, he stayed in the carriage, he would pull his sister's hair. It's a wonder that girl has any hair left. A lot of screaming and crying has come from that carriage. Thus, taking the two of them on an outing was hard work, but I persevered since the days seemed so endless otherwise. We went to all the playgrounds and woods we could find. Our

walks would mostly take us to uninhabited parts of town where I could let my little maverick run around without him toppling over other people's picnic hampers or belongings. This would give both him and me a breathing space. The chase stopped for a short while.

And his baby sister. She just existed in all this chaos. She was such a calm child, an early developer and easy to handle. She slept well and ate well. She was healthy, started walking by the age of nine months and talked fluently at 18 months. I never had to worry whether everything was all right with her. She was always there, on the side, but there. She was so good at taking care of herself. At six months she sat in her high chair and ate by herself. It was as if she wanted to tell me:

- I know how to do this, Mummy. Look, I can do it myself.

Of course she could. All the time. All of a sudden she was able to dress herself. Eat and drink. Use the potty. Talk. She was happy, amiable and calm. Played her own little games and sang her own little songs. She could sit on the sofa and sing quietly to herself for a couple of hours.

Of course she also would scream from time to time.

- Mummy, Mummy. Me too!

The screams made Fred extremely unhappy. He ran over to her and pulled her hair, pulled her down and dragged her along the floor. I would yell at him, prise his wet hands off her hair. His hands were covered with wisps of hair. She cried, roared and screamed for me to get him off, that it hurt.

He tried to bite me and ended up biting himself. Screamed. Bellowed.

Whom should I try to comfort first?

I had to make her calm and quiet, otherwise he wouldn't calm down. But how do you comfort a child who has been scratched and had her hair torn out when her attacker is still roaring and screaming? I don't know.

CHAPTER 5

As if he wasn't there

I gave my mother a call. (This was while she was still there for me to talk to.) I moaned about Fred. Talked about him and how hard it was to cope, that it was such hard work and how little sleep he needed. I told her about the mess he had created that day. About the books he had shredded to pieces and how he had been throwing up.

After I said this, Fred looked me straight in the eye.

He went over to the window and pulled down a flowerpot which crashed to the floor. He tore the leaves off the plant and emptied the compost on the floor. I hung up and shouted for him to stop.

- Stop! I screamed. You bloody fool. Stop. You drive me crazy! Crazy. CRAZY!

He looked at me with his mouth full of soil.

And I saw. HE'S LOOKING AT ME. INTO ME.

Suddenly I was hit by a new realization.

HE UNDERSTOOD WHAT I SAID TO MY MOTHER. HE DID UNDERSTAND.

How much did he understand, though? Everything? Some? How much? Did he notice my words or the tone of my voice? He had definitely understood that I was badmouthing him. It had taken me four years, but I finally realized that I couldn't talk about Fred over his head. I really shouldn't talk about him as if he weren't there.

I pulled him close and asked him to forgive me.

- Please, forgive me, my son. I do love you so much. But I can't stand your behaviour. Still, you should always know that I love you, more than my own life.

Fred just looked confused. There was no way for me to know what went on inside his head. How much did he understand? I felt sure that the concept of asking for forgiveness was beyond him, but surely he must have felt that my arms were soft and that my eyes were filled with love. And still, when I cried, he laughed. Or tore my hair. It was so hard to love and not be loved in return. At least not in a way that I could relate to. What were his feelings? Did he feel loved? Or just confused? Was he able to structure his thoughts? Or did he just exist in the present? Was "right now" all he could understand? Still, he must have been able to feel that all I wanted was his best? I desperately wanted my love to come across to him. Still, sometimes I screamed. And sometimes I hit. What was he to think – he, who was already so confused?

What does that big person want, the one who calls herself Mummy? Sometimes she is good and sometimes she is bad.

He ate the soap that lay on the washstand and promptly threw up. Soap stuck to the back of his teeth and I tried to scrape it off carefully. It made me cry. My darling, that soap tastes awful, don't you feel that? When he stuck his hand between the door and the frame and opened and shut it so his fingers were caught in between, I cried. Why, why? Why did he hurt himself? Was it my fault? Had I made him confused? Didn't he feel loved? I had smacked his fingers and his bottom too. I had yelled at him, screamed and shouted and cried. What was he to think? What if he didn't feel loved by me? Still, I had hugged him, read stories to him and loved him all day, every day for a lifetime, it seemed. I only ranted and raved because I couldn't cope any more. I should be able to cope, though. I had to cope. There was no one else.

He went on looking into my eyes. Sometimes. Not all the time. Far from every day. But, from time to time. Those moments almost made my heart stop with happiness.

Have you ever felt, at a very special moment in time, the happiest, the shortest of moments, that your body's movements cease, maybe for 100th of a second and you feel timeless? That's how it felt.

These moments could come during a play session on the floor. He would suddenly stop playing and look straight into my eyes. And I looked into his. I felt so close to him, he was so close to me. For a brief moment, I almost…almost reached in to him, or he out to me. For a second or two we were suspended in time…come on, come…come… I waited, breathless…my child, come to me, so close, so close, we can reach each other… At that moment, I felt as if he had all the answers, that he really had a choice…

Then he closed up. His look wavered. The moment passed. Had he ever had a choice?

Longest time

many

days

minute by minute by minute

hours came and

hours

went

Became

months and

years

and I forgot how to cry.

Lonely in this empty home
he and I – for moments short
For a second he came close
and I saw his inner self
Eyes were meeting, searching, kissing
and I walked on such thin ice
Into him – or he
out of himself, into me

But he turned
Yes, he turned back
Stayed within himself

Oh yes, he was there. He had shown me that he was there behind that massive, yet so thin wall. Still:

On his own
In himself

CHAPTER 6

Lights – camera – action!

Surviving. In the end it's all down to surviving that particular day. Surviving for just one day more. Planning or thinking of "tomorrow" or "another day" is a concept that does not exist. Surviving is the only thing that does.

Thoughts came and went. Great tenderness and love towards that child of mine took centre place. And still – the impossible situation. Fatigue paralysed my thoughts and my reality. Fatigue that overshadowed everything. The strong need to hide our reality from others. The need to embellish. To hide the truth in order not to hear the words that so often caused pain and suffering. In order not to show how bad the situation really was, how exhausted we really were.

But the human mind is amazing: the inner Force was there, ready when I was. I became an inventor, actor, author, singer, radio presenter and film star. Being a film star turned out to be the best trick of them all! In order to prevent myself from giving up, from screaming at my children, from ceasing to care about my home, my appearance, from dying, I became…yes, that's right…*a film star!*

There came a day when I couldn't stand it any more. Fred was four years old. I could take no more. My life was over. My home was a barren space with a few pieces of furniture screwed to the walls. The bookcase was an empty hole. A few sad plants tried to survive in their

pots on the windowsills. My daughter had fallen asleep. But my son raced through the rooms like a whirlwind. I tried to entertain him, keep him busy, hug him and talk to him. I sang to him, played the guitar. Nothing calmed him down. The baby woke up and cried. I tried to comfort her, while Fred kept on as if trying to balance on the cornice frantically screaming like a parrot. I started to cry. The prison walls grew higher. I wandered through the house trying to calm my children. I carried first one then the other in my arms. My aimless wandering took me from room to room and suddenly I found myself in the hall. I caught a glimpse of myself in the mirror. A fat woman, badly dressed, with no make-up and uncombed hair. I was 28 years old and totally worn out. The image didn't give me a shock but it gave me something better: a sudden flash of salvation. An offer of a life buoy. The thought worked its way to the surface of my mind, it bubbled up through the surface of water in my brain. "No one can help you. You, YOU, only you can help yourself and all of you." Only you. Only I. No one else. No, I hadn't started hearing voices - I listened to myself even though I didn't understand it. The thought grew. That's when it all started.

Not right away. It wasn't as if things solved themselves just like that. But little by little. It started all so simple. I tied my hair in a braid with a ribbon. I put on a nice skirt with matching jumper. I varnished my nails. I contemplated my role.

Suddenly I heard loud thuds coming from the bedroom. He had torn all our bedclothes from the bed. The mattresses lay halfway on the floor and he was happily checking out the bottom of the bed. I had only just made the beds. But it didn't really concern me. I was playing my role. I was in this movie about a mother and her two children, of which one was autistic. I calmly spoke my lines.

- My little darling, what an exciting bottom that bed has. That's right. That's what it looks like. When you are finished with it perhaps you can help me put the mattresses back and make the bed.

He looked at me, friendly as ever, and pushed the mattress further out on the floor. My lines then went:

- It doesn't matter. You know what? Mummy will go to the kitchen and make us something to drink. Why don't you come as well?

I was aware of the film cameras and the film crew watching us all the time, filming away. I packed a hamper with some cinnamon rolls and fruit drinks and laid it all out on the floor and we pretended to be on a boat. I was able to create short periods of calm.

And I sang and played guitar to the audience who found the children so nice and well behaved.

- Look children, can you see all the fish in the lake? Let's sing for everybody who wants to listen the song about the fish in the lake.

…it was a chilly night, night, night, I steered my boat, boat, boat…on the wild sea, sea, sea…

Yes, you know that song, and now let's have some juice and rolls. Come on children. Look here, I even packed some napkins.

Everything became easier this way. I could cope for yet another hour. But I was walking a tightrope. When I became angry and screamed at them, I also became a little angrier and screamed a little louder. But when I decided that I didn't want to be the screaming mother but the mother on the boat instead, everything was fine.

Of course, when I took part in the filming of my life I couldn't very well scream and lose control. I had to act normal. I dressed neatly, cared about my appearance and played film studio. Sometimes I would change the scenery a little. I was being interviewed for a radio programme. I would then talk to the interviewer; tell him or her about my family, about our lives and myself. I would explain about the pain, about other people's lack of empathy. I would tell him or her about my own inner loneliness. I described my love for my son and my wondering as to how to interact with him. Meanwhile, I would take care of the children, coo at the baby and try to find a way of communicating with Fred.

ME: Having a child with autism means that you have a child who shuts himself in his own body to a lesser or greater extent. My child has an intellectual disability with autistic traits. He is relatively sociable and tries to make contact. But he is extremely hyperactive and needs very

little sleep. That makes it hard for our family to deal with day-to-day business.

INTERVIEWER: So, what kind of help do you get?

ME: Well, help, what kind of help is there? I only get help if I specifically ask for it. And sometimes I don't really know what to ask for. What do we need? You won't exactly find anyone coming here helping us to find solutions. And it's not easy to ask for help when you want to be able to take care of your own child, just like everybody else does. Sure, it would be wonderful if there were someone who could take care of him occasionally and let him sleep over at their place. It would have to be someone who cares for him and likes him so we would know that he was safe.

INTERVIEWER: And isn't there someone like that around?

ME: Well, there is my mother. But she hasn't got much time to spare and other relatives have so much on their hands as well. Maybe some people don't find it easy to understand the needs that are involved either. Some that I don't even want to ask. They only give me the kind of answers that I don't want to hear.

INTERVIEWER: What kind of answers would that be?

ME: Well, for instance that I should send him away. If I mention that I am exhausted, they sometimes tell me that I could always send him away. Of course I don't want to do that. And it makes me dreadfully upset when they say things like that. He is a very special little person with his own worth. I love him and I want him with me. Sometimes I have the feeling that I can't go on living, I can feel so very lonely. Loneliness is there inside me like a great well of emptiness. I can look at my children and just feel that emptiness.

And sometimes I get so angry. That's not good. Instead I know that things work much better when I decide to work things out.

Well, you can see for yourself what a lovely little boy he is. I love him just as much as everyone else loves their children. That can't be so hard to understand. But he's not like other children and people find that hard to grasp. I believe they pity us, but that's no help.

I've tried to find ways to reach him and help him to develop and find a way to express himself. But I don't know how to go about it. One night my husband and I watched an American film after the children had gone to bed. It was about an autistic boy and his life until his so-called "recovery". I didn't know that autism was an illness. Fred is healthy! But he does suffer from a disability!

The boy in the film was spinning things around all the time. The family lived in a house and I think the father was a doctor. In any case, both parents decided to stay at home and give the boy what he needed, treatment and support in any way possible. The film ended with the boy as a teenager, sitting on a bench in a park with an older woman, maybe his "nanny". An intellectually disabled person came walking past the bench and the teenage boy asked his nanny why the person passing by was acting so strangely. And so we were all told that through all the treatment and love that he had received from his parents, the principal character was now "cured" of his autism. That's what they claimed. I can tell you that we were totally quiet when we turned off the TV that night.

- I see, said my husband, it's that simple. Well, what we should do is quit our jobs and give him treatment and love.

- I see, said I, it's that simple. We went to bed full of sorrow and silence.

INTERVIEWER: What's it like then, being the mother of an intellectually disabled child?

ME: Well, I have hopes for the future. I think things will get better. I want to be a good mother to him and I want to help him in every way possible. I think that I can play a vital role in his life in a positive way. Having two children is important as well. My daughter is still a baby but she means so much to me. It's lovely when she smiles and says

"mummy" and tries to find a language. I will enjoy following her development.

To be honest I don't know what it is like being the mother of an intellectually disabled child. I have my son and can only say what it's like to be his mother. It's okay. If I take it one day at a time. One day. Not more. But I'm strong and I'm happy. We sing a lot and he likes music.

Was I going mad? Was I close to a mental breakdown? Multiple personality? I don't know for sure, but I do know that this was the start of my own salvation. All the time I was 100 per cent aware that I played this game because I needed to. I always knew it was a game. I was totally aware that I was playing the film star when reality got too much for me. Different roads crystallized, from my inner self, means of saving the children and me. Of saving the children from me, from the sides of my character that I didn't want to acknowledge. The dark, unknown part of my soul.

I used whatever means I could find. I recovered my own dignity as a human being. In my own eyes I was worth something again. I acted in a way that I could live with. I wasn't balancing on the edge of the precipice all the time. Even if everything around me collapsed I was back to being a human being again.

CHAPTER 7

Pre-school

When we had been given Fred's diagnosis we soon understood that we belonged to a Team. We suddenly belonged to so many things. Our Team was Team Number Two. Not Team One or Three or Four. No, it was Care Team Number Two. We belonged to one welfare officer. And one psychologist. We belonged to them, not them to us. Sometimes they would visit, call on the phone and ask if they could come over for a chat. I always accepted their wish to come and visit. At least they listened. They were good at that. But there were so many different people. They were forever quitting their jobs and new people would take their place. As soon as we had grown used to one of them and finally told them about how our family was functioning, off they went, on parental leave or moving away.

Some were good. Some not so good. The best ones were those who dared have an opinion of their own. One even dared to say:

- Yes, I can see that it's hard for you.

That felt good. Most psychologists and welfare officers didn't have the guts or didn't want to see. They were the ones who just asked us how we felt about the situation and what help we needed.

One of them, I think it was Lena, a welfare official, told us that Fred could start at the county council's special pre-school. He was already three years old by then. Three years.

Many thoughts went through my mind. An integrated pre-school. What did the word integrate mean? A strange word that I had never heard before. But my main reaction was: this will never work. How would the staff be able to understand him? How would they be able to keep up with him and be in time to stop him when he climbed too high? And, what if they didn't see when he ran out on the road? He was so fast and they had other children to care for. And what if he didn't like it there? If he didn't want to be there. And, the other children, how would he react to them? Beat them? Be beaten by them? Scream and fight when they cried, like he did at home with his little sister?

And still. He would be able to spend three hours there. Three hours! EVERY WEEKDAY! THREE HOURS! An eternity! I would have 180 minutes. Could I really have that much time to myself?

My husband and I talked about it, and asked to come and see and talk to the staff. I dressed up in my best jeans and my new blue blouse. Fred was wearing his snappy brown dungarees, which I had sewn, and I had brushed his curls. His baby sister lay in the carriage wearing her little rose bonnet. I think Fred's father was the calmest of us all. We took the car. Happy and expectant we talked about what was going to happen. I sat in the back seat with my little boy on my lap and talked, blew in his ear and hugged him a lot. He squirmed like an eel but that didn't matter when we only had two kilometres to go. Were on our way to meet people who maybe would be able to help us by sharing the responsibility for a while every day.

- Do you really think this will work? Fred's father asked nervously.

- I don't have the faintest idea, I answered, just as nervously. But what if it does work? After all, they do have a lot of experience of children who are intellectually disabled. And the baby does need some time to herself.

Meeting the pre-school staff turned out to be a real experience. They told us about the other children in the group. There was no one with Fred's specific problems; they all had Down's syndrome. "Integration" meant that so-called "normal" children would be a part of the group as well. The group would consist of around ten children. We met

the teachers: Ulf, a pre-school teacher, and Märta, his assistant. They formed the core of the staff. Plenty of other assistants would come and go during the years that Fred spent with them. UlfandMärta became a beautiful, forged and ornamental hook on which we could hang our tired hearts. Their names became synonymous with understanding and light in the dark. When first we met they greeted first me, then my husband and…something altogether new happened. They greeted our son. They actually said "Hello" and talked to him as if they thought he was a real human being. Not many people had done that before. They saw in him a real human being. Not many people had done that before either. Everyone, even Fred's father and I, talked about him and over his head. But UlfandMärta talked to him. He was somebody, his own little person. They SAW Fred. Not just a scoundrel who made trouble for everyone around him. Not just someone who ruined his parents' lives and should be sent away somewhere. Not just someone who was stark raving mad.

I was a bit sceptical to start with. The teachers asked us about Fred. They thought he was beautiful. My heart warmed to them. They asked about his behaviour. They watched him, in a benevolent and friendly manner. And they said that they would like him to be a part of the group. I think that's what clinched it. They not only offered us a place but also wanted him to be there. They wanted him! They liked him. They found him interesting. They thought that everything would be okay and we had the feeling that they actually understood some aspects of our situation.

We almost decided immediately to go ahead, but not altogether. The next time we came to visit other parents were there with their children in tow. We started talking and realized that we shared many experiences. One woman told us that her mother had photos of all her grandchildren displayed all over her apartment. But the newest grandchild, the one with Down's, her photo was left in a drawer. When the mother asked why, she got the answer:

- It's better that way. Otherwise there are so many questions.

We talked about having to run after the children, the lack of sleep, bad communication and isolation. It was wonderful. We had felt com-

pletely unique in the world. No one had a child like ours and no one else was living through what we were living through. But here! Here there were more parents and siblings. Admittedly, their experiences were not exactly the same as ours, but some were similar.

We agreed on a two-week trial. These two weeks went smoother than I could have dreamed of. Fred's baby sister, who needed to be nursed from time to time, and I were present the whole time. We rode in the car with Fred's father in the morning and walked back at lunch time. The baby in the carriage and the son in his special seat on top.

He wasn't like any of the other children in the group. He was alone, in himself. There were plenty of toys on the floor and the children were sitting around playing. With his eyes, as usual, fixed on the ceiling, his arms raised and his hands forming stereotypical movements, he moved elegantly between children and toys. He didn't fall over and he never faltered and stepped on any of the other children or toys. He never openly observed anyone or anything. He now had a fixation on certain objects, dark colours and stripes. A grooved mat in the hospital entrance hall. The latticed fireguard. Lattice work in general. Pianos with their keys in black and white. Often he would run around, aimlessly it seemed, with a piece of lattice in his hands but sometimes he would sit down on the floor and raise the lattice towards the ceiling. He would watch it intently for a long time. What did he see? Or did he see through it? Did the light refract through the latticework? Did it make a pattern?

He rarely met anyone's eyes, not even mine. I found it so hard that my son denied me this as well. Was he disappointed? Sometimes I would take his small head in my hands so that he couldn't look away. But instead he would lower his gaze or look to the side. I couldn't force him to meet my eyes. He didn't want to give or receive hugs. He didn't want me to take his hand but sometimes he would come and take mine. It would always be from behind. I loved him in every way possible and wanted him to love me. Love me in a tangible way. But he closed the door and locked the gate. I was the only one showing love at this stage.

He started at the special pre-school when he was three years old. I felt as if I had been thrashing around in a hole in the ice and now someone had handed me some ice sticks. He went to and from school by bus. All the children went on a small bus together with an assistant. The children lived all over town so the ride could take a while.

To me, these hours were like a precious stone, so valuable, so priceless. I hadn't made any big plans about what I wanted to do with my time. Just read the paper, without it being torn out of my hands and scattered round the floor in a thousand soggy pieces. Drink coffee. Play with my daughter in peace. She had only just learned how to sit. People said:

- Now you really have to come over for a cup of coffee.

- Sure, we'll see…soon, I answered evasively.

I was devastated when the doorbell rang. I didn't, did not have any time to give away. I didn't have time to sit and chat with anyone during those three precious hours of the day. I didn't want the phone to ring either. I wanted to read the paper and play with my daughter. I wanted to hold on to time. Hold hard.

One day UlfandMärta called from pre-school.

- Everything is working out just fine, they said. Why don't you come and visit and see how nicely everything has been arranged?

- Thank you, I said, it's impossible right now but soon. I will come soon.

They called repeatedly, but it took almost a year before I felt that I could give away one whole day's three-hour's freedom.

I could go to the toilet without preparing the house. I could read the paper while it was still intact. The air was still for a short while. My pulse rate stayed normal for a short while. I could do a bit of cleaning and take leisurely walks with Fred's baby sister. I had time to enjoy her. I looked at her from time to time and thought to myself:

- What will you think of life, little one…what kind of life have I brought you into? How will you cope?

Fred struggled with his asthma and his ear infections. To me it seemed as if he developed in spurts and, strange as it may seem, after every recovery from an illness it seemed that a "development spurt" come along. In between, when he was relatively healthy, he was a bit

calmer and could concentrate better. He had acquired quite a lot of understanding and we noticed this development in different ways. He could tell one book from another and turn on and off the lamp when asked to. He could fetch things if I told him where to find them.

Later, after I had started working again, I said to him in the mornings, "Mummy is going to work now", and he would be upset and start watching me. If I said, "Aunt Ewa will be here soon" he would go wild and go to the hall to wait for her. He was very attached to his aunt Ewa who helped us whenever she could. She was young, only 14 when he was born, but she was a great support. Just her coming over was great.

We found out that he could remember things that we had done and things that had occurred. We went to Ikea where he played in a room full of balls, and when reminded of this he would turn calm and thoughtful. He enjoyed it when we played the guitar. I had started hiding it under my bed since he handled it so roughly. Once, when we hadn't used it for several weeks, I asked him to fetch it. Immediately he ran over to my bed and tried to crawl under it. He knew so much.

UlfandMärta became our conversation partners. They made a contact book, which Fred carried in his backpack every day. I would write in it every day and they would answer promptly. The contact book was important. It would tell them how Fred had been that day and what he had been up to. With the book as a basis I could talk to Fred about his day. So many things happened. They decorated the school, sewed, printed on fabric and did finger painting, had picnics, went swimming and generally enjoyed themselves.

Fred loves taking a bath in a tub, it said one day and after that Fred seemed to be bathing almost every day at pre-school. It turned out to be the type of relaxation that UlfandMärta offered him when he was upset. They wrote to me that he enjoyed it and visibly calmed down.

It was my impression that Fred really liked it at pre-school. He was his happy, easygoing self beaming with joy. When I wasn't too exhausted I was able to appreciate his happiness, but often his incredible energy overshadowed the positive feeling. We had managed a

whole day's work by the time he went to pre-school at around eight in the morning.

