Adult life with SMA 2

Three people behind a diagnosis

Text: Jørgen Jeppesen
Translation: Annette Mahoney

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"I almost only have good things to say" was how Marinus Brock ended our conversation when I called and asked him if he would tell the story about his long life as the father to a son with muscular atrophy. So here we are, seated in his living room, flipping through eight decades of photo albums beginning at a small farm near Allingåbro in 1929 and ending in the village of Aastrup today. He stops when he sees a photo of Dan lying on a table looking just as delighted as the naked baby who is wriggling happily on Dan’s stomach. It is his grandchild Bianca, Dan’s niece.

"When Dan comes to visit, we put a mattress on the table for him to lie on," Marinus explains brushing his palm across the oak-wood table. "It’s the best place for him to sleep and the easiest way too, both for his personal assistants and for himself. And “it’s not like I’m going to fall down”, is what he says."

Marinus is a skinny, sinewy man in a blue and white plaid flannel shirt. He and his golden retriever Bessy came out to greet me after I had parked my car in front of a lush greenhouse behind the house. The only thing that immediately gave away the old age of this light-footed 79-year-old was his hearing aid. And apparently it is working pretty well since he does not ask me to repeat anything I say during our four hour long conversation.

What did you mean when you told me on the phone that you almost only had good things to say?

Marinus gets up and fetches a packet of cigarettes from the coffee table – the long Prince 100 kind – and takes a long draw with a pleased look on his face before he begins.

"You see, Dan has always been disabled, and when he was two we got his final diagnosis. We were also
told that we shouldn’t expect him to live to be more than 18 years old. That’s how it was, and of course it was a terrible thing to be told. But first of all it wasn’t true – he turned 47 last Friday – and secondly, we’ve had an amazing time with him.”

Amazing is a much used word, but it sounds new coming from Marinus.

“When Dan is home we usually end up talking about life over a glass of whisky, in the wee hours, after a great meal. You know, life as it turned out to be, the things we have seen and done together and the problems we’ve had too.

We always plan on going to bed early, but suddenly it’s three o’clock at night, sometimes even five. And we’ve done that many, many times when he comes home. Time simply flies, and we always have so much to talk about. I don’t think I’ve ever felt like we were running out of things to say.

If we have a problem, and I guess most families do at some point, you can always talk to Dan about it. He’s good at fixing things. I don’t think there’s anything he can’t fix. I certainly haven’t found any, you know, figuratively speaking.”

It is May 2008. Spring is for sale everywhere along the winding roads of southern Funen in the shape of new potatoes and green asparagus. But this story already took its beginning in the darkness of December, in a cabin at a water sports center. Dan and I met there for the first of five long interviews about his life. The neighboring folk high-school, Egmont Højskolen, which Dan attended back in 1978 immediately triggered a couple of stories. The one about the principal who ran off with a kitchen maid. And the one about the philosophy teacher (and former military psychologist) who, for some inexplicable reason, borrowed a brand new watch from one of the students, threw it onto the floor and stepped on it until it broke – only to buy a new one for its owner the next day. The same teacher also had a habit of locking up the students in the classroom, telling them that they would not get out until they had solved an (insoluble) philosophical problem.

But it was the joy Dawn was bringing into his life which was most prominent back then in December. We took a walk along the water and saw the ferry to Samsø sail out of the harbor with a shining Christmas tree in the rigging while Dan’s personal assistant Anders was preparing fried plaice with Brussels sprouts and melted butter. After dinner Dan told me about his falling in love: How he and Dawn had accidentally met in Second Life back in May, and how they talked now every day on Skype. She was supposed to visit him here in January, but a much desired job as a library assistant had gotten in the way. Dan, for his part, would not be able to take the trip to Toronto in January since it’s much too cold in the winter when you have spinal muscular atrophy. Maybe he could travel next summer.

“I’ve never had a real girlfriend before. Now it’s suddenly happened and I hadn’t planned any of it,” he said.
I don’t wish for a cure

Who are you, Dan?

“Yeah, who am I? That’s a really hard question you’re asking me there. Who am I? I’m a man who would like to embrace as many people as possible. And who’s able to do so most of the way. I often invite Jehovah’s witnesses in, simply because I don’t understand them. I don’t understand how someone is able to believe so deeply.

I’m extremely patient and take things as they come. Some people may characterize me as a person who puts up with too much. But I don’t think so myself. I’m good at looking at things from different perspectives, but I’m not good at saying no.”

We met again at the end of January at Dan’s place. He explained what muscular atrophy means to him.

“I can’t separate the fact that I have muscular atrophy from the other side of me. I can’t say that this side of me is like this because I have muscular atrophy and that side of me is like that because I have studied Chinese. I can’t even separate it physically.

Of course I can say that I would have been able to do this and that if I hadn’t had muscular atrophy, but it’s all theory, isn’t it, since I do have muscular atrophy. So I’m not trying to envision how things would have been different if I hadn’t had muscular atrophy.

It’s not the muscular atrophy as such that has made me the person I am. I can give you the medical explanation, of course, but in my mind I don’t think about muscular atrophy very often. If there’s something I’m not able to do, the first thought that springs to my mind is not that it’s because of my muscular atrophy. It just something I can’t do.

And I can’t imagine anything I would need in order for my life to be more perfect. Let’s say that I entered this machine and came out tomorrow walking and as physically capable as everybody else. It would be extremely difficult for me to get used to. Suddenly there would be loads of things I had to do, and I have always been used to asking people for help. Not to mention that my pension would be taken from me just like that. So, looking at the pros and cons, I don’t wish for a cure.”

Have you ever dreamt that you were able to walk?

“Yes. In many of my dreams I’m capable of doing much more than I really can. But often, when I move from point A to point B in my dream, I can’t remember how I actually got to point B. Often its neither by walking nor by chair, but in some strange way, I have just arrived at point B.”

And does that surprise you?

“No, it doesn’t really surprise me.”

What’s it like to dream that you’re walking, when you have never tried to walk?
“How can I explain that? In fact, I don’t think I can. I haven’t thought of it as something strange.”

But you know that you are walking in your dream?

“Yes.”

How do you know?

“Sometimes in my dream, I can see, that I’m moving my legs. And I have a feeling of standing and walking, whatever that feeling is. In reality, I don’t have it, but in my dream there’s no doubt that I’m walking. It’s not like I dream about walking per se, it’s just a part of the dream that I move. Just like I have dreams where I fly or float. It’s not like I have tried that either.”

“I think it’s a dilemma when I visit a school class and say, “Listen, I would really like you to see me like you see everybody else.” Other people who don’t have muscular atrophy don’t go into a class and tell them to see them like they see everybody else. That way, I’m in a dilemma. I make myself special and I do so because of my disability.”

So you’re not like everybody else?

“No, I’m not.”

But you’re also like everybody else?

“Yes, I’m also like everybody else.

When I first started school, I joined the physical education classes. I didn’t participate in the exercises as such, but I was part of the group, in the locker room. To me, it was like participating. Sometimes I counted goals or timed people when they crossed the finish line. At some point, I began to find it boring and asked to be excused from that part.

From I was 7-8 years old, I was a boy scout in a troop with both disabled and non-disabled children, and there I met other kids with a disability. We knew very well that we were a special troop. Sure, when there were races and competitions there were things we couldn’t do the same way as the others but we still had a feeling of being a part of it all. My brothers were scouts too, but in another organization. I might as well have joined them, but there I would have been the only person with a disability.

The first time I seriously thought about myself as being disabled or different was when I started at the Egmont folk high-school. I was 17 years old and met some other people with disabilities. I didn’t think I belonged in that group but at the same time it was a relief to talk to other people about things I had never shared with anyone. Like the future.

But hey, I must have gotten the point already by then – that I was there because I was a wheelchair user. That’s just not the way I remember it. I don’t think I understood the concept of being disabled and what it entailed.”
Are you still in contact with Dawn?

“Yes I am. And we’re still fine. She has started in her new job at a library and she’s very happy about it. But because of that, we’re not really sure when we can meet. As it is now, I think it’s going to be me who travels first. I have been doing some research on public transportation in Toronto since it’s expensive to rent a car. But I think it’ll be possible to get around.”

At Christmas, Dan told his father and brothers about his connection with Dawn. His Christmas gift to Dawn was a work of art by an artist from Toronto. He knew she liked the painting so he got in touch with the artist and asked him to deliver the gift. He also sent her a book with Hans Christian Andersen’s fairytales and a CD with the Danish band Savage Rose.

What did you get from her?

“A bunch of small things. Knick-knacks I would almost say. And a CD too. And some Christmas ornaments because I had told her that I don’t make a big deal out of Christmas.”

The screen saver on Dan’s computer is a composition of 12 portraits of Dawn with different hairstyles and colors. He spends a couple of hours every day in front of it talking to his girlfriend. A few months after they had met in Second Life, it became urgent for him to explain what he can and cannot do.

