



Academisch Centrum voor Epileptologie
Kempenhaghe & Maastricht UMC+

Empowering resilience in children with epilepsy:
care is so much more than giving medication

Meet Sara.....



Namaste, the Boston University-Harvard University Global Project in Humanism in Child Neurology
Supported by the International Child Neurology Association (ICNA)

Sara's story...

In 2016 Sara was diagnosed with absence epilepsy at the age of 4,5 years. Until then she had been completely healthy and had even never visited hospital. She visited a regular school and was a cheerful little girl. For Sara and her parents a journey full of challenges followed. Fortunately they did not stand alone in this journey.

Their pediatric neurologist, who worked in a regional teaching hospital in Tilburg, the Netherlands, started treatment of the epilepsy. Treatment consisted of explanation about the type of epilepsy and the possibility of a trial with daily anti-epileptic drugs. In addition to this, the impact of the diagnosis was addressed from a humanistic perspective. Being a paroxysmal disorder, that can happen at any moment, it has impact on many aspects of life. Parents and other caretakers and teachers, have full responsibility of the well-being of a child. With this diagnosis this responsibility changes. For the child itself, the reaction of the parents and caretakers decides the amount of impact on daily life. Also the reaction of the teacher and the peers in the classroom decide how stressful the child experiences the fact that she has epilepsy. All aspects of life can change due to the diagnosis of epilepsy.

In order to assist Sara and her parents in this process, guidance by a team of educational specialists with expertise in epilepsy, outside the hospital was started. This service is obtainable for all school children in the Netherlands: a special ambulatory educationalist school guidance service for children with epilepsy.

For Sara this additional guidance service was very necessary, as the diagnosis of epilepsy brought a lot of insecurity for her and her parents.

The diagnosis of epilepsy caused a decline in self-confidence for Sara and thereby a decline in her school results. Sara stood at the beginning of her school development, all kinds of activities for reading and mathematics and preparatory writing skills.

An absence seizure may look small, and not harmful. However, imagine that you have to be constantly busy putting together the pieces of a puzzle, to sort out what the teacher has instructed you to do, or which word your spelling test was about. Imagine that much of the information at school comes in tiny fragments, and not in the fluent way your peers pick up the information.

In some instances you don't even notice that you have missed some parts of essential information and you do not ask questions. As soon as you realize this is the case, your self confidence in the functioning of your brain and body and hereby your self-esteem are harmed. You suddenly realize you cannot trust your body or brain anymore, you cannot trust your experiences anymore.

Your balance in life is weakened. You and your parents start to get worried.

There are suddenly certain rules and restrictions that prevent you to freely enjoy outdoor activities such as swimming or climbing, or taking part in gymnastics at school.

These safety rules force you to accept and adapt, in your family, in your social surroundings, while playing with friends and at school.

Pediatric neurologists in the Netherlands can work together with a special team of ambulatory educationalists who are specially trained for the guidance of children with

epilepsy at school and have knowledge about epilepsy and the effects it has on the learning process. This group of educationalists reaches out to children with epilepsy and their caretakers at school. Thereby their interventions can make a full circle from hospital to home.

As soon as a child is diagnosed with epilepsy, a referral to the educationalist service is started, so that the socio-emotional pitfalls of the diagnosis of epilepsy can also be addressed as soon as possible, in order to prevent unnecessary delay of making emergency protocols at school, answer questions from teachers, so that there is no unnecessary anxiety in the classroom or insecurity of the teacher who suddenly has a child with epilepsy in the classroom. In this way stigmatization can be reduced as well. This reduces anxiety in the child and the parents.

In addition, the service consist of the possibility to observe the pupil in the classroom for presence of absence seizures and how to deal with this. It is complementary to the necessary hospital visits and checkups, and even reduces anxiety about that part of the process.

Sara's story continues...

In the meantime, an ambulatory educationalist was involved at Sara's school. Mainly for observing Sara during class to advise the teacher and to support in any relevant questions from the school. The ambulatory educationalist had short conversations with Sara on questions she had: "What is happening in my head? Why is my brain not functioning the way it should, compared to other children? Why do I have to put more effort in everything I do and still not seeing the aimed results?" Sara and the ambulatory educationalist talked about brains, how they can work faster and better, how they can grow by practice and determination. Sara is not only an epilepsy patient, she is a girl with many talents. She is the boss of her own thoughts and can decide on what she thinks and does.

The ambulatory educationalist started the conversation with the teacher and the parents of Sara to discuss and advise on how to make it easier for Sara to follow class. They also made agreements to enable Sara to experience success in school tasks, to improve her self-esteem and motivation.

Advise on small adjustments for the teacher were for example:

- Reaching out to Sara individually after instructing the class in general, to make sure Sara has understood the instructions and knows what to do
- Dividing tasks into smaller or shorter pieces, to make it less complex
- Sara needed more support in practicing reading skills, she experienced more difficulty in automation of letters.

Also thinking along with the parents on pro-actively preventing any difficulties during her scholar development.

