FILADELFIA

Epilepsy and autism
– a challenging dual diagnosis

– for social educators, psychologists, teachers, youth guidance advisers, and local-authority social and healthcare employees

Dear Reader,

It can be difficult for professionals in schools, daycare and residential institutions, and job centres to know how best to support people with a dual diagnosis such as epilepsy and autism.

Special Advisory Services for Epilepsy advises on the challenges every day. We hope this leaflet can contribute to your daily work relating to people with epilepsy and autism.

Use the booklet as a reference tool. If you have any doubts or questions, please contact us. With us, advice is free.

The booklet is a translation of the Danish version, which was itself a translation from the original Norwegian. Thank you to everyone who contributed.

Happy reading!

Special Advisory Services for Epilepsy
Filadelfia

Table of contents

EPILEPSY AND AUTISM

Epilepsy is one of the most common neurological diseases. Autism is defined as a pervasive developmental disorder with extensive functional impairment.

Comorbidity is when a person has several diseases at the same time. However, the symptoms often overlap. Epilepsy and autism will therefore be referred to as a dual diagnosis or comorbidity.

People with a dual diagnosis are a heterogeneous group. Their cognitive, communication, interaction and motor skills vary greatly. Most will be mentally developmentally impaired, have a low level of functional ability and a continuous need for supervision and support. Some will be able to go to school/work and have a high level of independence. They may need personalised services and follow-up based on the best available knowledge and experience relating to the individual issues.

Distinguishing epileptic seizures from behaviours caused by autism is often challenging, and treatment approaches vary widely.

AUTISM

Autism spectrum disorder (ASD) refers to conditions characterised by qualitative functional disturbances in three areas. The most dominant symptoms, also known as cardinal symptoms, are often seen as difficulties relating to social interaction and communication/language, as well as repetitive behaviour or specific and limited interests and activities. The conditions are designated as pervasive because the difficulties affect most areas of functioning and development.

Autism is a developmental disorder characterised by a different and often delayed development of social and communication skills.

All children and young people with suspected early autism should therefore be referred for a child and adolescent psychiatric examination. Given the often positive effect of early intervention, it is important that the referral is made as early as possible. A referral to a child and adolescent psychiatrist must be based on a reasonable suspicion and a prior examination by, for example, the educational-psychological counselling service.

Prevalence

The Danish Authority of Social Services and Housing estimates that 35-55,000 people in Denmark fulfil the clinical criteria for an ASD diagnosis. The gender split is four boys to one girl (4:1) when ASD does not occur together with developmental impairment. In contrast, the ratio is 2:1 when ASD occurs together with developmental impairment. However, the figures are subject to uncertainty because Asperger's syndrome and its traits are often not diagnosed until late in childhood or adolescence.

Causes

ASD is biologically determined. The cause does not lie in a single gene, but probably in an interaction between different genes. Pregnancy and childbirth complications can, like brain infections, increase the risk of the child developing ASD.

Primary difficulties and additional problems

To understand autism, a distinction can be made between the primary symptoms, which are specific to the diagnosis, and additional or comorbid issues. The primary difficulties relate to the ability to understand and engage in social interaction, the ability to communicate socially, and a particular behaviour characterised by routine/repetition that manifests itself in play, interests, activities and movement.

Especially if the person has learning difficulties together with ASD, repetitive behaviour may be evident that can be misinterpreted as epileptic seizures. Examples of this are stereotypic movement disorders, such as body rocking or hand waving. With age, this repetitive behaviour may transform into an extreme addiction to certain routines. Professionals need to discuss what difficulties are part of an autistic developmental trajectory and whether there are any other challenges that are closely associated with ASD.

Comorbidity is estimated to occur in 70-83% of autism cases, and between 26-41% of people with autism have at least two comorbid conditions. This means that 70-83% of people with autism have a condition in addition to autism, such as epilepsy, and that 26-41% of this group have another diagnosis in addition to autism and epilepsy, such as developmental impairment.

When diagnosing autism, attention should therefore be paid to the presence of comorbid psychological and medical conditions, such as mental disorders, neurological or genetic diseases.

**Comorbidity
occurs in**

70-83%

of autism cases

**Of people with epilepsy and
autism**

26-41%

**have an additional diagnosis,
e.g. developmental impairment**

EPILEPSY

Inorder for a person to be diagnosed with epilepsy, they must have two unprovoked epileptic seizures more than 24 hours apart.

76,000 people in Denmark live with epilepsy. This equates to around 1% of the population. Epilepsy is a diverse group of diseases with recurrent epileptic seizures as a common denominator. The seizures are an expression of episodic/transient disturbances in brain function. In addition to seizures, these disturbance can cause lasting cognitive challenges and thus have psychosocial consequences. The disturbances are caused by brief abnormal electrical activity in a network of nerve cells, mainly in the cerebral cortex. Epilepsy is a chronic condition. Epileptic seizures can sometimes be triggered by specific circumstances, such as fever or stress.

Brain injury or disease (congenital or acquired) increases the risk of epilepsy. Epilepsy occurs in all age groups. In approximately 25% of cases, the epilepsy begins before the age of 15, and similarly after the age of 65.

