Epilepsy – more than seizures

Scientific paper: This article provides insight into what it can mean to have epilepsy, and where the emphasis should be placed when kindergartens and schools make accommodations for children with epilepsy.

***Marte Årva**, Special Needs Teacher at Solberg School – Specialist Hospital for Epilepsy (SHE)*

***Silje Systad**, Advisor in Special Needs Education at the National Centre for Rare Epilepsy-Related Diagnoses – Oslo University Hospital (OUH)*

***Christiane Sørensen**, Special Needs Teacher at Solberg School – Specialist Hospital for Epilepsy (SHE)*

Every year, about 600 Norwegian children are diagnosed with epilepsy (Aaberg et al., 2017). There are great differences among children with epilepsy (Nakken, 2010), but they all share a risk of having or developing related conditions.

Knowledge about epilepsy and common related conditions, as well as an understanding of the importance of epilepsy for learning, development and functioning, is necessary in order for successful accommodations to be made.

What is epilepsy?

The word *epilepsy* means 'to be seized upon', reflecting the fact that epilepsy has traditionally been defined as a seizure disorder (Dalen & Engelsen, 2002). Today, epilepsy is an umbrella term for a number of disorders and syndromes caused by a disruption to electrical activity in the brain. Epilepsy is often accompanied by neurological, medical, developmental and psychiatric conditions (Aaberg et al., 2016; Nakken & Brodtkorb, 2015) and can be the cause or contributory cause of children's difficulties.

Epilepsy is the most commonly occurring chronic neurological condition. Around 0.66% of Norwegian children under the age of 10 live with an active epilepsy (Aaberg et al., 2017). Kindergarten children, in addition to adolescents and the elderly, are most prone to developing epilepsy.

A diagnosis of epilepsy is given when the individual has:

- two unprovoked epileptic seizures less than 24 hours apart
- one unprovoked epileptic seizure and a probability of further seizures that is at least as great as with those who have had two unprovoked seizures (greater than 60% risk)
- a defined epilepsy syndrome (www.epilepsibehandling.no)

Although epilepsy is a clinical diagnosis based on the individual's symptoms and medical history, this diagnosis is supported by examinations such as electroencephalograms (EEG), brain imaging (MRI, CT) and genetic tests.

Epilepsy is not a single disease, but includes a number of epilepsy diagnoses and epilepsy syndromes that differ with respect to incidence, cause, seizure type(s), age of onset, chronicity, other symptoms, prognosis and more (Nakken, 2010). The range of seizures, signs and symptoms

is very broad. Epilepsy in children can also result in subtle symptoms that are not immediately associated with epilepsy.

Epileptic seizures

An epileptic seizure is a transient manifestation of sudden and uncontrolled electrical discharges in the brain. The electrical discharges are due to an imbalance in the mechanisms that inhibit and activate electrical activity in the brain cells (neurons). The discharges can take place in a limited area of the brain or spread to the entire brain. Epileptic seizures are therefore divided into two main groups: focal seizures and generalized seizures. During focal seizures, networks of brain cells in a limited area of one cerebral hemisphere will have epileptic outbreaks. During generalized seizures, both hemispheres are affected. If there is a lack of information to classify the seizure as either generalized or focal, it is referred to as unclassified.

How do epileptic seizures develop?

There is great variation in how epileptic seizures develop. The electrical discharges can cause motoric, sensory, autonomic, emotional, cognitive and behavioural symptoms (Henning & Nakken, 2017).

Generalized seizures always result in loss of consciousness for a shorter or longer period of time. Otherwise, they behave very differently. Some of the seizures are undramatic and almost imperceptible, while others can be experienced as highly dramatic. Seizures with loss of consciousness, and contraction of the muscles together with shaking (generalized tonic-clonic seizures [GTC]) are often associated with epilepsy. However, only around 30 percent of the epilepsy population have such seizures. Other generalized seizures of a motoric nature are contractions (tonic), shaking (clonic), sudden loss of muscle tone (atonic), twitching in the shoulders and arms (myoclonus) and epileptic spasms. Generalized seizures can also be of a non-motoric nature, called absence seizures (absences).

