FILADELFIA

# Children and epilepsy
## - practical advice

- for teachers, social educators, educational-psychological counselling services and local-authority social workers

# Dear Reader,

Special Advisory Services for Epilepsy advises employees in Denmark's local authorities so we can support children with epilepsy in leading a better everyday life with their disease.

Most families who have a child with epilepsy are under a lot of pressure. The support must meet the family's overall needs. In this booklet, we have brought together practical advice for professionals and basic information about the disease and the difficulties it causes.

We hope it can contribute to your daily work regarding children with epilepsy. It is primarily intended for the child's teachers and social educators, educational-psychological counselling services and local-authority social workers.

You can use it as a reference guide.

If you have any doubts or questions, you are always welcome to contact us. With us, advice is free.

Happy reading!

Special Advisory Services for Epilepsy
Filadelfia

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# PRACTICAL ADVICE FOR TEACHERS AND SOCIAL EDUCATORS

it is often teachers and social educators who can most easily spot possible signs of epilepsy, as they are with the child for many hours every day.

## Seizure management and key characteristics

**Below is a checklist of key characteristics that can be used to spot epilepsy:**

- Periods of confusion
- Different behaviour – repeated aimless movements
- Blanking out, staring, losing the thread academically and socially
- Pronounced fatigue
- Varying academic performance and varying daily form.

It is crucial that teachers know what the child's seizures look like and what to do if the child has a seizure. Classmates should also be informed about the child's epilepsy, seizures and what to do if they see a seizure. We recommend that schools and daycare institutions draw up an action plan if they have a child with epilepsy.

Please refer to the Danish Authority of Social Services and Housing's booklet "Elever med epilepsi – inklusion i skolen" ("Pupils with epilepsy – inclusion in school").

## Cognitive difficulties due to epilepsy

**As a direct consequence of epilepsy, difficulties can arise with:**

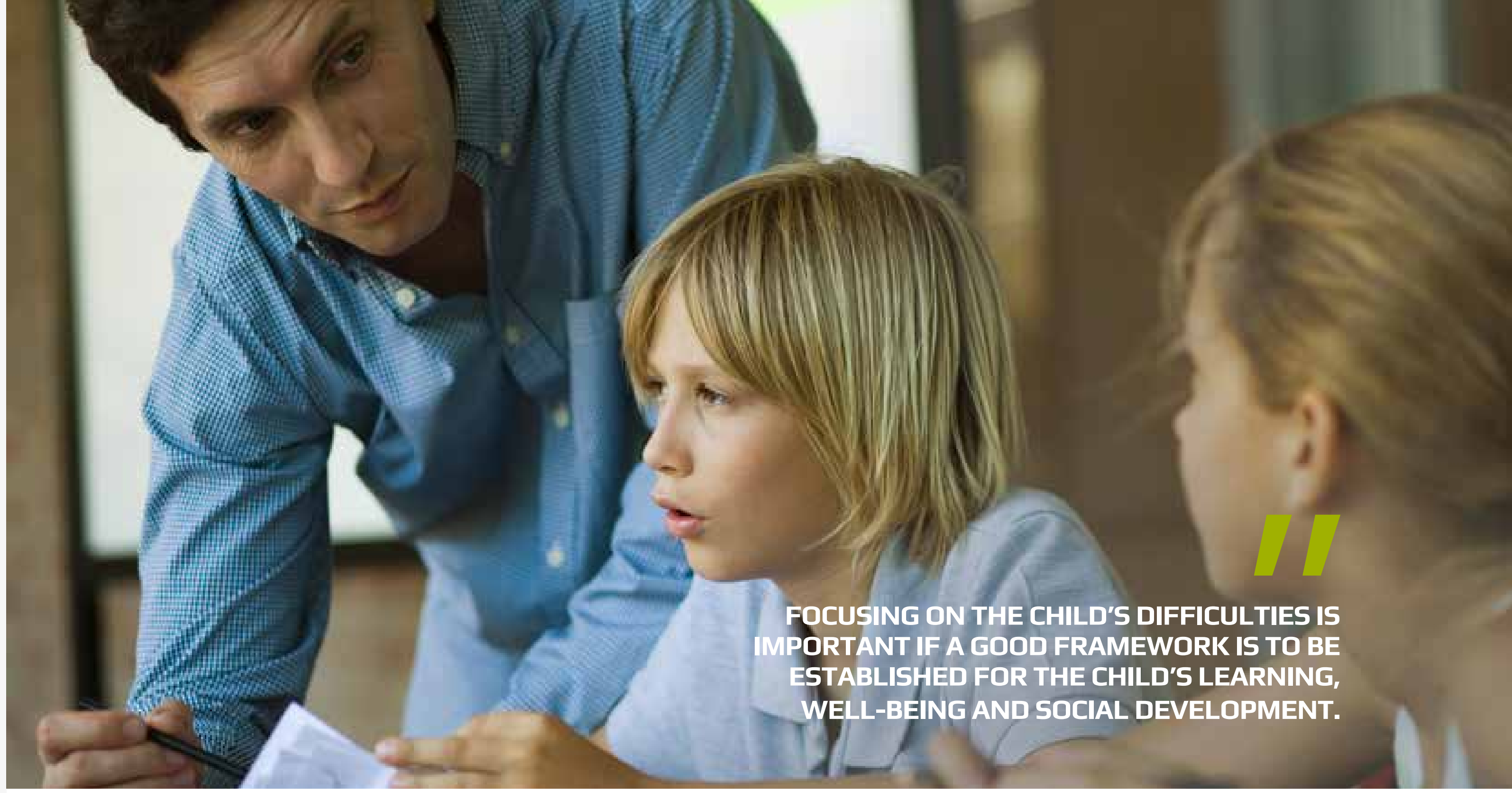
- Attention and concentration
- Memory
- Language and communication
- Academic performance
- Behaviour
- Activity level
- Social skills
- Self-esteem and self-awareness
- Fatigue.