We had a real lie-in today, until four thirty, I would write somewhat ironically in the contact book to UlfandMärta, and when I wrote that he had been "*calm*" I used quotation marks. It meant that the night had been calm Fred-style.

Soon I will not have any hair left, I wrote when he had, once again, torn big tufts of hair from my head. I had a humouristic message in return: *It's a good thing you have such thick hair!*

The mornings were the worst part of the day. He was wild and frantic, running around with unbounded energy, hitting and tearing everything apart. I locked his father and sister in their rooms so they could have some sleep.

The mornings were the best part of the day. He was cuddly and warm and could sit on my lap and let himself be hugged.

He was everything in so many ways. Never predictable. Sometimes an early morning could mean chaos and madness and I would curse, beaten and knocked about before he went off to school, but sometimes a morning with Fred could be heaven. When he was obviously present in himself. Why wasn't he always present? What were those forces staging a war in him? Of course, I had good and bad days as well and this played a part in shaping each morning.

The day when the photographer was coming to our home, Fred was four years old. The photographer was going to take photos for us to give to Granny and Nan for Christmas. Fred climbed on the tables and tore his white shirt to pieces, the one I had bought especially for this occasion. His baby sister, a year old, watched him with big eyes when he balanced on the empty shelves of the bookcase and cried in terror when he came near her. He was lying on the uppermost shelf throwing up when I lifted him down. Immediately his wet hands grasped my hair and tore it in two directions on each side of my head. His face was a vivid red and tears spurted from his eyes. This made his sister cry. The distressing sound of her "Mummy, Mummy!" made me realize that I had to take her into consideration more. She had to be given more time, more peace. If not, how would this end? Little one,

why does it have to be this way? It was clear that he went for his little sister when she cried. He wanted to shut her up.

I learnt, years later, that loud noises hurt him. It took me such a long time to understand this. Why didn't I understand then, why couldn't I see the connection between loud noises and violent outbursts? WHY? How could I be so blind?

Lisa and Lena started crying and he was disconsolate. He started tearing all the children's hair, one after the other. We had a real circus here, I can tell you, UlfandMärta wrote from pre-school. But I still didn't understand. And neither did they. He didn't need the circus. He needed calm and quiet from the start. I know that now. Twenty years too late.

One morning, when he was five years old, I wrote in the contact book:

He is totally crazy today. Everything is awful. I can hardly talk to him. He doesn't see me. He is tearing everything to bits. We have finally removed all the plants from the windows so the rooms look bare and wretched. I never thought I would take the plants away but I can no longer bear to see them being pulled off the windowsills and hear the leaves being torn to pieces. And besides, I'm sick and tired of sweeping up the dirt as well.

Still, the next day I wrote, *The plants are back. I guess I'll do the sweeping a little while longer.*

Life was unpredictable. Some days, many, were fine with a son who was seeking contact, eyes alert, and moments of hugs and kisses.

Life is hard, but I'm content anyway. Take this statement with a pinch of salt, though. I wrote one cloudy morning in March when we had been up since three in the morning. It was so hard to admit that I couldn't cope. Humour and jokes had to work as camouflage.

In May I wrote:

I was a bit upset yesterday because I had done some sowing. I wanted to start a vegetable patch. When he came home he ran straight over and jumped up and down so the seeds scattered all over the place. Of course, it was my own fault since I didn't look after him well enough. When this made me sad and upset he ran in and pulled down three plants in one go. But I understand him. I caused that reaction when I became angry.

I constantly blamed myself. I wanted to make excuses for him or rather I wanted to understand. I desperately wanted to understand

why he did the things he did. I wanted to discern between cause and effect. Then, somehow, the abnormal could become normal.

He went through periods of material interest. We had the constant Battle of the Plant Pots. Then came the Era of the Far-Flung Paintings. And the Era of the Torn-Down Curtains. He wanted to tear and pull as soon as he had a chance.

Still, a curtain is just a curtain, I wrote in the contact book.

Everything will be okay, you will see, the staff tried to comfort.

His vomiting came and went. He put his hands in his mouth and it wasn't easy to know whether he caused the vomiting by doing this or not. If he did, then why? The pre-school had started going to the swimming pool on Fridays. Fred loved it but was often turned away because of his throwing up. Did he throw up when he really enjoyed something? When things got too exciting? Or when he didn't want to take part? Fred's father and I speculated. UlfandMärta speculated.

I put four or five extra jumpers in his backpack every day because I didn't want him to go around in messy clothes. We did notice, though, that he tended to throw up more when he was tense. For instance, when he was perched at the top of the slide.

Then came a relaxed period. He was able to sit for a long while during morning assembly and at meal times. He was a beautiful child with light brown corkscrew curls and intensely blue-blue eyes.

The comment from pre-school would sometimes be, *he is wild and loud, but in a very good mood.* And of course he was. He was every way. Wild, but with core of gilded joy. An inner, shining light was there through all the bad times. Is there.

Sometimes UlfandMärta would write that he was hard work. In a way that was a good thing because this acknowledged our situation at home. I mean, if he were all good and well behaved at pre-school, then I must be exaggerating the situation at home. That feeling would hit me from time to time, that people thought I exaggerated, especially about the early mornings. I saw doubt in their eyes when I told them that we woke up between three and five almost every morning. Someone actually asked:

- Is that true?

It was.

UlfandMärta helped me to survive. At home we spent nearly all our time out in the garden. That was always best. He was happier then. Later, he would go for walks with an assistant at pre-school as well, just him without the other children.

I started working again when he was five and his sister three. They gave me back my old job, the one I had left when our Princess was born. It felt safe coming back to this well-known place and I felt confident since I knew the job. I started working half-time, between eight and twelve. His baby sister got a place with a childminder who lived on our street. She didn't want that at all. She felt insecure and scared and wanted to be with her mummy. But her mummy also needed to get out a bit and meet other adults. This is one of the things I have regretted most, that I didn't listen to her. She was a sensitive child. She had seen things in her life that other people don't have to experience during a whole lifetime. And now I wanted to throw her out into the world at such an early age. And when, on Sunday night, I reminded her that she was going to the childminder next morning she said:

- Please Mum, let's not talk about her.

But I wrote in the contact book:

I thought he was going to tear the ceiling down today. He had the most awful fit, screamed and kicked and flailed his arms. He was totally wild. I'm sorry, I seem to grumble a lot today. My dears, you know how it is. Still, sometimes I can feel my blood boil. Now I'll go to work and have a well-earned rest. Thank God that I have a job to go to!

A week or so later I wrote:

A new day, new hope. Can you imagine? Fred slept until six thirty today. So far, he is very calm and sweet.

Life with him was a roller coaster with no end station.

Then came Berit. She was hired as a personal assistant to Fred. She was to function as a special resource for him at pre-school but also walk home with him and stay for a while at our place. Berit became my good friend, but most of all she was Fred's friend and pal. Her view of Fred was fresh and new. She was young and gloriously free from preconceived ideas. She didn't dismiss him as the intellectually disabled

one who didn't understand anything. She didn't talk about him over his head. She tried to get behind his strange conduct and understand why he used it. She respected him in a way that was all new. It was a rare thing.

- Why does he do that? she would ask.

Myself, I had stopped wondering.

I think I subconsciously thought: he does it because he is intellectually disabled.

One day Berit talked about Fred's love of cars. Yes, I had noticed that.

- He loves cars, she said. He's definitely a little boy. Engine crazy at this early stage. When we went past the parking lot close to Lillsjön, he said: "Ca ca ca ca ca ca."

- Okay, I said sceptically. He does say that at home sometimes as well.

- Well, don't you think it can mean "car"? She wondered. "Car, car, car…"

Maybe he did mean car. A while later he didn't say "ca ca ca" any more but he loved Berit's car. It was a beige Volvo Amazon that Berit also loved and of which she took very good care. After Fred had been going in that car a while he had trashed the back of the passenger seat. He had also torn off the ceiling that was made of light blue, perforated plastic. I kept on wondering when Berit would hand in both hers and the car's notice.

On days when we didn't see each other she and I would write messages in the contact book. I felt good about that.

Yesterday was good, I wrote. *He didn't pull his sister's hair once.* Berit often wrote of positive things, like the bath he enjoyed and that he had eaten well.

Fred works frantically all the time. He prefers to climb up on my knees and throw himself backwards so he ends up underwater. I wouldn't say he's scared.

She stayed a few extra hours with Fred at the pre-school. When Fred eventually started school she was there with him. Sometimes she was at home with us. We would take both children out in the afternoon and have a picnic. We would plod through deep snow in the winter and trudge through the woods in summer. Sometimes we would take her car and go for a ride. Spending time outdoors was so much easier

than staying inside. Indoors both Berit and I had to watch him constantly and prevent him from doing harm.

Berit had another quality as well, when she came to our place she spent her time with Fred. Some later personal assistants, after the wonderful Berit era, have followed me around the house. Wherever I've been the assistant has followed, talkative and longing for company. I've had to take care of Fred myself. And I have felt trapped. Sometimes I've tried to get away. Because it is so hard to teach them their job.

I should have told them: "You're here to occupy Fred, not me."

But it's hard to find the courage to say things like that. Especially the first few years. Before you've trained yourself to say things even though you don't dare.

At six years of age he created his own way of communicating. I was sitting at the kitchen table reading the paper and eating an apple. He was racing around as usual. I could hear some bangs but I knew the sounds by now and these weren't the dangerous kind. Knew what they all meant. He suddenly came into the kitchen, came up to me and looked into my eyes for a long while. A long, long while.

- What are you thinking inside that head of yours? I thought. What is it you want? I asked.

He took my hand and pulled at it until I stood up. He pulled me over to the fridge.

- What do you want? I asked.

What did he want? Did he want anything at all? He pulled my hand. The fridge.

Brain wave. Do you want an apple as well? Open the fridge. Peel an apple. There you go. He took it. He let go of my arm and was content.

Wow! What happened?

He came up to me another day. Of his own accord. Looked me in the eyes for a long, long time. Took my hand and pulled me out to the front door.

- What do you want today then, Fred? Do you want to go out?

He let go of my hand straight away. His eyes happy.

On with jacket, cap and boots. Oh, these long cold, snowy winters but, what did it matter? He had shown that he wanted something himself.

HE HAD MANAGED TO SHOW ME WHAT HE WANTED. HE HAD ACQUIRED A LANGUAGE! Not exist? As if he does not exist? He very obviously did exist! He created a language for himself and he did it all on his own. Albeit a limited and laborious way of communicating, but still. I admired him enormously. I felt pride. What ingenuity. His own language!

But there were limits to what he could communicate. What do you do when you are thirsty in the middle of town? There's no sink and no tap there. Or, when you are hungry? There's no fridge there. I realized this. It wasn't a very useful language.

So: how could we help him to a useful language?

I called the team psychologist.

- Help us. How are we going to give him a language? What training methods are there? What help can you give us?

Answer: there is nothing.

!!!

There were also the awful, the terrible school breaks. Everyone else enjoyed the school breaks, doing things together as a family and generally having a good time. The very same school breaks that we nearly didn't survive.

We've had a reasonable Christmas, given the circumstances, but we're so glad that it's back to school and work now. That's what we like best, I wrote on the first day of the new term. No one else knew the circumstances of our Christmas. The Christmas tree hit the floor at least once daily; our Christmas decorations lay ruined on the floor. At Christmas dinner Fred's father and I spent a total of five minutes at the table. Outdoor activities all day every day, even when the thermometer hit 25 below. All this to survive yet another day. Christmas breaks, mid-term breaks and Easter breaks, they were all the same. But most of all there was the confounded summer break. Long, everlasting when you didn't have an ounce of strength left in you. The summer he turned five, Berit was there for us. The pre-school was closed so she spent the time at our

place and hers. But Berit and Fred also spent time at a local student home for children and took part in their activities.

That was the summer when we saw an ad for a bicycle sidecar. We sent for it, it cost 1200 kronor, and attached it to my old bike, a black sidecar with a seat.

Today has been a tiring afternoon, I wrote to Berit in the contact book. *I feel that it is my fault; I still get so tired of it all… I'm not strong enough to be the cheery one who's forever picking everyone up. Anyway, at this time of the day, the house is quiet, I've picked things up for the umpteenth time, and I can relax. And just now father and son went out for a bike ride in the dark.*

The bike was a blessing for a long time and I've sent many grateful thoughts to whoever invented that thing. I think that person must have special needs children himself.

We grew totally dependent on Berit. I've sometimes wondered how that felt for her. I'm pretty sure that she realized our dependence and most probably it made the situation more sensitive for her. She took on a lot of responsibility. And she made life easier for us. She cared and I could talk to her about Fred, about fear and hope and others' lack of empathy. With her I found total understanding. The most comforting fact about her was that she liked Fred. She took him under her wings and defended him, even to me.

- Yes, but you have to remember…she could say when I whined.

Her insight and sympathy made it possible for me to admit to her when I couldn't cope. I'm sure that must have been a burden for her. Maybe she felt how much we expected from her. I couldn't even entertain the thought that she would leave one day. She was with us for five good years. Good years for Fred. She was there when Fred left pre-school and for the first couple of years at school. Then life moved her in a different direction. But Berit is still with us. Even though we haven't seen much of each other and she has had a hard life. She is there. Small in body but massive in warmth and spirit.

Around the time when Fred was due to leave pre-school, politicians were thinking of shutting the special pre-school down. This was the early 1980s and everything was to be normalized and integrated whatever the cost. I joined the fight for the pre-school's survival. I was

a member of a group consisting of representatives from the organization (FUB: The Organization for Intellectually Disabled Children, Young People and Adults), and staff and assistants from the pre-school itself. We met with politicians and officials from the county council and explained our feelings and how badly the children needed their pre-school. I tried to convey my feelings about all children not being alike, that total integration in so-called normal schools could be a good thing for some children but not for all.

- These children are individuals, with different abilities. People with an intellectual disability or autism are not just like other people but with different characteristics, made from the same mould, I told them.

We, parents from the pre-school group, pre-school teachers and assistants, also discussed trying to keep the group together when they started school since it consisted of children of about the same age. They had grown used to each other from the age of three years and had learnt to interact with each other. I will never forget little Jennie Karlsson, a girl with Down's syndrome who was on the same school bus as Fred. When Märta, the school assistant, came out to meet the bus in the morning, four-year-old Jennie said:

- You go ahead Märta. I'll take care of Fred!

Fred's last term in pre-school started. He was turning seven and starting school in the autumn. We received a note from pre-school announcing a parents' meeting. The team psychologist and welfare official would attend. They served coffee and sandwiches and we enjoyed meeting with the other parents. We discussed the importance of keeping the group together and how much we needed each other. Suddenly, I almost choked on my coffee. I realized that Fred didn't count as part of the group. Our whole sense of security was about to be shattered. In a few words one of the pre-school teachers told us that Fred was different. He didn't fit in. They hadn't reached any decisions about his future yet but the rest of the group were to be kept together at school where this pre-school teacher was to be their special needs teacher. I don't know what I felt. I was numb. I, who had been such an active participant in the discussions. I asked my husband in a whisper whether if it was true.

- Yes, he confirmed, that's what they said.

We remained seated. I couldn't swallow a morsel of my sandwich. I NEED TO GO HOME. I NEED TO GO HOME. I NEED TO GO HOME kept going round and round in my head. My head swam. I felt empty. I stood up. Everyone turned silent.

- I have a headache, I said. I'm sorry but I have to go home.

Of course the others were concerned, and the pre-school teacher explained that I suffered from separation anxiety. Nice words. Nice to know. But such words don't heal any wounds. They don't even work very well as pain relievers. So that's what they call it, "separation anxiety", that dark sense of abandonment. So, that's what it's called. Well, I didn't know any posh words to describe how this separation anxiety felt. The teacher knew the term. I only felt it inside. Hurt from being severed. Separationpain. Separationhurt. Ill from having to part. All these feelings. And you all get to keep each other. You will still share the same, familiar world. The same teacher. The same children. The same parents. No one ever contacted us after pre-school ended that spring. It was like we had ceased to exist. On the other hand, I never got in touch with anyone either. After all, we were rejects. We weren't good enough for their posh, united Down's syndrome group. I see. So that's called separation anxiety.

I realized somewhere inside that no one *wanted* to hurt us. Somewhere I got the message that they considered Fred to be better off in another group which suited his needs better. With my brain I understood full well. But for a while I really hated the people in charge. I hated them secretly because they didn't want us any more.

The 9th June. Last day of pre-school for Fred.

The last day. It feels so weird, it can't be true. Four years have passed by too quickly, I wrote in the contact book. Fred lived his life between the lines of that book. He cried his eyes out, often had a bad tummy. Threw plates around sometimes and cried even more. Threw up and tore down. But he was also a sweetie who would sit on my lap with his arms wrapped around my neck. He was also the apple of my eye, my beloved child and the light of my life.

My family and I also lived our lives between the lines of that book.

Today we were woken at three o'clock by the sound of all the eggs ending up on the floor, I wrote during that last summer before school started.

This was the summer when Berit and Ewa took care of him for two weeks so that Fred's father, little sister and I could go to Skåne for a holiday. We used the FUB's summer cottage just outside Helsingborg and recharged our batteries.

And the most wonderful thing about that holiday was coming back to our little beloved rascal again. Of course, five minutes after having come home I realized that my batteries could never be fully charged again.

CHAPTER 8

A few minutes of rest in borrowed peace and quiet

or

The difference between real solutions and makeshift ones

Time stretched out. And when the welfare official asked us if we would like some time off – wanted someone else to step in – we said:

- No, we don't need any help. Why should we?

Everyone is capable of taking care of their own children, aren't they? Of course they are. At least we should be able to. And while we had pre-school everything was different. We had never had that much help before.

But above all:

We didn't know what kind of help was needed. And to be honest, we didn't know what kind of help was available either. And – we didn't think that we deserved any more help. Besides, we had somehow lost

perspective on what constituted a "normal" or ordinary life any more. Our life was normal to us. I needed the psychologist to be very specific:

- I CAN SEE that you are having a very hard time. I THINK that you need some relief. This is what I can do to help… And so on.

I needed to hear her say that she thought I needed help. Maybe I needed to hear it as some sort of absolution for not being able to cope all the time. If only someone else saw and absolved me, I could allow myself to need.

But what did *relief* mean in the eyes of society? By questioning the psychologist we got the follwoing explanation.

Well, first it was a question of support parents or a place at a children's home. What would we prefer? What did she mean by *support parents*? What did she mean by *children's home*? Once it was clear to us that a support family could be an ordinary family who would take care of our son and be paid for it, and that a children's home was a place where several children with intellectual disabilities lived with staff who took care of them, we chose to try a support family. Fred was so little and we thought it more likely that a family would form a personal relation with him and like him for the person he was. Staff members at a children's home could be very able and nice but to some of them it was just a job, or so we thought. Of course staff members are also able to like their charges but we wanted to try a support family.

One day the welfare official called us and told us that she had found a family who were prepared to meet with us and who considered becoming support parents. The family had a farm in the country, just what I had dreamed of. Fred would be able to roam around there. The family consisted of a man and wife and their two children plus a couple of dogs. How would it turn out? Well, when you haven't known that any relief was possible, you leave no stone unturned.

First, the family came to our house to visit. The man and wife were a few years older than us but not much. The wife had experience of intellectual disability through her job. That was a plus! Her own children were around Fred's age, three to four years old. The first visit passed well enough. The wife seemed an easygoing person who was given to laughter. I could see, in my mind's eye, their farm in the

country and I started hoping… I felt a quiet joy at the way things were unfolding. Someone would be there to help us struggle on. These people had just taken on our responsibility for a few hours. Relief made my heart light and Hope made this light even lighter. Suddenly it felt as if I had an entire sunrise inside me.

A couple of times we went to visit the family at their farm. The farm was beautifully situated on the hillside and had a few outbuildings. Wonderful, I thought and was able to see how lovely it would be in the spring even though the snow was still piling high outside. These were very pleasant visits and we felt welcome, had both a chat and coffee. Then the Saturday came when we had agreed that we would leave him for a couple of hours for the first time. I gave him a hug and said bye, bye. He didn't look at me. As usual. Just stood there in the kitchen, with his eyes fixed to the ceiling. We left.

It seems my heart had changed place with my uterus because it rested deep down in my stomach, like a heavy stone. Unshed tears gave me a headache. Where on earth was the Relief and Gay Abandon that I had expected to feel for at least an afternoon? My baby, I wonder how he felt? Deserted? Alone? My heart must have weighed a ton. The whole me weighed a ton. What if he thinks that we will never come back? Of course, I was also a bit concerned about what could happen. They weren't used to having to chase a child around all the time. And I had seen the dogs' food bowls on the floor and all the other things were kept in full view, the way people usually do. What if he wrecked something? What if he hurt himself… What if they didn't like him? What if they couldn't handle him? What if…what if…what if… I sat on tenterhooks sitting in the car during our ride back to town. The radio was playing in the background and we sat silent. All was peaceful in the car. Quiet and calm. No one to worm his way out of the safety belt, no one to kick the back of my seat, no one to pull my hair. No one was screaming and yelling. No one was throwing up on the seat. It was calm and restful. And it felt good. It felt good.

But we were one child short in the back seat.

When we came home we started to clean the house. And we went on cleaning the house. We had several hours of silence and peace. We

wolfed down our dinner by force of habit. In just under five minutes. We had to remind each other to slow down. Today we actually had the time to enjoy our food. We were able to leave the plates on the table, the food in serving bowls. We were able to hunt out a candlestick and light a candle. Make ourselves comfortable. My heart was still stuck down in my stomach but at least there was a bit of relief in our borrowed peace.

But we were one child short at the dinner table.

We picked him up that evening and everything was fine. We were so grateful. Our sense of gratitude knew no limits.

The welfare official got in touch to tell us that the family had officially agreed to be Fred's support family. My overriding sense was of gratitude. Endless gratitude that people like them exist, people who would voluntarily help others, not only to survive – but to live. Because these people did just that. Helped us to survive. And we, well, we felt our lives depended on this support family. The knowledge that we would, from time to time, have a couple of hours' or a day's relief became vital. Sometimes this knowledge was the bridge that carried us over the dark water of long, hard days.

We left Fred with the support family a few more times. The wife worked in town so she picked him up on her way home. Then came the time when Fred was going to stay overnight for the first time. I suffered agony. Would she tuck him in at night? He always kicked his duvet off during the night. What if he wanted to sleep in their bed and weren't allowed to? Would she stroke his cheek? Would he be able to sit on their laps? My little man whom I loved so much. Relief and Peace were intermingled with Remorse and Longing.

We picked him up on Sunday. We had spent a restful night in front of the TV and a morning when we woke up early, true to custom, but were able to stay in bed a while. The family told us that they had had a tough night. Their own children had slept in the parents' bed and Fred had ended up there as well, curled up at their feet. Fred had woken up early. Earlier than they had expected. Maybe they had thought, as had so many others, that we had exaggerated the hours he kept? The

support mum said that they had had a very good time but it was such hard work.