In focal seizures, the child has either maintained or reduced consciousness. Focal seizures can also be of a motoric or non-motoric nature, depending on where in the brain the epileptic discharges are taking place. Non-motoric focal seizures may produce autonomic, behavioural, cognitive, emotional, or sensory symptoms. Some seizures have a focal onset but develop into generalized convulsions.

While many people have one type of seizure throughout their lives, others have several. For example, with some epilepsy syndromes there are certain types of seizures in infancy that are replaced by new types of seizures as the child grows older. Many seizures occur without warning, and start and stop abruptly. Others increase and decrease gradually. Seizures occur both when awake and during sleep. Falling asleep and waking up are often periods of vulnerability that increase the risk of seizures.

Frequency and duration of seizures

The frequency of seizures varies greatly from person to person. While some have few seizures during their lifetime, others have hundreds or, in rare cases, thousands of seizures on a daily basis. In general, children have more frequent seizures than adults. The frequency of seizures can also vary from period to period for the same individual.

The duration of epileptic seizures also varies. Some last for brief moments (less than a second), while others last for many minutes. The vast majority of epileptic seizures (95%) stop on their own within one to two minutes. On rare occasions, seizures do not go away on their own and can last for hours and days. In children, seizure activity beyond 30 minutes duration is usually categorized as status epilepticus. The same time frame applies to seizures that repeat themselves without the

child recovering between seizures. According to the knowledge-based guidelines on epilepsy, there is currently agreement on an operational definition, which for GTC status limits the term to seizure activity that lasts longer than five minutes (www.epilepsibehandling.no).

Status epilepticus usually requires hospitalization. Cases of status epilepticus where the individual has seizures with loss of consciousness, contractions and shaking (GTC) are particularly serious and potentially life-threatening. Hospitalization is thus necessary (ibid.).

Seizure-suppressing medication

Some epileptic seizures require first aid in the form of treatment with seizure-suppressing medication. The medication should be administered according to the doctor's written instructions (treatment schedule), after a set time, and in the correct dosage. The medication must be kept with the treatment schedule and be available at all times, but at the same time stored securely so that it is inaccessible to unauthorized persons. Circular 1-5/2008, 'Håndtering av legemidler i barnehage, skole og fritidsordning' ['Management of medicines at kindergarten, school and during after-school programmes'] states that kindergartens and schools are also responsible for assisting in managing medicines such as seizure-suppressing medication.

In Norway, the specific medications used are Buccolam (midazolam) and Stesolid (diazepam). Buccolam is administered by mouth, alternatively into the nose. Stesolid is administered into the rectum. It is important to be aware that the dosage changes as the child grows, and that the expiry date of the medication should be checked at regular intervals. In order to know if and when to administer seizure-suppressing medication, it is important to count the time elapsed from the onset of the seizure. The characteristics of the onset and end of the seizure should be clearly defined so that one can assess whether the seizure has stopped or whether seizure-suppressing medicine should be administered. In the case of convulsions (GTC), for example, the time should be taken from when the contractions begin until the symmetrical shaking throughout the body stops. You can use the stopwatch on your mobile phone or a wristwatch with a second hand. If seizure-suppressing medication is administered, most seizures will stop within 5–10 minutes. If seizure-suppressing medication does not stop the seizure within five minutes, contact the Emergency Medical Communication Centre on 113.

Proper training in seizure-suppressing medicine is vital for the child's safety. It is recommended that the training is given directly by health personnel, but in collaboration with parents. A nurse, GP or epilepsy nurse, nurse and social worker at the country's paediatric wards and rehabilitation services can usually help with this training. Where there is no access to professionals with sufficient competence, it is possible to seek advice from the Specialist Hospital for Epilepsy (SHE). For those who have a rare epilepsy-related diagnosis, contact can be made with the National Competence Centre for Rare Epilepsy-Related Diagnoses. There is a video on YouTube showing how Buccolam is administered. (https://www.youtube.com/watch?v=xOk9y9b9Ej8).