“We’ve met in some kind of fantasy world. We haven’t been us for real, we haven’t touched each other. I had told her that I was a wheelchair user but at some point it became important to make sure she knew that when I tell her that I’m putting my arm around her and kissing her, that’s not something I can really do. I wanted to make sure she wasn’t getting any wrong ideas about how much I was capable of. I wanted her to know how far-reaching my muscular atrophy really is and how it would affect our relationship in comparison with a normal relationship.

Also, if we are to meet each other, and we will, I don’t want the first thing she says to be that she can’t imagine how this is going to work. Or that she would like to think about it. I didn’t see any point in having those thoughts come up at our first meeting. And the longer we date, the harder it will most likely be for us to realize that it’s not going to be us, if that is the case. It may not be important at all, but I didn’t want her to come to Denmark or me to come to Canada, and then it would be a surprise to her. Of course I think it’s hard for her to imagine how little I’m actually able to do. Or rather, imagine what it would mean to us, that I’m not going to be the physically active part. I can be that in our fantasies when we talk.”

What did you tell her?

“I told her that I can only raise my hand a little bit. That I can only sit in my wheelchair. I can’t stretch my legs. I eat very slowly. That my home is laid out in a way that makes it possible for me to do a lot of things in my wheelchair, but when I’m other places I won’t be able to do much because things are not at the right
height."

Were you nervous?

"Yes, I was. I was anxious and nervous about what she would say. She said she’d seen pictures of me and that it was mostly what she’d expected. And that she was glad I had told her. I guess that was more or less what I had expected her to say – and hoped she would say of course."

What does Dawn look like?

"She’s a big lady, not very tall. At the moment her hair is dark and straight. She has a lovely smile and a great sense of humor, very ironic and dark, very much in line with my own. Her voice is not at all what you would expect. It’s mostly like a little girl’s voice, except when she yells at her kids."

Dawn is 46 years old, divorced and has three sons who are 12, 15 and 18 years old. She is white. Doesn’t like fish and liver, but enjoys a good steak.

"It’s not a feeling I’ve ever had before. It’s strange, amazing, weird, wonderful. It’s something to look forward to and want to. If I go out, I tell her that I’m not at home. I’ve always just done what I wanted to, but now I want to involve her in everything I’m doing."

What do you think she likes about you?

"She likes that I’m open. She feels she can say things to me and I will listen. And she likes my sense of humor."

What do you think about the fact that she has three children?

"What the children think about her spending so much time on me? They know about my existence but I’m not quite sure what she has told them about me. She describes me as her very good friend from Denmark but I don’t think she mentions the word boyfriend to them. They also know that I’m a wheelchair user."

She divorced her husband six months ago. How do you feel about that?

"That there can be a number of reasons. But that those thoughts won’t do me any good."

You call her your girlfriend?

"Yes."

Is that also what you call her when you tell people about her?

"Yes."

And you don’t keep the relationship secret to your friends?

"No. Not anymore. I mean, my family didn’t learn about it until this Christmas. In fact, they were the last to know. I’d been wanting to tell my dad about it for some time, but I also knew it would be difficult for him to understand that it’s possible to have a girlfriend who lives in Canada and who you’ve never met for real. So I wanted to be face to face with him when I told him. It was really great to get it off my chest."
Dawn had also included a Christmas present to Dan’s niece Bianca.

“I don’t think my Dad really understood it until I spent some time with him after Christmas and talked to Dawn on the phone and she told me to say hi to him.”

Is there anything she doesn’t know about you?

“You might say that there are things I haven’t told her. But then again, there are so many episodes and stories from my life that she doesn’t know about yet. I’d say that, on the whole, there isn’t anything she doesn’t know.”

Do you feel like you know each other?

“I’d say she’s the one I know best. Maybe except for a couple of friends that I know just as well.”

He only cried twice

This morning, Marinus has been mowing lawns. He has 18 clients – beach house owners in the southern part of Funen, who want their property mowed and ready when they rush in to relax for the weekend. Once a week he drives up to Rynkeby to help his middle son, Kim, in his nursery. He was there yesterday. When he was 15 years old, Marinus embarked on his first business adventure: mushroom farming in an anti-aircraft bunker. He was a gardener apprentice in Randers when he heard about the method from a colleague. He rented a bunker, shoveled in a load of horse dung and installed a wood-burning stove. Unfortunately the mushrooms would only grow right around the stove.

“Then I happened to run into Mona, the mother of my boys, and we decided to get married. I applied for a job as a security guard and had hoped to be hired in Randers, but they told me that if I wanted to work for them, it had to be in Copenhagen! So we ended up there.”

In 1954, right after the wedding, he and Mona moved to Copenhagen. They lived in a small summer cottage in one of Copenhagen's working class areas, Sydhavnen. He worked as a night watchman, she as a sandwich maker. In their luggage they carried a debt of 13,000 kroner from a failed investment in flowers. In 1965, after 11 years in Copenhagen and the birth of three sons, the family settled on Funen, and after several failed attempts flower gardener Marinus Brock finally succeeded with his great dream: To have his own nursery. Right there in Rynkeby near the town of Kerteminde was where Dan and his big brothers Steen and Kim grew up.

Would you have raised Dan any differently if you could do it all over again?

“We almost forced him to walk so and so many meters with braces on. I guess it was both good and bad. He also had to lie with sandbags on his butt in order to straighten his hips. It must have been close to torture for him. And for a long time, he slept with braces on his legs at night to straighten his knees. It may have done him some good, but I’m not really sure if he would have been more or less mobile now. It’s hard
to say.”

Marinus learned some methods from a reflexologist but stopped giving Dan treatments after a year or so. Because, “it was also like torture”.

He has seen Dan cry twice. One time when he hit his chin hard on the floor, and the second time on July 10, 1967, when he and Mona took their son to the first of a series of annual training camps at the physiotherapeutic hospital in Hornbæk.

Away from the family

“I clearly remember the day my parents dropped me off in Hornbæk. I cried and cried. I felt the world had come to an end. I didn’t understand why I had to be in a hospital. I didn’t see myself as someone with a disease.”

Almost every day there was a letter from home. When we met for the third interview, Dan had gotten them out of their hiding place somewhat yellowed and with bent corners. Some on ruled paper, some on checked. The envelopes had been thrown away.

Dear Dan,

Now it won’t be long before you come home. When you receive our letter it’s Friday, the next day is Saturday, and then uncle Alfred and Marianne will pick you up. Remember to bring back your track suit and your slippers. Today mom has been busy cleaning the house and making everything ready for your return. Because when you come home, we don’t want to do anything - just sit and chat with you. I hope you’re doing well sweetheart. Mom didn’t have anymore cards, so you’ll have to make do with a letter today. Take care until we see each other again on Saturday.

Lots of love from your dad and mom, and many hugs too

“It must have been extremely hard on my parents, especially my mom.”

How do you think it was hard for them?

“I’ve talked to my dad about it later, and he told me they found it hard to send such a small child away from the family for such long periods of time. Three to four months at a time, I think, although it felt more like years.

But I also think they felt guilty about it. They did it because they thought it would help me physically. Which it didn’t.”

Was it harder on them than it was on you?

“I’d say that at the time, I thought it was hardest on me. The first couple of times I was there anyway.
Later, when I started school up there, it got a little easier. Maybe I looked like I was happy. But the things I remember from there are things that didn't make me happy.

For instance, I don't remember any of my roommates. But I remember the matron, who we all thought was horrible. Who would tell you that you didn’t have to pee, even though you had called her because you had to pee. Then you just had to wait.

She was different when the parents were there. My mom and dad actually thought she was very good. That way I felt like I didn’t have anyone to turn to. When even my parents couldn’t see that she was a bitch, who could I go to?"

"I think I must have felt like I had to do well; that the physical exercise was important. I had to do well to make my parents happy. But looking back, I can clearly see now that it was a waste of time. And I think it was a mistake to take a child away from his friends at home."

What exactly did you do up there?

"I remember I had to stretch out a couple of times every day at the physical therapist. Later I had surgery so that I could stretch my legs enough to have braces and with the help of crotches and a person next to me I was able to stagger around a little. I think it was silly. Maybe because I was disappointed. I guess I had expected that I would be able to walk."

So do you think that all the exercise and the surgery was just a lot of suffering in vain?

"Yes, I do. And then you have to remember that when I came home, my parents did the same exercises with me several times a day. The nights were worse though; I was wearing those night braces, you know. And part of the night I had to lie flat on my stomach with sandbags on my ass to straighten me out. It was terrible."

Who invented all this?

"I don’t know. You still do it today, to some extent anyway. We still put people on tilting boards. But it seems like we have found a way to fit it into their everyday lives."

You seem to have a strong opinion about that?

"Maybe we keep people active a little longer, maybe their backs are a little less crooked, maybe it’s good to exercise our lungs and all that, but it also takes some pretty valuable time away from playing with your friends.