The ambulatory educationalist continued supporting the parents with their questions. Together with the teacher and internal supervisor they framed the educational needs for Sara. What kind of skills are needed from the teacher and how can these skills be improved? The teacher was actively thinking along and being very creative in drafting possible solutions and small supportive tools to improve Sara's ability to learn.

Impact on family and social life, by Sara's parents.

As a result of Sara's epilepsy it felt necessary to quit my job. We didn't have family to rely on, so we had to manage it ourselves. Besides that it also influenced Sara's social contacts with friends. It is not visible on the outside if somebody has epilepsy. Sometimes she felt an outsider when she was not asked to play with other children, or when other children made fun of her because she had more trouble with reading and writing. Also other parents didn't invite her because they were afraid of a possible seizure. There are even children with epilepsy and emergency medication who are refused at certain schools, unbelievable... When she had an active epilepsy, she was not allowed to go outside cycling or to play in the street on her own.

Rosie, her little sister, was not yet born when Sara was diagnosed with epilepsy. She never saw and experienced an actual seizure of Sara but she was aware of the tension and sadness of Sara and her parents. There was a lot of talking about Sara's school and epilepsy. Rosie had to adjust to the situation and she did wonderfully well. Getting diagnosed with epilepsy is a diagnosis for the complete family and everybody has to deal with it. It's in many little things...

At a certain moment, the pediatric neurologist referred Sara to a specialized Academic Centre for Epileptology, since the medication was not sufficient in preventing seizures. There also was an indication for a long video EEG registration to get a good impression of the frequency of absence seizures, and the influence of these seizures on her functioning. The pediatric neurologist of the Academic Centre of Epileptology has reviewed the medical treatment, the development in school and at home. A nurse specialized in epilepsy, visited Sara's home twice to support in some practical tips. How could the parents deal with the epilepsy at home? The issues Sara encountered at school, were also experienced at home. How could her parents deal with the exhaustion of Sara after a day at school and how can they deal with the process of putting her to bed in the evening?. The Anti-epileptic drugs (AED) caused a side effects: She needed more time during the evening to prepare for bed and she had some difficulty to get things done in the right order.

Neuropsychological examination was conducted to show the strengths and weaknesses in cognitive functioning and attention span of Sara. Together with all professionals that were involved, the parents, the teachers and the educationalist, practical agreements were made, based upon the outcomes of the examinations. This plan aided the improvement of Sara's wellbeing, her educational and social development.

To improve Sara's confidence, she was referred to a medical psychologist at the regional teaching hospital . Together with the psychologist Sara was able to share her thoughts and questions. Also, Sara's parents could express their feelings and concerns during these conversations. The main goal was to strengthen the wellbeing of Sara and her parents.

Complementary to the psychological support, a video interaction guidance was started by the ambulatory educationalist. Short video recordings of Sara were made during class to find out what's going well, what makes Sara happy and what makes her stronger. Each week Sara chose two videos which made her proud. The ambulatory educationalist edited these videos into a short movie to show Sara all the things that are going well as a

reminder. Sara is very creative and made a token (a kind of necklace), to remember all the good things she achieved so far.

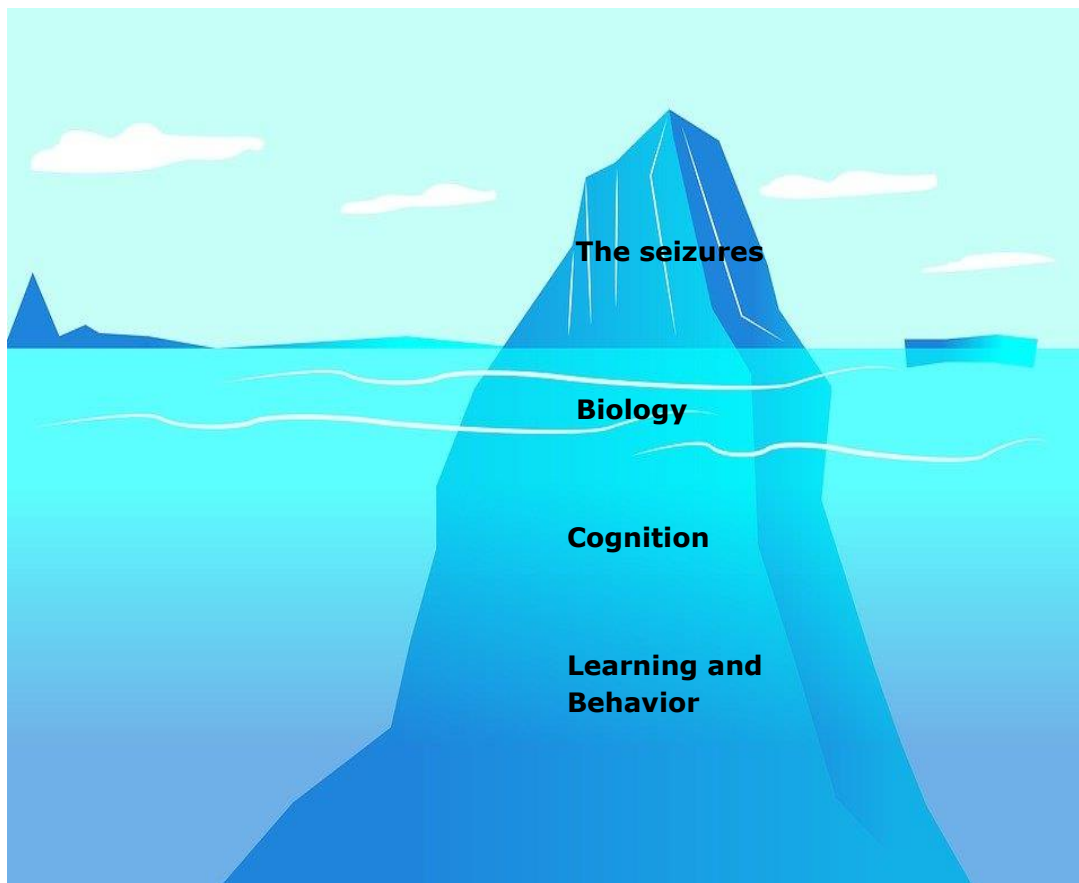
After 30 months, at the age of 7 Sara and her parents received the wonderful news that they could start reducing the dosage of the anti-epileptic medication. However, this also created a certain tension: how would she react to this change? Luckily Sara was reacting very well, she is now seizure free for more than a year. She is relieved from the impact of epilepsy on her daily life. As a celebration of this milestone Sara shared treats in her class at school and went on a trip with her family.