Causes

The causes of epilepsy are divided into six groups

1. Genetic epilepsy, where the cause is, or is assumed to be, an inherited or acquired defect in the genetic material. An example of genetic epilepsy would be one of the early-onset epileptic encephalopathies (diseases of the brain), such as Dravet syndrome
2. Structural (previously symptomatic), with a known underlying disease that causes a major or minor brain malformation. Examples of structural epilepsy include epilepsy in a child with a congenital malformation or a degenerative (worsening) disease in the brain, such as tuberous sclerosis
3. Metabolic, where changes in the organism's metabolism are the cause of the epileptic seizures, e.g. changes in the genes that code for sugar transport into the brain
4. Infectious, where the cause may be a central nervous system infection, such as meningitis
5. Immunological, where the epileptic seizures are due to changes in the immune system, e.g. Rasmussen's encephalitis.
6. Unknown, where none of the above can be identified as the cause of the epilepsy, e.g. cases with epileptic (infantile) spasms.

Some epileptic seizures are so subtle that they can be extremely difficult to detect, while others can be obvious and dramatic.

Epileptic seizures are not just the convulsive seizures that many people think of when they hear about epilepsy. In addition to convulsions, other symptoms can include blanking out, eye blinking, head turning, stiffness, twitching, falls, etc. Many people with epilepsy experience incontinence, foaming at the mouth and sweating during a seizure. Each specific type of seizure often looks the same from one episode to the next, but several different seizure types can occur in the same person. Epilepsy can also occur without immediately visible seizures. With nocturnal brain activity (detected via EEG), symptoms may be limited to nocturnal agitation and poorer daytime functioning in the form of mental fatigue and reduced learning ability.

Assessment

A comprehensive medical history, including a detailed seizure description and clinical/neurological examination, is very important.

In addition to a detailed analysis of epilepsy type and seizure type, it is important to have a broad, multidisciplinary assessment of functional
ability. For example, it may be relevant to look at mental functioning, including cognitive complaints, other consequences of epilepsy and comorbidities. This allows a more thorough and customised assessment in order to implement individual measures.

Many diagnoses are associated with an increased prevalence of epilepsy, such as ASD, hydrocephalus (increased fluid pressure in the brain), cerebral palsy and developmental impairment. Many people with epilepsy often have mental health issues, such as anxiety and depression.

Treatment of epilepsy

Treatment of epilepsy usually targets the symptom, namely the epileptic seizures. This means you cannot eliminate the cause of the epilepsy itself.

The treatment is usually medical – epilepsy medication must be taken as agreed with the treating doctor. There are many considerations to be made when choosing a medication – the determining factors are seizure type, epilepsy disease, age, gender and comorbidities.

It is important that the person with epilepsy, their family and their carers are thoroughly informed about the medical treatment, both verbally and in writing. The most common side effects are often transient, and by postponing an increase in medication, the side effects often disappear. In many cases, the effects of antiepileptic medication can take weeks or months to become apparent. If epilepsy medication is stopped abruptly, there is a risk of triggering seizures. Changes in medication must therefore be agreed with the treating doctor.
In some cases, it is very clear to the person with epilepsy and their carers that there are events/activities that trigger seizures – for others, it is not clear. It can therefore be particularly important to pay attention to a person's daily life and energy management.

Some people, depending on their epilepsy type, may be offered epilepsy surgery, including vagus nerve stimulation (VNS), while others may benefit from a special diet.

Side effects

The medical treatment can have various side effects. Non-epilepsy medication can also be affected by epilepsy medication – the effect can be increased or decreased. The treating doctor should always therefore be informed which medications the person with epilepsy is taking – including natural remedies – and what side effects they are experiencing. The doctor should be consulted about behavioural changes, cognitive challenges, increased fatigue, changes in appetite/weight, etc.

EPILEPSY AND ASD AS A DUAL DIAGNOSIS

There can be many different causes of both ASD and epilepsy. What they have in common is that genetics often takes centre stage.

In people with epilepsy, there is an increased prevalence of ASD and vice versa. While approximately 1% of the population have ASD and 1% have epilepsy, approximately 25-30% of people with ASD also have epilepsy. Up to 50% of people with ASD show epileptic activity in an EEG. People with epilepsy and people with ASD represent diverse groups, and there is as much variation in seizure types in people with a dual diagnosis of epilepsy and ASD as in people with epilepsy alone.

Early onset of epilepsy increases the risk of behavioural symptoms similar to those of ASD. Epilepsy and autism-like traits are common in diseases such as West syndrome, Rett syndrome, Angelman syndrome, Fragile X syndrome (FXS) and tuberous sclerosis.

Recurrent, consistent seizure phenomena should always raise suspicion of epilepsy. Epilepsy manifests in many ways, including in people with ASD. Although ASD is not linked to specific epileptic seizure types, studies suggest that focal seizures with affected consciousness are the most common. However, it is important to be aware of any episodes that may cause suspicion of epilepsy. This could be changes in behaviour, newly occurring language problems or sleep disturbances.

EEG examination

An EEG examination can provide a good basis for assessing a possible link between seizures and epileptic activity. If seizure triggers are known or suspected, it is crucial that they are reported prior to the examination.