I asked them if they could see themselves setting up a regular schedule where Fred could spend a weekend a month with them or something to that effect. The family didn't want that but thought that we should call when we felt the need for some relief. Setting up a fixed schedule would have been much easier for us. It would have been possible for us to plan if we wanted to do anything special like go away somewhere. Furthermore, in time it would have become a natural part of our lives. Instead I felt as if I had to beg every time I called. I didn't like the idea of calling and avoided it as far as possible. It's hard to beg. Especially if you are already at a disadvantage, already the one who's forever craving assistance. And they did say no from time to time when it wasn't convenient. That made it even harder to ask.

Then one day I called to see whether they could take him the following Saturday and the wife answered the phone.

- I am sorry, she said. We can't go on acting as Fred's support parents. We can't handle him. It's too much hard work.

- I see. Well, thank you for the times you've helped us, I said and hung up.

I didn't say anything else. Well, I think I said that I could understand their decision. I was in shock. I felt my head spinning. What could I say? Hope left again. I was alone. Again.

My husband sat at the table. I remember just sitting down in silence and his asking:

- What is happening? Couldn't they do Saturday?

- No, I said. Never again.

What with all the stress under which we lived and the exhaustion we felt, we had hung our lives around the help we received from the family. We counted on them. We had bent over backwards to suit them; if they said no, we didn't insist. They didn't want a set schedule and we didn't push the issue. We knew that our position was a weak one and we tried to please them. Still it hadn't been enough. Still they had felt that they couldn't cope with Fred. I realized that support parents are staff as well. I realized too late that I had seen them as something more.

Disaster. That's how it felt. Alone again. Temporarily paralysed, but not for long. Fred balanced on tiptoes, high up on the kitchen table, his eyes fixed on the ceiling. Time to save him again. I raged, against the support parents, against the welfare official, against the world and against God.

- How could they cheat us this way? I screamed. How could they? Didn't they realize what they were in for? How could they do this? Didn't they realize that we counted on them? What about us? How are we going to cope? HOW are we going to cope? HOW ARE WE GOING TO COPE?

Rage didn't help much. It didn't help at all. I realized that the support family had all the right in the world not to be able to handle him, and had the right to say so. Of course. OF COURSE! As always, both before and after this event, I had to understand. My role was to be Understanding. I always had to understand all the others, those who couldn't cope. I was the one who had to comfort them and be objective and UNDERSTANDING. But the fact remained. I was on my own again. We were on our own again. Alone with the work, the lack of sleep, the screaming and the tearing apart. The shreds, the chaos. But also alone with the love and the joy. Because he also gave me that. Even at the darkest point times. His inner light has always shone with joy.

A while later we were asked whether we wanted a new support family. We agreed on another attempt. Hope stirred again, though maybe we didn't feel as optimistic as last time. Believed again, but with the knowledge that everything comes to an end. Our need was so great, and that's when you really need to hope. Finding a new support family proved to be very difficult. It took time: a year, to be exact. But finally the welfare official put us in touch with a young, single woman. She had some experience working with children with intellectual disabilities. She was hired partly as a personal assistant and partly as a support parent. This meant that she sometimes functioned as an extra supply teacher at pre-school and sometimes she would take Fred home with her in the afternoons and for a weekend here and there. She and Fred were able to take part in the activities at one of the student homes in town. The summer when he turned five she had him for a few days

while we went on a trip to Finland. His baby sister stayed with Grandma.

The day we picked him up. Summer, the weather warm and sunny. In the afternoon. I came into the student home, filled with anticipation at seeing my son. I think I would have outrun the car on the way home if I'd been able to.

Then I see him. He is half lying, half sitting on the lap of the support parent, with an almost apathetic, uninterested, resigned look on his face. When he hears my voice I can see him make a start, open his eyes and look up, perplexed. And I run to him lift him up. Finally, I'm with him again. And he nestles up close to me, doesn't leave me, while I pack his small bag, thank the staff for having him and take him home. His eyes are deep wells brimming with joy but also with sadness and questions. Did I cause that sadness? I was the one who left him. Did he think that I would never come back? Did he have the ability to wonder and wait or did he just long for that familiar figure who had disappeared into thin air? I regretted having left him, if only for a few days. I regretted thinking that I needed time without him in order to cope. Did this make me a bad mother? A bad person who kept whining about not being able to cope? A person such as I, who had such a beautiful and lovely son. Round cheeks, thick brown hair. Big, blue eyes, just a small squint. Tanned and brown like a gingerbread man. Ready to laugh and ready to cry. The softest of them all. With arms to love, round and warm around my neck.

The next minute he would cry out like a parrot, pull big tufts of hair from my scalp and laugh that the eerie laugh that was all wrong and made me crazy with grief. When I cried over our inability to meet, he laughed wildly. And pulled a little harder.

We kept the support parent/assistant for another year or so but when she left as well, we didn't want to try again. Failure was too painful. Too painful to bend the bow, take the plunge, hope, maybe believe…then see loneliness again. The isolation. The hopelessness of it all in some strange way, having to struggle all the time was better. You knew what you had. And you didn't have to be disappointed.

We were back to having no relief even a night here and a weekend there. The welfare official then came up with an emergency solution. One of many over the ensuing years. Berit, our wonderful assistant, was asked whether she would consider caring for Fred every once in a while. She accepted! She ACCEPTED! Berit, whom Fred loved so much and would follow as meek as a lamb and who made us feel so secure would take care of him. It was arranged that Fred would spend a Saturday now and then at a children's home. Some weekends he would also spend the night there. Berit then slept there with him. He could use the bed of one of the residents who went home for the weekend.

There were times when Berit took Fred home to her parents for a whole weekend. At these times I managed to relax. I knew that he was safe. Funny how important feelings can be. Knowing that he was with a person who wished him well, who cared about him. Who gave him comfort when he cried. Who gave him a hug. Who wasn't just doing her job.

CHAPTER 9

School

Fred started school the year he turned seven. School started in August and his birthday was in September.

His teacher was a woman who had a great deal of experience in working with intellectually disabled children. She was a sweet person. Each morning at Assembly she pulled out a small box containing different items of interest. Exciting things in it. And every morning she would make up an exciting story about whatever she had put in the box that day. It could be a toy car, a toothbrush or a tambourine.

- Today Fred, it's your turn to pick something from the box. What did you choose today then, Fred? Oh, it is a tambourine. A tambourine. A TAMBOURINE. Do you want to play on the tambourine?

She made it all so clear and easy. Fred knew exactly what a tambourine was and what you would use it for.

She would also bring out the calendar every morning. One of the children would tear off yesterday's page so that you could see today's date. She would tell the children that it was winter, what month and date it was. What day of the week and whose name day it was. And if anything special was to happen that day.

- Today is Tuesday. It is Tuesday today, and today is the day when Peter comes to visit. Today Peter will come and we will play music.

Peter is an eccentric. He comes from *Norrbotten*, at least he sounds as if he does because he speaks in a very broad dialect. His hair is black and he drives a red moped. Peter is also a music teacher and one of the few people to have been around all through Fred's school years.

Sometimes Fred would come home from school and pat himself on the head. Pat, pat, pat.

Strange. It would happen increasingly often. Pat, pat on the head. He would run around at home as usual but with this new addition, the pats on the head. Pat, pat.

One day I went to visit the school. At Assembly Fred took a blue piece of board with felt on the back and his name written in black block letters on the front and put it on a larger piece of board. Fred's colour was blue. Everything that belonged to Fred was blue.

Amazing, he chose the right piece of board. Was that just a stroke of luck?

- No, said his teacher, he recognizes his own name and colour, or maybe just the colour. But he knows which piece of board is his.

Wow!

It was time for music. I got to meet Peter for the first time. He was young and enthusiastic and played his guitar. Fred's teacher, Anna, brought out a basket full of instruments and all the children chose one each. Fred chose a tambourine. We sat in a ring and started singing and playing our instruments. We sang about the fish swimming in the ocean and a song about all our names. My name was Mummy. "Mummy, Mummy, Mummy. Mummy is here today. Mummy, Mummy, Mummy, we're glad that you are here."

We then sang a song about colours. It went something like this:

Blue, blue, blue is the hat I'm wearing
Blue, blue, blue the clothes that I wear.
Everything blue, blue I think is lovely
'Cause the sailor is my favourite friend.

The colour of the hat was indicated by a pat on our heads, the colour of the clothes by a pat on our chests and so on.

Anna, the teacher took Fred's hands and helped him to pat himself softly on the head. And it hit me!

- Anna, I called, he knows the movements to this song. That is why he has started patting his own head. Who knows, maybe he is singing at the same time!

Maybe it is possible to sing quietly, without anyone hearing? To sing inside? Yes, of course you can. I could too, I realized.

The class consisted of two girls and one boy, apart from Fred. The boy was several years older than Fred and so was one of the girls. The other girl was the same age as Fred but she was under heavy medication which made communication very hard. She would often sleep or just lie there drowsing when I came to visit. Fred was a bit intimidated by the older boy, especially when he raised his voice. When this happened Fred would cry. I could see no direct, visible, contact between Fred and the other children. No games or mischief going on but every activity had to be directed by the teacher and her assistants.

We started discussing sign language with Fred's teacher. I took an evening course and passed on to the family what I had learnt. The signs I learnt were those used by deaf people but they were simplified. I would talk to Fred and, at the same time, I would reinforce the most important words in a sentence with signs.

For instance, I would say, "Do you want a sandwich, Fred?" and at the same time I would make the sign for "sandwich". I would move one hand, palm downwards, over the other, palm turned upwards. I would do this a couple of times. It was a bit like spreading butter on a sandwich.

After a short while he had learnt to make the sign for sandwich himself. OH BLISS! He knew, he understood. We signed. I would sign with my hands and with his. Far later I would be able to put his hands in the starting position for the words "Mummy" and "Daddy" and he would finish the sign.

We worked on supplying Fred with a language, both at school and at home. But they were a lot more consistent at school. They never wavered. Everyone had to use both spoken and sign language simultaneously. It was harder to adopt the sign language at home. I used it but

the rest of the family was not as sold on the idea. I tried to convince them about the importance of Fred having a language, but my efforts were feeble and they all petered out because of Fred's lack of response. The only signs that he ever mastered were those for "sandwich" and "what". No more.

Thinking back I know that Fred's inability to make himself understood is based on his greatest problem, his lack of communication skills. A person who can't communicate himself doesn't receive any communication either and I wonder why? It's always a question of giving and receiving for us all. When a person like Fred only can receive communication, and not give it the way we expect and are used to, the rest of us turn silent. Just then, when giving is most important, that is when we stop. We turn and walk away at the time when it's most important to give, give and yet again put up with just giving. Indifference, impotence or lack of empathy, the reason is not important. To Fred, the consequence will always be the same.

He lives alone in silence
Where screams and shouting
camouflage
the Anxiety of Silence
This chaos in not understanding
He lives there in Silence of Silences
When I can no longer give
but turn away

When he cannot turn
towards me
When he cannot see
into my eyes
When he cannot speak
my language

Then I turn away
I look away
Then I fall silent

Everything turns dark
his life and mine
I cannot see the path forward then
Life falls silent then
though sounds still go on
the air vibrates
life is tenuous
Everything turns into silence
in the midst of jarring sounds

Just when he needs
more interaction
more eyes meeting
more languages being spoken

But I did not understand
I was the one who didn't understand

what he needed
and how much

and all the time

Life went on. It billowed back and forth. We followed the waves. Back and forth. Efforts at communicating. Dejection. Oblivion. New efforts. Repeatedly. We continued our struggle with the sign language, each to the best of his or her ability, but Fred only ever made the signs for "sandwich" and "what". But surely, as time went by, it was easier for him to understand us. We talked and signed and sometimes he would

surprise us all when we least expected it. One day I said, to no one in particular that "I think we'll have pancakes for dinner today", and he opened the fridge and took out the margarine.

Pancakes were his favourite dish and regularly appeared on the dinner table. Had he picked up what ingredients I used? Well, he must have known that margarine was one of them. But, how could we supply him with a working language? How? Why wasn't he able to learn to make signs? Was it due to his lack of fine motor ability? I do not know and I guess I never will. But we did not have anything else so we continued using signs.

One day Fred's teacher called and told me that there had been some trouble in the school canteen. Two other teachers had contacted our teacher, Anna, and complained about the noise and behaviour at Fred's and his classmates' table. The class was integrated into a school with so-called normal students. Fred and his classmates' lunch break coincided with the other students' break and they all had lunch at the same time. Now there were complaints that there were unpleasant noises coming from the table at which Fred and his classmates sat, and that they made a mess. Fred, who had mastered the art of eating on his own, at the age of five, did make a big mess and the food usually ended up on his bib and chin. This was obviously unbearable for some. The teachers claimed that their students' eating environment was being disturbed and wanted Fred's class to have their lunch in the classroom.

What did it imply? To me it meant: get rid of them. If you have to keep them at this school, at least spare us from seeing them and their revolting behaviour. But of course, you cannot say that aloud.

The teachers had complained. But was it really on behalf of the students or was it the teachers who couldn't bear seeing Fred and his class? I will never know. But when Anna asked me to come and talk at a teachers' seminar about what being Fred's mum really involves, I jumped at the chance.

I told them of many things, both good and bad. I also made a point of telling them in detail about my sense of accomplishment and satisfaction when he finally managed to eat by himself. How he would throw plates and food around the kitchen, day after day, week after

week, and year after year. How we fed him but also let him try feeding himself. How we held his hand and showed how it was done. How we searched high and low for special cutlery, like a spoon with an extra thick handle and plates with high edges. How he, after many days, weeks, months and years, finally managed by himself. His dad or I would sit beside him and assist but still… By himself. We praised him and told him how clever he was. He was happy. How he learnt to drink by himself. At first, he would only push the glass down on the floor. Time and time again. I wiped the floor. Many a time. Then he started to lift the glass but seemed to forget why he had done so. He emptied it over himself and I had to wipe him and change his clothes. Eventually he would lift the glass; take a sip but forgot to put it back down on the table. Dropped it on the floor. Day after day. Week after week. Month after month. Until the day when he actually took the glass, put it to his mouth, drank and put it back down again.

Oh victory! VICTORY! Being able to eat without help. Drink without help. BEING ABLE TO EAT AND DRINK BY HIMSELF! It was not a matter of course to us. Nothing was a matter of course. He could eat and drink. By himself. He could.

And now some teachers at school thought it looked messy. I was saddened. I lay awake at night and thought about the unfairness of it all. I dwelt on this. Why can't people understand? If they haven't lived through what we have lived through, why can't they at least leave us well alone? I reasoned with myself. I reflected over this many a night. I was sad. But it passed. Life went on and I lived through this as well.

Fred and his classmates went on having their lunches in the canteen. But we changed their lunch time so they ate before or after the other children.

Fred's development during these junior-school years consisted mostly of starting to handle his own feelings in a way that was easier for me to understand. He started to laugh at, what seemed to me, the right moment, and to cry at the right moment as well. He was easier to reach. He would more often, sometimes searchingly, look me in the eyes, actually sought the contact and wanted to be understood. It felt right and wonderful.

At the same time, his hyperactivity continued unabated. For the observant reader there is a lot to pick up in the contact book between us and school.

Fred has really had a circus. Not a painting left on the walls. He's trailed the garbage all over the floor and everything is suddenly in turmoil, I wrote.

Our mornings were still early. Day after day. Year after year. He continued getting up at three or four or five o'clock in the morning.

Got out of bed at half-past three. I'm using up some sort of reserve that I haven't really got, I wrote one morning when Fred was in second grade.

Last night he woke up at one o'clock and started playing. I tried to keep him pinned to the bed. When my arms were almost out of joint he went back to sleep for a couple of hours. But he has been up since three thirty. His father has had middle watch tonight but it is still hard to sleep through all the banging and noise that goes on. It is six o'clock now; his father has gone back to bed for a little while and Fred and I are starting our morning routine. He's pretty wild, wants to move furniture, throws things and tears things apart.

By the time the school bus arrived, Fred's father and I, or sometimes both, had often been up for three to four hours. It would often be me getting up. It was awful when both my husband and I were worn out and both of us just lay there waiting for the other to get up. I lay there hating him for "never" getting up. "Always" I had to do it. Sure, he would wake up and take care of his son when I asked him, but why did I always have to wake up and fight for my needs? And when I was the one who had got up in the night and he finally woke and got ready for work, I would make a lot of clatter when doing the dishes. I would snap at him when he talked to me and generally punish him for everything that I had to do and he hadn't done. I did not have words for the inner loneliness that I felt; instead I chose, albeit unconsciously, to bang doors and things, snap at him and argue. The atmosphere was stifling to say the least. Every member of the family was angry. For many years I was so angry. I know that I was unfair because I did get to stay in bed sometimes and my husband did get up to be with Fred.

Fred's teacher Anna wrote to us about him throwing up at school. He would put his hand in his mouth and cause himself to be sick.

How do you live with it all? she wrote.

And I answered, *When he rolls the table over I put it back up again.*

Anna would also write about the other Fred, the cuddly, calmer boy: *You have a wonderful boy now. He's all laughter and contentment today.*

It was like that. He was unpredictable. Different.

Early rising again. Up at three. He is happy and alert but his soul is calm today. On moments like this, it's quite okay, I wrote early one morning. Early rising did not always mean hard work. It did not always coincide. Some mornings were cuddly.

One day they told us from school that Fred had started to understand the use of the toilet. He had done a wee in the toilet and Anna wrote that he *does it when he wants to.* He started to understand a lot of things. Anna wrote: *This morning he is helping me. He passed me the hammer when I needed it. Nice to see how he knew that.*

There were many new activities at school. Sports and woodworking and domestic science. Swimming on Fridays. Fred was always happy on Fridays. He had always been a bit of a water creature and loved water despite being sensitive to cold. It did not take long though, before he was banned from the pool for throwing up in the water. We tried giving him as little breakfast as possible on Fridays in order for him to be able to participate again. Until he was banned again. For a while. And he so much loved to go swimming. Oh dear.

He would often be unsettled and violent, screaming, tearing our hair, biting or if he could not reach us, himself. It was very hard to come to terms with these violent outbursts.

One morning I wrote in the contact book: *A long, cold winter weekend. Fred has been up from three both Sunday and Monday. He has been unusually wild so things have been bouncing off the walls here. I actually feel quite worn out.*

But a couple of weekends later: *This weekend has been quite good. We have had the energy to be there for each other. On Saturday we had a hot-dog-and-Coke picnic on a blanket in the family room. It always works out okay when you have the energy.*

And once again: *Today he's torn down a ceiling lamp with a couple of sharp tugs. Some live wires emerged, but he didn't touch them, I still break out in cold sweat when I think of it. He has been totally wild since four o'clock.*

Then he went to school. *Fred has been my best pupil today,* his teacher wrote on the very day of the lamp incident. Who was he really, my son?

There was no end to Fred's wanting to talk now that he had people around him to help sign the words. He, himself, only had sounds in his mouth, but he became increasingly interested in social contacts. He was eager to obtain a language even if he did not really understand how it was used. But he did notice that he could make himself better understood.

When Fred started middle school he finally saw a speech therapist. He did not start to speak but he liked it there and he developed. He learnt how to blow in the harmonica. And he got a new teacher called Ragnhild. She worked separately with Fred at certain times during the day. She made a board and put it on the wall. On this she hung different objects: a toothbrush, a fork and a toilet roll. When it was time for lunch Fred was supposed to get his fork, marked with his blue colour, and go to lunch. This marked the start for big changes for Fred. This was the start of a schedule which made it possible for Fred to make sense out of all those inexplicable things that happened during a day.

When our beloved Berit left in order to start a family of her own, a great source of security and love disappeared. Fred did have others to lean on as well but we all felt the loss.

Then came Ingela.

The period between Berit and Ingela had passed with several different personal assistants staying for varying lengths of time. This period was also full of emergency solutions. Relief assistance now and then. A disorganized period of Fred's sleeping away some Saturdays. He brought his blanket from home to use as comfort when longing for Mummy and Daddy. As if that would be enough! Pangs of conscience. Pain in the heart. Treachery. Oh, how I let him down during this period. He was still so small. He needed me so much. But I did not have the strength to be there all the time. And there was no obvious person there to take care of him for me.

Ingela was hired as Fred's personal assistant at school. She was young and at first I felt a bit sceptical. But she took us all by storm. She was, like Berit, a natural. She understood, long before I did, that the

key to knowing Fred was to TALK TO HIM. She talked to Fred. Talked incessantly. Discussed. Used sign language. With her own hands and with his. She talked in every way possible. She followed him home from school every day. They would often walk even though the school was two or three kilometres away.

A new love blossomed. It was a thrill to me when Ingela wrote in the contact book. It was special somehow. I first got to know her through the contact book. She was young. She was Fred's pal. She described Fred in such normal terms. Not so many reports about doing a poo or a wee and time indications, but just that: *We have made something in woodwork today. We painted it green. We both felt it was a stupid colour. It really makes Fred laugh a lot.*

I wrote back to her: *Fred is so HAPPY when we talk at home about the wooden thingy that you made.*

Ingela continued the correspondence: *We had FA (Free Activities) at school today. They played music and all the children stood round a table and worked with modelling clay. They gave a piece to Fred and he stood there, delighted, for a long while. When we came back into our classroom he went straight over to the contact book. He wanted me to write and tell you! Sometimes it is just so wonderful. Then we went out sleighing. Phew!*

Ingela did new things with Fred. They would often go to the library and listen to music. I would never have dared to try that myself. It was so good for Fred to form new acquaintances. New ones, who hadn't been there before but who did new things.

Hello! Guess where we are right now? At Wedermark's café where we have had lemonade and a cinnamon roll. We have also listened to the fan dryer in the toilet and dried our hands under another fan – there's so many fun things to do!

But Ingela would also write: *Phew! Fred is keeping us busy. He is not easy to please today. I hope he'll calm down soon, my little pal.*

She was honest. She was positive. She kept on writing.

We've just had ice cream. Hooray for THE SUN that is shining down on us. We listened to a street musician today and we both liked that.

She was genuine. She was unaffected. She was honest.

I wrote to her: *He only slept until four today – didn't want to go back to sleep. He is listening to "Macken" on the tape recorder while dawn is breaking. The sky is purple pink in the south-east. He's been violent again.*

They came home one day, Fred and Ingela, their cheeks red and they were bursting with laughter. Ingela told me that they had started on their way home (Fred looked so happy with his backpack hanging on his back). They had come to the crossing by the car retailers. Ingela turned right and Fred refused to come with her. He WOULD not. Ingela had tried to persuade and cajole him into coming with her but he just sat down on the pavement. After a long while and lots of cajoling he stood up and went with her. About 100 metres further on she realized that she had done a wrong turn at the crossing and that the street that Fred had chosen was the right one.

She admitted her mistake to Fred and they happily went home hand in hand.

- You see, said Ingela, he understands so much and he knows so much. I am sure he could find his way home if we let him.

Fred was 11 by then and I was ecstatic. My baby. He knew so much.

One day the phone rang. It was my neighbour on the line. She had been on her way home from work when she had seen a young couple up ahead. From a distance she noticed that they were having a lot of fun and that they stopped and talked animatedly to each other every once in a while.

- It was Ingela and Fred, she said, and they really looked like a couple of good friends having fun with each other.

Those words warmed a mother's heart.