Symptoms before and after seizures

It is important to be aware that many children show signs both before (pre-ictal phase) and after (post-ictal phase) the seizure itself. The phases can last from minutes to days. The post-ictal phase (recovery phase) lasts from the onset of the seizure until the person has regained normal function, and is not always easy to distinguish from the seizure itself. However, it is important to distinguish the recovery phase from the seizure in order to know when to administer the seizure-suppressing medication and when to establish status epilepticus.

In the pre- and post-ictal phase, some children experience a functional change. They may become restless, inattentive, or have difficulty remembering or speaking. The post-ictal phase manifests itself in different ways, and its severity varies according to the individual (Josephson et al., 2016).

Fatigue and a need for sleep or rest often occur. In addition to those symptoms mentioned above, the child may also act inappropriately. Effective accommodations for children with epilepsy should also take into account symptoms before and after seizures.

Epileptoid activity without seizures

Many children who have epileptic seizures also show epileptoid activity without seizures. On the other hand, epileptoid activity without seizures also occurs in children who do not have epilepsy. Such activity can only be detected by EEG and occurs both in the conscious state and during sleep. With certain syndromes of epilepsy, some individuals only show epileptoid activity. Although these children do not have epileptic seizures, they currently still receive an epilepsy diagnosis (cf. the definition of epilepsy).

Epileptoid activity without seizures is found in some children with autism spectrum disorders, among others (Ghacibeh & Fields, 2015). The same applies to children with language difficulties (Systad et al., 2019). Studies have shown that a small proportion (0.3–2%) of the normal population has such activity (Nakken, 2010). However, Cavazzuti, Cappella & Nalin (1980) argue that people with epileptoid activity do not represent the normal population because they are often described as having difficulties.

Frequent epileptoid outbreaks can have serious consequences and cause a stagnation or regression in cognitive functioning (Camfield & Camfield, 2019; Holmes, 2014). This phenomenon is called epileptic encephalopathy. Continuous or almost continuous epileptoid activity during sleep is believed to affect wakefulness and general condition, memory function, behaviour, language and communication, learning and processing rate (Camfield & Camfield, 2019; Maltoni et al., 2016; Tuft et al., 2015).

Epileptoid activity can disappear in adolescence, as it usually does when acquired aphasia with epilepsy (Landau-Kleffner syndrome) is diagnosed. Landau-Kleffner syndrome is an epileptic encephalopathy in which healthy children with normal development partially or completely lose the ability to perceive, process and interpret sound (auditory agnosia). Unfortunately, the difficulties that have established themselves during the progression of the disorder often persist to a greater or lesser degree, even if the epileptoid activity disappears.

Causes

There are many causes of epilepsy. For example, injuries, tumours and diseases that strike or affect the cerebral cortex will increase the risk of epilepsy. In addition, epilepsy occurs in connection with structural changes (including malformations) and as a result of immunological or metabolic disease (www.epilepsibehandling.no).

Moreover, pathogenic genetic changes (gene mutations) are a cause of epilepsy. Some gene mutations are inherited, while others are novel (de novo). It is believed that gene mutations are both a direct cause of epilepsy and lead to changes in the brain that cause epilepsy (ibid.). Research into human genetic material (DNA) in recent decades has revealed a number of gene mutations associated with epilepsy. Further research is likely to reveal more. In around 60–70% of patients with epilepsy, no definite cause of epilepsy is found (ibid.).

Prognosis

The prognosis varies from child to child and is influenced by factors such as cause, epilepsy diagnosis, seizure type and seizure frequency. Factors such as age at onset of epilepsy, how long the child has had epilepsy, and the effect, or lack of effect, of epilepsy medications will also play a role in the prognosis. Environmental factors, including pedagogical arrangements, will naturally be able to influence how the child develops.