Medical treatment of epilepsy and ASD

The combination of epilepsy medication and psychotropic medication can significantly increase the risk of side effects. Special care should be taken when using epilepsy medication, which can cause psychological and behavioural problems, such as anger, irritability, depression and externalising behaviour. This type of antiepileptic medication can exacerbate existing behavioural problems.

Side effects can be difficult to detect, especially in people with impaired verbal communication. Malaise, anger, refusal to eat, agitation and other specific symptoms may be side effects of the medication. On the other hand, natural fluctuations in the disease itself can be misinterpreted as side effects. Medications that inhibit epileptic activity can make a person more alert and active, which can be interpreted as side effects.

Epileptic seizures or symptoms of autism

People with ASD with mental developmental impairment often have complex psychosocial and behavioural difficulties.

It is important to investigate the symptoms, as different causes require different treatments and actions. If the cause of the symptoms is not investigated, there is a risk that the person with ASD will be given epilepsy medication on the wrong basis. This could cause serious side effects without improving the symptoms. Conversely, it is pointless to initiate a therapeutic intervention if the symptoms and behaviour are due to epileptic disorders.

Assessing seizures against behaviour

An epileptic seizure usually looks the same for each individual from one episode to the next, although many people experience multiple seizure types. If the pattern of the seizure varies from one episode to the next, it may indicate a behavioural issue. Epileptic seizures usually start and end abruptly. This is not always the case for behaviours rooted in autism or developmental impairment.

Conditions that can influence and cause seizures are called seizure triggers. Seizure triggers vary from person to person, and in some people there are no real triggers. Examples of seizure triggers include negative/positive stress, irregular taking of medication, lack of sleep, irregular lifestyle, hormonal changes such as menstruation, fever and constipation. However, conditions in the environment of the person with epilepsy can trigger behaviour that can be mistaken for epileptic seizures. Sudden changes in routine or an overly demanding daily schedule can be stressful and trigger seizures, but the same factors can also trigger unwanted behaviour.

Sometimes family/carers may have different perceptions of the person's symptoms. If the symptoms only occur in one arena, for example, when the person is in respite care, it may indicate that they are behavioural responses to a particular environment and not epileptic seizures. On the other hand, a particular environment may be stressful for the person and trigger seizures.

A seizure description may include the following points:

- What happens during a seizure – consciousness, movements, behaviour?
- How long does a seizure last?
- What was the first thing the person having the seizure felt/noticed?
- What was the person doing when the seizure started – sleeping, awake, eating, watching TV, etc.?

EEPILEPSY OR ASD

Here, we present the most common issues that residential institutions, schools and other places working with this target group may encounter on a daily basis.

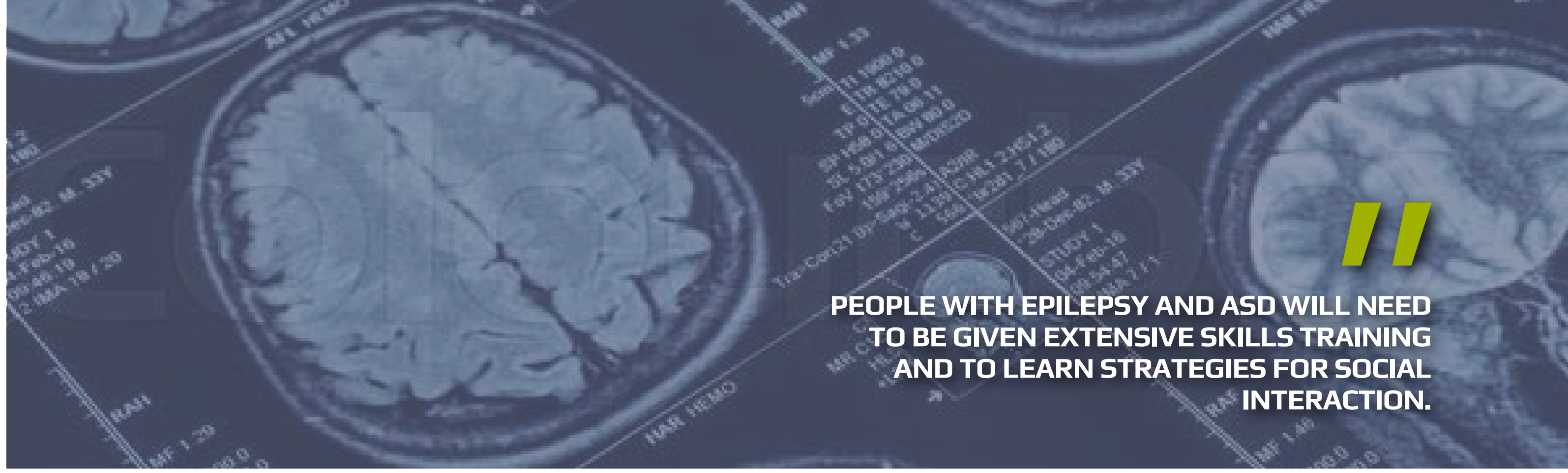
Episodes of blanking out, where the person does not respond to speech, can be part of an epileptic seizure, or they can be a symptom of ASD, so-called 'autistic aloofness'. Episodes of withdrawal, where the person is not contactable, are relatively common in ASD. The episodes can be difficult to distinguish from a seizure even for experienced professionals. The surest way to find out if the blanking out is due to epilepsy is by taking an EEG recording during a seizure.