I can only use myself as an example since I don’t know how it is for other people, but I often think that they must be disappointed – 'because you don’t get any better. It’s not like you can say that if you practice hard, you’ll be able to walk an extra four steps tomorrow. With muscular atrophy it’ll always be one step back at some point; even if you’re able to maintain a few functions for a while.

When I think about all the sandbags I had on my butt and ankles and how much energy I spent every
single night to try to shake them off and then just pretend that it had just happened when my mom or dad came in to turn me! The way I remember it, I almost did that every night.”

Has that made you allergic to doctors?

“No, I don’t really think it has. What I think it’s done to me is that it has made me believe that sometimes I know just as much as the doctors – sometimes I even think I know more. Or that I have the courage to do what I feel is right instead of listening to authority figures.”

Dear all

I hope you’re doing well, because I am. Except that I have to lie down all the time. But I just tell myself: I guess it helps me. I’m here with some kids who are sad they have to be here. How are you sick people at home? Are the animals doing fine? Is Pussi still sleeping in your bed at night? Now I can’t think of anymore to write, so I’ll end this letter.

Love Dan René Brock.

”Pussi was my cat. We’ve always had a lot of animals: guinea pigs, parakeets, always a dog, chicken, ducks, peacocks, and a tame rook every once in a while.

My dad and mom have always thought I had such an amazingly a positive approach to life. But maybe I had because they didn’t fuzz over my muscular atrophy. Instead they tried to solve some practical problems like how I would be able to see and do the same things as my friends and my brothers. I don’t remember one single talk – except for one – about the fact that I had muscular atrophy.

That one time was when they had met Evald Krog (chairman of Muskelsvindfonden, the Danish Association for Neuromuscular Diseases, auth.). They had attended a meeting with him and Jette Møller (an occupational therapist, co-founder of Muskelsvindfonden, and then wife of Evald Krog, auth.), and when they came home they were so enthusiastic. They had put a lot of thought into my future. What would happen to me when they were not around anymore? What about education, girlfriends, etc.? But after that meeting it was like it wasn’t all that important anymore. That night when they came home, they were both very happy. And relieved too, I think.

They didn’t make any special rules for me. We all had the same chores and they gave us pocket money. We all had to help out at home and I had a home-made three-wheel vehicle that my dad had helped design. I used it to bring strawberries from the field up to the road where they were sold. And I mowed the lawn with it too.”

”Here’s a letter from my teacher. A pitiable guy. One of the people who couldn’t really handle the transition from being allowed to hit his students to not being allowed anymore. A somewhat strange
character, we thought. He had a garage filled with things he’d collected and which he showed to us every once in a while. For instance, he had a cigar butt Winston Churchill had dropped when he visited Kerteminde, which he had picked up. The strangest things. It could also be things that had washed ashore. Or post cards from abroad."

Did he ever hit you?

"Yes, but only one single time. But I could get away with much more than the others."

And did you take advantage of that?

"I think so. Sometimes I was the one who started something, but I never got the blame. That was one area where I could take the lead."


dear Dan,

I just thought I wanted to send you a brief letter here from Rynkeby. I hope the address is right, I have found it in the directory. On Monday we have the day off in respect of the King's funeral. There will be a lot to see on TV. I suppose you will be watching the event where you are? Yesterday Mr. Brinch was out skating. Suddenly he fell through the ice and got soaking wet. So he had to hurry home. There he took a warm shower – he was able to touch the bottom – and a cognac. It all helped him get warm. It is a bit hard to start the car in the mornings in this cold weather. But with a little patience, I have succeeded so far. I suppose it is nice and quiet in Hornbæk at this time of year. In the summer it is swarmed by tourists. The drive from Hornbæk through Ellsinore and down the coast highway is maybe the most beautiful in Denmark. Your classmates from 4th Y send their love. We work hard in math, the best we can. I do, however, wish that everybody were as good as you at remembering the tables, Dan. For the first time in the school’s history, one of the students was sent expelled for eight days because of bad behavior. It had to be done. Now I hope you will enjoy your time in Hornbæk.

I send you my warmest regards,

Arthur Sørensen

"I actually did like him. When I said before, that I thought he was a pitiable guy, I don’t think it was how I saw him then. I wasn’t old enough to think like that. I often went down to see his collection in the garage. But he wasn’t popular among most of the students. Because he hit. And also because he was too kind. His classes were never quiet, he couldn’t handle it. Once he might have had a lot of authority, but it must have crumbled away over time.”
It hasn't been a cross

On the shelves behind Marinus, surrounded by porcelain figurines, there is a black and white photo of a dark-haired woman. The hair style points to the 1970s. She is smiling at the photographer, but no more than she has to. It is Mona.

“At that time, you were told that it was the woman who carried the disease. It was how we understood it then. She sort of felt it was her.”

Did she think it was her fault that Dan had muscular atrophy?

“Yes, I think that was how she felt.”

Mona died in 1994 of a stroke the night after she had undergone surgery for a bulging disc, 57 years old. How did it affect your relationship with Mona that Dan was born. It is not exactly what you expect, to have a child with muscular atrophy?

“No, and especially not after having two who were perfectly well physically. It’s no fun. But I think it quickly became something we just lived with in. Like when his mother had him on her arm while she was stirring the pans.

And it hasn’t been a cross to bear, like some people describe it. A lot of people don’t understand when I say that. But it certainly hasn’t been a cross.”

Do you think his life has been inferior to that of his brothers?

“No. I almost think I can say that for a fact. I think it’s he – when I seriously think about it – who has had the best quality of life.”

What did Dan inherit from his mother?

“Of her psyche, I’m happy to say nothing, because she was very edgy. We had a lot of good years for sure. She was a heck of a workaholic, more than I. But we also had some years that weren’t so good. When she had one of her bad days, and I could always feel that tonight we will have a fight, then Dan stayed up to watch a movie on TV. Just to postpone the fight. That was one of his things, already then. That’s why I say that he has an amazing gift for avoiding trouble.

As a mother, Mona was just great with Dan. I think she was more hung up with him than I was in our everyday lives. That may have a lot to do with her unstable nerves.”

An amazing woman

Do you remember your mother when you read her old letters?

“Yes I do, I remember her a lot.”

Do you think back on her with a feeling of loss, of happiness or something else?

“I definitely have happy memories of her. And of course I miss her too.”
Did she mean a lot to you?

“Yes she did. Both my dad and my mom. But I spent more time with my mom. My dad worked a lot, my mother was at home.”

What was your mother like?

“She was an amazing woman in a lot of ways. She was a loving person and she listened to me when I was sad. One time – I guess I was around 16 – I was examined at the hospital in Odense and they decided that I had to sit with some kind of shield for four to five hours every day. I was extremely unhappy when we got home. She was the one who comforted me and tried to figure out what I was so unhappy about. I simply couldn’t wear that shield. I only think I wore it one time, two at the most. Then she let me use it as a target instead. For darts. And then it became an amazing shield. And it was my mom who said, “Well, why don’t you use it as a target then. She had a great sense of humor which could turn a lot of things around.”

“What I also remember is the other side. She had a problem with doctors, was really, really afraid of them. She had back troubles and had seen a lot of doctors. And if she had to be in the hospital, she went completely nuts. Yelled and screamed that she would kill herself. Walk out on us, leave home. I remember that part as well.”

Did she have a psychiatric diagnosis?

“No, she didn’t. But there was obviously something wrong. It was so intense, that every time she walked through the hospital doors, she fainted.”

But she was OK going to the hospital with you?

“Yes, she was OK with that. As long as it didn’t concern her.”

Did you talk to her about it?

“No, because it was almost impossible. When I got older, I tried, but it wasn’t possible. I wanted her to get some help. As she got older, her back got worse and a lot of times it was really bad. She's probably had the same problems when I was a child, but I don't remember that at all. Not until I was an adult and still lived at home at 25, am I able to recall it.”

Were you shocked when she died?

“Yes I was. It was completely unexpected. But I also remember thinking – and I have thought about it later as well – that the way she was feeling, what with her pains and anxieties, it was somehow fine that she didn’t had to go through anymore. We talked a lot about having her committed to a mental institution, ‘cause when she really hit the bottom, she couldn’t make things work at all.”

How did you feel about those periods of her life? You still depended on her, didn’t you?

“The last year I lived at home, it was my dad who helped me get up in the mornings and did all the lifting. My mom always cooked and things like that, and she was able to maintain that function during those
periods, although there were days when she just couldn’t.

But it was more the uneasiness at home that got to me. We had to tiptoe around the house, smooth things out to prevent her having a fit. Abstain from doing this or that."