It is estimated that 60–70% of the epilepsy population has an easily treatable epilepsy. For example, children with Rolandic epilepsy often have seizures that are easy to treat and that cease spontaneously in adolescence. In the remainder, the epilepsy is categorized as difficult to treat or treatment-resistant. Epilepsy diagnoses and epilepsy syndromes such as some epileptic encephalopathies (e.g. Lennox-Gastaut syndrome and Dravet syndrome) are associated with very high-frequency and/or severe seizures, which in addition are treatment-resistant and lead to continuing hospitalizations.

Epilepsy is usually a chronic condition. However, about one-third may eventually be able to stop taking medication. It is estimated that about half of children with epilepsy are seizure-free in adulthood (Aaberg et al., 2017).

Epilepsy is not a static condition, but changes many times over the course of the disorder. In some subgroups of the epilepsy population the disorder will have a progressive course with varying degrees of cognitive decline (Seidenberg et al., 2007).

People with epilepsy have a two-to-three times increased risk of premature death. The reason for this increased mortality is first and foremost the underlying cause of the seizures, but also seizure-related accidents and status epilepticus. In addition, sudden unexpected death in epilepsy (SUDEP) is a cause of death (www.epilepsibehandling.no).

Comorbidity and related conditions

Children with epilepsy have an increased risk of comorbidity and related conditions. In a comprehensive study based on data from the Norwegian Patient Register, 78.3% of children with epilepsy had one or more comorbid conditions (Aaberg et al., 2016). Some epilepsy diagnoses or epilepsy syndromes are associated with high comorbidity and related conditions, while others are not. The greatest risk is found among epilepsy that affects the very youngest, as well as in difficult-to-treat epilepsy. However, it is worth noting that comorbidity and related conditions are also common in children with what is known as uncomplicated epilepsy (Aaberg et al., 2016).

Comorbidity and related conditions may occur before, at the same time, or after the onset of epilepsy. They may be the cause itself or share the same underlying cause as the epilepsy. Comorbidity and related conditions can of course also occur independently of the epilepsy, or be consequences of epileptic seizures, epileptoid activity without seizures, and epilepsy medications. These conditions often present greater challenges for the child than the epilepsy and seizures (Aaberg et al., 2016; Soria et al., 2012).

The list of possible comorbidities and related conditions is long. It is comprised of conditions that affect brain function and development (neurological), as well as a wide range of medical, developmental and psychiatric conditions. Slightly more than one in ten children with epilepsy has additional neurological, medical and developmental/psychiatric difficulties (Aaberg et al., 2016). Common neurological conditions in children with epilepsy include cerebral palsy (CP) and headaches, while additional medical problems include sleep problems, eating and nutritional problems, asthma, gastrointestinal problems and vision problems (Aaberg et al., 2016). Of developmental and psychiatric difficulties, a variety of learning difficulties, developmental disabilities, autism spectrum disorders (ASD) and ADHD, as well as others, are reported. The incidence of such comorbid difficulties is significantly higher in children with epilepsy compared to the normal population. For example, around 20% of children with epilepsy have developmental disabilities (Berg, Tarquino & Koh, 2017), while the incidence of developmental disabilities in all children in Norway is 1–3% (NOU, 2016: 17). The incidence of ASD and ADHD is also elevated in people with epilepsy (Besag, 2018; Auvin, 2019), although the rates of incidence vary from study to study. Aaberg et al (2016) found that almost 8% of Norwegian children with epilepsy have ASD

and that around 12% are diagnosed with ADHD. In addition, almost all children with the dual diagnosis of epilepsy and autism spectrum disorder also have developmental disabilities (Berg, Tarquino & Koh, 2017).

Many children with epilepsy have significant difficulties even if the criteria for an additional diagnosis are not met. For example, many children have attention problems even though they do not have an ADHD diagnosis. Many also struggle with other executive functions, such as planning, getting started and finishing, as well as regulating behaviour and emotions. Variable general condition and increased fatigue are very common. The same is true of memory function, language and learning difficulties. Many have a low processing rate (Wodrich et al., 2011), and it has been documented that setbacks or difficulties persist. Thus, there is no longer any basis for calling something 'just epilepsy', or as the authors Berg, Tarquino & Koh (2017) stress: 'There is no such thing as just epilepsy'.