Self-harming behaviour is rarely part of an epileptic seizure. In contrast, epileptic disorder – with or without visible seizures – can impair sleep and concentration, and reinforce autistic behaviours such as repetitive movements.

People with epilepsy – especially children and adults with intractable epilepsy – may have an increased prevalence of epileptic disturbances and seizures at night, which causes sleep problems. The cause of sleep problems is often complex, and it is important to have a broad focus in the assessment phase in order to get the full picture.

In addition to the epileptic disorders and symptoms of ASD, sleep problems can have physical causes, such as reflux, pain, enlarged tonsils, or psychological causes, such as anxiety and depression. Sleep problems are more common in children than adults. General sleep advice often helps, such as winding down well before bedtime, avoiding sleep in the middle of the day, having a dark and cool bedroom, and avoiding large meals before bedtime. Sleep disorders can be very stressful for the individual and the family. Lack of sleep not only increases fatigue during the day, but also lowers the threshold for epileptic seizures.

Communication problems and learning difficulties are common in ASD. Epileptic disorders both with and without visible seizures can also cause cognitive and behavioural disorders that affect attention and language development.



> **PEOPLE WITH EPILEPSY AND ASD WILL NEED TO BE GIVEN EXTENSIVE SKILLS TRAINING AND TO LEARN STRATEGIES FOR SOCIAL INTERACTION.**

A neuropsychologist, preferably in collaboration with a special needs social educator or speech therapist, should test/assess the individual to determine how much the epileptic disorders are affecting cognition and language development.

People who have language difficulties due in whole or in part to epileptic activity often have a history of normal language development that has stagnated or regressed. They often have periodic language deviations, and language mastery fluctuates over time. If the language difficulties are caused by epileptic activity, in some cases there may be improvement with medical treatment.

Externalising can occur in people with ASD, especially if they have mental illness, epilepsy and mental developmental impairment. However, externalising is rarely seen during epileptic seizures.

Well-being and security can in themselves prevent seizures and at the same time reduce anxiety, agitation, anger and externalising behaviour. People do not necessarily experience fewer symptoms of ASD even if they become seizure-free or have a normalised EEG. ASD is a chronic condition. Most people will need some form of follow-up from the public authorities and help organising their environment throughout their lives. For some people, however, treating the epilepsy will improve the symptoms of ASD. Fewer seizures, no seizures or reduced interictal epileptic activity can contribute to a better quality of life.

CHALLENGES AND USE OF DAY PLANS

Many people with a dual diagnosis of epilepsy and ASD often face significant challenges in daily life. There may be days when they feel good, when they take pleasure in things or tasks that motivate them, and when they function well. Then there may be other days when they have real problems managing tasks they would otherwise perform without difficulty.

- What causes these fluctuations in everyday life?
- How can things be organised so that everyone feels safe and can cope even on the bad days?

The importance of being understood

In order for a person to be able to communicate their wants, needs and feelings, they need to make themselves understood and be able to make sense of the world. People with epilepsy and ASD often have significant problems adapting to their environment or understanding what might create change in their daily lives.

People with ASD cannot take in, interpret and organise sensory information such as body language and facial expressions. Epilepsy can also exacerbate problems with organising everyday life. Many people have very little sense of context and only see a few logical connections in what is going on. This can manifest itself in problems interpreting non-verbal communication and the behaviour of others, or adapting and regulating own impulses and emotions.

Communication and comprehension issues can make it difficult to communicate verbally. Attempts to express discomfort or insecurity may instead manifest as aggression and compulsive behaviour. The behaviour is often misunderstood by those around them and met with reprimands or sanctions. The network and supporters may be frustrated that on bad days the person is unable to complete tasks that they can easily manage on good days.