“It was my dad’s birthday recently and I gave him an old video that I had someone transfer to a DVD. It was from when my mom and dad and my oldest brother Sten visited me in the Philippines. It was Christmas 1992, and the last piece of footage of my mom. She was very happy, and it was good to watch it again. In fact, I haven’t been wanting to watch it since she died. I was afraid how I would react. It was such an intense experience having them come out there to visit me. They had never traveled before and we had never, ever been able to make them leave the nursery. We tried many times, and finally my brother succeeded in making them go. I didn’t know anything about it. Suddenly they were there.”

Dan studied Chinese language and culture during the years 1988-1995 including a year of studies at the Fudan University in Shanghai. During that period, he made several travels in China and Southeast Asia and at some point he stayed a couple of months at a friend’s who worked in the Philippines.

Is it one of the last memories you have of being with your mother?

“Yes and it’s one of the really good ones. I also have memories from the Christmas when she died in January. That Christmas, she knew she was going to have surgery, and she was extremely tense. She did her best to make it a good Christmas, but the atmosphere was depressing.”

Dan has decided to have his bachelor pad painted and wallpapered. A local painter in Trige has been chosen for the project among three bidders. The floors also need an overhaul, the varnish is worn off where Dan drives his chair. But the sanding and varnish will have to wait since there's not enough money in the maintenance account.

If a woman was living here, the rooms and furniture would be different: The antique oakwood shelf system with the leaded panes would be sent into exile, things would be laid out according to their decorative properties and not only with regard to practicality.

Dan plans on ordering a ticket to Toronto when he receives his pension on March 1.

“I got a gift from her for Valentine’s Day. Some candy and chocolate, some postcards and a CD with the soundtrack from a new movie. That’s a tradition I had never thought I would be involved in. I sent her flowers.”

What kind of flowers did you send her?

“Roses and lilies. I chose pink roses, I don’t remember the lilies. They didn’t come in the color I had chosen.”

He wants to go at the end of June and spend three to four weeks there. But Dawn doesn’t know whether she can take that much vacation. She’s temping for a woman who’s on maternity leave, but the position
may become permanent and she does not want to jeopardize that opportunity. Dan has told her that he will have to know soon because he has to plan his personal assistants' vacation in not too long.

**Seen and done the most**

Bessy gets up on her ten-year-old legs, jogs around the coffee table and positions herself at a new observation spot. The Brocks have always had a dog, and they appear almost as frequently in the photo albums as the people.

By request of his sons, Marius has begun to write down his memoirs. Playing with thoughts is the working title on the some 60 pages he has written so far.

“I get very surprised when I look at it from above, down on a piece of paper. It’s like you suddenly see the big picture. Why this didn’t work out and why that went really well. There have been some disappointments but also a lot of exciting moments.”

In the mid-sixties, Marinus accepted an offer to manage his uncle’s stock of seeds at a farm in Funen. But he had not given up his dream of running his own business. Some years later, a property in Rynkeby was put up for sale.

“Mona was at a boy-scout camp with the three boys, and then I bought the property. Well, I couldn’t finalize the deal before she came home and signed the papers. But when we got out there and she saw it in the evening, she cried bravely all the way home. I do admit it was shabby looking. I remember there was a door to the mud-room with a rat hole in the corner, so I positioned myself there in front of the rat hole so that Mona wouldn’t see it.”

The property was situated in hilly terrain which Marius could see a lot of possibilities in. There was even an underground source that could be turned into an artificial lake and supply the future greenhouses with water.

“I tried to convince Mona by fantasizing about how we would sit in the evening sun on a terrace facing west watching all the flowers. She couldn’t imagine that at the time, but later we had that. And we stayed there for 32 years.”

At some point Marinus laid out a grass-covered road around the entire area “for Dan to ride on and for us to have something nice to look at.” Dan helped with the work on Jumbo, his home-made vehicle, constructed with a starter motor, a tractor seat and a steering wheel from a car among other things. It was slow but it could haul some heavy loads.

“We made the grass road piece by piece. Dan pulled the roller with Jumbo. I let him do that. Or when I say “let him” I actually mean “had to”. It was his job.”

“Way back when we first started out in Rynkeby, I remember I was often thinking about his puberty. It
was really the reason why we made that grassy road – I don’t know if I’ve ever told Dan, but it doesn’t matter if he knows it now – and then we planted some trees and hedges. I thought that it would be nice if there was someone he was hoping to run into there that they had that whole area to themselves.”

Marinus sold the nursery in 2001 and moved further south with Bessy and his girlfriend Sigrid. But they broke it off last year, Sigrid has moved out and Marinus has put the house up for sale. He is planning on moving back to Rynkeby into one of the new senior homes they have built close to his old nursery.
He tells about Dan’s many travels around the world: USA, Canada, China, Taiwan, Thailand, Zimbabwe, and about when Steen and Kim arranged a surprise trip for him and Mona to see Dan in the Philippines.

“If we are to talk about the things we’ve seen and done, I really think Dan’s the one who’s seen and done the most in his life - which is also what I tell people when they start talking about the ‘cross’.”

**Off duty**

Dan often gives speeches about what it is like to have a personal assistant. For his part, he has had some 35 to 40 since he moved away from home in 1986, almost half of them women.

We met again in April and talked about what it is like to depend on help and PAs.

Are you good at having personal assistants?

“One of the things I’m good at is that we solve the problems through a form of dialogue. That it’s something we have to work out together. When I get a new PA, I seldom go into details, because I think that everyday things can be carried out in a thousand different ways and still be done perfectly well. The washcloth doesn’t necessarily have to face this or that way. It also means that someone can start here and show me some new ways.”

Have you ever fired any personal assistants?

“I’ve only experienced having to fire a PA one single time. Then there were three times when we agreed that it was probably best to terminate the employment. The one I had to fire had only been employed for a very short time and I couldn’t point to any specific problem. I could just feel that I was irritated and that I was sad when she was at work. And I had to tell her that, and naturally she was very upset about it, especially since I couldn’t give her a good reason. And I could perfectly understand that. It is a kind of criticism of the person actually – of some of the qualities of that person.”

Do you know any bad employers?

“Yes I do. I know I wouldn’t work under those conditions. For instance the way you talk to your PA. When he or she is repeatedly told – even when there are other people present – that this or that isn’t good enough. I would never start such a discussion when there are other people there. I don’t think it’s a public issue. And you really put the PA in a dilemma, because if he wants to explain himself, he exceeds his job
description right there. You don’t really give the PA a chance to defend himself.

I’ve seen a tendency in several people that the less they are able to do themselves, the more controlling and finicky they are in what they demand. To some people, controlling everything becomes such an important factor in their lives that it almost becomes a job in itself.”

“But it’s also interesting to be so close to another person. When you need help with everything, the Personal Assistant will inevitably see things that maybe not even a girlfriend will see. Because you don’t have your girlfriend at your side in all situations. But your PA is there.”

What situations could that be?

“When you’re at a bar with your friends, getting wasted. When you’re in the middle of a family quarrel. At a funeral of someone who was very close to you. When you’re negotiating your salary at work. Your PA will experience every facet of this person. And this person is so dependent on the PA being there. And even though there’s a mutual respect, the balance is tipped in the PAs favor from the beginning.

It’s the disabled person who has the absolute greatest need, isn’t it. Of course the other person depends on his salary but there are other jobs – and of course there are other PAs as well - but if the PA walks out when you’re in the middle of your biggest life crises, you’re just screwed. You can’t tell the PA to go to hell because then you can’t go to bed. You can’t go to the bathroom. You can’t do anything. That’s why I say the balance is tipped. You’re in the middle of your biggest life crises but there are other things. And that’s why it’s a challenge to make it work.

It’s like almost all other bosses can go home when they’re off. I can never go home. I’m always at work. I never have vacation. And I certainly never get any bonuses. I’m never off work. When I need to be turned at night, I’m at work.”

Is that one of your most profound wishes: To be off duty every once in a while?

“Yes. Luckily I’m still able to do a lot of things. I often tell my PAs that it’s ok for them to come at noon. Then I have the mornings to myself. I sometimes like to drive around in the woods for three or four hours, alone.”

“When I was young and still lived at home and didn’t have any PAs, I often asked strangers to help me. I would even ask them to help me go pee. It was extremely important to me to be able to do that, because it gave me a kind of freedom. Now it has become more difficult to go to the bathroom and I’m also older and more cautious, so I don’t ask strangers for that particular favor anymore, but I’ve been able to do that and it has been important for me to be able to ask strangers for help all by myself.”

Are you saying that it’s important to have learned to ask for help?

“Yes, to me it’s important to have experienced to be forced to ask a complete stranger for help. It gives me the freedom today, that I can sit down with somebody I don’t know and ask them for help.”
What kind of freedom is that?

"The more I’m getting used to having my regular PAs – they know how to handle everything – the more insecure I feel about asking other people. What if they spill something on me? That would be embarrassing. I would get shy. It’s much easier to ask a person who knows everything, isn’t it? But that also means that I need that PA around me all the time. And that makes me feel stuck.