On their last summer together before Ingela left she took him to Stockholm on a visit. It was her home city and she had borrowed a flat through some people she knew. She and Fred spent a few days there and had a holiday together. They went to Stockholm by train – six hours! – and back home again, six hours as well! They ate in restaurants, took in a concert and just strolled around. They even went to visit her family.

At home we really enjoyed those days off. It was quite okay to enjoy oneself knowing that Fred was safe and with someone who

cared and whom he trusted. This sense of security was nice for us all. It is the basis for everything.

Ingela taught us a lot about the importance of communication. Speech. Talking in every way possible even though a person couldn't reciprocate. Trying to supply him with a language. Making him participate. Making him listen. To this day I do not know whether Ingela had a conscious strategy for working with Fred. She never tried to tell us how things should be done but by DOING it she showed us the results. I believe that she instinctively understood Fred's need to be understood and respected. She gave all of that to Fred and her friendship as well.

Then Ingela chose to go on in life. We had to lose her as well. But I did not show her how much I grieved. I happily wished her all the best. Ingela gave us all, but Fred in particular, much of her time and emotions. I am very grateful and happy for that.

In my heart, though, I relived all the other times when staff had left. And I began to shut down my emotions. Everybody leaves. There is no use in loving them. Neither for me nor Fred. That is what I felt. And gradually that feeling started to bear with it some consequences. Did I sometimes seem cold when people took my hand and said good bye? If I did, it was in order not to show them how much it hurt when it was someone whom I had liked, or someone whom I knew that Fred liked.

But Fred's teacher Ragnhild stayed on and so did several of the others. She told me that once Fred started his activities at school, he was very focused. At these times everything worked very well. But he had turbulent mood swings that we all wanted to understand. For obvious reasons, I was keenest to understand. What lay behind these violent swings? Back and forth, back and forth. He threw up and had tantrums, went wild and threw things at three o'clock in the morning. And suddenly he could be nice and happy and everything around him felt relaxed and calm.

When Ingela stopped working as Fred's assistant the wonderful visits to the library stopped as well.

We went to the library and listened to music. Fred sat still and listened for an hour!! Ingela wrote on her last day at work. *Classical, electronic and pop. He laughed heartily at the weird electronic music! We also read an Alfons Åberg book about saws and other tools. I helped Fred to put money in the soft drinks dispenser and we had a cinnamon roll. It was such fun! Sometimes it is so much fun to be able to do things by yourself,* she concluded.

Fred was 14 years old when he started in a special class for pupils with autism.

The first time I heard someone mention pictograms I wondered what they were. Anne-Marie, Fred's new teacher, had lots of new ideas. She told us about the TEACCH method and made pictogram pictures as if there was no tomorrow. TEACCH stands for Treatment and Education of Autistic and related Communication handicapped Children. The method has been developed and applied since the late 1960s by Professor Eric Schopler and his assistants in North Carolina, USA. In recent years The National Autism Society of Sweden has promoted this method. TEACCH is a method that is visually illustrative to show people with autism clearly what is expected of them. By describing, showing, making and using pictures, the teacher is able to create a structured way of working. For instance, it can define a task including when work starts, what is involved and when it finishes. Something comes before and something comes after. It is easy to understand that such a plain way of working creates more security in the daily chaos that life can present people with autism.

The pictograms were white, stylized symbols on a black background with the word written in white letters above the picture itself. Anne-Marie glued each to a wooden board which would stand the wear and tear of a destructive young boy who liked biting and chewing on things. This was exciting. And new.

- He is so good with the pictures, his teacher told us after a while. If he needs to go to the toilet he goes over to pick up the card with a toilet on it. He gets the home picture to find out if it is time to go home soon. And he makes the sign for sandwich when he wants one. He is so happy he is nearly bursting with it. THIS HAS TO BE DEVELOPED! she said and her force and belief in the future stimulated us as well.

Fred practised dressing himself in school as well. His teacher decided when he should start using both hands for taking his shoes on and off.

- And he needs to learn to hang up his own jacket, not just give it to an adult to do it for him, she added sternly.

- You demand a lot of him, I said, but somewhere inside I knew she was right.

It turned out to be much easier for the people at school to be consistent with the dressing exercises. Fred knew very well that Mummy and Daddy would give in eventually. We never really mastered the consistency thing and went shamefacedly to his teacher to confess. She said it did not matter.

- Home is one thing, she said. There is a difference. And that is how it should be.

It felt good to hear her say that.

Fred liked his school most of the time. When he was 16 the class consisted of him and two classmates.

Fred's tantrums became harder to handle as he grew in size and strength, but he also grew calmer and the outbursts came less frequently. I felt sure that his new-found calm stemmed from the fine structure that slowly developed at school. He had a schedule made from pictograms on the wall where he could see what was going to happen from when he arrived until he went home. First, there was Assembly. Then he had a period of working by himself. He would sit in a secluded, cosy corner that was his very own workspace and where he would not be disturbed. He could work on his own, putting red bottle tops on wooden sticks of different heights and performing other simple tasks. When it was time for recess he would take his recess picture, which was a tape recorder, and go to the sofa and listen to music. Waiting for his turn was always difficult. Anne-Marie then introduced the "Waiting-for" chair. She put Fred's name in black on a blue background on the Waiting-for chair. Fred would sit there and wait; waiting was now an activity in its own right.

Märta from pre-school came back to work as a classroom assistant in Fred's class and that was nice. Our town is not big and Fred had met

her from time to time over the years. He remembered her well and greeted her with a big smile. He became more and more accomplished and most of all, he became CALMER. His eyes were more alert and his pictogram language was important, very important. Eventually he carried the 15 most important pictures around with him on a string. He didn't treat them carefully and they would often break and his teacher scolded him when this happened. But she would make new ones and that was very important to Fred. He needed his language.

His classmates meant a lot. Not that they played in the ordinary sense of the word, but still. They were there. David, calm and smiling. Pauli and Hampus. Different boys through the years. I would sometimes visit. They treated me to coffee. I stocked up on reassurance and hope for the future every time I went there. When Fred met me in the door and took my hands in his, he would move them from side to side in the sign for the word "WHAT?", and I would answer:

- Today I am here to visit. We are not going anywhere but Mummy is just visiting to be with you for a while.

Big smile and a big hug. Lovely.

I would sit down with Fred, his classmates, teacher and assistants and we gave each other pictograms. We each had three pictures in front of us. The teacher would tell me to give Fred the picture of a BICYCLE. I did so and he took it. She then told Fred to give David the picture of a CAR. He did so. When she told David to give Hampus the picture of an ELEPHANT he gave Hampus the picture of a HOUSE instead. Fred laughed so heartily that eventually we were all lying on the floor laughing. And Anne-Marie told Fred:

- Okay, now you can help David to give Hampus the right picture.

Fred immediately took the ELEPHANT picture and gave it to Hampus with a big smile. I leaned back in my chair and thought.

- Oh Fred, you do know a lot, you little rogue!

Oh School. Why did You have to end? Why does Time have to pass? Of course, it has to. And Everything has an End. But what comes Next can be good as well. It has been, sometimes. Not always, though…

During his time in school I felt safe in the knowledge that his teacher had a comprehensive view of Fred. She attended conferences at the student home and, later on, at the sheltered accommodation. She taught the staff a lot about the TEACCH method, its structures and the importance of helping Fred achieve a language. When Fred left school I felt that no one took over that holistic view. After school finished I became the one to be responsible for "all of Fred"; that is to say, that all the different parts of Fred's life work out. I find that many issues fall between the chairs when co-operation between the different factors doesn't work. When people who know a lot about him disappear out of Fred's life. Many things fell apart when Fred left school and was supposed to start at a day centre. And when the management tell me that it is "unfortunate", it's just not enough. Fred is the one who has to pay. All of it! All the time! All his life!

Fred left school the year he turned 21. His school had been the entire family's security and we met many new Friends. Supporters. And we sure needed those.

CHAPTER 10

The children's home

At the age of eight Fred was offered a place at a group home for children where earlier he had been in day care. We decided to accept the offer. He would now be able to spend a few hours after school and some weekends there. In fact, he could have moved there altogether but we wanted Fred to live at home. There was never any question of him moving away altogether. But we needed the help and support.

We met the entire staff at a conference and told them a little about ourselves and a lot about Fred and his background. I very much wanted them to understand why we could not manage on our own. I wanted them to realize that Fred was my child and I was not leaving him. He was only to stay there occasionally in order for us to cope the rest of the time, all the other days and nights. I needed their kindness and understanding so badly.

We tried to ease him gently into going there. He brought his duvet and some other things from home. We left him and picked him up. Every time I left him I felt a tightening in my chest, Heavy Stone of Black Despair. One Saturday it was time for him to spend his first night at the children's home. We had tried to prepare him for what was to come. We left him there in the afternoon and the staff were full of good will and welcomed him.

- You go ahead! We will take care of the little guy! Everything will be just fine!

He stood in the hallway and watched us leave.

Heavy

Stone

Weighed

A lot

A lot

We went home. Completely numb. Sat at the table and looked out the window. Fred's father took out the vacuum cleaner. His sister claimed attention. Thoughts. Difficult thoughts. Did he long for us? He was just a baby! My little eight-year-old. I longed for him. Our home felt

empty. Wonderful. Gloriously wonderful. Everything calm and quiet. Our Princess played peacefully and sang a little. I woke early as usual and everything was peace and tranquillity. There was no little "rascal" waking me. I wondered if the staff at the home were good to him. The way I defined good, that is. Of course they were good people, I understood that very well. Most people mean well. But if he woke at three in the morning and started throwing things about. Would they yell at him? Would they be mad at him? Would they pick him up on their knees if he cried? Our home was wonderful right now. And empty. And quiet. And nice. And awful.

When we went to pick Fred up the staff were so good to us. That night I wrote in my diary: *I so much enjoyed talking to them and they are so positive about Fred. It warms a mother's heart to hear that.*

I felt that it was important they were so positive. I was very observant of their ideas and opinions. That they understood why we left him there from time to time. This occupied my mind for many years. I looked for understanding from others. It might have been that I needed their understanding in order to be able to forgive myself. For abandoning him.

A year later Fred spent every afternoon after school at the children's home and some days during school breaks. Those damned school breaks when all routines were broken. First, there was summer. School ended and everything was turned upside down for ten long weeks. Fred was disturbed and objected to this by becoming very agitated. Every summer was the same. And when he finally started to realize that school was gone, it started again and Fred went into a rage. He would revolt, throw up, sleep badly, fight…and…how do you tell people? The shorter breaks were bad as well, but the summer breaks…time stretched long ahead of us. A lifetime when neighbours, full of expectations of nice weather, brought out their barbecues, tanned themselves, listened to summer programmes on the radio, took a nap in the hammock, socialized or went on holiday. Summer. The most difficult period for us. The idea that an enlightened society like Sweden keeps on treating people as if everyone were the same, with the same need for holidays and breaks, is preposterous to me. Some

people really suffer through it all. Whole families are torn apart by having to spend all this time with their children, small or big. I do not understand this. Or rather – those who take care of our tax money and plan how to use it do not understand. I refuse to believe that they don't care…

Of course things got better when Fred had his place at the children's home. But we had to fight with our consciences. We used the home as much as we could live with. As much as our hearts and souls could take. Despite the hard work and heartache it gave us we needed Fred at home as well. We needed him because we loved him. That is why we couldn't let him move away altogether.

I would write in the contact book:

No comments about last night. He's been running around crazily since one o'clock. Slept from time to time but up since three o'clock. I won't deny that I like the thought that I will be able to get some sleep when he spends the night with you tomorrow. Otherwise he's been in a good mood and, apart from the fact that we're soon left with an earthen floor, he's been behaving himself. Our flower pots are flying around the room. I hope you will have a good day. Me, I'm off to work to recuperate.

I sometimes had this in return: *Fred woke at three and came into the staff room. I let him sleep there and he slept until 6.30. He's been a darling and happy all day. No flowers on the floor today. Yes, I must say he's been behaving very well.*

I had a warm feeling in my body at the thought that he was able to have his morning nap with the wonderful staff.

We and the staff discussed why he slept so much better in the mornings at the home. And we worked out different solutions to make him sleep better at home.

Hold his arms and pin him to the bed.

Lock yourself in the room with him and unscrew the light bulb so he can't turn on the lights.

Try a sleeping pill.

Sing.

Talk to him.

Nothing helped. Not the darkness or the locked door. Or the talk. Or the singing. Or the silence. Or the sleeping pill. Or holding him hard. Or letting go. Or anything. At all. "His spells" ruled. Sometimes it was very hard work and early mornings for a long period. Then a calmer period would come and he would actually sleep until between five and six in the morning. We had theories about where these periods of insomnia originated. Was he in pain? Was he in a state of anxiety? Did he see things that we couldn't? Was he scared? Was he dreaming? Was he in pain? Pain was my biggest fear and many doctors were called in to check his stomach, teeth, legs, but no one found anything wrong.

I must say that when the staff at the home told us that he had woken up at three o'clock and pulled down the stereo, I felt quite "good". Of course I didn't *want* this to happen but I wanted them to understand that we didn't make these incidents up.

Fred stayed at the same children's home for four years. He spent afternoons there and after two years also every other weekend. He adjusted well. And we adjusted well. We needed this. Even so, every time I left him there on a Saturday, that Heavy Stone would fill my body and it was a heavy weight to carry. All the time. I still carry that Heavy Stone inside. I think I will never be able to leave him with a light heart. I don't seem to be able to get used to that. But I did get used to him being there. I got used to the staff and I deduced that he was content to be there. I attended staff meetings regularly. I needed to know. I needed to talk. They were there.

Then, just like that, he was to change to another children's home. We were offered a place at a home that was Specially Equipped with Specially Trained Staff and Special Financial Possibilities to take care of Special People with Autism. I hesitated. We liked the old home. But those who offered us the place, the psychologist and the community official, spoke highly in favour of moving Fred to this new place. Everything would be so perfect. Special competence. Special training. Especially good. Goody good. Good better than now.

- Will it really? we asked.

- Yes, of course, they said. This is a great Opportunity for Fred.

And just how do you say no to an Opportunity for Fred? We didn't. We thought that we could try. What if it was as good as they said, a Big Step Forward?

The first year was hard.

Hard to adjust to a new place. Separate from everything old and familiar. Separate from the staff. We were the new kids on the block once again. Fred was new to it all. And we intruded on them. Wanted them to know who we were. Wanted them to understand that we didn't just leave him because we couldn't be bothered. Wanted to be someone to them.

But everything was new. Not bad. But new.

And it was hard. The atmosphere was tougher than at the old place. And we were careful. The staff had had a long and hard job with a young person who had been living there for a while. They had thrown themselves into this task and through this dedication managed to help a very disturbed and self-destructive young person. I have a feeling that the staff had worked miracles on this person's life. And all credit to them for this. They had passed the most trying period when we arrived. Then we came, something totally different. And a completely new person for them to "deal with", but not in the same way.

Fred's right leg had started to grow in a crooked way and sometimes he would walk with a limp. After examination and x-ray we were told that the growth zone on the inside of his right leg grew faster than on the outside. This led to the leg growing crooked quite rapidly. They decided to operate.

I would like to forget.

My own anxiety increased. Sometimes I would suffer from panic attacks. I called the staff at the new place. Told the person who answered the phone that I felt awful. Fred threw tantrums from time to time. He fought. Came home with bruises. Finally I asked them not to tell me everything that went on. I tried to protect myself. My anxiety increased. Sometimes I would lie on my bed shivering. I had to get a firm grip on myself when Fred came home.

The operation. I can't avoid talking about it any longer. He was put under general anaesthetic. They nailed five big staples to the bone

around the growth area on his knee, to help the area not to expand any further. This was in order for the leg's outside to catch up and his leg to straighten again. I wasn't there when he woke up. One of the staff members was there to help his father. I was at home. Migraine. Panic. Is that a good enough excuse? I didn't go to the hospital that evening after he had come around. But his father slept there that night. Early next morning I went over.

His eyes when they met mine. He sat on the hospital bed. Thirteen-and-a-half years old. His eyes were like those of a wounded deer. Like a wounded animal's eyes.

I went into the nurse's office to hear how things were going.

- What have you given him for the pain? I asked the attending nurse.

- Nothing, she answered. It says in his journal that he can't feel pain.

- But for heavens sake, look at his eyes! Can't you see he is in agony? I said, though I wanted to scream, rant and hit someone. And most of all myself for not having been there earlier.

They gave him painkillers then. Almost 24 hours after the operation. He was in agony and whoever had the idea of writing in his journal that he couldn't feel pain I've never been able to find out. He must have been in such pain, my child. And I wasn't there.

This took place in 1989. Do these things still happen in hospitals? Do some hospital staff still believe that if you can't say the word "painkillers", then you don't need any?

He had long convalescence. His leg was put in a cast and he had to use a wheelchair for several months. When he started walking again his leg needed a splint to keep it straight. A year later the leg was much straighter and the staples were removed. That operation was much more simple and eventually he was almost completely recovered. His doctor was pleased. He still bears the scars and his right leg is much thinner than the left one. I will never know how much he suffered and for how long. But I do know that he has been in pain. And he still limps from time to time.

Fred experienced a lot during that year. Change of children's home and surgery to boot. And a mother who had less and less strength and energy.

At his new home they worked on tiring him out as a way of solving his sleeping problems. Eventually, when his leg had healed, they took him for long walks in the evenings. They would sometimes walk all the way to our home, about eight kilometres, when they were due to leave him at home.

I often worried about these walks because of his leg. But on the other hand. So many people thought these walks were good for him. Maybe they were. And certainly, a boy of 14 or 15 can take a lot of exercise.

- Just think of all the boys who practise ice hockey for hours on end every night, the staff would tell me.

And they were right. It was so easy to think that he was just a little boy, Fred. And I worried about his leg. After all, he couldn't tell us when he was in pain.

When Fred turned 14 we made a new, extended schedule for his sojourns at the home. He would stay there every other weekend and three or four nights on alternate weeks.

When people asked me whether he still lived at home, I would say:

- Of course he does. He lives at home. Yes.

Though, in reality he spent as much time away as he did with us. Still, to me he lived at home. It was important. He Lived At Home.

I wrote in the contact book that: *I'm so happy when Fred is at home. He is so happy and wonderful right now.*

The next time he was home: *He's trying to pick a fight all the time. He wants to hit someone and is on the verge of doing it.*

It was never the same. Never predictable. Sometimes this and sometimes that. Wild. But radiant. And calm and collected too.

He was worried as well. Took my hands and asked me "WHAT?", using the sign he had learnt. "WHAT, Mummy????" He wouldn't calm down before I had told him many times what he would do that day and, most important of all, WHERE HE WOULD SLEEP. I thought to myself:

- I always want to know where I will sleep. I want to feel secure as well. It's not just him.

His language became even more important. And he would ask again and again. And again.

His outbursts grew worse. Harder to handle. He picked fights, sometimes seemed to completely lose control. Ranted and raved, pulled hair, bit me if he could get to my hands and arms or he bit himself if he couldn't find something else. My lovely boy. Why? Obviously my love wasn't enough. Why isn't love enough? What more did he need?

Peace and Quiet? How could I give him peace when my own anxiety was so acute? When I was falling, steadily, down the precipice. There was no peace to be found at the home either. Three young people with different needs lived there as well as different members of staff. His own room of about eight to ten square metres. No peace to find there either.

I sang to him a lot. Held him close and leaning my head against his, I sang the old song:

My heart, it is yours
And your heart is mine
And I never will give it back
My joy, it is yours
Your joy, it is mine
And mine are the tears
That you cry.

Love is so strong. My love for him is endless and will never stop. It overflows. But it's not enough to help him.

I spent a lot of time talking to the staff members. I met them at conferences, talked to them over the phone. I shared a lot of my own anxiety with them. I needed for them to KNOW WHY my son spent so much time there. With hindsight I wonder why this need was so great. Why should they understand? Why should they have to listen to

me? Some of them did. Some understood, well at least as much as was possible.

I went into therapy a few years later and realized that I should have had that kind of help from the start. I'm sure the rest of the family would have benefited as well. Later I also realized that our care team could have helped with so much more than they did. But I had no idea that the family actually had the right to therapy at difficult times. How was I supposed to know to what help we were entitled? Maybe I should have understood that, and phoned them and asked? But when you're used to being an upstanding citizen and standing on your own feet, you go to your own doctor and, if need be, you go to your local hospital. My view is that care teams should be much more visible and tell us, who need their services, what they can do to help. I don't think there's been enough of that.

I read in the contact books occasional remarks about:

Fred is longing to go home.

Fred has been going on all day about going home. He's picked up the pictogram picture HOME. We've told him repeatedly that he will go home tomorrow but it seems he can't wait.

Of course it hurt that he had to long for home but at the same time it was a natural state of affairs. I wrote back to them:

It's noisy and messy when Fred is at home, but very good for my soul.

When Fred had reached 16 he still spent half the week at home, but gradually he spent more time at the children's home. My increasing depression and panic anxiety was the major cause of this. Yet again he had to pay a very high price.

During the six years when Fred lived part of his life at this second children's home we experienced some bad, but also some wonderful, situations. Both him and us.

Lack of empathy.

And empathy.

Staff members who didn't really know why they were there.

Staff members who knew exactly why they were there.

Stupidity and indolence.

But also warmth and compassion.

The staff members must sometimes have found me strange. I would be silent and reserved and keep them at arm's length just because I thought they lacked empathy. So many times I tried to make them understand. Because I was sad. Because I was worried. And sometimes because their behaviour was hurtful. I guess I should have tried harder to explain myself. But it might be easier to understand my behaviour when you think of how many different people I had to meet. It was hard to face yet another disappointment.

But they did understand sometimes and I was offered a cup of coffee when I got there, and I felt good about that. Sometimes I would write in the contact book: *Thank you for being there for us.*

Many of the staff members were wizards at coming up with fun things to do and Fred had a lot of good times during these years. I'll never forget how happy he was when they all went to Ulvön, a small island just off the High Coast in Ångermanland. They had been staying in a room above an old salting house where they used to prepare fermented herring. They had been swimming in the ocean and had dinner at a local restaurant!

Or – think about when he went to Gothenburg and the holiday village in Skara – and I later saw photos of Fred flauntingly riding on a huge tractor tyre in the turquoise water.

Camping in the mountains. Wednesday night dances. New activities all the time. They came home and I was told:

- Fred likes girls! Especially blondes! And he needs some new dance shoes!

To see Fred's big smile in agreement!

Life was tenuous. Our love was great and ordinary days were hard work. For me. Us. But mostly for him.

CHAPTER 11

It has always been us needing the staff – they have never needed us

Have you thought of how we live up to expectations?

One morning when I came out to meet the school bus, the driver ran out, he was so angry that he jumped with both his feet together, and yelled at me:

- I can't keep on driving him if he keeps on throwing up every morning on the bus!

- Oh, I said. This is the first I've heard about it.

None of the other drivers had said anything.

I put Fred on the bus and fastened his seat belt. The driver started yelling at him immediately about not throwing up.

- You will not throw up on the bus!

- Listen, I said. Of course he will throw up if you expect him to do just that.

In the afternoon Fred came home and I was told that he had done it again.

We arranged for the driver in question to drive another bus. And he never threw up with any of the other drivers.