Making accommodations

Although vulnerability to comorbidity and related conditions in children with epilepsy is well documented, kindergarten and school staff often focus on the seizure-related aspects of the conditions (Olsen, 2007). For example, questions are often asked about how seizures develop, what to do in the event of a seizure, and not least how to deal with seizure-suppressing medication. Obtaining answers to such questions is of course highly necessary, but still not sufficient for effective adaptation in kindergarten and school. In other words, knowledge about the management of seizures is not sufficient to make accommodations for learning, development and quality of life in the individual child. What is needed is an understanding that, in addition to the medical and seizure-related situation, also includes the developmental and psychiatric situation, as well as knowledge of how these situations affect each other.

Pedagogical adaptation

There is a great difference between children with epilepsy, and it is therefore difficult to generalize in terms of making pedagogical adaptations for the group.

Moreover, research on children with epilepsy is especially limited, so it is often recommended that adaptations are made in the same way as for other children who have similar difficulties. Based on our experience, we nevertheless highlight some circumstances that are particular to and often relevant for children with epilepsy.

Understanding

It is important to seek knowledge about the diagnosis and the child's possible related conditions (see the end of this document for useful places to seek knowledge). It is equally important to get to know each individual child through one's own experience and that of colleagues as well as through the knowledge of parents.

All children with epilepsy have a brain dysfunction. This means that both the underlying cause and epileptic activity can disrupt the maturation processes in the brain and affect the brain's development and organization (Lepeta et al., 2016; Holmes, 2014). For some children, this has an impact on how the brain works, how efficient and flexible it becomes, how it affects the conditions for learning, and what difficulties they have. Because many of the difficulties are contingent on the brain as an organism, it is important to acknowledge that the child cannot simply 'get over it'. Much of the adaptation is therefore more a question of offering rather than expecting learning.

Evaluation

Kindergartens and schools play an important role in detecting signs of developmental delays, developmental disorders or other difficulties in children with epilepsy. Kindergartens and schools should therefore regularly chart and assess the child's development. The assessments should be carried out even if there is no suspicion that the child has difficulties. One should be attentive to common difficulties in epilepsy in general, and for prominent difficulties in the epilepsy diagnosis the child has in particular. Comparing assessments made on a regular basis from an early age will provide good insights into the child's development, and will aid in detecting difficulties at an early stage. Children with epilepsy are children at risk, and many require extra resources and special needs assistance or special education (Wodrich et al., 2011). The threshold for referral to the educational and psychological counselling service and other agencies should therefore be low. Assessments can take a long time; it is therefore important not to wait for the conclusions from studies, but to ensure the best possible adaptation at as early a stage as possible. The adaptation can then be adjusted as the reports are completed.

It can be easy to give epilepsy both too much and too little weight. On the one hand, attention difficulties can be explained as a consequence of frequent absence seizures when in reality it has roots in ADHD. On the other hand, difficulty with concentration can be attributed to ADHD when in reality it has roots in frequent seizures. In both cases, there is a risk that the adaptation will be misjudged. An important part of the evaluation will thus be to highlight all potential difficulties, study them individually and in relation to each other, and investigate causal factors.

Since epilepsy is not a static condition, it is essential to evaluate potential difficulties regularly so that one always has an updated understanding of the child's situation and causality. It is important to be aware that what you experience as effective adaptation at one point in time will not necessarily be so later. As the course of the disorder progresses, there will be a continuing need to increase the number of measures.