The child's development and well-being should be closely monitored. Inclusive behaviour is important if the child is to develop optimally. Some children will have such severe difficulties due to their epilepsy that they need special lessons in a special class or special school.

The teacher should pay close attention to ensure that the child does not stagnate or lose skills. Attention should also be paid to changes in behaviour that are not directly related to adjustments in medication.

At times, it may be necessary to lower expectations of a child's academic performance at school, focusing on maintenance of skills rather than new learning.

Children do not want to feel different because they are ill and do not want to be treated differently. When a child sits in the corner while other children are playing, it is not to appear interesting and seek attention. It is necessary because the child is tired, cannot be bothered to participate or feels left out.



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> FOCUSING ON THE CHILD'S DIFFICULTIES IS IMPORTANT IF A GOOD FRAMEWORK IS TO BE ESTABLISHED FOR THE CHILD'S LEARNING, WELL-BEING AND SOCIAL DEVELOPMENT.

# SOCIAL-EDUCATIONAL RECOMMENDATIONS FOR LESSONS

Many children with epilepsy do as well as their classmates without epilepsy. However, there is an overrepresentation of children with epilepsy who have learning difficulties. They may need support that targets their specific issues. Focusing on the pupil's difficulties is important if a good framework is to be established for the pupil's learning, well-being and social development.

Here we describe elements that in our experience can provide support, help and greater calm in the classroom for the pupil with epilepsy, their classmates and the teacher or social educator.

## Support with fatigue

Most children with epilepsy have less energy than their healthy classmates, 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 for the child to learn because they do not want to stand out and be different from their classmates. Fatigue is not just ordinary tiredness, but a more exhausting and intense tiredness that requires lots of breaks to recharge. The adults around the child need to be supportive and help the child prioritise how to use 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 intervals of varying length with built-in breaks, as some children can only work in short intervals 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.

## Learning demands and volume of information

Break up large tasks into small subtasks, limit the volume of information, make copies where possible and cut out anything superfluous. Agree with the child how long they will work on the task and give them the necessary breaks. At times, it may be necessary to reduce the demands for new learning and instead focus on maintaining skills. As a teacher or social educator, it is important to relate to the child with the approach that they are genuinely doing their best. Learning difficulties are usually not an expression of a deliberate power struggle or defiance, but more often an expression of the child not coping with the situation. Extra support for the child may be the solution. As with all other children with cognitive difficulties, it is important to consider the individual child when organising support.

## Predictability and structure

Predictability and structure are vital. The days should be as similar as possible. An overview of the day's activities can be written on the child's information board, possibly visually supported by pictograms. It can also be a good idea to repeat daily rules, such as raising a finger and keeping quiet/listening when others are talking. Use a work timetable at the child's workspace.

## Information boards

The child's information board should be used to give them an overview of the lesson/day/week. Use the information board for the week plan, day plan, lesson plan and current task plan. For example: Start with this, then when you have finished move on to this, and so on. The only limit to how the child's information board can be used is your imagination.

## Pictograms

Pictograms are a visual tool comprising symbols, drawings or images that visualise tasks, appointments and time to create calm and predictability for the child. Put the pictogram on the child's information board so they can always refer back to it if they lose track of things.

## Time Timer

A visual clock can train the child's sense of time and create calm around a task. The clock indicates how long the child has to do an activity for and shows how much time is left, with the field getting smaller and smaller as the time passes. This can create calm and predictability.