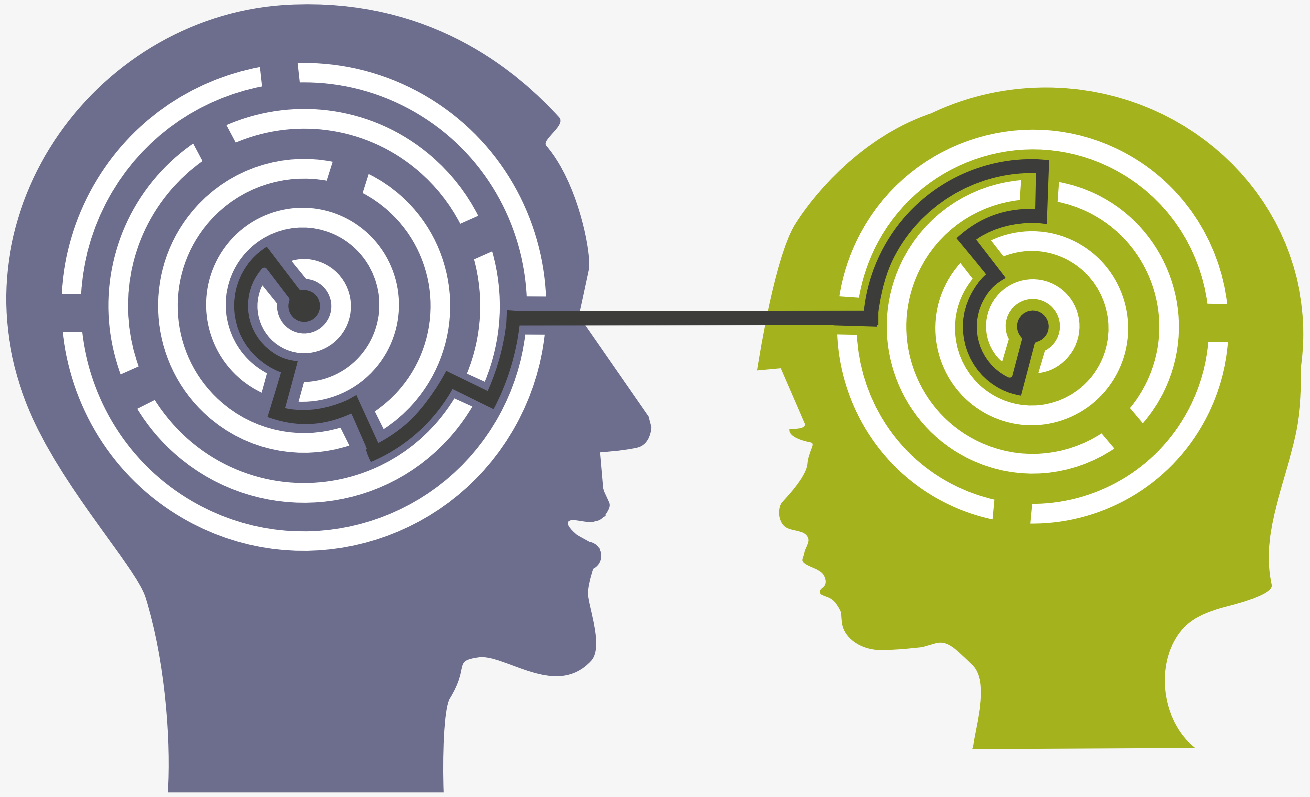
Not being met with understanding and flexibility, and especially the possibility of reducing demands on bad days, can lead to problem behaviours, such as aggression or self-harm. Others may react by withdrawing and trying to avoid situations they cannot handle to prevent feelings of loss and defeat.

People with epilepsy and ASD will need to be given skills training and to learn strategies for social interaction – skills that others learn without much effort. Regardless of the personal reaction pattern, failure to adapt on bad days will lead to fewer opportunities for positive social contact and good learning situations. An aggressive behaviour pattern will also make others feel unsafe and may make them want to keep their distance. In the long run, this can lead to isolation and loneliness.

Organisation of the intervention

Multidisciplinary collaboration
It is important to carry out a thorough multidisciplinary assessment to identify what might be causing the challenges in daily life. It is particularly important to test the level of functioning, both mental and physical, to identify the personal resources and limitations of the individual. The treatment and measures to alleviate or prevent the problems will be specific to the person depending on the outcome of the assessment.

Structures in everyday life – day plans as a tool
Many people with epilepsy and ASD need routines and help to organise their lives. They can find surprises and sudden unforeseen events very unpleasant. A day plan has specific goals and defined activities for the day. The plan should contain specific information about what activities are to be carried out, when they are to be carried out and who is responsible for carrying them out. The goal of a day plan is to structure the daily routine and give the person a sense of predictability and control. The plan should serve as a memory aid and source of information. A good day plan can prevent a lot of frustration and challenging behaviour. The plan can also help ease the transition between activities.



> "
> A GOOD DAY PLAN CAN
> PREVENT A LOT OF FRUSTRATION
> AND CHALLENGING BEHAVIOUR.

Day plans and communication

The day plan becomes a way of communicating, and it is important to find a form that is adapted to the individual's conditions and needs.

Many people with epilepsy and ASD have trouble reading and often use a day plan in the form of images – that is, pictograms customised for the individual. Others may struggle to understand the connection between the image and an object or activity. In these cases, specific objects can be an alternative. Often it can take time to train the person to use the plan, just as it takes time to learn a new language.

Day plans and participation

A good day plan will be based on the individual's personal resources and interests. It should be motivating and provide a feeling of coping. The person must be able to add activities to the plan. Using a day plan also helps temporary and part-time workers who do not have in-depth knowledge of the individual to maintain planned daily and weekly patterns.

People with epilepsy and ASD who lack verbal language often need to be interpreted by carers. The starting point for the day plan should be the individual's needs so that they can set their own boundaries or say what they can manage and thereby gain a sense of control. It is important that everyone in the network has a common understanding of the person's behaviour and that they work together. Using a day plan is a method that needs to be constantly adapted to the individual, taking into account their reactions, daily life and initiative. Developing day plans is a process that needs to be flexible and continuously assessed.

Alternative day plans

For the individual, everyday challenges can be so great and fluctuating that it can be difficult to make a plan for learning. Trying to implement an existing day plan on a bad day can lead to frustration, despair and behavioural problems.

If the challenges of everyday life are significant, it may be necessary to have an alternative day plan that is used on bad days. It may be necessary to create two or three day plans; plans A, B and C, where plan A can be implemented on good days, plan B on less good days and plan C on bad days.

Adaptation difficulties, stress, coping and well-being are important factors when evaluating the use of a day plan.