I think I see that in some of the young people with muscular atrophy. They have a PA almost from birth – well actually that’s not true – but in the very early school years they get a personal assistant and they’re almost unable to do anything unless he’s there."

Are you saying that they’re getting too much help?

"I don’t know. I know I could have used more help sometimes when I was young. I just think it’s important to be aware of the fact that they also need to have some time without the PA. Take the PA away from them every once in a while. I’m not saying they’re spoiled because they have a real need for help. But I don’t think you do people a favor if you make them dependent on professional help. Then you lose some opportunities."

The trip to Toronto has not been booked yet. Dawn still has not been able to find out whether it is possible for her to have Dan come visit in the summer.

A risk I’m willing to run

Deep Purple’s *Child In Time* is flowing out of the Bose speakers, one at each end of Dan’s living room. The sound is grand, more dark than light just like the leaves outside which have already turned a lush green here at the end of June. We are listening to Dan’s favorite music. He has just bought a ticket to his sixth concert with the band when they play in Odense in August. After that, we listen to other favorites with Creedence Clearwater Revival, ABBA and Gasolin.

Sometimes he and Dawn listen to music together, either by playing the same song on their respective computers almost synchronously or by Dan adding some background music to their conversation on Skype. Next week he is going to Sweden and Norway with the North Cape as his final destination. The trip to Toronto is not going to happen just now.

"I need to know whether the good things Dawn and I have together will still be there when we’re face to face. In my heart I believe it, but I still need some kind of confirmation. Is our relationship just a fantasy? It’s not, because it’s too real to be just that. But am I building castles in the air about this woman – my girlfriend – placing her on a pedestal and making her even more wonderful than she actually is? Of course, I don’t believe that, and one way to find out will be to look each other in the eyes, touch each other and sense each other. Will we still be excited about our relationship then?"
You might want to ask: Can’t I just enjoy what we have? Because when we talk, it is amazing. And when we don’t have anything to talk about, it’s nice just to be together. But in the long run, I don’t think I can stand not having met her at some point."

Do you fear that it will never be?

"Of course I fear that. But it's not like, at the back of my mind, I think it will never be. I’ve known from the very beginning – objectively and without the rose-colored glasses – that it will always be a relationship full of obstacles. There are so many questions. Can we live with the fact that we’re only able to see each other once a year or even less often?

There are so many good things in that relationship that I can’t say beforehand that I probably shouldn’t be in it. I have to try. Then I’ll have to live with the pain if it turns out we can’t make it work. It’s a risk I’m willing to run. Take the blow if I have to. I can’t say, “No, it’s stupid, it’s completely unrealistic.”

When I studied in China for a year, there were doctors who told me that it was stupid of me to go. Many of the things I’ve done have seemed unrealistic from the start, but I have always succeeded in doing them anyway.

She simply means so much to me, that at the moment, I just can’t tell myself that it won’t last. And definitely not because of more or less practical problems. I can’t do that.

Not many people understand that we can have such strong feelings for each other. And that we’re willing to date for over a year without having met each other at all. It's so different from almost anybody's idea of a relationship. Of course there aren't many who can say, “I understand, I've experienced the same thing.”

But just because I’m not going now it’s not like a lot of things have changed between Dawn and me. Nothing has happened really. Things aren’t any different between us."

So you’re still boyfriend and girlfriend?

"Most certainly. We are."
Dan with his brother Sten (left), his father Marinus and his brother Kim. (Private photo).
Today, Mette has let her hair hang loose. The brown locks flow softly over a white crochet shawl. She is about to go dancing. Her handbag is hanging on the back of her wheelchair - a Miu Miu made of yellowish leather.

Yesterday at the interview, she wore her hair in a ponytail but the shoes were the same. Black and shiny. She told me about her fascination of movies, ways of being alone and her new-found love of dance. “That’s something you have missed. To be able to use your means of transportation for something elegant”, she explained about wheelchair dancing.

“You” have missed. Mette likes to refer to herself as ‘you’.

“It’s one of those things you’re reluctant to revive. You don’t want to loose the mood and memory from that time”, she said about the reason why she seldom has had an urge to watch ET again – maybe the most important movie of her life.

Or, “You don’t need to sit and think about the fact that, in principle, you’re all alone in the world, a thought that sometimes strikes you. Then you know that you need to do something tomorrow, don’t you?”

Maybe the ‘you’ is just the remains of her original dialect. She is a newcomer for sure. When her voice becomes eager she reveals a singsong tone of voice that people born and raised in Copenhagen do not have. Mette Estruplund is from the northern part of Falster, an island south of Sealand, and she likes geographic precision. Every time she accidentally says “Falster” she corrects herself, “North Falster. She grew up with a four-year younger sister in the outskirts of Orehoved, a few kilometers west of where the Storstrøm Bridge hits land. Her parents still live there and, “there’s still a bed in my old room to sleep in when I’m at home”.

In 1996, 22 years old she moved into the corner apartment in Østerbro, one of Copenhagen’s nicer neighborhoods. She still lives there in a relatively new, yellow-brick, handicap accessible building complex.
From a social housing perspective it is a welcome step ahead, but architecturally it is an incomprehensibly hole in the block. Already in 1994, she enrolled in German studies at University of Copenhagen, and commuted all the way back and forth between Orehoved and classes several times a week – sometimes in vain when classes were cancelled on a short notice. Moving away from home was a “huge mouthful” when at the same time, she was learning how to run a 24 hour personal assistant scheme.

In 1999, she quit the German studies in favor of film and media science and is now only a master’s thesis away from graduating. She is hoping to turn it in by the end of 2008.

From German grammar to cinematic storytelling? A giant leap for Mette although both subjects are rooted in her childhood North Falster: with a feared but much admired German teacher and with the leading film rental place in the local area, the convenience store in Nørre Alslev.

The mountain climber

“German was my favorite subject. I had an amazing teacher. Super strict, the quintessential of a German teacher. Nobody liked her, but we learned so much.”

Did you like her?

“Yeah. But she was a character. We all had a deep respect for her.”

What did you like about her?

“She was in control of things. You got your act together. You didn’t want her to get on your case. She was also funny though. She could talk for hours about her accomplishments around the world.”

Birte Fabricius – “we just called her Birte” – was also a mountaineer and used her vacations to travel all over the world. At home in class, when the verbs had been conjugated and the occasion was right, she would sometimes entertain her students with the most amazing accounts of her journeys.

Originally, Mette belonged to the school district of Nørre Vedby close to Orehoved. But it was a giant building full of stairs, “so that was out of the question.” Instead, she had to attend the public school in Nørre Alslev while her best friend went to Nørre Vedby, but, “then we would compete on who had the best books.”

In high school the procedure was repeated. Mette waved goodbye to her classmates who were all going to high school in nearby Nykøbing F while she travelled to the stairless high school in Vordingborg. This time, however, accompanied by her best friend.

“It was like some external things always had to decide, but it always ended up being real good anyway.”

Did you like going to school?

“Yes! I liked doing my homework. Writing Danish essays. And spelling exercises. And then of course German. And home economics.”
You have mentioned almost all subjects – except for math.

“Yeah, I was completely in the dark. I didn’t like it, was almost a little scared of it. I couldn’t make heads and tails of it.”

**Queen of the class**

The constant competition on who had the neatest handwriting is what Mette remembers most vividly about the other girls in her class. Better than she remembers their names.

What was your handwriting like?

“I remember thinking it was neat. We had a notebook where we had to write a whole page of for instance ‘b’s or a certain word. You were told that it had to be exactly like it was in that book. Then when you get older they give you more leeway and you’re able to find your own style.”

What is your style like?

“I’d say it’s fairly normal, girlish. I prefer it to be straight, definitely not reclined. If it’s slanted at all then it should be inclined like cursive.”

Girlish. The word can also be used to describe Mette’s apartment. Already in the entrance room the style is set: a full length mirror framed in gold, lit up by a soft yellow light from a miniature fringed lampshade instead of a sharp incandescent spot light.

And then, it’s not completely girlish. In the living room you cannot help noticing the comfortably looking olive green armchair with an undisguised cigarette mark in the middle of the seat. Acquired for a couple of hundred kroner at a flee market in Nykøbing F. The heavy dining table with four matching chairs signals durable functionality. A bargain made at a garage sale in Vordingborg. Otherwise everything is light and airy.

“Sometimes I think it looks sort of bohemian. You want the perfect style but it’s hard to go through with. I also want to have things that don’t match all the other stuff. I couldn’t stand living in a completely cream-colored home.”

Mette has only experienced being teased once.

“That’s probably why I remember it. The girls had argued about something and the class was at war. “If you could walk, I would beat you up”, one of the other girls said. I still remember her name and where she lived. I remember everything. That really upset me.”

The special needs assistant that followed Mette during her schooldays had to comfort her.

Why did it upset you so much?