His hair… The hair was a big problem during the first years. It grew and grew fast. Fred had worked through the town's hairdressers

pretty soon and was not welcome to any of them any more. When I called to make an appointment for him to come back a second time I was turned down by everyone. Sorry, but they were fully booked. And I sympathize. He was unruly and practically impossible to give a decent haircut. It happened at the time when time had passed and Fred's hair had grown too long. His fringe was down to his nose and he had a pageboy hairstyle. That Sunday he stayed for the day at a children's home in our town. When he came home that night his hair was neatly cut in a boyish style. His ears and his beautiful big blue eyes were visible. The contact book let me know that the stand-in used to work extra as a hairdresser and she had very kindly agreed to cut his hair. I suppose I should be grateful. But I wasn't. I felt insulted. They had cut my son's hair without asking my permission. Their intentions were good and I am sure that they expected me to be happy about it. If they had only called me and told me beforehand. If they had only called and said that:

- We have a girl here today who has offered to cut Fred's hair. Would you like that?

Yes, I would have agreed with gratitude and admired him when he came home. But instead I felt wronged as a mother. *I* was responsible for his hair being cut. The next day I noticed that he looked very nice in his new haircut. She had done a good job. But her scissors had slipped and given me a cut in the heart. It felt so important to be involved, to be a person, to be needed as Fred's mum, an important person in his life.

Because I am Fred's mummy.

I was angry and hurt when doctors and nurses called Fred's children's home or school to arrange for appointments and visits. I wanted to be the one they called. I was Fred's mummy. Not the staff. And I became upset when the dental nurse called the children's home and arranged for visits and appointments. I wanted to do that. I was, after all, Fred's mummy. The members of staff weren't. And I always accompanied him to these doctor's and dentist's appointments. I wanted to make the decisions about his clothes. And haircuts. It took time before I started to let go of some of the responsibility. It took time before I let

a member of staff call the hairdresser and arrange for an appointment. It actually took so long, that Fred was almost an adult. But I needed that time to let go, step by step. And I will never relinquish my role as Fred's mummy. He is *my* child. Not the staff's.

Once, when visiting a children's home where Fred would occasionally spend some time, some members of the staff told me about a girl who lived there.

- We feel so sorry for her, they said. It's awful to see how her parents treat her. They don't give a damn about her. They never get in touch, except on Christmas Eve, when they dutifully turn up with a Christmas gift. They should be ashamed of themselves. They could just as well not come with a present at all when that's the only time they care.

But I thought to myself that we don't know their circumstances. I'm sure there are few, if any, parents who don't care about their children. I think they feel bad about leaving her there, and every time they come to visit, they have to leave her all over again. It's hard to be reminded of the pain and to stand leaving her over and over again.

Maybe it's their way of coping, the Christmas-gift model.

There were others who said the same about the aged mother who was 75 years old and whose son had moved home to their village. New winds were blowing and they had closed down the big institution where he had lived until he was 50.

- Fancy her not getting in touch more often and practically never visiting now that he's living so close! It's strange, isn't it?

Yes, fancy that!

But I'm pretty sure that, 50 years ago, some doctor advised her to send her son away to an institution. That's how things were done back then. And you were told to forget about it all. You never disobeyed your doctor in those days. So maybe she tried to do what she was told. And she and her son met sporadically during those 50 years. Would it be an easy thing to meet with a son you hardly saw in 50 years? Whom you hardly know and of whom you have thought with a bad conscience for all those years. It can't be easy to start bleeding again.

When you're 75.

And all things considered.

Other memories. Like when I called the children's home just to hear how Fred was and I asked:

- So, how are you?

A member of staff whom I knew to like his free time answered the phone:

- Okay I guess, since this day is nearly over and it's time to go home.

- So that's the best part of work then? I asked.

- Yes, the hours are good here, he said.

- You've never thought about another job?

- No, I don't think there are many jobs where you get as much time off as you do here, so I think I'll stay on. Summer is best!

- So, you don't like the work in itself, then?

At this stage he started to see what I was getting at. And I cried after I had hung up. All these people who didn't even know why they were spending time at their jobs!

But, of course there are all those who do know! Anders, who works with Fred today, now, and who takes out Fred's language book and talks to him whenever he has an opportunity. Anders, who puts in a lot of time and effort into interpreting Fred's signals and who helps him to choose his dinner or what he would like to do.

Thank you, God for people like him and others who can SEE and UNDERSTAND and DO.

Thank you for the times when I call up and Anders answers the phone and says:

- No, we didn't answer the phone earlier tonight because Fred wanted to go dancing. Then I explained to him that there is no disco on Mondays, so he had to choose something else to do. He wanted to go on an outing. So we decided to visit Kalle instead, to have coffee and cookies and listen to music. We have only just got in and Fred wants his night snack soon. He's pleased as punch and has a big smile on his face.

And I can hear the smile when he comes to the phone and his sounds are strong and happy.

- That's lovely, Fred, I say.

And so, my evening is happy as well.

I felt so good when I came to the children's home to pick Fred up that day. The day when the girl with the blonde hair was on duty. When I went over my stomach was heavy and my heart fluttered. But I was happy at the same time. Fred was coming home to me, to us. We would be a family again. Half the week we were a whole family and half the week we were 75 per cent of one. When I pushed the bell I was nervous. That's when She opened the door. Said:

- Oh hello. How nice to see you. Do you have time for a cup of coffee so we can have a chat? Come on in!

And me. Joy sprung out like a flower in my chest, the sun came out. Last time I came to pick up Fred, He was on duty. He, who lay on the sofa in front of the TV and who didn't say anything until I had called several times and eventually found him lying there. On that occasion I quickly sneaked into Fred's room and packed his bag, took his hand and shouted my good bye from the hall. Then I left. Quickly. In the car I cried thinking of what life must be like for Fred at that place when I wasn't there.

This sure was a different situation altogether. She made me feel happy and welcome. She took the time to make coffee, set out some ginger snaps and, above all, she exchanged some words with me.

- Yes, Fred has been happy, though I'm sure he's been waiting for you to come. He's happy here but I think he's missed you.

Good. He had been happy with them. That's good. And still. How unselfish and caring of her to say that she was sure he had missed me. To grant me importance in Fred's life. I took my time packing the bag and gave her a hug before we left. And I could see in her eyes that she understood.

And I think to myself… There are so many times when the staff must have thought me weird. So many times when I was quiet and reserved and stand-offish, just because I didn't think they understood me at all. So many times I tried to make them understand. But they saw Fred and me from a Completely Different Perspective. We and, above all, he were part of their job. Part of their working week. For as long as

they chose. Then they could leave their job whenever they felt like it. But to me we are Life. I can never leave my Job. Life.

I was disappointed the day I met him in the town centre. He was in the midst of a group of other youngsters with disabilities and three staff members. The clothes he was wearing weren't his. They didn't fit him and was not the kind of clothes that I would have chosen. He was wearing cowboy boots. He was dirty and his clothes were stained.

I sneaked behind a corner. I didn't want to meet them there and then. Disappointment burned. Did they really think so little of him that they didn't even keep track of his own clothes? Was it okay to go out on the town with dirty clothes? Would they like to go out on the town in dirty clothes belonging to someone else?

Since Fred lacks the ability to choose his own clothes, I buy them for him. We, in our family, have our own style and choose to dress Fred in clothes that tally with our taste and way of dressing. He can't choose himself and therefore I feel it's important that he wears clothes of the same style as his family. This gives him an identity and a sense of belonging. A background. I may be wrong, but I do what I think is right. Fred appreciates being nicely dressed. He understands when he gets new clothes and enjoys looking at himself in the mirror.

Cowboy boots are okay. I have nothing negative to say about them. But in our family we don't dress in that type of clothing. Neither does Fred. On that occasion it was hard to be a mummy. It was hard to start asking. And I didn't. Not that time. I just felt regret. But there were other occasions and the time came when I actually asked about it. They answered:

- But it's not so easy to know which pair belongs to whom. Is it really that important? They fit, don't they?

I asked them whether they would like to show themselves on the town in dirty clothes belonging to someone else.

The answer:

- But I don't have to. I know which trousers are mine.

!

I remember the time when I came to pick him up and he was out walking with a male staff member. It was winter. When he came back I

noticed that he was wearing a pair of shoes that I had never seen before. And they were too small. He hadn't been able to push his whole foot into them but had been out walking with his heels sticking out. I was upset. It must have hurt to walk around like that.

- But I didn't notice that the shoes didn't fit, said the staff member.

Fred couldn't put on his shoes himself. The staff member had put them on for him.

I know that these occurrences are sometimes due to negligence and indifference. I feel sure that that staff member didn't care a hoot whether the shoes fitted or not on this occasion. This time it wasn't a mistake. And yet, I don't think he was evil or bad. But he didn't have enough knowledge for the job and the importance of treating people with dignity. He thought that when a person cannot understand, you don't have to pay attention to him. Then it's okay for him to walk with the heels sticking out.

At other times Anita could call me and tell me that:

- Today Fred has been to visit at my house, Lyckebo. He's been very busy, helping me to carry logs of wood. And the sun was shining so he could take his shirt off and bask in the sunshine.

Or that rare stand-in who dared to ask me:

- How do you want things done when you are here visiting Fred? Do you want me to leave and you do everything yourself or do you want me to help him to go to the toilet and such stuff?

Of course it was important that we agreed on things like that. Otherwise we would end up with a confusing situation and with neither of us knowing what was expected and neither of us daring to ask.

There were all sorts.

Those who understood a lot. And those who understood very little.

Maybe the second category lacked the imagination to put themselves in Fred's shoes. Imagination is important. To be able to think outside the box. One step further.

One day when Fred arrived home he had a large bruise on his right upper arm, shoulder and down towards the chest. His father discov-

ered this when they were taking a shower in the evening. I heard his exclamation:

- What in the world is this?

I ran upstairs and saw the large blueish-red area.

- Who has hurt you, Fred? we cried, who?

But he just stood there, silent as ever, watching us.

I ran to the phone and called the staff at the home where he had last spent some time.

- Do you have any idea what has happened? I asked the first one to pick up the phone.

- Yes, he said. I did it.

He explained what had happened. He had been holding a girl who was having a panic attack in order to stop her from hurting herself. Fred had joined the fight and pulled the staff member's hair, hard. This member had then, according to his description, grabbed hold of Fred's clothes to push him away until someone else could come to the rescue and take Fred away from there. After the incident the staff had examined Fred but had not noticed any bruising on his body, and they had therefore decided not to mention the incident to us parents.

I questioned whether you can actually grab someone's clothes so hard that there is severe bruising and not notice what you are doing. Don't you realize when you are too rough? I questioned where the rest of the staff was at this point. There is one member of staff to every person. Why did this have to happen? That a person living there was so disturbed that she sometimes had to be pinned down was one thing, but why wasn't she taken to another room at those times? Why did everything have to take place in the common living room, where everyone would be disturbed by these incidents? Where Fred felt that he had to take part in the fight? Why didn't the staff react more quickly to help the girl, or Fred to get into another room?

I contacted the manager. I asked for us all to meet and talk about what had happened. We set a date, shortly after the incident.

It was on a Wednesday. They had already started their conference. My item on the agenda was to start at ten o'clock. I arrived at ten o'clock. Knocked on the door, opened the door and went in. There

were about 15 people sitting round a long table. There was a free seat straight ahead and I sat down. No one said anything. To the left of the chair sat a psychologist, the staff instructor. I waited. Silence. The air was heavy with emotions. I was shocked. I had never met such a wall of hostility before. I felt as if everyone was against me.

Then the manager spoke:

- Well, Maud, you're the one who called this meeting, so maybe you should start by telling us what you want to achieve by this.

I started by recounting the incident and why I wanted us all to meet like this. I wanted to tell them about my view of what had happened, how distraught, sad and extremely worried it had made me. I wanted to hear how we could improve supervision so that this couldn't happen in the future.

Quickly one member from staff interrupted me:

- You trample all over our professional pride, and you don't understand our situation. We do everything we can for your son and now we get this shit!

Hostility lay like a blanket over the room. Everyone's eyes were on me. No one said anything. And I started to cry. FOR THE FIRST TIME in years I cried. The tears just came back to me. For the first time ever I cried in front of other people and it felt hard that it should come in front of this group, where I could feel such anger and aversion towards me.

I started talking. I didn't plan what to say but I tried to convey my feelings. I tried to make myself understood by telling parts of how my life had been until now, how things had felt, how this latest thing felt. I cried and talked at the same time for 20 minutes. Another member of staff said:

- But you have to understand our feelings as well, we're only doing our job.

I asked her to put herself in the position that her child comes home from school with bad bruising on his body.

- Are you telling me that you wouldn't have given his school a ring to see what had happened, I asked her? Wouldn't you have done that for your child?

- Ye-es, she said. I guess I would.

Of course, I did for my child what every other parent would have done for theirs. But again, a parent of a disabled child is not allowed to question things, just like they are not allowed to complain.

I remember my despair when I got up to leave the room. I didn't feel any warmth from anyone present. No comforting words. NO ONE stood up or showed with a sign or gesture that they had understood or respected my point of view. Or that I did it all from love of my child. I ended by saying:

- When you, who sit here today, have long since stopped working and have forgotten about Fred, I will still be talking to staff groups, still trying to make Fred's life more tolerable. All the time, new staff groups, to whom I try to make myself and Fred understood.

- But, exclaimed one of the staff members, that's bloody tragic!

!

I will never forget her exclamation, because therein lay a world of ignorance. It was painfully obvious that she had never thought along those lines.

I went back to work and sat there with my head in my hands. What I waited for never happened. No one called. No one got in touch with any soothing words that told me that he or she had understood that I wanted to protect my child, like any mother would. No one got in touch. Not even the psychologist.

I was told later that they had started guidance sessions within the staff group. I am pleased that the incident at least accomplished this. Most important of all to us, who depend on the staff, is that they know their job and why they're doing it. That they know why they are there and what the job entails. It was crucial for the staff to receive this guidance.

But I still had reason to ask:

- What about us?

We needed therapy just as badly as the staff but there was none available. I don't even think it occurred to anyone that we might have needed to address all our despair and our questions. How do you, as a parent, interact with the staff? How do you become good enough for

them? The staff have the power, and I've always been the underdog. *I've always needed them. They never needed me. Fred has always needed them. They never needed him.*

It has always been us needing the staff. They have never needed us.

CHAPTER 12

Are you a bad person when you can't cope any longer?

There came a day when I couldn't see the light any more. Fred could have been 14 at the time. Maybe 15 or 16. It didn't happen just overnight, but everything turned dark and gloomy inside. I felt sick but didn't realize that I was having anxiety attacks until a friend told me. Anxiety? Me? Strong as an ox.

My mind was obsessed with Death. Often I found myself sitting at the kitchen table looking out at a naked birch tree against a cloudy sky.

I displayed all sorts of physical symptoms and at times I was sure that I had a fatal disease. I went to see a doctor at our local health centre. I told her that I thought I had cancer and, a few visits later, told her that I thought I was losing my mind.

- What if I have a breakdown and have to go into a mental hospital or into psychiatric care?

- Would that really be such a bad thing? she asked.

- Yes, I said, that would be the worst thing that could happen. Almost worse than death.

The doctor tried to make me realize that I was not dying of any fatal disease, and that I wasn't going insane. She asked me to talk about

my home life. I told her about myself, my husband and my children and she asked:

- You haven't considered that you might be completely exhausted?

ME? NO, WHY SHOULD I BE?

I only did what I had to do. Lived the life I had been given. And everything was a bit easier now that Fred had his place at the children's home and actually spent a couple of days away from home.

- That's usually what triggers it, she said.

- What?

- Well, the tiredness, she said, maybe one doesn't have the strength to do everything any more. Have you considered having Fred stay at the home a bit more, to have some more help taking care of him?

- I don't want to! I said. He already spends a few days there a week. I love him. I DON'T WANT him to live anywhere else. We're the ones who love him. He NEEDS us. He's so wonderful. He needs us. He needs me. He needs me. I love him. He will live at home. He will live at home. I love him. I'm all he's got. He needs me. I'm all he's got. He needs me, needs me, needs me, needs me…

But days passed. Slowly. The nights even slower.

One Saturday afternoon my husband and I were invited to dinner by a relative. Fred was staying at the home and we had brought his little sister. I suddenly started to perspire. My face turned red and flushed. My hands lost grip of the knife and fork and they fell on the plate with a clatter. I started shaking. My heart beat hard and very fast. I'm dying, I thought. My heart pounded, sweat ran down my face and neck and my body shook violently. I could feel the smell of sulphur at the bottom of my nose.

- What's the matter? the hostess asked. You've turned all red in the face.

Fred's father looked at me with a worried expression.

I lay down on a bed. Stayed there for a while. My body shaking. Died, again and again. Thoughts rushing through my head. They say that you will relive your whole life in a few seconds when you're about to drown. That's what it felt like. I came to terms with my life and death. But there wasn't time enough to come to terms with everything.

Life was precious. I stayed under the blanket until I could make myself grab the phone and call the doctor.

- I'm dying, I told the doctor on the phone.

After having heard all my symptoms the doctor set an appointment for seven o'clock in the evening.

- What if I die before then? I asked.

- You won't, he said with great certainty. See you at seven, he added and hung up.

My heart calmed down on the way home and my face felt less hot and flustered. The tremors in my body continued for a while. At seven I arrived at the doctor's surgery. I was still alive. He gave me a general check-up, too general in my opinion, and mostly wanted to hear about my day-to-day life. I told him about my life. He said that I was exhausted and had had an attack of anxiety hysteria. Anxiety hysteria? No, I was not exhausted. My life was easier now than it had been in a very long while with all the help I was getting. I didn't understand anything. What was happening to me? I was scared. I found it difficult to breathe because of a great big lump in my throat. Was I developing throat cancer as well? I had a sense of panic. Was I going mad? What if I was going insane? What if I was going to die? What would happen to my children?

Thoughts crowded in. Dark thoughts. Death. What if I was dying? What if…horror. What if I was going insane, so insane that I could kill myself without really wanting to? What if? What if I had a fatal disease? What if I was to die? Die. Die. Die. Every morning. Death. Death. Every hour. Every moment. Every pulse beat…and one and two and three and four and five and death and death and death and death and… Dark windmills of darkness, black as night, grinding in my head. Wing beats of dark ominous birds in my body.

Colonies of ants crawling through my veins
The houses trembling to the ground
in a world that used to be so snug and secure
When the handles of the clock
never move
When the day never turns to night
so I can sleep

Sleep away the pain
if only I could
sleep, the only repose
Until sleep deserts as well
When the surfaces of my skin
merge into one trembling nerve
Frail
on the outside

So, what was happening to me? What was it? This wasn't like me at all. Colleagues and friends always told me that I was such a positive person!

- You're always so happy and content, they would say.

Well yes, it was easier that way. If I was happy no one would ask awkward questions. I didn't want to die. I DIDN'T WANT TO DIE.

The birch tree in our garden was cold and naked. Its branches stretched out like thin, dead arms towards the ground. The sky was icy blue and cold as well. I sat at the kitchen table and watched the birch tree every day. I went to work almost every day, except that summer when Death almost got the upper hand and I lay in my bed with nervous spasms and tremors. I lay there for six weeks just waiting the enemy out. Fear had me in a tight grip. Paralysed by fear I waited for Anxiety to hit. The force from outside that would hit me whenever I expected it the least. Otherwise, I tried to act normally. I often did

splendidly. There were times when I felt a little better; those instances felt like warm sunny islands in an ocean frozen by despair.

Minutes became hours. Hours turned into days. Day to day. Night to night. I kneeled at my bedside and called out to God:

- Why, why have you abandoned me? How am I ever going to learn to live again? Will I ever find my way back to life? Will I ever see the light again?

My existence was black. The doctor gave me Diazepam to take when I needed it. The pills scared me. I was scared of losing control. Then I tried one and actually experienced a short period of peace. For a couple of hours. I would take a tablet when things seemed especially dark. I was very frightened of tablets and of becoming addicted. But the drug wasn't all bad. There were some good aspects as well. A bit of rest from that Stinking Anxiety. I also felt that my family, through their need of me, pointed me in the right direction. There had been a time when life had a meaning. But how to find that sense of purpose again? Through all this I tried to find the strength to listen to baby sister, pick her up from school, prepare dinner for my husband when he came home from work and keep up with my own half-time work. It all went fairly well, apart from that summer, the longest summer.

The lump in my throat made it hard to eat. I became much slimmer and people around me thought that I had never been more beautiful. Slimmer. I ate when I could. Mostly yoghurt. It slides easily down a throat closed off by that great big lump.

Days turned to weeks, months and years. I continued to see Lillemor, the female doctor at the health centre. One day she said something very significant to me:

- Honestly, Maud, she said, why can't you see that you have gone through a very hard and arduous period? Why can't you see that it's impossible to go on like this? Because no one would be able to go on.

- Yes, I will! I said. It's not too much to ask. He needs me.

- BUT, she said, IF ANYONE ELSE HAD COME TO YOU WITH THE SAME BACKGROUND, SOMEONE WHO HAD EXPERIENCED THE SAME THINGS IN HER LIFE, WOULDN'T YOU HAVE THOUGHT THAT PERSON HAD A DIFFICULT LIFE AND

THAT THE PERSON HAD HAD THE RIGHT TO CHANGE HER LIFE AND GIVE HERSELF SOME REST?

- Yes, I said. I would. I would have understood had it been someone else.

I think of that as a defining moment. When I tried to put myself on the outside looking in. When I tried to measure myself by the same standard as I would measure others, that is to say, without standing in judgement. Maybe I didn't need to manage more than others? Or maybe not even as much as others? Maybe I didn't have to live up to expectations of "Super Mum". Maybe I didn't even have to live up to my own expectations?

But what would that make me? Well, who was I now? Just one thing, namely: *Fred's mummy.*

This is Fred's Mummy:

Capable
The Best
Objective
Capable
Understanding towards *everyone*
That is: staff, local authority officials, politicians, other parents, teachers, other intellectually disabled and/or autistic persons, family, friends and acquaintances etc., etc., etc.
Discerning
Capable
Never angry
Good at getting things done
Capable
Good at arranging Fred's life
Capable
Helpful to everyone (everything from fixing a new zipper to looking after other people's children and baking bread)
Secretary for six years for the FUB in my county, Jämtland (the Swedish National Association for Persons with Intellectual Disability)

Member and later Chair for 11 years for the FA in Jämtland
(the Autistic National Association for Persons with Autism)
Informant for politicians and local government officials
Lecturer for medical students and nurses
Capable
Understanding
Knowledgeable

Who would I become if I had to be only me? Who was I, just I? *Maud.*

Would it suddenly be enough *to be just myself*? I had forgotten how to be Maud. I only knew how to be Fred's mummy. I was totally bewildered, a spring flood of emotions, breakers tumbling against the rocks, and washed back like giant question marks into the sky.

I *needed* Fred. It was me who needed him to be able to live.

I didn't exist. I was nobody. All I knew was anxiety. There was a darkness in me whose existence I had never even suspected before. Anxiety had only been a word. Now, Anxiety meant that I clearly saw the thin thread that was my life. To Live or To Die was the question. I didn't question the fact that I wanted to live. But how to go about it? I didn't know any more. I could dimly remember that I had felt happiness sometime long ago. Now I wasn't able to reach it. Would I ever be able to?