Due to her epilepsy Sara remained an extra year in the same grade. For closure the ambulatory educationalist visited Sara's class once more to observe and have a chat with Sara. She is a happy and relaxed girl who is feeling well. Sara is now able to finish her scholarly tasks in time, do some extra work and knows how to stand firm in life. (Below mentioned quotes from Sara reflect on how she is doing at the present moment.)

All involved practitioners are proud of the treatment process, guidance and support of Sara and her parents in the past years. While looking at Sara they see a resilient girl who is facing her future with confidence together with her parents and her 4 year old sister.

By using each other's qualities, knowledge and strengths the practitioners and Sara's parents were able to create a full circle of support around Sara. They covered all areas of humanity: physical health, personal identity, development, relations, social functioning, psychological health, cognitive functioning, behavior.

The "epilepsy iceberg" is used as a model to explain which factors play a role in children with epilepsy in daily functioning at school: the iceberg illustrates that there is a lot more going on below the surface .



The humanities are about what it is to be human. As health care professionals we constantly have to be triggered to understand what the effects of a disease are on all areas of being human. By making yourself realize the impact of a disease on all areas of life, you realize how much work there is to do with your patient to make life work again.

As Professor Raymond Tallis stated as follows (Philosophy Now, 2009) : "there is a distinction between the epileptic fit, and the person who has the fit, and the actions by which he tries to cope with it." It is in this complex constellation that we tried to make all factors work together, to reach synergy at last, in an important period of the development of a young child , the period of learning how to read and write. Also a period in which children need to experience success in scholarly tasks to build self-esteem, that is necessary for future functioning.

If we keep a close eye on the human factor in our day to day health care practice, as we have tried to show in this paper, it is possible to empower patients and their caretakers. This results in a very rewarding experience.

Quotes from Sara and her parents....

Parents: "We worried a lot, so it was very helpful to have guidance of a pediatric neurologist who is providing more than just the medication"

Parents: "All practitioners focused solely on Sara's needs and wellbeing"

Parents: "Sara felt lousy, she just wanted to be just like her friends. She gained a lot in meeting the other children with epilepsy. Having EEG threads on her head during breakfast at the Academical Centre for Epileptology together with the other children makes her feel like she is not alone anymore"

Parents: "We appreciated the complete approach. We didn't have to invent it all by ourselves. The care for children with epilepsy in the Netherlands is well organized which helps in preventing problems. Everybody in this process just cared for Sara and her wellbeing"

Sara: "Mathematics is going much better, as well as language education, orthography and writing. Reading, I love it, all those books! I also want to write a book again. Yesterday evening I was reading and writing. I was in a wonderful fantasy world. Reading is so nice, once you get better at it"

Sara: "I am so happy to go to school. I am hopping to school. Sometimes I wish schooldays would last a little longer. Comprehensive reading is very easy and fun to do. In crafts I can make very creative objects"

Sara: "Sometimes I rate myself with an 8 or a 9 and sometimes a 6. For instance, when I'm a bit upset while waking up. I try to think of something nice. When I think positive, I start to smile, which is an advice I got from my teacher. I have to say it out loud and it

works! I am very happy when I rate myself a 10. You can see it in my eyes. My eyes are very cheerful”

We, as practitioners involved, are very grateful for Sara and her parents for giving their permission for publication of their story.

Practitioners involved

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A special ambulatory educationalist school guidance service for children with epilepsy