“Because what she really meant was: You’re not worthy to be beat up by me as you are. You must be able to walk in order for me to feel you’re an equal.”
The girl was very popular with the boys. She was the one they wanted to go out with and the one the other girls wanted as their best friend. In the summer before 6th grade, she had a serious virus infection and didn’t return in class until later that year. In a wheelchair. After several years of rehabilitation, she was able to walk with a limp.

“It’s a little bit funny isn’t it. Of course it was awful at the time. But also a little bit funny, don’t you think. Now, that we’re talking about it.”

Did you also want to be best friends with her?

“Yeah, but I never was.”

She was also one of the girls who had a beautiful handwriting so naturally “you tried to write like her”.

Do you know what she’s doing now?

“I know for sure that she moved back to Falster. I saw her in ‘94, when she and two other girls from my old class came to visit me after I had back surgery. She still didn’t walk very well. I don’t really remember who the other girls were.”

Playing with fire

It took Mette five years of increasingly futile German studies to finally muster the courage to accept that her favorite subject was more about phonetics and grammar than language as a medium for stories. It had almost become her least favorite subject.

“I was sick and tired of it. In fact, I had been sick of it for a long time before you realized it. It really bugs me now when I think about it, ‘cause it slowly wears you out. But I’m just so happy that I started in the first place. ‘Cause it felt right in the beginning didn’t it?”

From her bed in the combined bedroom/office she can see Nosferatu, The Vampire, the poster of Werner Herzog’s vampire movie from 1979, tower over her footboard. “It’s much better than Coppola’s newer and possibly more popular version which is just over the top”.

She expects to do her master’s thesis on the horror genre – a genre she has previously covered in papers about terror, suspense and Hitchcock.

“It has to be in the more sinister department which is what I’m interested in. The alternative is that you don’t get it done. What you write about has to come from deep inside you. Otherwise you don’t get it right.”

Why do you think you have chosen that type of film as your specialty?

“Well, I suppose I like to be scared.”

But do you get scared?

“Yes you do.”
But isn’t it sort of a contrived scaredness?

“That’s exactly the point. You don’t have anything at stake in a movie. Expect maybe for a little uneasiness in the days after.”

Does it meet a psychological need?

“I think I’m sort of testing myself. To make sure that things are ok here. See what terrible things happen to them. Glad you’re not part of it. You play with fire without touching it.”

Her shelves are lined with movies. DVD or VHS with titles such as Rosemary’s Baby and Mulholland Drive. James Dean is looking cool from a life-size poster on the wall at the end of the dining table. In the adjoining bedroom, he and Jack Nicholson in postcard format are competing on who take up most space on the sides of her bookshelves. It looks like a tie. Dean is there because “he’s a good-looking guy”; Nicholson, because “he’s my favorite actor. But not my type.”

Mette’s type has white teeth and brown eyes. That was the case anyway when she fell in love for the first time.

“There was this guy in my class who all the girls had a crush on. The one who teased me and he were the couple. They weren’t dating, but they were Mr. and Mrs. perfect. Somehow they belonged together. He was so good looking. All white teeth and brown eyes. The ideal boyfriend.”

Are you seeing anybody now?

“No.”

Have you had a boyfriend?

“Yes.”

A lonely movie

Mette grew up with film thanks to her father who has always had an insatiable appetite for stories in moving pictures. On numerous occasions, after having picked her up from school in Nørre Alslev, they dropped in at the local convenience store.

“We had always planned that this time we want this and this movie if they still have it. I hope it’s not out. And then hurry home and see it right away. The kiosk is still there”

She wasn’t very old when there was hard-core horror in the VCR: The Exorcist, Jaws, Poltergeist.

“He let me watch them when I was little. They had a formative influence on me. I don’t easily get scared now.”

“It’s like that with a lot of things that happen in your childhood. They can affect the rest of your life. There are movies that can almost change your life, your entire existence. I know it sounds really exaggerated, but that’s the way it is.”
Are there any movies that have changed something in you?

“Something happened the first time I watched ET. And The Never Ending Story. They are the two great
movies in my life. They really started my love for movies. The ability to enter into another world. They
started a lot of things.”

What was it that was so special about ET?

“It’s a bit hard to explain. It’s such a lonely movie in many ways. I mean as a topic. A boy who’s sort of an
outsider, but then he’s lucky enough to find a good friend who turns out to be from outer space. And who
has to go back home. I thought it was very powerful.”

How old were you?

“I must have been eight at that time. It came out in ’82. It’s actually a movie I haven’t seen very many
times ‘cause it’s one of those you’re sort of reluctant to revive. You don’t want to lose the mood and
memory from that time”. When I see it now or hear the music, you get this inexplicable feeling back. You’re
suddenly eight again.”

For several years, Mette has been a film critic at www.handicapportalen.dk. In her most recent review of
the Danish movie Flammen og Citronen she gives out five out of six stars.

The quiet times

When Mette was little, her father was a stay-at-home dad because, “one of them had to take care of me
while I was little and during my youth. So he got the job.”

Her father worked in a hardware store in Vordingborg until Mette turned two. Her mother was a banker.
Now that they have both retired, they often come to visit her, sometimes as often as once a week.

Mette and her mom shop while her dad, equipped with the newspaper, studies life in the shopping mall
from a bench. Or checks out the newest TVs at the radio store. Or is rummaging through a bin full of movies
in the hunt for a bargain.

Usually there is also some work for him to do in Mette’s apartment. Meanwhile her mother inspects the
kitchen, “and then you might as well give it a good cleaning while you’re there, she seems to think. We’re
just having a very good time. Very good.”

So you’re actually a very social person?

“I’m getting better.”

Didn’t you used to be?

“I definitely know that I’m more social now. I do more and more things without thinking about it.”

Do you ever feel lonely?
“You mean in the negative sense of the word? Only if there was a specific reason for it. I think I’m pretty good at being alone. I’ve become much better at it. But you have to be, haven’t you, because that’s what you are. I don’t think I could stand having people around me all the time. Well, I guess I do have people here all the time, you know with personal assistants and all. But then again, you don’t.

But I like to be alone. There’s always something you can do. You don’t need to sit and think about the fact that, in principle, you’re all alone in the world, a thought that sometimes strikes you. Then you know that you need to do something tomorrow, don’t you?

You also need time to do the things you have to do. It’s not like you can party all the time? You need time alone. Then it gets more intense when you spend time with other people, doesn’t it? You absorb things differently when you also have the quiet times.”

Mette visits her home in Orehoved every other month or so and usually spends a week with her parents every summer. She has also spent some of her vacations at a folk high school. Last year she was on the road as a volunteer at the open-air concert tour arranged by the Muskelsvindfonden, and it got directly into her blood. She almost can’t wait to go on this year’s tour. There is, she points out, a huge difference between just being a one-day volunteer to being a real member of the crew.

She is hoping to find a job when she graduates from the university. Preferably something that has to do with the release of new movies.

“In a distribution company for instance. To help prepare press material, call around, set up interviews, do marketing stuff – to work in that field would be a dream scenario.”

The sky-high couch

During the interview, Mette’s personal assistant placed a small dish of cookies on the dining table, but it was not until an hour and a half to two hours later that Mette positioned her free right hand and slowly let it pick up a chocolate cookie. She ate it just as slowly, in very small bites. That is how you eat when you are 33 years old and diagnosed with spinal muscular atrophy type II.

When she was a child, she did not have any problems eating but then her parents made restrictions - remoulade and fried onions like her classmates had on top of their rye bread with salami were out of the question; only one cola per week and not nearly as much candy, cake and sodas at birthday parties as her friends - all to prevent her from gaining too much weight.

“My dad usually drove me to birthday parties because it gave him the chance to pull the mom out in the kitchen and tell her what I could and could not have. It was complete humiliation, really. That some grown-up person was asked to keep an eye on me.”
The part of Mette’s childhood that has to do with muscular atrophy and visits to the hospital is full of bad memories. She also declined the invitation to participate in the national study of adult life with spinal muscular atrophy type II, which RehabiliteringsCenter for Muskelsvind carried through last year.

The physical examinations sounded a “little too unpleasant”.

“It was also a little traumatic what with all the things I went through in my childhood. Braces, lace-up boots and brutal pediatricians who just grabbed you under your arms so that you almost broke in half. Without asking. And you almost came home with a sprained foot when you had been to the Cerebral palsy clinic in Copenhagen because they didn’t think at all. I hated it. And maybe I still feel a little bit like that. I was scared to death every time I had to participate in some kind of project or whatever it was. The doctor at the clinic was just the worst. A nice man really, but I felt that he was such an authority. And you had to get up on that sky-high couch that looked like a big dinner trolley. It was extremely tall, and I had to sit way out on the edge. You know, where you don’t really know if you can keep your balance. You never fell down but your heart beat really fast, you know, like will they catch me if I fall? Why did I always have to sit way out there? I’ll never forget that.”

Do you think they did something wrong, the doctors and those who examined you?