Flexibility

Many children with epilepsy are marked by variable days and good and bad periods (Aldenkamp & Arends, 2004). This means, among other things, that there is variation in their ability to concentrate and retrieve the knowledge they actually possess. Parents and kindergarten/school staff often describe that the child 'can do it one day, but can't do it the next'. For kindergarten and school staff, it is important to be sensitive to the child's daily routine and to be flexible with regard to adaptations. Many rely on one-to-one supervision to ensure a sufficient and continuous level of flexibility. The general condition of children with epilepsy can also fluctuate over the course of the day. For a variety of reasons, some children are out of sorts in the morning and therefore work best in the afternoon. Other children with epilepsy can become very tired from a day at kindergarten or school and thus be in their best shape in the morning. Considerations should thus be made in each individual case whether it makes sense to plan cognitively demanding activities earlier or later in the day.

Since the difficulties are related to the brain as an organism, they are out of the children's control. They therefore have few opportunities to work towards improvement. On the contrary, it can seem upsetting to children that emphasis is placed on skills they do not possess. An effective strategy may be to offer the child alternative ways to respond or participate. For example, one can invite the child to respond in words or by pointing to pictures. Because it is often easier to recognize than to recall, having aids in the form of pictures or writing will be of great help to a child with epilepsy. Visual aids can also alleviate the inability to keep track and organize oneself, although many are still dependent on appointed adults in this context.

The children's variable general condition and variable access to skills mean that they are dependent on adults who are flexible. They need a system that can adapt to them at any time. As

such, an individual teaching plan (ITP) can be divided into plan A and plan B activities as appropriate. This outlines which activities should be offered on a good day (plan A), and which activities should be offered on a bad day (plan B).

Shielding

Children with epilepsy are vulnerable and need varying degrees of shielding during a kindergarten or school day. The reason for this is that many become disturbed when there is too much information and too many sensory inputs to which to relate. For example, playing outside during breaktime with many other children can be very tiring and may not necessarily serve as a break activity for all. It is not unusual, then, for them to require a rest after breaktimes.

Many children with epilepsy have difficulty separating relevant sound inputs and are easily disturbed by ambient noise. They thus have difficulty understanding general messages or following classroom instruction. For some, shielding in the form of one-to-one adaptation is crucial in learning situations. Many children with epilepsy are sensitive to sound and become tired by noise, and need their own space to which they can withdraw.

Adaptation according to capacity and interest

Children with epilepsy generally have less capacity than other children (Kwon & Park, 2016). Many of them have a reduced processing rate and need more time to understand and process information and perform tasks. It can be difficult to concentrate and sit still for longer periods. Even though they may become exhausted from cognitively demanding tasks, they may still have the capacity for play and other types of pleasurable activities. We often experience that children with epilepsy require more frequent breaks, more air and more movement than other children. For some, frequent breaks combined with short sessions and varied teaching and learning, often of a practical nature, will work best. Likewise, teaching and learning on the basis of the child's motivation and interests will work well. For school-age children, the amount of academic material often has to be reduced, and homework dropped.

The acquisition of new skills is difficult for some, and it is often seen that the automation of skills is particularly challenging. Kindergarten children may have difficulty learning counting rhymes, song lyrics or rules by rote, while school-age children may have difficulty learning the alphabet or multiplication tables. When skills are not automated, nor is memory unburdened so that capacity can be freed up. This means that for children with epilepsy, cognitive exercises are more energy-sapping than for many other children. In this case, appropriate adaptation may be filled with contrasts. For example, repetition, which is important for automation, may be unsuitable since the capacity of many children is limited. It is often necessary to offer learning through alternative and compensatory measures. Many children benefit from digital tools and teaching aids.