Everyday life

Some people with ASD and epilepsy develop externalising behaviour. Others self-harm. We see young people and adults who are big and strong where family and staff run away or retreat to get away from difficult situations rather than preventing them. Schools, kindergartens, daycare institutions, residential institutions, etc., have social-educational skills that parents and other network persons should have access to as soon as the need arises. Contributing with organised systems and routines that allow the person to function, as well as possible despite the diagnosis is important for the person, for everyday life and for future development.

People with ASD and epilepsy can develop rigidity, where even small changes have big consequences for behaviour. Many sensory impressions, a lot of commotion or sounds create an uncomfortable environment with subsequent reactions. It is difficult to accompany the person in social contexts because demanding situations can quickly arise, for example, in shops or when visiting friends. Parents in particular experience being perceived as bad parents who are unable to control their child when challenging situations and behaviour arise. People with ASD and epilepsy do best when the day follows a fixed and predictable pattern. So, set routines should be followed, day after day.

SOCIAL-EDUCATIONAL CHALLENGES IN DAYCARE INSTITUTIONS

Here we review general principles for good social-educational organisation regarding people with epilepsy and ASD. It is important to examine the impact of the epilepsy and the prerequisites for learning so that the individual's case is sufficiently informed before considering and creating individual learning/action plans in a local context.

Epilepsy as a complicating factor in people with ASD

- What kind of epilepsy does the person have?
- Should it be investigated further?
- What professional competences are needed to adequately illuminate different aspects?

Epilepsy increases the risk of both general and specific learning difficulties and social difficulties. Cognitive difficulties can be permanent, transient and of varying nature, but long-term prognoses show that epilepsy has a negative impact on educational level, labour market attachment, marital status and ability to independently manage daily life.

The negative impact depends on the epilepsy diagnosis, epilepsy onset, seizure frequency and presence of other additional diagnoses. Reduced psychomotor tempo, fluctuations in day-to-day form and a tendency to stress are common in people with ASD and epilepsy. Epilepsy medication can cause side effects that can exacerbate difficulties.

Epilepsy in people with ASD is often associated with low cognitive function. One in three people with developmental impairment and ASD also have epilepsy, compared to one in twenty among higher-functioning people with ASD.

Social-educational approach

- How do we understand and interpret different behavioural cues?
- What is epilepsy and what is it not?
- What are this person's particular challenges and competences?

Multidisciplinary assessment

People with both epilepsy and ASD need a specialised approach when it comes to diagnosis and designing social-educational measures. The special challenges of ASD need to be addressed by taking into account the developmental level, seizure issues and difficulties related to the epilepsy.

Teachers and special social educators are vital contributors in multidisciplinary collaboration in relation to people with epilepsy and ASD.

Lack of knowledge about living with epilepsy and/or autism can complicate social-educational efforts and everyday life for the person, for example, as a result of making demands that are not adapted or misinterpreting behaviour.

Often there is uncertainty about whether behaviour is autistic or could be an epileptic seizure. The type of epilepsy and type of seizure can be crucial for how professionals interpret behaviour, organise learning and choose to engage with the person.

"

MENTAL HEALTH ISSUES ARE MORE COMMON IN BOTH PEOPLE WITH EPILEPSY AND PEOPLE WITH ASD AND DEVELOPMENTAL IMPAIRMENT THAN IN THE GENERAL POPULATION.

Does the person have episodes of blanking out with full or partial loss of consciousness? How long are these episodes and how are they observable? Are there any behaviours that indicate the onset of a seizure – more adult-seeking, irritability or rigidity? How does the person behave after a seizure – more sensitive to noise, need for rest, etc? These are all questions that may be relevant for consideration.

Challenges require understanding and flexibility

Many children with a dual diagnosis of epilepsy and ASD often face significant challenges in daily life. The child's well-being, coping and quality of life are important elements and need to be expressed in good learning goals. Fluctuations in day-to-day form are often seen.

Children with epilepsy often perform on a par with their classmates. However, there is a significant overrepresentation of specific and general learning difficulties among children with epilepsy. This target group needs special support to be able to participate actively and equally with the rest of the class in lessons. Teachers and school leaders need to pay special attention to whether the child is developing age-appropriately, both academically and socially, or whether the child has started to lose skills.

For a period of time, the child may benefit from supplementary teaching in one or more subjects. This might be a specially organised teaching programme with different variations, a two-teacher scheme or one-to-one tuition. At least once a year, the school should assess whether the child's special teaching arrangement should continue, be modified or be brought to an end.

Children with epilepsy are more likely than other children to have problems with

- Attention and concentration
- Learning and memory
- Communication and language
- Behaviour, self-esteem and self-perception.

It is important to take the individual child as a starting point when organising support.

Social-educational recommendations for lessons

Predictability and structure are key

- Information board for, e.g. day plan
- Pictograms as a visual tool
- Time Timer can train the child's sense of time and create calm around a task
- Breaks – regular short breaks during the day so the child is not unnecessarily overloaded
- Hearing protection is a great social-educational tool for children who need extra quiet in class
- Language – speak slowly and use a few short phrases that are not abstract and do not contain irony
- The '9 HVs' is a Danish educational tool for children with special needs. It is based around the idea that children benefit from knowing the answers to nine questions, all of which begin in Danish with the letters 'hv'. The questions in English include 'what?', 'where?' and 'how?'.