“Well, yes, it was really horrible when they just grabbed your leg and stretched it. ‘Cause they always grabbed you really hard. It was a complete nuisance. And I ask myself if kids have to go through the same things nowadays? Maybe even more because science is more advanced now?

Doesn’t it have to be that way? It’s a disease that people could really do without?

“No, I would rather do without those examinations. I don’t want to get rid of who I am, because you can’t. You don’t look at it that way when you’re in it yourself.”

I’m thinking about it the way that you go to the hospital because you have this diagnosis and because someone thinks he can do something good about it?

“But you don’t understand that when you’re little.”

What’s the alternative then?

“I don’t know.”

Would you rather that they stopped it altogether?

“I don’t know. That’s the darned thing about it.”

Mette stopped seeing a physical therapist right before she finished elementary school and quit swimming when she graduated from high school.

“Because I didn’t feel like it. I think it was a waste of time. Irritating. Hurt too. Not the swimming, but the other thing. Bend and stretch, heck no.”
Right up my alley

We arrive at the Pedersborg gym in the northern outskirts of Sorø just before 4 p.m. Every Thursday, Mette drives 75 kilometers west of Copenhagen to practice wheelchair dancing from 4 p.m. to 8 p.m. only interrupted halfway by a light supper.

The others have already arrived including Mette’s steady dance partner Selma, and everybody greets each other warmly. Some walk, but sit down in a manual chair depending on type of dance and dance partner.

A group of mentally retarded people pass by and position themselves in the far end of the gym. They are here to play boccia.

It’s only been a year since Mette started dancing. It was after seeing a couple of dancers from Sorø perform at one of the Muskelsvindfonden youth courses.

“I was hooked almost right away. Somehow it’s a freeing experience. You get a really good feeling. It’s right up my alley.”

“What do you mean by that”?

“That you’re not just some huge thing on four wheels – like a steamroller. Here everything is structured, there’s good music and you have to feel the rhythm. You move your body as much as you’re capable of. It’s all much more elegant. And you’re allowed to move around a lot. I think that’s something you’ve been missing. That you can also use your means of transportation for something elegant.”

The dance team from Sorø Handicap Forening has just been in the Netherlands, in the city of Cuijk, for the annual World Cup. The Danish team was there as observants and didn’t participate in the actual competition only in the opening ceremony. You can see it on You Tube under “rolstoeldansen” and “cuijk”.

Today the group is practicing for an open house arrangement, which hopefully will attract new members. The boombox fills the gym with sentimental dance tunes that almost get past your pop musical immune system. My right foot moves to the beat.

First a march. Then St. Bernhard’s Waltz followed by Fado Blanquita, Tennessee Waltz and a Wild West dance. Three big boys who have watched the dances with great interest are invited to join in for an extra round of “cowboy” dance. Three manual chairs are found; the boys are playful and learn quickly. “How nice”, they shout appreciatively.

“Hit it maestro,” Mette yells happily to Palle who controls the boombox. Let the dancing begin.
Mette Estruplund: “The picture was taken at my niece Sophia’s second birthday last fall. My mom and I gave her the balloon bouquet which we bought from a man who makes balloons for almost every occasion – except for funerals I guess.” (Private photo).
Coming home - From children's home to housing cooperative

It was at the beginning of the 1960s that Karsten learned to long for freshly baked French bread. It was when he lived at Invalidebørnehjælpehusens Børnehjem, IBH for short, a home for disabled children in Hørsholm north of Copenhagen.

“Even though they made their own bread we always had to eat up the left-overs first,” he recollects, still with a trace of disappointment in his voice.

It may be an overstatement to say that was his reason for stopping at the bakery on his way home from work today, but the pleasant smell from the bread bag which his personal assistant dropped on the floor behind the wheelchair suddenly reaches my nose again as I picture the cook’s forbidden homemade temptations.

IBH was Karsten’s second home until he turned 20. When he reached school age, he could not stay in his childhood home in Brøderup with his parents any longer.

“Back in those days, you just couldn’t attend an ordinary elementary school. I know that some kids were able to, but it wasn’t always easy,” he points out.

It’s the Monday of Shrovetide, which is traditionally celebrated in Denmark by children dressing up in costumes. We met this afternoon at Center for Hjælperordninger in Århus, a public employment service teaming disabled people and personal assistants. At closing time we hurried home to be on time for the food team meeting at 4 p.m. in the dining hall kitchen. Outside we saw a child-sized blue package complete with ribbon and bow trailing after his mother.

It is night and the winter darkness has fallen on Lysningen in Malling outside Århus, a housing co-operative with some 50 residents of all ages where Karsten has lived since it was built in 1991. The many mouths have been feed with Italian meatballs – “three for each person” as the chef diplomatically pointed
out – in a pesto sauce with potato wedges served with a white cabbage salad with oranges and Jerusalem
artichokes; and ketchup, although it is served mostly to the young kids.

“The best thing about living here is the closeness to other people,” Karsten explains. “Everybody knows
one another, and some people become your personal friends with whom you share your interests. But it is
best during the summer – when you hang out and talk to one another, and sometimes many hours pass
and you hadn’t planned any of it.”

Tomorrow it is Tuesday, Karsten’s day off. He will wake up slowly to the smell of freshly ground coffee
and a slice of the baker’s homemade bread.

What do you do if there is someone you don’t like?

“Well, the
you don’t do anything. We have made sure that there are plenty of people here, so that’s ok. We are 18 families and if there’s one family you don’t really like, well, then there’s room for that.”

He once lived in a commune. Seven years “of joint decision making. That’s a fine experience when you’re
20-25, maybe a little older, but after that it’s nice to have your own place where you can close your door
and say, ‘What’s in here is mine.’”

He has also experienced feeling lonely in an apartment. He couldn’t take it in the long run, so when he
saw an ad in the newspaper in which a group of people who were planning to build a housing co-operative
were looking for like-minded folks, he seized the chance. That was in the late 80s.

“The group had their eyes on a piece of land. They wanted to build a place for young and old, children,
single people and families. I liked the idea. We had meetings every single week for a couple of years about
how we would build and how we would live together.”

Karsten’s commitment has not slackened off. He is still webmaster of the co-operative’s website which
he established as early as ten years ago, and a visit to www.lysningen.dk reveals that the chairman of the
coop’s board of directors is called: Karsten Jühne.

The one he looks like

He seems to be plenty busy. He works 19 hours a week – Mondays, Wednesdays and Thursdays – at Center
for Hjælperordninger (translates to Center for Personal Assistant Schemes) which he co-developed back in
the days and which is run by the Municipality of Aarhus. Since 1994 he has been permanently employed at
the office.

“Assistant Schemes, this is Karsten,” he says, headset on, when the phone rings.

This afternoon somebody called to ask about holiday legislation, and Karsten seems to have an answer to
everything concerning that particular question. Vacation periods, times of notice, rights and duties were
translated into clear, informative Danish presented by Karsten’s fine treble voice to the caller in astonishingly logical order.

The call before that was an assistant who no longer wanted a permanent position but would like to work as a temp. The change is routinely registered in the computer, which Karsten controls by slowly moving a red king size trackball embedded in a cordless mouse. It is a study of patience and fine motor muscular atrophy type II.

Once again when another young man enters the office and eagerly announces that he would like to offer his services as an assistant – the sooner the better, “I’m extremely flexible” he informs us – Karsten, with the air of an expert, hands out the necessary formulas and information. The record-low unemployment rate has triggered a need for people who want to work as a permanent full-time assistant.

On the notice board above his desk he has pinned a photo of three sleeping kids, sprawled on a king-size bed, who have fallen asleep on the spot like puppies in a dog basket. My nieces, Karsten says, pride in his voice. They are the daughters of his younger brother, photographed about a year ago when the family lived and worked temporarily in Santa Barbara.

“It was too good not to hang up. They e-mailed it to me and I improved it in the image processing program and made the print. But it’s the only private thing I have displayed here.”

Rumpole! That’s who Karsten resembles. A barrister in a British television series, Rumpole of the Bailey, who appeared on TV-screens – well, when? Probably no one remembers, but many people may recall the mustache, the characteristic forehead and the eyebrows that are lowered and raised as he speaks. Not to mention his gruff kindness, from subtle irony to biting sarcasm, often with a mischievous voice and expression.

Above the picture of the children hangs another photo. It is a Ferrari, parked along an empty sidewalk somewhere in the south, as red as only a Ferrari can be. The car was shot in Monte Carlo.

Every year in September, Karsten and two of his good friends vacation in Southern France some 80 km from Monaco. They are all wheelchair users and stay at a vineyard with plenty of space and very helpful and obliging hosts. They make the 1900 km trip non-stop even though it is hard. But it is better than going through all the trouble of finding lodgings for three space-demanding wheelchair users and unpacking and packing various aids.
She was not abusive

“I was born in Korsør in 1955. My parents were both teachers. We lived in an apartment in Halsskov, but I don’t remember it. When I was a couple of years old, we moved to another house where my grandparents lived on the first floor and we lived on the second.”