Seizure-related accommodations

Children with epilepsy will need varying degrees of seizure-related accommodations. It is often necessary for someone to keep an eye on them at all times so that seizures can be detected. A description of seizures should be available to those who work with the child, and be made known to all staff at the kindergarten or school. The description should include how the seizure begins, how it progresses, and signs that the seizure is over or about to be over. If the child shows indications that a seizure is in progress (aura), information should be provided about how this can be recognized. Considerations that have to be taken into account after a seizure, such as the need for rest, shielding or sleep, as well as what to do in the event of a seizure, should also be noted in the description of seizures. Many people find that exchanging video recordings of seizures is helpful. It is also useful to exchange videos of seizures, or suspected episodes of seizures with the doctor in charge of treatment. As described earlier, all children with epilepsy should have a

treatment schedule for seizure-suppressing medication. This procedure should describe when and how to stop seizures. The medication and the treatment schedule must be kept together in a secure location and be available to all those responsible for the child. It may be useful to gather everything in a small bag that can, for example, be easily carried on trips.

It is important to keep a record of how many seizures the child has. Accurate records and observations of seizures are often especially important when changing medications. However, it can be a challenge to keep a record of all seizures. It may, for example, be difficult because the seizure is short and inconspicuous, or because the child has very many seizures. In such cases a pragmatic approach is to keep a record only of large or conspicuous seizures and to set aside 30–60 minutes every day as a fixed period of observation. It is recommended to clarify with parents precisely how seizures should be recorded. For example, suitable booklets for the recording of seizures (seizure calendars) are available. Printed seizure calendars can be downloaded from the website of the Specialist Hospital for Epilepsy (SHE). Seizure calendars can also be purchased via the Epilepsy Association's website or downloaded as an app. An ordinary notebook (communication book) also serves the purpose. In such communication books there is room to write more about general condition, kindergarten and school activities, events, messages and so on. This can be important for an overall assessment of the child's condition and the development of the disorder.

A common issue is whether the child should be taken home following a seizure. Apart from seizures that require hospitalization, it is recommended that kindergartens and schools be given training so that they have sufficient knowledge, and are allocated sufficient resources, to take care of the child following the seizure. However, because needs and wants vary, this should be individually tailored. While some parents want a phone call or wish to collect the child, other parents think it is sufficient to receive information when they collect the child at the end of the day. Another issue that is relevant to discuss is: When must the child be kept at home? For example, should the child remain at home following night-time seizures, or can he or she come to school later in the day?

Although we rarely know when a seizure is going to occur, we know of several seizure-inducing factors. Stress, of both a positive and negative nature, is one example of such factors. Thus, accommodations that reduce stress can improve the child's seizure situation. Stress-reducing accommodations may include safeguarding the child's needs and providing a sense of being able to cope with kindergarten and school life. There are separate guidelines for swimming activities for people with epilepsy. Kindergartens and schools must familiarize themselves thoroughly with these guidelines.

Checklist for cooperation between kindergarten/school and home:

- What type of epilepsy does the child have?
- Descriptions of seizures
- Is the child able to recognize that a seizure is coming?
- Any special precautions?
- When should parents be contacted?
- Is there a need for rest and recuperation after a seizure, and for how long?
- What should be observed, reported?
- Information for staff, children and parents. How much? Who?
- Procedures for seizure-suppressing medication
- What are the consequences of the epilepsy?
- Any related conditions?

Parental cooperation

For many parents, letting others assume the responsibility for their sick children is a difficult task. It is especially difficult at an early stage when there is often a great deal of uncertainty associated with the child's illness, seizures and prognosis. For parents of children with difficult-to-treat or treatment-resistant epilepsy, the situation is demanding over an extended period of time because the situation often remains unresolved. Among other things, repeated tests and hospitalizations are a strain on both children and parents. In addition, changes to medication are often time-consuming, with it taking several months before the effect of some epilepsy medications becomes clear. Many epilepsy medications have undesirable side effects and lead to the child needing to change the medication.

Parents of children with epilepsy have an increased burden of care. Therefore, the parents' needs for relief should be assessed. Among other things, there is an increased incidence of stress, sleep problems, depression and anxiety in parents of children with epilepsy (Rodenburg et al., 2007; Ellis et al., 2000). They also exhibit a higher degree of worry related to the medical aspects of epilepsy, such as seizures, seizure management, epilepsy medication and seizure-suppressing medication. Concerns about the child's development, learning, social participation, comorbidity and related conditions are also common (Jensen et al., 2017). As the child approaches adulthood, these worries are often associated with their prospects of gaining an education, getting a job and living independently.