The Lord was my Shepherd; before I started to want
He made me to lie down in green pastures:
He led me beside the still waters.
He restored my soul and led me ahead.

But now that I wander through the valley of the shadow of death,
I fear everything evil: For thou art not with me.
Thy rod and staff do not comfort me.

Life abandoned me. I was…alone.

Alone

in

a

great

and

lingering

and

pitch black

darkness

Alone

He in himself
and
me in myself

Alone

It felt serious and even life-threatening to be all alone inside myself. I realized that I am alone, the way every single human being realizes that, when Life is tenuous and hangs by a thread. And this thread is very frail. I, and I alone, had to live through the darkness that had turned off all lights inside. I was conscious of everyone around me, my husband, my children, my friends, but I could no longer be the Eternal Rock on which everything and everyone leaned. Not then. Alone in myself. In the darkness. There was a Fence growing outside my house, right across the street. The Fence had no gate. I couldn't climb over it. The Fence locked me in my house. I tried to go shopping but I couldn't get past the Fence. No one else could see the Fence because it grew inside me. My family wanted to go to Stockholm during that summer. I tried. But the Fence locked me in. I couldn't climb over it. Darkness reigned. And the Fence.

In that darkest of summers my sister Ewa carried me through Time. I could hear the children's voices coming in through my open bedroom window, where I, under my duvet, had found the one secure place I knew. I could smell a waft of meatballs from the kitchen. But it left me indifferent. She cleaned the house and cooked for the family and talked to me when I even lost my words. Until finally, one day, she sat down by my bed and insisted on taking me to the hospital.

- You need to be admitted, she said. You don't eat. You don't talk any more. You're here and yet you're not.

And I. Slowly. Through her words I felt a Miracle happen. Whatever Power I had struggled against the Anxietypower. I sat up in bed and took the first tentative step on the road back to life.

A miracle happened that day. Not one of those miracles you read about in newspapers, but big enough for my sight to become clear and I said to her:

- I'm taking control over my life again.

The first meal in weeks waited for me in the kitchen. Herring and new potatoes have never tasted better.

It didn't happen over night, but life got better. Day by day and month by month I won back Life and Purpose. Shakily, when Anxiety

won back some lost terrain. But steadily, when I realized that I was still here, despite the gloom and darkness around.

During this battle, when I didn't really have the strength to exist, I still tried. I tried to arrange for the whole family to have a reasonable life. I tried to arrange for extra help with Fred. I tried to cope with him. I got out of bed and routinely did my chores. Fred was on the school bus every morning, clean and well groomed and with extra clothes in the bag. It was so hard to find energy. I had nothing to give. Sometimes I would get phone calls from school and the children's home where Fred spent half the week. Usually when something had happened. I told them everything. I tried to tell them how sick I was and that I wasn't even sure whether I wanted to go on living. I thought they would understand. They didn't. Well, maybe someone did. Finally, I had to tell them not to phone and tell me about everything that went wrong with Fred. I said I couldn't take it right now.

I couldn't see a light but after a while the Fence collapsed. I could go to the shops. I could go to work again.

The days grew indistinguishable, a long distance of days when one day was rather like the next. You wake up in the morning. The first couple of seconds you just have a feeling that something is wrong but you don't know what. What's wrong, you ask yourself? The next thought follows. Death. Suicide. Some people do take their own lives. Help. Not me!! Dear God. Help. I don't want to die. I don't want to die. What if I get so sick that I lose control and kill myself? I don't want to. I want to live.

Get out of bed. Dress. Smile at the family and say good morning. They notice that my eyes don't smile. My 14-year-old daughter has searching eyes. She can see everything that I try to hide.

- Are you upset, Mum? She asks.

- Oh no, I say, just a little tired.

Her face doesn't clear. She knows.

Breakfast. (What if I have to die? What if I commit suicide? HELP, HELP, I want to live. Where is life anyway? How do I get there, to life? Panic!!!)

Everyone ready. School bus. Children off to school. Husband off to work. Me off to work. Nice clothes, nice hair. Lipstick and mascara. Enter the door at work.

- Hello, Good morning. You're a welcome sight. Happy and smiling as always, Maud. It is nice to see someone smiling all the time like you do.

Oh yes, I'm so happy, happy, happy and dead, dead, dead.

I had my lovely family and a handful of loyal friends. I more or less wore my friends out. There were two in particular whom I would call every day. Several times a day. They called me as well. When I was so bad that I even stopped calling, they called even more. They're part of the inner circle, the ones who saved my life. I kept on asking:

- Do you think I will die?

- Maud, said the friend who would always have to answer that question, you are not dying. I'm a 100 per cent sure that you are not dying. You are not dying.

- How do you know? I said. Are you sure?

- I am COMPLETELY sure, she said.

- I'll live today then, I said. Then I called her again.

- Do you think I will die?

- I'm positive that you won't die. I know that you won't die.

- Okay, I trust you, I said. Because I don't trust myself any more.

That was the hardest part, not believing in myself. To lose trust in myself. I wasn't sure that I could handle my Anxiety. I wasn't sure about myself. I scared myself senseless. I trembled. I perspired. I couldn't eat. I had a big lump growing in my throat. This pain lasted for five years. For five years I lived in Darkness and Shadow. Darkness was close but my friends held on tight:

- YOU'RE NOT DYING, they said. YOU WILL SEE THE LIGHT!

My friends became my guiding stars, because I believed them every day. I repeated their words:

- You're not dying. I'm not dying. I'm still alive. I will live. I will find my way back. Or forward. I will find the light again. I won't die.

I wanted to cry but the tears were gone. They had left me the day my mother died. She took my tears and they were gone. As was she.

- Practise, urged my friends. Practise your crying.

But what do you do when the tears have disappeared? I yearned for the tears to come back. My strongest wish was to be able to cry out all the darkness into the sun where it could all dry in the sunshine. My life was over because I was empty. Empty of everything. Still, every day meant work that, somehow, held that emptiness together.

I didn't get well just like that. No, but my inner strength, which had lain dormant for such a long time, started to make itself known again. Quite feebly to start with but stronger and stronger. When my sister refused to take responsibility for me any longer I had to stop being small and afraid. I was forced to regain control over my life, bit by bit. This was a new, positive realization. So, I could actually gain control over my own life. During the bad years I sometimes thought of the Anxiety as a force from the outside. It could therefore attack me at any time when I least expected it. Finally, after many serious attacks of anxiety and periods of depression, I realized that anxiety could actually be spelt with small letters.

And I realized, through the help of good conversation partners, that it had started within me. Therefore, I must be able to control it. But controlling anxiety is hard work. Maybe it's not even a question of controlling it but of learning to handle it better. And better. I now know that I will never reach that deepest pit of darkness again. I've been on my way down many times again but never as low as that. There are times when I can feel the flutter of dark wings in the pit of my stomach. I know then that I have to take a few hours to rest, a few hours or even a day. I try to arrange some time off from everything. Nowadays it's possible for me to do that. It doesn't take long for those dark wings to disappear nowadays.

But the hardest thing to understand and what I couldn't accept, was that I had to move Fred away from home. In order for me to cope with life and give the family a chance to live a reasonable life, Fred had to move away. That was the hardest part. It was a decision that I couldn't make. I wanted him to live at home. My child. My son. My beloved son. But we couldn't go on living as before. Yet what about

him? Would he always have to live with our decisions? He had to move away whether he wanted to or not.

- But, everyone said, all young people move away from home. It's natural. That's the way to look at it, Maud!

That's what everyone says. And they're not lying. But most young people move away because they want to, of their own free will. Their parents don't throw them out. And most of them don't have to move at such a young age. Still, the fact remained. I no longer had the energy to live at the pace which Fred's hyperactivity demanded. I couldn't live like that all the time. The decision nearly killed me. I had to reach the bottom and nearly die before I could give myself permission not to cope.

He had to move away from home. He had to learn to live without me.

I had to learn to live without him in everyday life.

When I become me

The world, it is a giant mirror
made by many small
In every person's own emotion
I see me
See my reflection
see but a glimmer
a smile
a back that turned away
and I ask what you see
In every person that I meet
I see her face present itself
her own, or maybe mine
Search for me in every meeting
asking what you see

Searching, looking, sometimes frightened
I don't know myself
The mirror lies
and it distorts
The mirror glass, it bulges, meanders
twists, when I ask what you see
Until, one day, I meet the gaze
I will draw near, distrustful now
The mirror glass smooth when I breathe
the sleeve, it rubs the surface clean
The eye are deepened, lips are tightened
Who is she and will I meet
the woman whom I have never known

The mirror cracks at encounters
broken pieces in a sea of glass
but I, I join them, glue and heal them
and sometimes I become just – me

CHAPTER 13

Moving to his own apartment

He already lived at the children's home half the week. I'm sure many considered that he already lived away from us. But not me. I considered him to be living at home. Him being away half the week was just so I could cope with the rest of that week. And the rest was the important part for me. He was still living at home. He had his own room. We shared most of our day-to-day lives. I washed, ironed and cared for his clothes. I sent him to school. Loved him. Living with him was important to me. When asked whether Fred still lived at home I would answer in the affirmative. Some may have considered me a liar, since he spent half his time away from us. I didn't. To me, Fred was still living at home. Because he was.

We now faced talking about him moving away completely. I didn't want him to live at the children's home. Partly because I didn't approve of the way they had put the group of children together. I had felt duty bound to accept it while he still spent half his time at home, but I would not if he were to spend all his time there.

I contacted the local authority officials responsible for this area and held several talks with them. In general, they understood. Understanding is good but it doesn't equal action. The problems within the children's home were not new to the officials. They all knew about it. They told me that there were plans in place to construct a new building

for a residential home for adults. Where that building would be located was still to be decided.

I called and requested meetings with various officials. They did keep me posted whenever they had something to report. I insisted that Fred had to move, not only away from home, but also from the children's home. I wished for something new, something that would be on his terms. Something good. I refused to accept yet another makeshift solution. The solutions I had accepted in the past were on my conscience and felt bad. Never again.

I maintained that I wanted a house in the countryside for Fred. My vision was a specially designed farm, with outhouses where he could gather and stack wood and have a fireplace in which to light a warm fire. Where he would find a reason behind the chores. I had a vision of him helping in the vegetable garden, maybe taking care of a few small pets.

A year went by. No concrete propositions. Just thoughts. And sympathy. I called persistently. I booked meetings and met with various people. They were kind and understanding. But they told me that these things take time. Well, the problem was that I didn't have any time to left for waiting. Neither did Fred. Our time was running out. I had made a decision, under a lot of pain and with Death in my heart. Now I had to fight for its realization. I had to fight hard to carry through a decision that I didn't want to make in the first place. That felt hard. I steeled myself to see it through. I couldn't do it but I still had to.

The staff fought to keep their children's home. I fought for Fred to move away from there and naturally this led to a strained relationship between them and me. There was no open conflict but I could feel silent hostility from some of them.

Then, one day, I heard that a lot had been found on which to build the new house. Not in the countryside, but on the outskirts of a residential area. I was shown the blueprint and my husband and I went to see the area. It seemed nice enough, a bit secluded but still close to the other houses. I was told there might be a problem with planning permission since parts of the lot were under a preservation order. Even so,

plans to start work went ahead and then, suddenly, it was all over. Nothing was to be built on this lot; there was a preservation order and it should be respected. To be honest, I wasn't surprised. Sad, yes, because there were no other plans and no date when we could hope to move Fred. It wasn't a good situation. It felt like the children's home was disintegrating, as if everything was rushing towards its end. And there was no new beginning in sight.

I was very tired and keeping up the fight was hard work. I tried to make a fresh effort and set up new meetings with local officials, from divisional managers to the Head of Social Services. Everyone shared my concerns. They told me that the decision was made; there would be a new building and Fred was one of the people who would get a flat there, but there were no concrete plans for the moment. They were looking for a suitable plot of land.

I felt completely powerless. What do you do with amiable politicians and officials? I'm not one for kicking and screaming and, for that matter, these people seemed to genuinely want a solution to the problem. BUT, FOR GOODNESS SAKE, HURRY UP! I wanted to scream. Can't you see that I've nearly died and that Fred is suffering and just HAS to be able to move on? HURRY UP!!! But a local authority cannot be rushed. A local authority is not a person even though it's full of individuals. For them, we were one of many cases they had to solve.

I pressed on with my calls.

- Hello, it's Maud.

- Oh hello, they said, no, nothing yet I'm afraid.

- But, there has to be something!

I made my own suggestions. Surely local estate agents must know of land for sale?

- Have you checked with all the estate agents? Doesn't any one of you know of any farms for sale or something?

We took our own car and went around the area to try and find a plot of land. What I was really saying was:

- HELP US!

My anxiety grew when I saw Fred struggle. His aggressive outbursts were getting more frequent again. Where should we turn? Everyone claimed to want to help but no one did. I wanted to be strong enough to take him home and let him stay there until we found somewhere, but I didn't have that strength. It tore me apart, seeing him suffer and not being able to do anything about it. My anxiety started to rear its ugly head again.

I remember one of my first meetings with FUB. I was then a young mother with a small child who sat and listened to the more experienced members talking. I recall her well, the beautiful, middle-aged woman with big, tired eyes, standing up and saying to the politicians sitting there on the platform:

- But mustn't it be cheaper in the end for the county council to do something for these children now instead of paying for all the worn-out parents when they have to go into hospital because they can't take any more? (This was when the county council was still responsible for disability care.)

I remember watching her with wonder, admiring her for her courage and wondering what she had gone through in order to say these things. NOW I knew. Now I was in her shoes.

The phone rang one evening. It was Rune, head of the committee with which I had been in contact. He wanted to come over to our place one evening with another official and present us with a new proposition. I told him they were welcome, baked a cake and decided not to get too hopeful. But, however much I tried, I couldn't help myself starting to Hope. Hope rooted itself in my brain, budding and starting to bloom. Hope couldn't be stopped. Rune, whom I had met now and then through Fred's years in care, brought Christina and a scroll of blueprints and even more Hope.

- Look at this, he said. On this address there is a plot of land. It's a nice area even if it isn't the countryside. It's on the outskirts of a residential area and adjoins common land. There is some woodland a bit further away and the lake is about 300 metres further ahead.

- This plot of land is beautifully situated, you will see, Rune said.

We pondered the blueprints. Fred's apartment would be about 50 square metres and contain a bedroom, his own bathroom, living room and a kitchen.

I will make this so nice for Fred, I thought.

- As long as it's all actually going to happen, I said aloud.

- Yes, we haven't actually got the building permit yet, Rune said, but we've received advance notification and it looks promising.

Hope, that strange sensation, didn't fade, though I tried not to let it grow too strong. When Hope withers and dies it really hurts and you grow frightened of letting it back in your life. But it seems that Hope has a tendency to grow whether you want it to or not. It doesn't die; it just sinks under the surface for a while. Then it pops up again. Hope has a life of its own. I suppose that's good.

However much I fought for a new home for Fred, the Change it would bring frightened me. At the same time I felt that I had to accomplish this Change. It frightened me because I didn't know what to expect. The unknown is frightening. You feel that maybe it's better to let things stay bad, because it might get even worse if you make a change. You never know for sure. But then I thought, what if it actually gets better? And I thought, it just has to get better.

Fred's father was even more worried than me about Fred moving to an apartment.

- How is Fred ever going to be able to live in his own apartment? he asked. He can't cook his own food; he can't dress himself or take a shower or do anything himself. And what if he gets lonely? And what if he runs off and disappears? And what if he doesn't like it? And what if he gets very lonely? Or if some weirdo gets in when he's alone?

- Yes, I said, what if.

I was scared and worried as well. What if everything went wrong? But since he couldn't take care of himself he would have staff around him all the time. So he wouldn't be alone. They would have to look after him so he wouldn't run off. But what if he didn't like it there? Still, the atmosphere would be much calmer and more peaceful and he needed that. I had to believe that this would prove to be a good thing

for Fred. And we had to take that chance for him because he couldn't do it himself.

Still, living on his own…

We talked through the blueprints with the officials in charge. The house would contain five apartments, three on the upper floor and two on the lower. The two floors would work as separate units, each part of their own division, with their own division manager; the reason being that the units should not be too big and therefore not resemble an institution.

We were still worried but felt positive looking at blueprints and planning a nice and comfortable environment for Fred.

In the autumn, about two years after the project had first been mentioned, the first sods were turned for the house and the foundation was laid. They told us that they hoped the house would be ready to move into in April 1993. Fred would be 17½ by then. I had a feeling of pure joy and certainty that Fred would have a good place to live under acceptable conditions as every person should. I knew from talks with the unit manager that they had advertised for personnel and had even started interviewing some people for the jobs. So, good things could actually happen to us as well.

Then the construction work was discontinued.

I learnt through an article in the local paper that some of the local residents, with the aid of the former town architect, had appealed against the building permit and demanded a stop to the construction work until the matter was settled. They intended to take the matter to the Supreme Administrative Court, if they had to. They launched an appeal among the neighbours, and many signed. The reason, they claimed, was the size of the house.

"The construction work is temporarily stopped and the foundation is covered with snow", it said in the article.

While the appeal-signers ate their cereals and hoped to be rid of the house through this action, we cried over our breakfast. Years of hope and months of planning were dashed. Some people considered the new house too big.

I couldn't go to work that day. I called officials in the town hall, who claimed not to be discouraged.

- Don't worry, they said, the neighbours won't pull this off. But it might take some time, because we have to wait and see. And for every appeal they launch time will drag on.

- But I don't have that time, I said. Fred hasn't got that time. We were supposed to move in this April!

- You can forget that. It won't be April. It will happen, but we don't know when.

Nobody understood our situation and it was a hard blow. Two days later I wrote an open letter to the neighbours who had launched the appeal. I went to the local newspaper and asked them to publish the letter. This is what I wrote:

Open letter to the neighbours who have appealed against building permit for a group home for adults

My son is 17 years old. He is a young man.

Like all boys of his age he's shot up and is now quite tall. He has his own interests in life, like cars and music. He is a source of deep and heartfelt joy to me. When he looks me in the eye and tells me, without words, "Nice to see you, Mum. I like you!" I feel a deep and strong happiness.

Whatever he is able to convey is made through signs and without words. He has no spoken language.

My son is severely intellectually disabled and autistic. We, his family, love him just as he is, but our situation also brings hard work and distress.

After much agony we, his family, decided that he should move away from home.

"Why agony?" you might ask. "It's natural for young people to move away from home!" Yes, that's right, but most of them

choose to move. It's not natural for parents to push their children out of the nest. When the child/youth is totally dependant on those closest to him/her, it's almost unbearable.

We see each other every week, but a few years ago, my son started staying for a few days a week in a children's home, run by the local authority. Two other intellectually disabled teenagers live there as well. They all have their own rooms and staff members are available at all times.

The environment they live in today is not acceptable. Two apartments have been turned into one, with a long corridor running between the bedrooms and the common living room. It's impossible to create a nice and homelike atmosphere! The apartment is situated in a block of flats and these young people in particular need more space.

"So, why do you let him live there if it's as bad as that?" you might ask. The truth is very simple. We do not have the energy and strength to help him with all that he needs any more. That is why we don't have a choice.

During these 17 years I have fought hard for my son, for decent schooling, for extra help when we've needed it, for good relations with staff and, later on, for a reasonable standard of living.

[…]

I wish that you neighbours could accept that a bigger house than normal be erected on the plot in question. We are not talking about luxury accommodation for one single family but an increased quality of life for people who have a hard life as it is. The house in question has been planned with these persons' special needs in mind. A functional house, like the one planned, would have a very positive impact on my son's, and his friends', whole lives. Considering this, I wonder if it might be possible for you to live with the negative impact of a house larger than you would wish for.

> To our family, me and my husband and our children, this appeal, and the possibility that it might go all the way to the Supreme Administrative Court, has been a real death blow.
>
> Where is my son going to find a decent place to live? When? These appeals may take forever. I feel despair right now. How are we going to cope?

Yes, that's what I wrote. But, truth be told, we all, family and friends, suspected that there was more to the neighbour's objections than just the size of the house. Driving around we noticed quite a few big and luxurious houses in the area. This house wasn't much bigger than many existing houses there.

I don't know what happened to the appeals, but there were no more articles in the paper and work was resumed during summer. My guess is that the majority of the neighbours were good people, who understood once someone explained the situation to them. Fred moved into his new home on 1 October. His flat was on the bottom floor. Apart from the flats there was also a common living room to be used by those who lived there, a recreation room and a staff office. Fred's father and I asked that the common living room between the flats be nicely furnished because we were worried that Fred would be isolated in his flat and not have the possibility of socializing if he wanted to. With time he had become more interested in socializing and actually initiated contact with others. The officials were flexible and didn't make any difficulties about this particular request.

This room, that seemed so important at the time, is now something that we wish we could remove. Four years on, it has turned out that, the bigger the space in which Fred can move around, the more space and people he feels he has to control. Olle, a member of staff, was the first to notice that when he spent time with Fred in his own flat, he was much calmer and composed. He could even sit down and relax for a while. I realized that it wasn't the extra living room in itself that provided quality but good staff with knowledge, empathy and imagi-

nation. And there must be enough of them. I believe that we, the people around Fred, don't have the right to decide whether there's going to be a common living room or not. I am certain that every individual has to be taken into account because all their needs are different. These decisions have to be reached with humbleness, sympathy and flexibility. Because every person is unique.

Fred had his own front door that led to the common living room. There was yet another front door from the common living room, and that door led out to the world. That made me very happy, I felt that Fred was secure. He had his name on his own door. His whole name, not only the first name. He had his own key. We talked a lot about "this is where Fred lives. This is Fred's own flat".

We started moving on a Friday night. He didn't have much but it still took some time. I can see him now in my mind's eye carrying a black bin liner full of clothes from the car. We brought him along on every tour we had to make that night trying to give him an understanding of what was happening. We bought a bed, bed linen, pictures and a beautiful blue leather sofa. We found a nice old oak chest in a flea market and let him have an old repainted kitchen table with chairs. And there were forks and towels and a ricer and pot holders and a vacuum cleaner and…well, everything. We bought as much as we could afford. Thus, in the end, he had an individually decorated home on which we felt we had helped him to put his own stamp, or as close to it as we could know. I slept with him in the flat for the first couple of nights but he soon settled in.

Once again Fred had to get used to new personnel and they had to get used to him. We, the family, had to let new people into our lives again, and they had to get used to us. As always, it felt important that we should get to know each other as well as possible. We started with a morning together when I told them about Fred's background. Together we laid down the general guidelines for the future. It felt important that they knew that the family wanted close contact with Fred. I had to tell them and show them our boundaries. I needed to be met with respect as Fred's mother and one of the most important people in his life. This meant that I wanted to retain responsibility for

certain areas of his life. I wanted doctors and the school to call me first. I wanted to buy Fred's clothes and whatever he might need for his home. It still felt important that Fred dressed in a way that tallied with what the rest of the family wore. The way you dress in many ways symbolizes to what group you belong and what your outlook on life is. I believe in the old saying, "Fine feathers make fine birds". I wanted to be the one who accompanied him to the doctor and the dentist, and to the hairdresser's.

