

The story about Sofia

By Anneli Frandsen 30.01.2012



Our family

Our beautiful Sofia was born on September 30th 2000 only three months before I turned 42 years ☺.

At the time I managed our home and Erik spend a good part of his time traveling abroad as an export manager for a medical technology company.

Today Erik has retired and I am working with alternative healthcare massage.

Sofia has two adult half-brothers (31 and 33) and a baby nephew, Anton almost one year old. Imagine being an aunt at the age of 10.

Pregnancy and birth

An amniocentesis in week 14 showed that we were expecting a girl with Triple-X syndrome.

Through the internet we found Dr. Johannes Nielsen, who had retired from his position at Århus University Hospital. He could however inform us about some families who had Triple-X girls.

The following weekend we visited a family some 200 km. away from Copenhagen. They had a 10 year old daughter, Sofie with Triple-X. We also called two other families to see how their daughters were doing. So when we came to our hospital (Rigshospitalet) three days later, we had decided to keep our daughter and we said NO thank you to the recommended abortion.

I had a normal, uncomplicated pregnancy and gave birth after 42 weeks. The birth went fine although they at last had to use a suction cup to assist. Sofia was a big beauty, weighing 3800 grams. She was 54 cm. long with a lot of fine dark hair. ☺

Milestones

Sofia developed fine – as fine as could be expected and she was breast fed until her ninth month. She only started to crawl in her ninth month and she started to walk when she was twelve months old. She was toilet trained just before she was three years old. She could bicycle when she was four.

Speech development

Sofia started making sounds like "Da Da" when nine months old, and her first words , "mum" and "dad" when she was 22 months. Not long after that, she started speaking in whole sentences.

She has had no speech problems or delay in her speech development.

Daycare – Nursery and kindergarten.

Sofia was at home until she was 17 months. She was fond of other children but she was a quiet girl.

When she was three years old she started in a kindergarten just next door to the nursery. After two weeks we had to take her out of that place, as it was very noisy and confusing for her and as she was not really taken care of.

After she had spend the summer at home she started in a small Rudolf Steiner kindergarten with only 15 kids.

A lovely place with two full time and one part time kindergarten teachers in a nice old house. The garden was fantastic and a complete adventure for the children.

The tradition in a Steiner kindergarten is to follow a schedule so that the children knows what is happening every day throughout the week. They have indoor activities as well as outdoor activities every day all year round.

Sofia enjoyed the next two years here until the place closed down. Fortunately we found another small kindergarten with 22 children. Sofia stayed there until she began school when she was almost 6 years.

Impaired eyesight and spectacles

Sofia had spectacles when she turned three. She had started to be a bit cross-eyed. She often stumbled over things, especially in the afternoon as she was tired when she came home from the kindergarten.

It became clear that she was very farsighted +4.5 had a slight squint and double vision. The eyeglasses helped right away correcting her squint and her double vision.

Today she is eleven and she is using + 6.5. She starts to be cross eyed very fast is she is not using her glasses. Our Ophthalmologist tells us that Sofia always will have to use glasses.

Hearing

Sofia's ears are normal, but it is difficult for her to discriminate and hear spoken words when there is a lot of background noise.

When she was nine years old she was tested for APD (Auditory Processing Disorder). ADP means that there is an auditory problem in the more central part of the auditory system.

She did not have it, but the examination showed that she had problems with "filtered words". Her ability to discriminate words against background-noise was diminished with 40%.

That may be the reason that she gets very tired when she is together with many people, and that may also be an indicator for why she tries to avoid crowds.

Short-term memory

Sofia has always had some problems with remembering what is happening right now. If we tell her something, she may ask about the same thing again one minute later.

When she speaks she often may pause to search for the right word. Frequently, when she is speaking, she also says: "what is the word?" to fill out the time, when she is searching her memory for the right word. She has a certain slowness when she is speaking. It is very important not to interrupt her in the middle of a sentence.

She is now eleven, and it is a problem for her in her daily life.