Fluctuations in day-to-day form

People with ASD and epilepsy can have large fluctuations in day-to-day form. These variations can have many and complex causes. Epilepsy is one of the factors that can clearly be linked to this. Epileptic seizures, post-seizure side effects and interictal epileptic activity are conditions that will affect daily functioning.

Always assess:

- Bad days, good days. What do we do next? (Plan A, plan B, plan C)
- What skills do staff have for handling the person's fluctuations – without fluctuating themselves?

Fatigue and ASD

People with ASD can become fatigued due to the many sensory impressions that they experience on a daily basis, for example, when participating in social situations, classes or in general. People with ASD and epilepsy can be further fatigued by seizures or medical treatment. For some people, fatigue can mean more seizures. Fatigue must be taken into account in social-educational and teaching interventions.

Support with fatigue

Most people with epilepsy have less energy than healthy people, which means they have fewer personal resources – both academically and socially. As a result, they are forced to prioritise how they use their energy. This can be difficult to learn because they do not want to stand out and be different from other people.

Fatigue is not just ordinary tiredness, but a more exhausting and intense tiredness that requires lots of breaks to recharge. In particular, the adults around a child need to be supportive and help the child prioritise where to spend their energy. It is important to keep in mind that the child's energy reserves have to cover lessons, homework, friends, family and leisure activities. If they do not have the energy for all of those things, the adults need to help the child prioritise so that the child is best served academically and socially.

Switching between activities

Lessons should be divided into sequences of varying lengths with built-in breaks, as some children can only work in short sequences on a given task. Others may find it difficult to switch between activities. Make sure you have a break before the child gets too fatigued.

Emotional stress

Stressors that should be assessed:

- What triggers stress?
- What activities can the person be involved in without social-educational control?
- How do you prevent situations from developing?
- Do you have good diversionary tactics?

Emotional stress is a common seizure trigger. Stress is also a major challenge for people with ASD and epilepsy. Stress can be triggered by a struggle to cope with everyday life. Struggling to cope can lead to frustration and anxiety. Stress can come from worries and expectations, both positive and negative. In a daycare institution or school, there are many potential stressors. The person has to deal with many people and demands, and situations arise that need to be interpreted and understood.

It is important to identify what the person experiences as stressful and at the same time take into account that positive stress, such as getting really excited about something, can also be a trigger for seizures. Mental health issues are more common in both people with epilepsy and people with ASD and developmental impairment than in the general population.

Reducing stress levels may reduce the frequency of seizures, increase the potential for learning and reduce the possibility of mental health problems later on. In engaging with this group, a social educator should adopt an open and flexible attitude within a framework of clarity and predictability, and with a repertoire of social-educational tools and possible activities – in other words, “a prepared unpreparedness”. It is important to have activities during which the person can rest.

This will vary from person to person, but can usually be linked to what the person is interested in and copes well with. Clarity and predictability alleviate some of the internal chaos experienced by people with ASD, but also those with epilepsy. Day plans and overviews adapted to the developmental level can provide a good framework in daycare or school and in everyday life. Professionals can be a great support for the person as they guide them through life's challenges.

Coping

Quality of life and coping are the cornerstone of social-educational work. The starting point is the person's developmental level, and their ability to interact and motivation/initiative.

In order for professionals who meet with the person in unfamiliar surroundings to be able to vary the requirements and content of their work, it is necessary for them to respectfully tune in to the person and utilise knowledge from family and other people in the network.

- Are expectations compatible with abilities and possibilities?
- Where is the zone of proximal development academically and socially?
- Are goals set with coping in mind?
- Are the current academic and social goals compatible with and supportive of the long-term goals?
- What would make this particular day a good starting point for further interaction and learning, and a good starting point for tomorrow?

Mapping the person's strengths and interests provides a basis for social-educational approaches. You can utilise interests at all levels. Someone who is very good at memorising factual knowledge can use patterns and layouts to increase knowledge in multiple areas and subjects. An object that a person is interested in can be used in play and activities that focus on joint attention and interaction. Sometimes more knowledge is a social-educational goal; other times focusing on the next stage of development is important for coping and well-being.

Epilepsy can affect language production and comprehension. People with ASD can face significant challenges in areas such as language, communication and social skills. Many will need training in augmentative and alternative communication. It is important that carers consider the following:

- Is there a need for augmentative and alternative communication as a social and academic aid?
- What will help the person engage with us and what can help us engage with the person?
- How should augmentative and alternative communication be implemented and how do we follow up?

The person's senses, motor skills, memory, motivation, developmental level and ability to learn must match the form of communication that is chosen, for example, sign language.

