A Tale of Terrible Times

By Olaug Nilssen, published at Samlaget 2017

«I am autistic, it’s true. It’s true in another way than that I am not. We are all autistic and nobody is.» Lars Amund Vaage,

«Finally I can get out of trying for an abstract life,» Ingrid Nielsen, *Hemmelig, men aldri som en tyv* («Secretly, But Never like a Thief»)

The diagnostic culture, must there really be a name for everything? Whatever happened to good, old ants in your pants and bug up your ass, why can’t someone just be the person they are, without having at all costs to call it something?

You race around carrying all your impulses, these never rest in their search for impressions. I am running in front of you and clearing away impressions, I am running after you and clearing away the rubble, every time I am too late.

It’s called ADHD. It’s called «childhood disintegrative disorder». It’s called autism. It’s called sub-clinical epileptic activity. The doctors say that it’s true, even though I try to deny it.

Your name is Daniel. You are a strong, nine-year-old boy.

My name is Olaug. I am a grown woman almost 40 years of age.

**The last Monday in November**

I wake up when I hear your sounds, look at the clock. 3:32. I lie in bed with my eyes closed, I know I don’t have to go in to check on you, they are not frustrated sounds, just irregular arcs of noise that vary in both intensity and length. At 5:08 you come out of your bedroom and I get out of bed and follow you into the bathroom. I help you take off your pyjamas and nappy, help you onto the toilet, wash you. When I have put a fresh nappy around your ankles and sung the «time to change your nappy» song and praised you for doing as I say, I turn around to take out your clothes and then you dart out the door and run laughing up the stairs. I don’t become stressed, because I know that I locked the front door and the doors into the sitting room and the kitchen before I went to bed yesterday, but I don’t waste any time either and go after you with the trousers, sweater and socks in my arms. I didn’t lock the door to the storeroom where the freezer is, so you are already standing with your hands deep inside, trying to open a carton of ice cream, unaware that I have frozen leftover soup in this carton, so it is not ice cream. I take the carton away from you, shut the lid on the freezer, and lead you out.

It was six weeks ago that I blacked out at work. I no longer remember whether it was tears, rage or if I fainted and if it was the fifth or the tenth time. But I remember how I caught a glimpse of myself from the outside and discovered that I was wearing old trainers, trousers that were too small, my face was severe, and my hair was grey.

I thought *it’s over.*

Already by the next day I thought: *What’s needed is reorganization.*

On the third day I thought: *The ability to work is more important than taking care of my appearance.*

I filled out an application for more assistance from an institution. Meanwhile, letters to the editor were being printed in the newspapers about how the best thing for children with functional disabilities is to receive care in the home, so they can receive love and spend time with their parents and siblings. These letters compared institutions to prison and claimed that the family is synonymous with security and warmth. This is a completely ordinary point of view, which it is impossible and inadvisable to dispute, so it shouldn’t rattle anybody. Not me either. I applied for 50 days per half-year. 50 days each half year at an institution. 50 days every half year means 100 days a year. 100 days a year is 27.4% of the days of the year. In an institution.

The institution is called Sunbeam. Sunbeam is simply furnished, the linoleum is grey, the bedroom has only a bed and a cupboard and a curtain that is attached with Velcro, so nobody can harm themselves if they try to tear it down. The sitting room has a leather couch that is easy to wipe clean. There are safety guards on all the doors in the kitchen. Newcomers will weep when they walk in there, the way I did the first time I came – *children live here*, even though I already knew that it was good, there can’t be too much stimuli, can’t be too much that can be destroyed, cosiness is not the same for you as it is for me.

We received a reply in early November that it was clear that we needed more assistance. The documentation included an interview with the staff at the school and at Sunbeam, while the decision was also based on my description in the application. But we were put on the waiting list, because there was no opening available. We would receive a few extra hours a week at the institution Vindheim while we were waiting for the additional days. I wrote to Vindheim and proposed that they take another afternoon each week. They didn’t answer my e-mail. After a few days I called to follow up.

The director said: «This is our responsibility.»

I said: «Great!»

The director said: «But we can’t discuss which day of the week it will be until we have received the go-ahead.»

I said: «We have received the go-ahead. The letter states that we have received an increase from five to ten hours a week while we are waiting for the increase to 50 days.»

There was silence on the line for a moment, then the director said:

«Yes, well.»

Then she interrupted herself.

«We’ll take care of this. Don’t give it another thought.»

I often went to see the family doctor because the whole time I had believed that one week of sick leave would be enough, a kind of breather to recover my strength, but it wasn’t, week after week it wasn’t enough. Anxiety is your breath getting trapped in your chest. The solution is to breathe from your abdomen. Breathe in through the nose and out through the mouth. I lay like that half the night every night.

I told the family doctor about the waiting list for more assistance. I explain how you were so agitated these days that you tried to bite me in the face and that I had to push you away again and again, forcibly and firmly I had to push you away.

I said: «This pushing is very symbolic.»

He got a kind of expression on his face and he put me on sick leave for several weeks, without asking any questions, instructing me to investigate the care assistance allowance again.

«But I don’t want the care assistance allowance. I want to work.»

«You can’t work more than you are doing.»

«But I want to work.»

The doctor looked at me.

«You are exhausted, but all the same you work all day long. You can’t hold down a job as well.»

He wrote out a medical certificate and gave it to me.

«Exhaustion is not something your subconscious invents to avoid responsibility. Exhaustion is something that exists. You can’t go to work as well.»

«But I want to.»

I lay under the duvet during the daytime with my eyes squeezed shut and my fists clenched. Breathe in through your nose, out through your mouth. *Sleep now, sleep*.

I waited. It grew darker outside. The rain accumulated like a thin river that gave off a reflection on the asphalt under the street light outside the window.

I waited. I spoke with my boss. I said that I would come back. She said that I mustn’t think about it, she said that nobody is indispensable.

I waited. I didn’t follow up on Vindheim, I thought I needed to give them some time to organize practicalities. I did as the doctor said, I called the public healthcare administration unit and asked if I could apply for a care assistance allowance.

«Well,» they replied, «that scheme is intended for children who take care of their parents when they grow old, but you can apply.»

«Will I qualify, then?»

«I can’t answer that. But if you qualify, you must be aware that it will be deducted from the relief benefits you already receive.»

«Okay,» I said.

«The care assistance allowance is not supposed to be compensation for lost earnings. It is an extremely low hourly wage.»

«Okay,» I said.

«There is also a deduction for the parent’s duty of care for own children.»

«That’s reasonable,» I replied.

I called Vindheim. No answer. All right then. That’s how it is. If I fall apart it’s no worse than if others fall apart. I have no more right not to fall apart, even though I can plead our case.

I can’t plead our case. I become frantic when I speak about our case. Always just as pleased to be asked, always just as afraid of not reaching the finish line, not reaching the part about «but there are many nice things, many happy moments» before the listener interrupts the story about everything else by saying it for me. They mustn’t get to the point of saying «one grows more fond of the children who are different» because then I gear up another notch and become quarrelsome, as if I am lying, even though everything I say is true.

I can’t stand pleading our case.

But then, I can stand it after all, not just stand it, I am compelled, I let it pour out of me like a loud, choppy siren, ACTING OUT SELF-HARM DEFECATION always inappropriately ready to explode, always inarticulate HOURS AND HOURS OF NOISES NIGHT AND DAY. My friends run away, EVERYTHING INTO THE MOUTH, POISON, CIGARETTE BUTTS, STONES were popped right into the closed face EVERYTHING IS DESTROYED and didn’t come out.