It was agreed that I would take part in the staff conference every other month and when I felt that I wanted to. I also talked daily to the staff on duty. I didn't want them to feel that I was checking up on them. No, my aim was to keep in contact with Fred. Even if he can't talk himself he is well able to hear Mummy's or Daddy's voice over the phone, and then answers back using different sounds. This contact with Fred also had to include the staff since we relied on them to hear what Fred had done during the day and how he was feeling. This made it possible to talk to him about his day. Often simple things, like him having helped to make the gravy, and sometimes exciting things, like having been to a disco.

The staff and we agreed that we had to be open and direct in our dialogue to avoid misunderstandings. None of us wanted any talk behind our backs and thought we had to be honest with each other. We've had our ups and downs but generally I feel it's worked out fine. It's so easy to fall into the trap of non-communication. It's meant a lot to us that the staff have a very good supervisor and a divisional manager who is very interested in their work.

There was a director working at the children's home where Fred had resided. And we thought it important that she was there. She was our link to what went on and a person to whom I felt I could turn. We were a bit concerned that there wouldn't be a director working with the staff at the new place. What would it be like? Would the group be able to work without direct supervision? Would it all end in chaos? Who would take the overall responsibility? Who would keep a holistic view of the group?

Answer: The divisional manager.

But the divisional manager had to cover a big area. She was responsible for both home help service and direct care. Could we ever have a personal relationship with her and would she be able to lead the staff as well? We needed someone with whom to keep in contact on a daily basis.

It has actually worked out well. I'm satisfied with having a divisional manager instead of a director working directly with the staff. I have talked to others about this and they claim that we've been lucky. That the system is only working because of this division manager's special capability. Maybe this is so, but she's my only experience so far. She has, very thoroughly, acquainted herself with autism as a disability. She is an extra link between the staff and our family which in no way hampers our direct contact with the staff. I find it easy to rely on her discretion and professional impartiality since she doesn't have immediate working contact with the staff. This is the good part. She is one of them when she needs to be, but she's not working with them. It's easy for me to discuss difficult topics with her. I can commit things to her keeping that I wouldn't have felt able to do with a working director. I have had earlier experiences of talking to a director and later finding out that she's told her staff, despite having promised to keep things to herself.

Of course, you identify with your colleagues and it's easy to take sides against troublesome relatives. Today I can actually have opinions about stand-ins for example. I trust my own instinct whether some fit in or not and I have the courage to let the manager know without feeling like a suspicious fool. Her position of being a link between the staff and us makes it easy for me to trust her. Naturally, her personality and attitude plays a big part in this.

I'm sure that many people might prefer a working director instead. The problem with a divisional manager can be that she may lack an understanding of day-to-day activities, staff issues and personal needs. Especially since divisional managers have so many different areas to cover. The risk is that it's all down to the person you find for the job. If he or she is good, then fine. If not, then… My conclusion must therefore be that, despite my own positive experiences, the closer the

manager is to the unit's day-to-day activities, the bigger the chances are for a good life for Fred.

Fred has lived in his apartment in the group home for four years now. Things are still hard for him. He can't dress himself or maintain his hygiene or cook his food. But he's more content, much calmer and happier. You can see that he enjoys life. The staff have worked parts of the TEACCH method into his spare time. On his kitchen wall there is a rack with pictogram pictures. There's a photo of the staff, very important, and a picture of the person who will be there when he comes home from the day centre. His time off is not scheduled as rigidly as his time at day centre but the schedule contains routines and if something out of the ordinary is to happen. It may be time to go to the hairdresser's or out for a meal for instance.

Fred also chooses what to have for dinner with the pictograms. It can be take-out pizza and he happily carries his own pizza all the way home. Then he's always in a hurry to get home.

Fred often comes home to visit but he never stays the night. His apartment is his home now and he's much calmer since we decided that he should always sleep there. He now knows for certain how every day will end. He used to ask and wonder a lot. He enjoys his time with the family but a few hours are enough.

When he is respected and people around him tell him what to expect, he has the ability to take part in his own life and that calms him down. He has stopped throwing things around without a cause. When he does we know that something has happened which he has not been warned about. Maybe some changes have been made that he can't understand. Too much may have been demanded of him. In these situations he still wants to lash out. Or throw things.

We visit him often, the family and me. He will come to the door and meet us, take our hands and make the sign "what?". We'll spend some time explaining that we've come to visit, that he's not going out this time. It's rewarding and relaxing to visit Fred nowadays. I can go into Fred's apartment and close the door behind us. We can make dinner or have a cup of coffee, just him and me. I can start baking on a Thursday night and sit down by the kitchen table and make up some

new curtains if I find a brightly coloured piece of fabric in the spring. Or we can sit on his sofa and chat and he will treat me to a big hug and a big smile.

I don't have to stay and talk to the entire staff and other autistic and intellectually disabled people living there! I do like that! It's Fred whom I want to spend time with. There's always time to talk to the staff when we leave, or we will invite him or her for a cup of coffee. But we do it when we choose to. We don't have to.

Fred can never live an independent life. His disability is too serious, but he's able to live more on his terms now.

I've also let myself start to live again. But if I have the smallest indication that something is about to change, my new-found strength is as fragile as ice that has formed overnight.

CHAPTER 14

The police report

The sun was warm. I was sitting on the porch listening to a summer programme on the radio when the phone rang. It was Olle, one of the people who works with Fred. I could hear that something serious had happened.

- I've something to tell you. Something that happened five days ago.

And he went on to tell me that he and his colleague had taken Fred and his neighbour on a ferry ride on the lake. They had a lovely trip, the sun and the air, everyone was having a wonderful time. That's when it happened. A large group of people had gathered on the pier waiting their turn. They pressed on and wanted to go on board before everyone had got off. Fred was among the last to get off and the crowd pressed on. Everyone wanted to hurry to get a place on sun deck. It's part of Fred's disability that he panics if he feels trapped in a large group of people and can't see a way out. Loud noises are also painful to him. We usually try to protect him from crowds of people, children crying and certain other loud noises that we know, from experience, scare him. The crowd pressed on even harder and suddenly Fred panicked and lost control. He grabbed hold of a little eight-year-old girl's hair and pulled hard. The girl's mother started screaming and a man rushed up and started pulling Fred's hair to "give as good as the girl got", and to make him stop. The screams and the man's behaviour

made the situation worse and, instead of letting go, Fred pulled even harder. In a relatively short while, Olle thought a couple of minutes, the staff had managed to solve the situation. They talked to the mother who was, and rightly so, upset for her girl. Did she see Fred as a monster who attacked her daughter without any reason? Probably. And what about the girl? Here comes a maniac and attacks her and starts pulling her hair, when all she had done was standing there with her mummy. Maniacs like that should not be let loose! Is that what they thought? Maybe. Probably. At least to start with.

Later that afternoon the divisional manager called me and asked whether Olle had called and whether I fully understood what had happened. She told me the rest of the story. The mother had taken her little girl to the doctor. The girl had scratch marks on her forehead and scalp. The mother wanted compensation for the cost. Of course! If the local council hadn't paid, I would have done it myself. I was very upset and asked the divisional manager's deputy to call the family and tell them that I would like to see them and maybe explain a bit about Fred and his disability. Mostly, I wanted to show them that I cared, that I knew what had happened and thought that maybe the girl would be less scared if she understood a bit about Fred's situation. Otherwise she might stay afraid in future of meeting people with disabilities.

The deputy called me back and told me that the family would like to meet with me, but not for a few weeks since the girl had gone to visit her grandmother.

I felt bad. I couldn't sleep at night. I had nightmares of awful things happening. I lay awake and fantasized about what COULD HAPPEN… WHAT IF… WHAT IF… WHAT IF it happened again when he went into town, WHAT IF he really hurt someone badly… WHAT IF he scratched someone's eye, WHAT IF… WHAT IF… WHAT IF… I contacted the manager's deputy. The manager herself was away on holiday.

I had to tell someone about my fears. Summer time means stand-ins. I've tried to tell the people in charge that Fred and his friends are very sensitive to change. Hiring stand-ins is a delicate subject. My wish is that all staff, even stand-ins, SHOULD HAVE PROFES-

SIONAL TRAINING OR EXPERIENCE, preferably both. To hire schoolboys and schoolgirls who have to work, on their own, with people like Fred after a short introduction is not justifiable. You have to be able to do your job and you simple can't do that if you're inexperienced and lack the education. I don't mean this as criticism against any specific person. ABSOLUTELY NOT, I'm just stating irrefutable facts. When I called the management, at an early stage to point out this question, I was told:

- Oh Maud, we can't find anyone like that to hire. We have to make do with what we can get!

After what happened, I will never again be able to accept that answer. Never again. It is not just other people who would be protected by staff having adequate training, it is Fred as well.

What did he go through after what happened and what help was he given to work through his anxiety? Always, without fail, Fred is very remorseful when he has had one of his aggressive outbursts. He hangs his head, doesn't want to look you in the eye. I don't know what his exact feelings are but he knows he's done something bad. I was informed of this incident after five days. Had anyone talked to Fred about what had happened? I hadn't, as I hadn't known about it. Since Fred is unable to talk he would probably need someone to raise the subject with him a couple of times and really talk to him. Not just to accuse him but in an understanding way and maybe ending with the words:

- I/we will help you, so this doesn't have to happen again. So you don't have to become angry and scared again.

Fred had to find a sense of security all over again. The staff who know Fred also know how to find a way out of tricky situations for him. He feels safe with them. If, for instance, Fred is going to a concert, you have to check whether there are any wind instruments in the orchestra. If there are, that particular concert is not suitable for Fred. If the music is suitable you should go but you have to find a seat near the exit and TALK to Fred about it.

- Look Fred, there's the exit, you can leave whenever you want to, when you've had enough.

It's enough for him to know that he can leave. He can handle the situation.

I requested a staff conference to talk about these issues. We had a good talk. Everyone understood the problems, but how could we start to arrange Fred's activities so this need never happen again? Finding solutions wasn't easy since we didn't want to limit Fred's life more than necessary. We still wanted him to be able to go to restaurants and on bus tours! Eventually we found a compromise. This otherwise awful incident did bring something good. Everyone LEARNT SOMETHING IMPORTANT. They learnt to plan activities from Fred's point of view. Is it Fred or the member of staff who wants to go to the fun fair? Is it Fred or the member of staff who wants to go to a concert? Is it Fred or the member of staff who wants to go into town and have coffee in a crowded café? I don't know. Fred seems to enjoy these things at times. I don't have the answers to my own questions, but maybe the questions can raise thoughts and maybe that's enough!

Sometimes, SOMETIMES, a nice picnic with nice food can mean a walk in the woods. That doesn't necessarily mean cold coffee and dry cheese sandwiches. You can bring the tasty lemonade and prawn sandwiches there too. And SOMETIMES it might be fun to go into town and have coffee at a café. Maybe this can be timed for days or times of the day when it's less crowded. It doesn't have to mean that you should be the only customer there. Normalization and integration is all very well but it has to be based on Fred's own needs. Normalization shouldn't be accomplished just *because*, or because the local council wants to look good!

Since the girl's family couldn't see us straight away I made a point of finding out the grandmother's address. I sent a letter addressed to the girl. I tried to explain how sorry we were over what happened and explained certain aspects of Fred's disability and why he had reacted that way. I also sent a bunch of flowers as a sort of consolation.

I had a postcard a week later where she thanked me for the letter and the flowers. She mentioned that she would like to see us and maybe see Fred's room. The next day I had a call from the stand-in manager.

- Are you sitting down, Maud? I have some bad news again.

I can remember starting to talk incoherently about everything, anything, the weather, the postcard I had received… I didn't want to hear what she had to say, but I knew that I had to. I got a grip and asked her to tell me.

- THEY HAVE REPORTED FRED TO THE POLICE FOR ASSAULT, she said.

My whole world crumbled. I started to cry. I had never met this lady but I cried and sobbed and sobbed and cried and told her that I couldn't take any more! How much can one person stand? Why can't it ever end? I can't take any more, can't, not any more. My whole consciousness was filled with this: I can't take any more. Why can't it end? I can't take any more.

I asked her to call the mother and try to find out why she had done this. I needed to know why. She couldn't do that. She couldn't put the mother on the defensive, she said. No, I didn't mean for her to do that, but I badly needed to know why. Why had they accepted our letters and flowers? Why? Why had they agreed to meet with us? Why hadn't they made the report straight away? Why had they accepted our letters and flowers? Why? Why? Why?

I asked the deputy to call the mother and tell her that I withdrew my offer to see them and emphasized that it wasn't out of revenge but because I couldn't do it any more. I was devastated. Devastated. It felt as if I was lying bleeding on the floor. Kept on bleeding. It didn't stop. I said that maybe later…

The family never contacted us again, but I know they received the compensation they had claimed from the local council. They never had a fair picture of what had taken place, nor a fair picture of Fred. And, because of this, they didn't learn anything from the experience.

I've never felt bitter, through all the years with my son, all that's happened, all the difficult times. But this time I felt the bitter taste for a short while, before I managed to ban it from my life. Autumn came and my sleepless nights continued. Thoughts of what might happen haunted me. Friends said:

- You can never say what's going to happen in the future. What must happen, happens. Stop expecting something that might never happen.

Slowly life grew easier again. Everything was normal and I started to trust the staff again when I saw their attitudes changing for the better and continuing to develop.

I have no answer as why this had to happen. At least we could put the problem on the agenda and learn from difficult situations. Work on routines, plan, learn to know our own limitations and do our best. Find new ways. When the holiday period was over I met with the people responsible for staff and we came to the conclusion that more training was necessary, as well as guidance concerning both Fred's day-to-day life and the staff members' role and meaning in Fred's life.

Discussion groups were started and guidance was given to the staff.

But what about me? Us? The family? Where was our discussion group? We were on our own. Always. This loneliness feels never ending. Once again: if I had only realized that we could have received help!

Will I ever let go? If I could, who would then take full responsibility, make phone calls and push those responsible into action, question things and make suggestions? Who? I once thought that my family and I could live a normal life again.

It will never happen.

I called the police the day before New Year's Eve that year. They told me that they had dropped the case a long time ago. It was seen as an accident and not an assault.

First, I had to find my own strength
then give comfort
to those who couldn't find theirs
I then had to be understanding
and objective
when they didn't even try.
And then find my own strength
again
But how?

CHAPTER 15

When a member of staff leaves – is it because he or she has died?

If you are Fred, what do you think happens when one of the members of staff leaves? Where do all the relatives disappear to? Fred lives in a vacuum. Where the rest of us have cousins, aunts and uncles, he has none of that. Fred's relatives, grandfather, aunts, uncles and cousins are all fine, good people. The reason they can't be there for Fred is in part his difficulty in coping with loud noises. Small children are noisy and unpredictable. It hurts his ears. He gets scared. So when my brothers and sisters have had children their visits to Fred have ceased more or less completely. Other people sometimes forget about him. It's easy to forget to visit a person who needs you and who isn't easygoing, can't talk and can't give much in a conversation. To Fred this means that we, his family, are all the more important. He has no one else. And it is also the reason the staff members become part of his select few. In a way they're Fred's extended family.

Fred meets lots of staff members. There are six employees working in his home. He likes them a lot and so does his family. We like some and we really love some of them. They make up a very nice group of people. They get on well and like working together too, that's obvious

to me when I hear their banter. And this is very important. They complement each other.

But the staff members are people. And life being what it is, they get sick, they have old parents who are ill and die. They have babies and go on parental leave. They go on holidays, and need stand-ins. And more stand-ins. And more.

The people standing in are also human beings. They also fall ill or get a new long-term posts as substitutes elsewhere. And so they have to be substituted with other stand-ins. New people who have to be trained and try to work with Fred. Of course he has to try and work with them as well.

Inevitably staff members leave. They go on in life to new assignments, they retire or go back to school. I understand this.

But sometimes I feel like screaming: please, please, don't leave! Please, stay on a bit longer! But I never say it out loud.

There was a time when I shut off all emotions when someone was about to leave. I'm sure that some people saw me as cold hearted. I went through the motions, shook their hands and thanked them. Sometimes I would even buy a small present, but I'm sure they noticed my coldness. The handshake was probably followed by eyes that looked away. But it hurt so much. And it happened so often. People whom Fred and I had learned to like very much disappeared. People who had helped us to survive, just disappeared. We really loved some of them.

We lost many before I was able to open up again. It's taken me a long time to realize, fully realize in my inner room, that this is the way it is, and will always be for us. It's taken me many years to be able to open up, and say "We are so sorry that you are leaving, but thank you for everything you've meant to us". And I now can tell them that I'm sad that they're leaving but that I understand. Fred and I always have to understand.

And then after they've left. Fred and I believe that all members of staff die after they've left! If they are alive, how is it that we never hear a word from them again? Never again! But we have no grave to visit.

I have no right to put pressure on a person, and neither has Fred. I'm talking about compassion, about giving a few moments of one's life to a person for whom it means everything. People, who meant so much to Fred during the years, why can't they ever come and visit, even just once? Or why can't they grab the phone and just give us a call? Or maybe a few simple lines on a postcard, draw a sun and put on a stamp? We would be able to look at the postcard and talk about our memories of that person, many times. About what we used to do together; we could bring out a photo and allow ourselves to long for him or her!

Fred is allowed to miss people, long for them and mourn their disappearing from his life! There is nothing wrong with that. I do that too when someone is no longer around. But I can keep in contact if I want to, I can talk. I have a choice. I can at least tell this person that I miss him or her. Fred can't. We who are around him have to talk for him. We have an obligation to help him mourn and miss and long for and work his way through these emotions.

I feel sure that much of Fred's anxiety could be lessened by us trying to see into his soul! What the staff members need is Imagination. Thinking out of the box. How he might feel. Try to empathize, try to imagine how it would feel for yourself.

What's it like to mourn when you can't talk about it? You can't say what you feel, you can't discuss it sometimes, when you want to. Why is she gone? When can I see her again? How could she leave me? Will I ever be happy again? How do you work through your grief when you don't get any input, when there is no understanding, no explanation even of where she's gone, the one you liked so much and relied on. How does it feel to – maybe – wait for her to come back – day after day – but she never does? When does he stop waiting and longing? When does he resign himself to the fact that she's not coming back? Why doesn't anyone talk to him and help him to work through all these feelings? Why doesn't anyone tell him what's going to happen?

"The kindness" that Fred is shown by not being told when someone is about to leave, is totally misdirected. If the staff has a leaving-do I think Fred should be able to attend on his terms. If he

can't go to the pub for a beer then there should be another party as well which he can attend. He should be able to say good bye, maybe with a gift, shake the person's hand and it should be made clear that the person is leaving. It's much kinder to be clear about this and let Fred be sad.

The staff members often become much more than just staff to Fred and me. Some become our friends and an extended part of our family. They know so much of our private lives. This makes it harder to part. And, this is why I wish the staff members who care, and so many do, would take time to call or send a postcard. After all, on your holiday you send postcards to your colleagues. Why not send one to Fred as well? He has his own letterbox and understands very well from whom the letter has come!

There are some who have this Imagination.

There are some who send postcards. Once in a while. That's wonderful and Fred is so happy when there's some post in his white letterbox.

CHAPTER 16

He's started at the day centre
or
The tale of budget and reality

Fred left school at the age of 21. The more understanding he had found with teachers and assistants the more things had calmed down. They attended courses and lectures and gained experience from having contact with Fred and his friends. They were our rocks. These people were his Security and Comfort. And he actually started to trust himself. He started to find SECURITY AND COMFORT IN HIMSELF.

And so he turned 21. And in Swedish society, where the Power and Glory are one, there is a law stating that you have to leave school at this age. And when you leave school you have to leave your teachers and assistants. Because when everyday life has finally…FINALLY started to function for you, you have to move on.

I thought, okay, it's the law. And I thought, this is what happens to us all. That whatever we need the most is taken from us. It happens to all of us. And he's one of us. Maybe happiness isn't what you need most in order to develop. And maybe not security or comfort either.

OK! He's one of Us, but he's also one of Him. His need of support is much greater than Ours. I have to let Time and Development take its course. No use in Fighting. Rather Be Wise and swim with the stream for a while. And be ready to Fight On later.

About eighteen months before he left school we met, together with Fred's teacher, with some people from the central day centre administration. The day centre had changed name to MICA. It's a very grand name and in Swedish it stands for: "The individual in focus – at work". Around these words there was a circle, almost like an embrace. A nice symbol.

The people from the day centre were very considerate and showed kindness. They agreed that Fred should be eased into work over an extended period. They were prepared to start planning in good time and looking into possible workplaces for him. They showed compassion and asked me to trust them. Everything would be fine. And I believed them. They must have long experience from working with people with special needs, I thought.

I met them again about six months later. Nothing had happened but they kept in touch. Through our contact book I learnt that they had also met with Fred's teacher and her assistants.

A year after the initial meeting, Fred started his last term at school. His teacher was very busy since all three students were to start going to day centres and needed an adjustment period. She stayed in contact with different day centres and with us parents. She really wanted all to work out well.

At the beginning of January I started to worry. Well, I usually worry when Fred is about to experience a change in his life. He usually goes through a bad period at first, a period that can stretch into months, sometimes years. The weeks passed and I couldn't calm down. Whatever concerns Fred also concerns us as a family. When he has a bad period we all do. And what about him? What did he understand? It was all planned over his head. Could we have let him play a more active part? If we'd taken the time? I was told that the day centre planned a whole new group around Fred and his particular problems. I

liked the sound of that! They had really understood the problem!!! I was happy!

Time passed and I began to wonder when they would start hiring people for the group. Fred must have a chance to get to know them before the end of the term, and they, in their turn, had to get to know him. I then heard rumours that nothing was to be done before March or April. Those responsible at the day centre couldn't do anything before that year's budget had been fixed.

But hello??? Why did they tuck away their experience from Reality? Budgets and Reality have never gone together. Surely they knew that?

I called someone at the local authority and he understood fully my concerns. He promised to contact the manager at the day centre where Fred was to work and inform them that they didn't have to wait for the budget report before they started hiring people. I felt reassured and let January and February pass into the mist of time.

By March I wasn't feeling so confident any more. My whole body ached with worry. My intuition and experience told me that something was very wrong. I called the day centre and talked to one of the people in charge. I presented my view and was calmly told that they awaited the budget and that nothing could be done before it was presented.

- But, I said, he promised!

- I don't know anything about that, she said, and besides, this is the way we've always worked.

Okay, so that's the way it was. "We'll do things the way they've always been done."

I was gutted when I hung up, even though I had acted as if I were very understanding over the phone. She had seen my point as well but her hands were tied. Why didn't I rant and rave? No, because I had learnt that you get much further with understanding and objectivity. The people you have to deal with won't take you seriously when you cry and sob into your handkerchief. They listen to me after I've learnt to talk their language. So I don't cry and I don't rave. What happens

inside is another thing. My thoughts are torn to rags and gastritis and ganglions burn and ache. But I don't cry.

The end of this story was that two people were hired in May to work with Fred. I had been told 18 months earlier, that they would be trained in working with autism and the TEACCH method. Needless to say, no such competence had been taken into consideration. They hired two nice, young people, who were interested in their work and eager to learn. I have nothing negative to say about them. On the contrary.