We have been thinking about contacting a speech therapist so that she may get some tools/techniques for easier accessing the right words in her working memory.

We also have the feeling that she has started to lose a lot of information in school.

School

Before she was five she could name and write all the letters in the alphabet. In addition she knew the numbers from 1 to 10.

She is bright and eager to learn and she was very much looking forward to starting in school.

She started in preschool when she was five. It is a beautiful small school with 167 schoolchildren. It is divided in three sections so that it is manageable for her.

From the very beginning she was supported with an extra teacher 12 hours a week to make sure that the transition from lectures to the breaks could run smoothly.

It is difficult for Sofia to understand that a common message also concerns her.

If she for some reason comes to a stop with her work, she needs someone to help her getting started again, and she does not ask for help.

It is difficult for her to shift from one activity to another both in school and at home.

Now she is in 5th grade. Her IQ is a little above average and she is good in Danish, English and mathematics. She has an attention deficiency however, and she needs thorough instructions and explanations.

When it comes to abstract thinking and social behavior Sofia is below average. She has difficulty formulating her own opinions and she is very weak in group contexts.

She needs help to function socially and emotionally. Without such support she will also get behind in her intellectual and academic development.

In order to develop her social competences she needs help from adults to handle conflicts and incidents which she does not understand.

She needs active support in order to engage in social relations and to keep them alive after school hours.

Her supporter must help here to structure the day and to cope with her experiences and to develop her competences.

Her needs have become more evident through 4th grade, and now in 5th grade they are so obvious that we are contemplating moving her to another school after the summer holiday. She will then start in 6th grade in a school with only 7 students per class and specially trained teachers, who are familiar with the type of problems that Sofia is struggling with.

We have not told Sofia about the possible school change yet. We will not mention it until we know for sure that she must change.

Strengths

Her academic development is normal. She is very good in reading and writing. Math is ok and she is learning English quite fast.

Sofia loves to write and draw. She is actually really good at drawing, and quick to.

She dreams of being a designer or architect.

She has humor and loves to be with animals. She is a scout - she loves the nature and is fearless when climbing trees. She is like a dolphin in the water, but still cannot swim properly.

She is curious but can often be seen as stubborn. It can be a challenge in her everyday life and an obstacle for her development.

Physical development

Sofia is tall and strong. Now 11 year old she is 176 cm and weighs 59 kg. She got her first menstrual period just after her 11 year birthday. So we are told that her final height will be approximate 185 cm. (according to the hospital.)

Sofia has some recurring compulsions. She clears her throat violently when she becomes uncertain. She must use a lot of energy to concentrate before she can express herself in greater assemblies. She has a tendency to compulsive behaviors such as washing glasses and change/correct her clothes, etc.

Physical development and motor skills

Although Sofia got glasses as 3-year-old she fell frequently. When she ate she spilled food and water all over herself. So we had to give her clean cloths 2 to 3 times daily until 3 grade.

She attended baby rhythmic between 4 – 8 months and baby swimming to.

Between 3 and 5 years she had music and movement (Eurytmi) in her kindergarten.

They had outdoor plays every day and walks in the forest every Monday.

When Sofia was 5 years we had a clinical observation made by an occupational / physical therapist. The examination showed problems in the static and dynamic balance, and coordination of the body.

Therefore when she was five she started horseback riding. She did that for a couple of years to strengthen her balance. She also had sensory motor training every week in that period.

She had, and she still has a weak trembling in her arms and legs. So she uses a lot of energy controlling her body, something which runs almost effortless for other children.

Therefore she easily gets tired and we have to see to that she has regular breaks during the day where she can relax.

It is also hard for her to shift focus, for instance from a book on the table to the blackboard on the wall. It take longer time for her than for other children.

Her gait is quite peculiar and she often mention that she feels like a trembling inside her body.

It is very difficult, close to impossible, for her to run, and her back aches when she tries. If she has not used her bike for a while it is almost as if she must learn that skill from the start again when she tries.