Effective co-operation between kindergarten/school and home is crucial in order to safeguard the child's health and self-realization. Close and continuous cooperation is especially important in order to safeguard the child's needs because epilepsy is often a condition that is under constant change. Seizures can change and difficulties can appear gradually and fluctuate over time. The foundation for good cooperation is that parents experience kindergarten/school as interested in understanding the situation and engaged in creating the best possible daily life for the child. It is also important that both parties involve and inform each other. When parents are confident that the child will be cared for in kindergarten or school, they are also given a real opportunity to engage in their own working life. Although it is up to each individual child and guardian, it is recommended to take an open approach to the child's epilepsy in kindergarten and school.

In addition to general procedures for effective cooperation, cooperation with parents should, among other things, clarify whether there is a need for extra resources (special needs education) or referral to the educational and psychological counselling service, individual teaching plan or core group, and the need for training and guidance must be assessed.

Useful websites and informational material

In recent years, a number of digital learning tools on epilepsy have been published. Free material is available on the website of the Specialist Hospital for Epilepsy (SHE) (https://oslo-universitetssykehus.no/avdelinger/nevroklinikken/spesialsykehuset-for-epilepsi-sse/anfallskalender-ved-epilepsi) and at Sjelden.no. The Specialist Hospital for Epilepsy's (SHE) website contains videos of seizures and other training materials in addition to the digital learning portal. Sjelden.no has an e-learning course about the seizure-suppressing medication Buccolam.

The knowledge-based guidelines for epilepsy are available online (www.epilepsibehandling.no), and the e-learning course 'Grunnkurs i epilepsi for helsepersonell' ['Basic course in epilepsy for health professionals'] can be purchased at helsekursportalen.no. Useful information can also be obtained from the website of the Norwegian Epilepsy Association: www.epilepsi.no. Patient information about the various antiepileptic medicines is available online: https://oslouniversitetssykehus.no/avdelinger/nevroklinikken/spesialsykehuset-for-epilepsi-

sse/epilepsimedisiner-antiepileptika. This states what side effects antiepileptic drugs often cause, among other information.

Films and books about epilepsy for children are available. 'Rudy og lynmonsteret' ['Rudy and the Lightening Monster'], 'Epilepsi – barn forteller' ['Children Talk About Epilepsy'] and 'Lyn i hodet – kul i panna' ['A Head Full of Lightning and a Bump on the Forehead'] are examples of books that address what it can be like to have epilepsy, and how it can be to have a sibling with epilepsy. The cartoon film 'Turen som falt i fisk' ['The Trip that Went Wrong'] also discusses what it is like to have this disorder. The Specialist Hospital for Epilepsy (SHE) can be contacted for further information on suitable children's material. You will also find information on the Norwegian Epilepsy Association's website, www.epilepsi.no.

About the authors:

Marte Årva trained as a kindergarten teacher and holds a master's degree in special needs education. She has worked at the Specialist Hospital for Epilepsy – SHE for a number of years and was recently employed as a special needs teacher at Solberg School – SHE. Previously, she was an advisor on special needs education at the National Competence Centre for Rare Epilepsy-Related Diagnoses, OUH, and a special needs teacher at a special needs education observation unit at the Specialist Hospital for Epilepsy – SHE. She is still affiliated with the competence centre and the children's department at SHE.

Silje Systad holds a master's degree in special needs education and a PhD in nocturnal epilepsy and language difficulties. She has recently become an advisor on special needs education at the National Competence Centre for Rare Epilepsy-Related Diagnoses – OUH, but previously spent several years working as a special needs teacher at Solberg School – SHE.

Christiane Sørensen trained as a kindergarten teacher and teacher for the hearing impaired and holds a master's degree in speech therapy. She has worked in the epilepsy field for a number of years and is employed as a special needs teacher and assessor at Solberg School – SHE.

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