What I do want to mention is the game that went on around these people. They were pawns in this game. They were hired so late that they had practically no time to receive training in the specific teaching method used and they only had ten days in which to get to know Fred. Fred, in turn, had ten days in which to get to know a whole new world. Furthermore, these ten days were in the last two weeks of term, a period when two further pupils were trying to acclimatize and when classroom activities were being wrapped up. The school would cease to exist by the end of that term.

The premises where Fred was to have his work would not be empty until August, so Fred and his new assistants would continue to use the school during summer while waiting for August to arrive and bring with it a new way of life. I think it was a good solution to let Fred and his staff start their relationship in the old familiar school building. Everything else was new: new staff, new treatment, changes in structures and safety and, furthermore, new ways of communicating.

The summer worked out surprisingly well. I met with the staff and told them about Fred's background. Getting to know them was important to the whole family and we wanted to show them our personal commitment to Fred and everything that concerned him. He remained quite calm and had no violent outbursts. At home, in his own apartment, he was rather calm as well. Thankfully the staff there were well known to him. They managed with only two substitutes over the summer and Fred already knew them.

August came and with it new premises that couldn't have been worse suited to Fred if they had tried. Fred's difficulties, in particular

with the noise and unpredictability of children, hadn't been taken into account at all. The centre itself was suitable but was situated in a lower school yard full of the noises of excited children at play, with a skateboard ramp directly outside Fred's building. So Fred was stressed every day; it was not easy for him to be calm and feel safe there. My worries increased. The staff had lots to do. Important things like new curtains and furniture. I can see that it's nice to furnish a new workplace. But shouldn't someone from his old school, someone who knew Fred and who also knew about the importance of structure and teaching methods for people with autism, have been there to help with tips on decoration and the environment as such? By this I don't mean the design of the curtains but more fundamentally the working environment, layout and colour schemes. The environment means a lot to Fred. If he is given too much space, for instance, he becomes anxious, runs around, fools about and gets more and more upset…then his aggressive outbursts come as sure as fate. These outbursts are hard to take, especially if you haven't come across them before. There have to be limits in the outer environment. But how were the staff supposed to know this when they hadn't been given the opportunity to learn?

I wanted to stay away for a month or two so the little group could settle in. But then someone told me – once again by pure chance, why bother informing the parents? – that two new people had been put in this group. At the same time I had signals from the staff in his unit that Fred was coming home very agitated and destructive in the afternoons. He had smashed his lovely vase to smithereens, he who hadn't done anything like that in a couple of years. He was angry and shook his fist at the staff and almost came to blows with some of them. I called one of the people responsible for the day centre and she told me that these two young men with special needs had been put into this special centre since there was nowhere else for them to go.

So much for the promise to form this group around Fred's needs. I saw my hopes vanish into thin air which left nothing behind.

Now Fred's mummy had to be strong again. I called people. Demanded. Move the new fellow workers. Start from scratch. And above all:

Give the new staff members knowledge and tools so they can work in a more informed way!

Turn to the school staff for information about Fred and pedagogics in working life. Co-operate for goodness sake! The people at the day centre weren't prepared to do that. I kept calling different people to ask for help and finally decided that Fred should stay at home from work. He didn't need that kind of pressure and not always being able to control himself. It could, I knew from previous experiences, have terrible consequences. I had to make that decision to help him help himself. He stayed at home that week.

What would happen when the staff at work didn't get – quickly – enough knowledge and experience? Would Fred have to lose the language he'd acquired?

And what would that lead to? Would he lose his newly accomplished calm? What if his aggressive outbursts come back? Then what? I could feel all the anxiety from the time of the police report flood back. How dared the day centre neglect to hire staff with the right training and without enough knowledge? How dared they play with people's lives like this? It really was this important to me.

I finally managed to persuade a day centre manager to attend a meeting with Fred's staff and me. This meeting resulted, after long and hard negotiations, in a promise that the staff would receive training concerning the environment, language, the TEACCH method and the need for structure.

This was just a small episode for the management at the day care centre, I think. I think that I was seen only as an overprotective and anxious mother in their eyes. At least that is how I felt. And I am usually right about these things. But to Fred and me, this was a very serious situation which could have ended very badly. It's so easy for something that one has spent years to build up to just crumble over night. There are serious risks that such situations might stop the development that has been built over lots of years.

Many things have happened during Fred's first years at the day centre. I always feel that I have to fight for every inch. Why?

Shouldn't the family, school and day centre work together as a team?!!! Should the day centre and the school be two power structures competing with each other? Shouldn't we all try to work together from Fred's perspective? We have to co-operate, of course!

Throughout all my telephone calls, questions and generally being Fred's mummy, all I think of is him. I only concern myself with Fred's quality of life. I have no wish to be a difficult mummy. On the contrary. I really want us all to work together, the people whom Fred needs to get through the day.

Then they tell me from the day centre:

1. Fred is an adult.
2. The school and his work are two things. There is a big difference.
3. It's not just Fred we have to concern ourselves with.

And that is it. I would have wanted something more. Because this is both true and untrue.

My answer to 1: *Fred is an adult.* Yes, age-wise Fred is an adult. But he is intellectually disabled and autistic. He needs much more support than a 21-year-old of average intelligence transferring from school to work. And even a person of average intelligence is often in need of some support. Going through changes is hard for everyone, but all the more so for Fred. He can't make his own way home, he can't say "no", he can't express his opinions, his fear and insecurity. To express this, he has to resort to destructive actions.

My answer to 2: *The school and his work are two things.* Yes, there's a difference between school and work. But, when I, during my own life, have gone from school to work, I have always been able to bridge over this difference and take experience and training with me to the other side. I am able, through using my language, to tell my boss and my new colleagues, that I feel insecure or that I need more training within a certain field. This way I can handle the new situation in a creative way.

Fred is not able to do this by himself. He needs help to build the bridge between different groups of staff. The new staff members need

support from the people who already know Fred. They also need education and knowledge of his disability, as well as methods for teaching and creating structure. He can't express his insecurity in new situations and what he needs more than anything is help to build a new sense of security. People who can't understand this need and who don't know how to go about it, how could they ever be of assistance to him and know that they are doing a good job?

There is a difference between school and day centre/work. It's easy for me to see the management's point of view and I do understand that they mean well. But Fred can't see this. He needs assistance and I am not even sure that it's so important for him to see the difference. To Fred it's most important to spend his days in a place where he gets support and help to develop a sense of self-esteem in work and to build his self-confidence. He can then manage ordinary tasks and develop as a person.

My answer to 3: *We work with so many others. It's not just Fred.* I understand that. That is why it's so important that we, who still have the energy, make demands. When I demand things for my son, my intention is that more people can gain from them. Solutions which the day centre uses for Fred should be available for many others as well.

Open the borders. Put yourself in Fred's position. Forget budget cuts, employment freezes and employment security.

You need help understanding why you can't stay in a place where you felt safe and happy. Maybe it's a bit like being sacked. You suddenly go to a new place in the mornings. The teachers and assistants have disappeared. Your classmates, who you have known for so long and whom you are so used to, are gone. Why? Will they ever come back? No one is using the pictograms the way that you know so well. No one knows how to treat you. When you ask them, they don't even recognize the sign "WHAT?".

The new staff members don't know what you want when you use the only language you have. You take their hands and make the sign "what?". They don't understand. They don't set the limits to which you are used. Other people suddenly join the group. Why?

It alarms you not to know. This feeling stirs inside. Restlessness takes a hold. Everything is new. Why? For how long? Why? What is happening? The sense of confusion is overwhelming. You are afraid. Fear leads to aggressiveness.

As a new member of staff you have no answers for Fred. There is no one around who speaks your language. You didn't have time to learn signals, methods and signs during ten days of training. Besides, this was during a period of confusion, of departure.

This happens in Sweden today. Our constitution gives us certain rights. Everyone has these rights. We have the Right of Speech. This presupposes a language. We have the Right to Vote. This presupposes the knowledge of how and why you vote. In a moral sense we acknowledge others' rights as well. There are tacit understandings between people in our society. I listen when you talk to me. I treat you in a humane way. I answer your questions. This presupposes my understanding of the question.

But put yourself in the situation where your understanding of the world is limited. Add also that you don't have a language. How then can you use your Right of Speech? You are the only one with obligations. You have to learn the language others use. No one can find the time to learn yours.

Yes, I am only Fred's mummy. But I do have a brain, eyes and ears to think, see and hear with. I want to co-operate with the staff. I may just be a mother but I do have experience and knowledge. I do have intelligence. And I use it as best I can.

I want to explain Fred to others. He is the day centre, MICA. He's the individual they talk about, who should be "in focus". This should never be just a trendy buzz word. Never. Fred is the individual who should be in focus.

Not me.

Not the managers.

Not the staff.

Still, we all exist, in that symbol, the embrace, around the word MICA. He needs us to be in that ring, our support every day, in his work.

My support.

The managers' support.

The staff's support.

It is not enough to have a generally benevolent outlook on people.

IT IS TIME TO SEE HIM AND HIS NEEDS. IT IS HIGH TIME TO GIVE HIM THE RIGHTS THAT THE REST OF US TAKE FOR GRANTED EVERY DAY. His rights are no different from those of other citizens. He has the right to influence his own life. He has the right to our help in his choices in life. It might make it harder on us, yes of course, but we don't just have rights, we also have obligations. It is my obligation to show my son and fellow human being the deepest respect.

And I have started to realize that my responsibilities will never end. And you object that, well, that's parenthood for you. Still, his needs are so much greater than those of my other child, so deep and far-reaching. I'm his interpreter, for life. He is my responsibility, out of love.

When they asked "How can you cope?"
I said I didn't know
I knew I couldn't cope with life
but did it anyway
I fought a battle, huge and wild
a battle going on
because I've only realized
my battle is for life

Though I've cursed and damned my day
and wished we both were dead
My life itself, it drew away
– and we are still alive
And though we're pulled together now
– now and for ever more –
He carries the heaviest load himself
his battle is for life

In silent prison – price is high
He lives his life in nights
of anguish and of rage turned loose
when no one understands
Sometimes with sorrow impotent
He still is here to stay
dependent on some other's will
of goodness – or of bad

"Surrounding world, please see just me
I am one just like you
a human being who can feel
the same that you can do
My lack of wisdom though, is great
and you may think of me
as very different from you
I love, I grieve – like you"

My love feels heavy, it's so solemn
until I meet those eyes
– a rogue's – he sparkles and he gleams
At moments finds his way
out to my world, if only for
a minute we might share
a Joy, we share the deepest Joy
It's deeper than the sea

And now he's 22.

CHAPTER 17

To forgive yourself

Perhaps a lot might have been different for Fred if I had only had more energy? If he hadn't lived through so many makeshift solutions? Maybe he would have developed more, better? Earlier? Maybe he would have been more harmonious? If I HADN'T ACCEPTED all these emergency solutions. Yes, this is what I feel, still to this day. I should have fought harder, been more forceful. But then I realize that right then I couldn't have done any more. The situation was as it was. I have to try to forgive myself. And that is the hardest. To forgive yourself.

When I wrote the chapter about pre-school and school I had to take out and read through all our contact books from that period. The first one was from 1978. Fred was three. The last one from the summer of 1994. He was 19.

I have many contact books. Many things happened during these years. It sometimes seems as if Fred lost ground in his development if you compare the books from different years.

Reading the text gives me a strange sensation. So many things are described as nice and beautiful and wonderful. But I can see things written between the lines. Short sentences about not being able to cope any more. When I had finished going through the books something caught in my breast. I grieve. I grieve for Fred. For all the things I

didn't do. For all the things I wasn't capable of doing. For all that he must have felt and grieved for.

I can never, not for a second, understand what being intellectually disabled is really like. Someone says, no, but maybe Fred doesn't either. True, Fred is not completely aware of his disability. But he has feelings. There must be so many situations where he has felt steam-rollered, sad, impotent, confused, angry and all those other emotions that you feel when no one listens to you. He can feel. HE CAN FEEL.

And how do we treat him? WE WHO ARE INTELLIGENT ENOUGH TO EMPATHIZE? HOW DO WE TREAT HIM? It's enough that I speak for myself. How do I treat him?

When he was little I loved him. More than everything. I cuddled him and admired him. I also hit him. My fingers left long, red marks on his thighs and bottom. I cried. Begged him to forgive me. I was powerless.

What am I talking about, couldn't cope? I should have been able to. I SHOULD HAVE! I SHOULD HAVE. Oh, God. I should have. I didn't fight as much as I should have done. I should have persevered. Fought harder. Done more. Not tolerated so many makeshift solutions. Assistants here and assistants there. Children's homes here and children's homes there.

And the stand-ins. And more stand-ins. And more. For thine is the Kingdom, the Power and the Glory forever and ever. Amen. Theirs, those who make the decisions.

They claimed to believe in this new solution. And the next one. And the next. I, I believed them. Especially when I couldn't manage any more. I wanted to believe them. It gave me some time off.

- You have to think of yourself. You have to manage, they said.

Why? If anyone had to manage, it was him. New places. New staff. New stand-ins. I wonder what it's like to always, always have to face new people. I enjoy coming home in the evening and being just by myself or with my family. Dressing down and taking off the make-up. Say the wrong things, put the knife in my mouth when I eat and sleep on the sofa with my mouth wide open. Those who love me will go on

loving me anyway. At these times, I don't want anyone there that I don't know very well.

But Fred. He is often stuck with someone he doesn't know. More often than not, someone nice and full of good intentions. Sometimes someone on a summer job doing it for the money. Someone with no experience of people with intellectual disabilities and no training whatsoever.

When I call the management about this, they tell me:

- Maud, you have to realize that there are no others available! What do you want us to do? At least they spend a day or two with the ordinary staff.

Well, maybe that is enough. In many cases I'm sure it is. But not all the time, this isn't good enough all the time. Am I really supposed to do their job? And it makes me wonder, all the unemployed that you hear about. Where are they?

- We can't get anyone else!

How did they look for this stand-in? They give so many friends and relatives a call when they need one. I am sure there are many brothers and neighbours and cousins who can do a good job. But where are the people who have experience and training?

Okay, so what about me? It's easy to blame everyone else! I didn't do enough either.

I blame
MYSELF

PROSECUTION: You keep saying that you did what you could. Is that true? Shouldn't you have managed more? Others have. But not you.

MYSELF: I should have done more for my son. I know. He could have had a better life! But how could I have accomplished that? Where did I go wrong?

DEFENCE: But you weren't to know. You were just a girl when you had him. Twenty-four is not old. And there you were with all that responsibility.

MYSELF: Yes that's right. But that is as it should be. I am his mother. But I failed so many times. He was so little when I started asking for relief during weekends. He was only four when he first had to sleep away from Mummy. He must have missed me dreadfully. Did he suffer then?

PROSECUTION: Yes, probably. It's likely that he would have developed into a calmer person if you had received help at home and made an effort!

DEFENCE: You did the best you could! You trusted the welfare official and the psychologist. You were there and helped him acclimatize. You got to know every assistant, even though there were so many over the years. And as some people told you, Fred then had a mummy with more energy when he came home – who knows, otherwise she might not have had any energy at all.

PROSECUTION: But later, when he really needed you. When he spent half his week at the children's home, in a group that was detrimental to him. Remember, there was one person in the group who was severely psychotic. Fred thought he had to defend her and ended up with bruises.

Maybe that is where his own aggressive outbursts stem from. If you had showed more stamina, or made sure that he was transferred to a better place, he may have been much calmer and content today.

MYSELF: I know. I should have had the energy. I should have *demanded* more help.

DEFENCE: But, you did your best in the situation. Besides, you were ill yourself at that time.

PROSECUTION: He has to suffer because you didn't do your best. And he may continue to suffer all his life. Did you fight to keep the speech therapist? He might have been able to say a few words today if you had persevered.

MYSELF: I agree. And the sign language. I should have demanded that the staff used it more. All the stand-ins. I felt bad about all the changes sometimes, especially in summertime. How must he have felt? HOW DID HE FEEL? While I was sitting at home in a deck chair resting at times. But I was ill. My soul was torn to shreds. Actually, all of me. I thought I tried as long as I could.

PROSECUTION: It wasn't enough. You didn't fight hard enough.

DEFENCE: But it might have been enough. After all, you did all you could.

MYSELF: Is that enough?

About doing the best you can:

- *Truth number 1*: Can you do more? Yes, I actually think you can. There may be something you hide behind when you claim to be doing your best. Maybe so you don't have to do more.
- *Truth number 2*: Still, we had another child. We had a marriage, or at least the semblance of one. Our everyday life was infected. It was a wound that oozed and bled. We were mean to each other. When you can't be mean to the children who raised hell and don't know better, then the adults can take it out on each other. When life was unbearable. Because it was. But, I sometimes wonder. Was it unbearable or was I a weak and bad person? Did I give up too easily? And I have to ask those around me who saw things from the outside. I have put a transparent blanket over my memories. The memories are all hazy. And the blanket is full of holes. Pain shoots through me when I suddenly fall into one of those holes.

Is it enough to do the best you can? Is it good enough, God?? IS IT??? Because, if it isn't, then I'm doomed.

Oh Lord, forgive me
for I did the best I could

My Pain is endless
It nails me down
for eternity
My hands beat, beat
until bloody
and my forehead

But my body's Pain
does not ease the pain
of my soul.
My Pain is endless
sharp and endless
Though I loved
loved so much
and still do
Measureless love
I hurt him
How much?

How can he forgive me?
Can he ever
Yes, I know.
And the Pain comes in waves
when I meet him
and he smiles
That loving smile
without distrust
without evil
without envy
He simply loves

"What do I have to forgive?"
he would say
if he could speak.
All he does is love
me back
Maybe because I exist
And that is enough

Then I finally have to forgive
Myself
I don't know When
or How
but I do know
that I must
Or else I will stand there
against the wall
Nailed to it, tattered and torn
and my defence is
too simple
too petty
too little?
I did my best.
IT WASN'T ENOUGH.

But when I do forgive myself.
when I can
On that day
but not before.
When I can.
If.
I Will Give Myself Absolution.

I have to forgive myself. It will be hard to live otherwise. My friend said to me:

- You couldn't have done more. You had no other choice in that situation.

Yes. It's taken me a long time.

But I do forgive myself.

CHAPTER 18

My fears right now

Sometimes the future really scares me. Resources are reduced. *Resource* is another word for *Money* and *Personnel*. But it's the money that is behind all the cutbacks. When I read in the paper that old people spend the night in hospital corridors, I get afraid. And when I hear them talking about once again centralizing different sectors, I get scared.

Our local authority has, over a number of years, attained good insight into and knowledge of intellectual disability, autism and care of people with special needs. We have people with comprehensive knowledge and understanding of different needs and differences.

But things happen. Time goes on. New politicians arrive on the scene. New managers. And others. Maybe people without any experience of care for people with disabilities. I'm sure their knowledge is great in other areas. You can't know everything.

But these changes make it increasingly important that politicians and officials listen to those of us who have experience. Especially when the Most Important Factor – MONEY – starts to rule, more and more.

Is it true that Sweden can't afford today's level of care for people with intellectual disabilities, autism and other disabilities? That's what I've been told. From several sources.

- We have to lower our standards, they say. Then they close down sheltered accommodation and put the residents into bigger, centralized units with a manager higher up in the hierarchy.

I don't think they save much money on this. Okay, I haven't done the sums but I'm sure that playing with people's lives turns out very expensive in the long run.

Don't enlarge the care units. Let the knowledge stay where it belongs, in the organization, at a local level. Because it means so much to a small minority in society, people with intellectual disabilities and their families.

You might say: there are so many different areas that need funding.

- Yes. I know. You have the young athletes. And roads. And the parks. And other disabled people. And old people. And the unemployed. And those who want to go swimming. And tourists. And still…

Remember Fred.

And Fred's family.

And all the others in the same situation.

Don't kill Life.

I'm sure the wallet will grow thicker during the two or three years that the current administration is in office. But please, do something for the long term instead.

The future is scaring me now. All the talk is of reorganization and lack of funds. What will happen if Fred can't keep the staff and the apartment he has today? What will happen if he has to move back home?

We exist. We may be different but we EXIST! WE EXIST.

Politicians! Why do you scare us so?

And don't tell me you didn't mean it *that* way. Or that you didn't mean Us.

Because, to us it is Serious.

I'm Serious. I'm Dead Serious.

I wish that Peace would settle
and bring some Rest
A choir of angels
on a cirrus cloud
and Rest just for a while

I wish that someone would call me
and say Relax, you will have some Rest
a choir of angels
of officials
Who build a bridge of Trust

I wish that money wasn't everything
and Budget and some Stressed officials
– A computer –
Did you say his name is Fred?
Let's wait and see, shall we?

I wish for Staff
who know why they go
into work
to see Someone
They might be all that Someone has

I wish to be just listened to
even though I'm just a mother
and not a
Politician
Not a great, big Manager

I wish Peace would settle
and bring some Rest
a choir of angels
on a cirrus cloud
And Rest just for a while

CHAPTER 19

Moving on

My beloved son.

You phoned me a couple of minutes ago. No one knew but me. For the first time you managed to push the short number to call us. To call your family. Your mummy and daddy and sister. I talked a little and heard your breath in the receiver. Then I heard you put the receiver down on the chest, I heard that. I also hung up and called the staff on their phone. I told them that you had called and needed help to hang up. Karin answered the phone and she was just as fascinated and happy as me. I am waiting for you to call again. I am sure it will happen soon.

Me, I am sitting at home in front of my computer. I have written a book about you and me. I hope you think it's good. Or that you would have found it good, had you been able to understand.

But when it's in print I will give you a copy. You can keep it on your bookshelf. After all, it's your book. You made it happen. You made me. You have given me so many new thoughts. And you have given me such Power as I never had before. I'm a bit nervous about what people will say when they read our book. Some may be upset. But I still have the courage to do it, because I think it's important. I do it for you. And for me. And for your father and sister. And for everyone whose situation is the same as yours. And for everyone whose situation is the same as ours.

I will call you soon unless you call me first. I know you want to talk about the holiday you are going on. On Sunday. You want us to talk about it all the time so you really know. When calling I will tell the whole story about what it will be like. That you and Anders and Karin will go to a cabin that you've rented, by a lake. That you will pack your clothes in a bag and put it in the car. Then you will go by car for hours. Maybe you will take a coffee break. Then you will get to your destination. You will carry your bag into the house and decide what bed you want to sleep in. Then maybe you'll have something to eat and go down to the lake and dip your toes in. You have the cabin for a whole week and Karin has told me that you decide how long you want to stay for. If you want to go home on Thursday then that is what you will do. But if you want to stay until Sunday, you will do that. You are so good at showing what you want. If you prefer going home you will show it by becoming unhappy and agitated. But if you are strong and happy and like it there I'm sure you will want to stay the whole week. Is that right? I think it is.

Then, just before we hang up I will say good night, because it's late in the evening. Karin will help you to shower then you will go to bed and draw up the duvet. And Mummy's throat will tighten with tears because I would have liked to tuck you in every night. And stroke your unruly hair out of your eyes. Instead I will tell you on the phone that when you have gone to bed, imagine Mummy coming to give you a big hug. For your mummy has so many hugs to give you. A whole armful. And I will soon be with you.

Goodnight Fred. I love you. And tomorrow is another day.