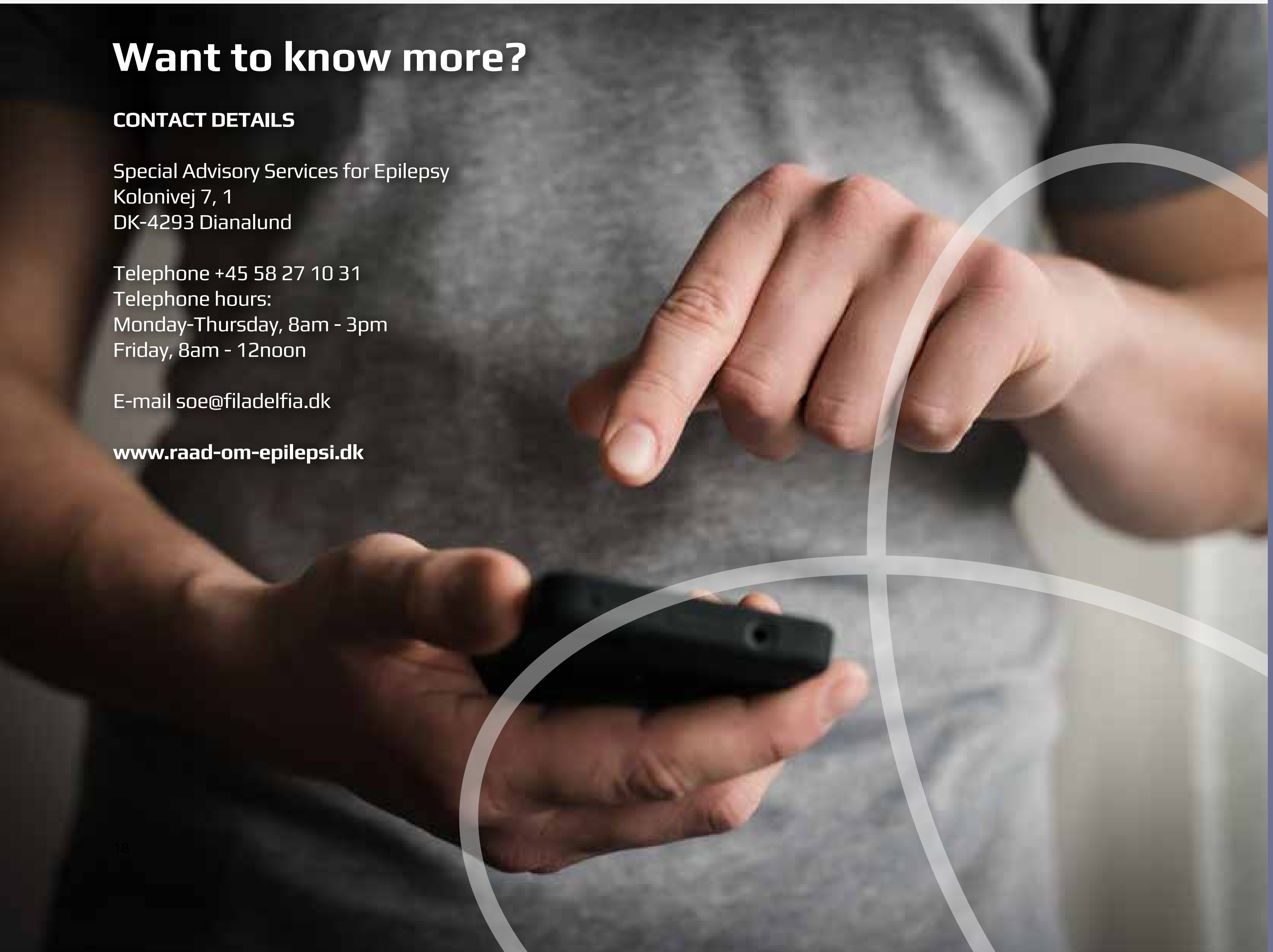
If you have a tradition of using a particular form of alternative communication, it might be good to think outside the box. This could increase the person's benefit from augmentative and alternative communication. Use photos of the person in key situations to communicate with the person and professionals in everyday life. Photos can also be tools for learning.

SPECIAL ADVISORY SERVICES FOR EPILEPSY

Special Advisory Services for Epilepsy, Filadelfia, is part of a network under VISO (KaS) at the Danish Authority of Social Services and Housing. VISO is the national Knowledge and Special Counselling Organisation in the area of social and special educational needs. We provide advice to professionals, citizens and relatives on tackling everyday life with epilepsy. Our employees advise, discuss and share knowledge about epilepsy and the psychosocial problems that often accompany it.

Filadelfia is Denmark´s only highly specialised epilepsy hospital and nationwide knowledge and rehabilitation centre for people with epilepsy and acquired brain injury. Every day, 800 employees work to access, treat and rehabilitate people with epilepsy. The daily collaboration with the hospital ensures that we have specialised knowledge of everything that people with severe epilepsy need.

The advisory services are nationwide and free of charge for citizens and relatives, local-authority employees, schools, educational-psychological counselling services and healthcare professionals.



Want to know more?

CONTACT DETAILS

Special Advisory Services for Epilepsy
Kolonivej 7, 1
DK-4293 Dianalund

Telephone +45 58 27 10 31
Telephone hours:
Monday-Thursday, 8am - 3pm
Friday, 8am - 12noon

E-mail soe@filadelfia.dk

www.raad-om-epilepsi.dk

SVANEMÆRKET
Tryksag
5041 0826

FILADELFIA - december 2024

Filadelfia
Kolonivej 1
4293 Dianalund
Tlf. 58 26 42 00
www.filadelfia.dk

FILADELFIA