How were you able to live there with your muscular atrophy?

“I wasn’t very old. They carried me up and down the stairs. It didn’t become a problem until later. In fact, it was a very practical arrangement because my grandparents were able to watch me during the day.”

A couple of years later, the family moved again. They were an older brother (his younger brother came some years later), Karsten, his mom and dad. His parents gained employment at a school with a staff house complete with two children’s rooms.

“We slept in one room and played in the other. But then, just before I turned seven, I moved into an institution for handicapped children. Somehow I was still living at home, if you know what I mean. I still had my room at home which I shared with my brother.”

Where did you move to?

“To Hørsholm. At IBH, Invalidebørnehjælpens Børnehjem Hørsholm. It was a very small institution with some 18 children and youths. I moved because I had to start school when I turned seven. Back in those days, you just couldn’t attend an ordinary elementary school. I know that some kids were able to, but it wasn’t always easy.

IBH was one of those private foundations where the conditions were miserable. There were approximately 18 children, a matron, a cook, two maids and a non-certified teacher. That was the staff. It mustn’t have been much fun for them either to work there.

The working hours were ruthless. There were 1-2 people available at a time for 18 children with relatively serious disabilities. That’s not a whole lot of resources for each child. It was very much like an assembly line. We all had to get up at the same time and go to bed at the same time. Assembly line-style.”

Describe how it was done?

“It was like this: If the staff were to get home at a decent time, they had to send us to bed right after dinner. It was according to age, and for a long time I was the youngest, so I was often in bed at seven o’clock at night. That’s early when you’re seven years old. And when you’re nine it’s very early. I didn’t read that many books during any other period of my life. What else could I do?

Actually, I was one of the luckier kids because I was at home with my parents about every other week. And most of the summer too. But for the kids who were never at home with their parents there were two outings a year. One was in the summer with some charity organisation and one was in the winter with
some other charity organisation. And then two visits to the dentist. That was how often the other kids went out.

Thank God, they don’t treat people like that these days. Well, maybe people in nursing homes but not anywhere else. Although, I hope we don’t treat people in retirement homes like that.

We had a bath once a week – all of us, on the same day. It started right after school on Fridays. Right after our bath we had to put on pajamas. It was pretty dang early to be in bed at three o’clock on Fridays. It’s not like we had to sleep or anything but it was still a little bit early to be in bed. Well ok, you weren’t alone in your room. We were three.”

What was the matron like?

“‘I’ll say it like this: She was a deaconess. In the strict Christian tradition. She wasn’t abusive although I did see her smack somebody in the face. And you’re not allowed to do that. But she did. That still happened in the sixties.

The food was not very pleasant either. Not like it had mould on it, but it was very plain. You ate what was on your plate and you ate up.”

It sounds like you were intimidated?

“Yes, we were. She was tough, the matron. It was almost absurd. I think I had been there for three years when we first had freshly baked French bread, because even though they made their own bread, we always had to eat up the leftover bread first.

She was also a very devoted person, however. I only remember her having one single day off in the three years she still worked there while I lived there. Then she retired.”

As time goes by

“I also got smacked on the head once.”

By the matron?

“No, it was one of the other employees – a teacher.”

Why did you get smacked?

“Well, I think it was because I was being messy. When you sit a lot in a sandbox you get rather dirty. I had probably also thrown a little too much sand around.”

But that’s what children do, isn’t it?

“Yes, that’s what they do. It wasn’t like she hit me very hard though. I think I was more surprised than hurt.”

What was school like?
“Well, you see, that was the whole point. That’s why I moved in there, because you had to go to school. We were taught there by a non-certified teacher. It was a handicapped woman whose only qualification was that she had gone to secondary school. But luckily, I had learned to read and write before I moved out. And I have always been pretty smart, so I learned to read, and write and do math – and I’ve read the history book at least twice.”

“After a while we got a certified teacher. And later, I was the first disabled student to attend school in Rungsted. And I had good teachers there, Vagn and Agnete Aarenstrup, or Mr. Aarenstrup and Nete as we called them.”

Today, IBH has been converted into an ordinary day care center and – naturally – Karsten has visited the place.

“Originally, it was a mansion that they added an extra wing to. It has probably belonged to some wealthy merchant from Copenhagen. At some point, it was a home for children and young people with brain damage – that is children who can’t possibly live at home. Because these days, children with a physical handicap no longer live in institutions.”

Were you ever angry with your parents for sending you there?

“No, not at all. But I was homesick. The first couple of years anyway. Then as time went by, it got better. We got a young, enthusiastic headmaster and his wife – a couple from Thy in Northern Jutland whose ideas were fundamentally different from those of the old matron. He also expanded the staff.”

Are your parents still alive?

“My mom died a couple of years ago. My dad is still alive. It’s not like they had a heck of a lot of choices. And when they started getting some – I mean, when it became easier for disabled kids to go to elementary school, I didn’t feel like moving back home. By then, I was fine where I was. It had somehow become my home, I had my things there, and they were easily accessible. That was ok. And as time passed, we were fewer kids there, and I was able to have a life – with all the natural restrictions that were there of course.”

Do you still have friends from that time?

“Not at all. First of all, many of them have passed away. But I know someone who I see from time to time, but it’s not one of my close friends.”
We must take good care of each other

Everything seems to have its own place in Karsten’s home: Arranged alphabetically, chronologically, according to physical size or an entirely different system. He is a practical man who needs to be in control of his everyday activities. His study resembles a warehouse with well-stocked, neatly arranged bookshelves.

A bit of a computer nerd, Karsten earned a bachelor’s degree in computer science from the University of Aarhus, and for a number of years, he and a couple of friends ran a small computer firm. He graduated from high school in 1975 with honors in the natural sciences.

But appearances can be deceptive. He started out as a student of literature, then changed to history, then paid a short visit to the department of Slavic languages, then enrolled in a folk high school – then jumped to computer science.

It was a turbulent time that began when Karsten graduated from high school and moved to Århus with one of IBH’s young female employees. They had already been dating for a couple of years which, in theory, was not allowed but the headmaster tacitly approved it.

It was also a political time when students almost automatically were considered left wingers. Karsten joined the Left Socialist Party of Denmark and today he is a member of the Red-Green Alliance.

“It’s not like I’m out there fighting. It’s more about the principles of how we treat each other; that we take care of each other in other ways than the Conservatives, the Liberals and the Social-Liberals think we should; and that we become better at distributing our wealth. Here in Lysningen we have discussed whether we should write up the price of our houses like many other cooperatives have done. I think it’s great that we decided not to do that, because it makes it possible for a greater group of people to move in. If we had let the prices skyrocket like they could have, a person like myself could not have afforded to move in here.

But I won’t claim that I’m active. When I was a member of the Left Socialists, we had an obligation to be active. That meant you had to be present at the department meetings and you had to be active in your group. If not, you were kicked out. Actually, I think it was fine, because if you believe in something, you have to do something about it. So I guess I don’t believe in it that much.”

Does your disability have anything to do with your political beliefs?

“Not at all. Well, I don’t think so. It’s not like I know for sure, is it? But I don’t think so. I don’t think disability politics should be top priority either ‘cause a disability is just something you have. It’s all the other things that we should focus on the rest of the time.”

In 1978, Karsten, his girlfriend and about 10 other people bought an old school house and formed a commune – but not the kind where they shared everything from clothes to girlfriends. Well, almost not.
“Not all relationships lasted. But almost all couples remained in the same house. In fact, none of us moved out because of a break-up even though none of the original relationships lasted.”

Did you and Ulla go through a break-up as well?

“Yes, at some point in the early 80s. We all went through that. Everything was like it was supposed to be. And you had to be mature enough not to move out. And in a way we were. We acted like mature men and women, even when new boyfriends and girlfriends moved in. It wasn’t always great fun, but we were mature people.”

Looking back, what do you think about it now?

“I don’t think I have any special feelings about it now. At the time it seemed like a natural thing to be able to act that way.”

But weren’t you jealous at all?

“Well, yes, I think I probably was. But aren’t we all eventually? We have all been dumped at some point in time. Maybe in favour of somebody else.”

In 1985 the members of the commune went their separate ways. After a couple of individual stopovers in large apartment buildings and a long and most inconvenient stay at the hospital that resulted in a permanent ventilator, Karsten’s future began to look brighter.

Tomorrow he has kitchen duty as chef. The menu: stew. It might well be Rumpole’s favorite dish – beef that has simmered in strong coffee, cream and a splash of schnapps.
Karsten Jühne: “The photo was taken in October 2007 at a restaurant on my older brother’s 25th wedding anniversary. He got married on my younger brother’s birthday to make it easier for him to remember the date ... I have removed any red spots and the like. Am I showing an edited version of real life? Well, of course. All photos do. As does the interview you’re doing right now.” (Private photo).