We are looking for new possibilities for sensory motor training for her.

Sensory integration problems

From when she was a baby she has been very sensitive to noise. Cloths often seems irritating to her for a lot of small reasons. It may be too tight or to lose. A seam can be extremely irritating or the tissue she may feel to be too coarse. Just a seam in the socks may trigger a very strong reaction. At home and in school she often walks barefooted if it is possible.

Sometimes she does not like to take shower.

Strong smells and bright light also irritates her.

Her sense of time is also very weak.

People normally will filter out most sensory signals and pay attention only to those that are significant.

For Sofia it is as if that filtering system is not working at all. She therefore easily gets disturbed by non-significant signals.

When Sofia is working with a task in school she may not at all be able to concentrate on that task because another student is talking or because her cloths irritates her.

In that respect Sofia is very different from other children her age, and she has started to realize, and actually at home to make remarks about that she is and feels different.

When we ask her to explain about how she feels, she cannot put words on her feelings. When she was between five and seven she was referred to sensory motor training to develop and strengthen her balance.

I can strongly recommend a web-page; www.sanseintegration.dk where you may find good information about what sensory integration is.

Sleep disorders

Sofia used to be a super sleeper. But from the age of 8 years it has become increasingly difficult for her to find rest and fall asleep in the evening.

Therefore it is also very hard for her to get up in the morning

We have a heavy pillow filled with small balls. It helped to some degree to fall asleep in the beginning, but not anymore.

From 9.5 to 10.5 Sofia had 3 mg Melatonin every evening 1 hour before bedtime. Melatonin is a natural sleep hormone. But Sofia was still very sleepy in the morning, and we saw small side effects such as headaches and that she became increasingly aggressive.

Therefore we stopped the use of Melatonin.

Sofia still has problems finding rest and falling asleep in the evening. It makes her mornings very difficult, and she often is late for school. We starts to wake her up at 6.00 but she rarely comes to school before 9.00.

Social and emotional development

Sofia has enjoyed contact to other children all her life. But ever since she was small kid it has always worked best with one to one contact. People regard her as a nice and happy child, both in kindergarten and at school.

Often she is a quiet girl who needs a quiet place where she can relax in the middle of the day and digest all the impressions and information.

When she was younger she often were hiding herself under a table or in a closet when something became too difficult to cope with at school.

She withdraws when she loses the overview in a game, in a group of children or in relationship to agreements about playing.

It is difficult, almost impossible for her to take contact to other children about plans for playing together.

On the other hand she quite often is repellent, when approached by other children, who wants to play with her.

It may be because she feels completely drained of energy in the afternoon after school.

Sofia may react physically when see feel stressed in a play or when communicating, as she does not always have a realistic comprehension of what is going on around her.

She is emotionally immature and it is difficult for her to verbalize her feelings.

At home she explodes on a daily basis when she is confronted with quite ordinary demands. When she feels stress the best strategy is to change subject and to talk about something different or to do something not connected to the present situation.

Diagnose 2

In the summer 2011 Sofia were diagnosed with Aspergers syndrome as her behavior had gradually changing in ways we did not fully understand.

Aspergers Syndrome is a psychological developmental disorder.

I participate in a closed international Facebook group for Triple-X, and here I have contact to a number of girls/women having similar problems.

May be it is caused by the Triple-X. We do not know, but certainly more research in the expression of Triple-X is needed.

We have not talked to Sofia about her second diagnosis yet. We will gradually inform her during the spring.

She knows that she is a Triple-X girl but she has only recently started to realize and to talk about that she is different from other kids.

The Dutch Contact group for Triple-X Syndrome.

We have found their informative web-page very useful, and we are thankful for the contact and support we have had from Thea van de Velde and Ida Bakker. They have done a great job collecting information and presenting it on: www.triple-x-syndroom.nl
Here you may chose among English, German, Dutch and French versions.

You are welcome to contact me at e-mail: annelifrandsen@webspeed.dk