## Breaks

Many children with epilepsy need to take breaks or have short rests during the school day. The best way of recharging will differ. It depends on the diagnosis and the individual child. Some children need to sleep, sit in a soft chair, be by themselves, be active, get some fresh air, play on their iPad, read a book, be in a quiet place, etc. Others rarely ask for breaks or only when they are completely exhausted. It is therefore a good idea to include fixed short breaks in lessons so the child is not unnecessarily overloaded. Talk to the child and the class about why the child with epilepsy has special rules.
During regular breaktimes, some children need to be left alone, while others need support with what to do and who to play with.

## Reduced school hours

Some children with epilepsy suffer from incredible fatigue. Some have problems sleeping at night, which affects school time. The causes of poor or interrupted sleep might be the disease itself, seizures or the side effects of medication. Whatever the cause, the result is the same, namely fatigue, which affects the child's ability to concentrate, remember and learn.

The tiredness that children with epilepsy experience is more intense than ordinary tiredness and often recurs. At times, it may be necessary for the child to stay home from school or have reduced school hours or a lighter timetable for a while to regain their energy.

## Hearing protection

Hearing protection screens out external sounds and stimuli when the pupil needs to concentrate in the classroom. Hearing protection is a social-educational tool for children who need extra quiet in class. It should not be used as a shield against all noise, but to create peace for a child who needs it for a shorter or longer period of time. Hearing protection is a great social-educational tool that works because you have various types of lesson where some children are working in groups and others are working on something where they need to concentrate in their own little universe. Hearing protection makes sense when working with differentiated teaching.

## Room design

At Filadelfia's Børneskole (School for Children with Special Needs), the teaching is carried out with groups of four to five children, and each child has a regular place at a common table in the centre of the room and a regular workspace for individual tasks facing the wall and apart from the other children. There are information boards at the workspaces to display the day's programme, pictograms, etc. There is the option to use music through headphones or hearing protection to limit disturbances. Each workspace must be kept organised and structured, which means the child only has one task in front of them at a time. The workspace is tidied up before the next task or lesson.

## Social situations

The child needs extra time to understand what is being said or what is happening, to express themselves, to carry out tasks and to get to grips with the material
. Without this extra time, the child can feel inundated with new information, which means they do not take in the first message and therefore do not remember it. The child loses track and cannot get started on the task. This is particularly difficult in social situations, where things happen very quickly. The conversation in a group is constantly changing direction. The child spends time on understanding what others are saying. By the time the child has understood, hypothesised, formulated their thoughts and is ready to speak, the others have changed the subject. So, it is important to give the child time to think and express themselves.

## Appreciative approach

All children will if they can. Adapt the framework to the child and not the other way round. Activities should be adjusted to the child's day-to-day form, because in some cases the epilepsy will have affected the day-to-day form of the child and the family. If, for example, the child shouts out, ask them to speak quietly. If you say "don't shout", you might give others in the class an idea. Experiment with changing your wording from "you mustn't..." to "you may..."

## Language

Speak slowly and use simple phrases that are not abstract and do not contain irony. Ask the child about what you have said and possibly get them to repeat it.

## Praise

It is important that children feel they can figure things out. That they regularly achieve small victories. If the child has experienced a lot of failures in their schoolwork, they begin to see themselves as not very good – a child who cannot figure things out. The child then loses motivation. Praise should be linked to what the child is doing, e.g. 'Now you're on track, that's what you need to do next time...' Praise should be specific. Experiencing success is important because at the heart of motivation is the child's sense of self. Motivation is a result of the experiences you have as a child. If they are positive, the child thinks: I'm good, I can figure things out.

## Reward systems

It can be motivating to receive rewards in the form of, for example, smileys after working on a task, reading a book, etc. A certain number of smileys could lead to a reward, such as iPad time, baking a cake, etc.

**The '9 HVs'**
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?’. This is a tool that helps add protective factors to the environment to support all types of pupil in participating in the best possible way. The tool is something you can work with as a teacher or social educator in a class. Especially classes that include children with special needs – though the tool is good for all children.

### Support

Many children with epilepsy have learning difficulties to varying degrees. Teachers and school leaders need to pay particular attention to whether the child is developing age-appropriately, both academically and socially, or whether the child has started to lose skills and could benefit from a period of 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.

**Physical training can**

**IN 30-40% OF CASES**

**have a seizure-preventing effect.**

**Intense physical training can**

**IN 10% OF CASES**

**trigger a seizure.**

### Physical activity

Many people fear that physical activity can trigger seizures and thereby increase the risk of injury. Physical activity is important for people with epilepsy. It is a misconception that people with epilepsy should not be physically active. Regular physical exercise can prevent seizures in 30-40% of people with epilepsy, while in 10% intense physical activity can trigger seizures.

Advising on physical activity should be on an individual basis. The choice of activity depends on, among other things, the type and frequency of seizures.

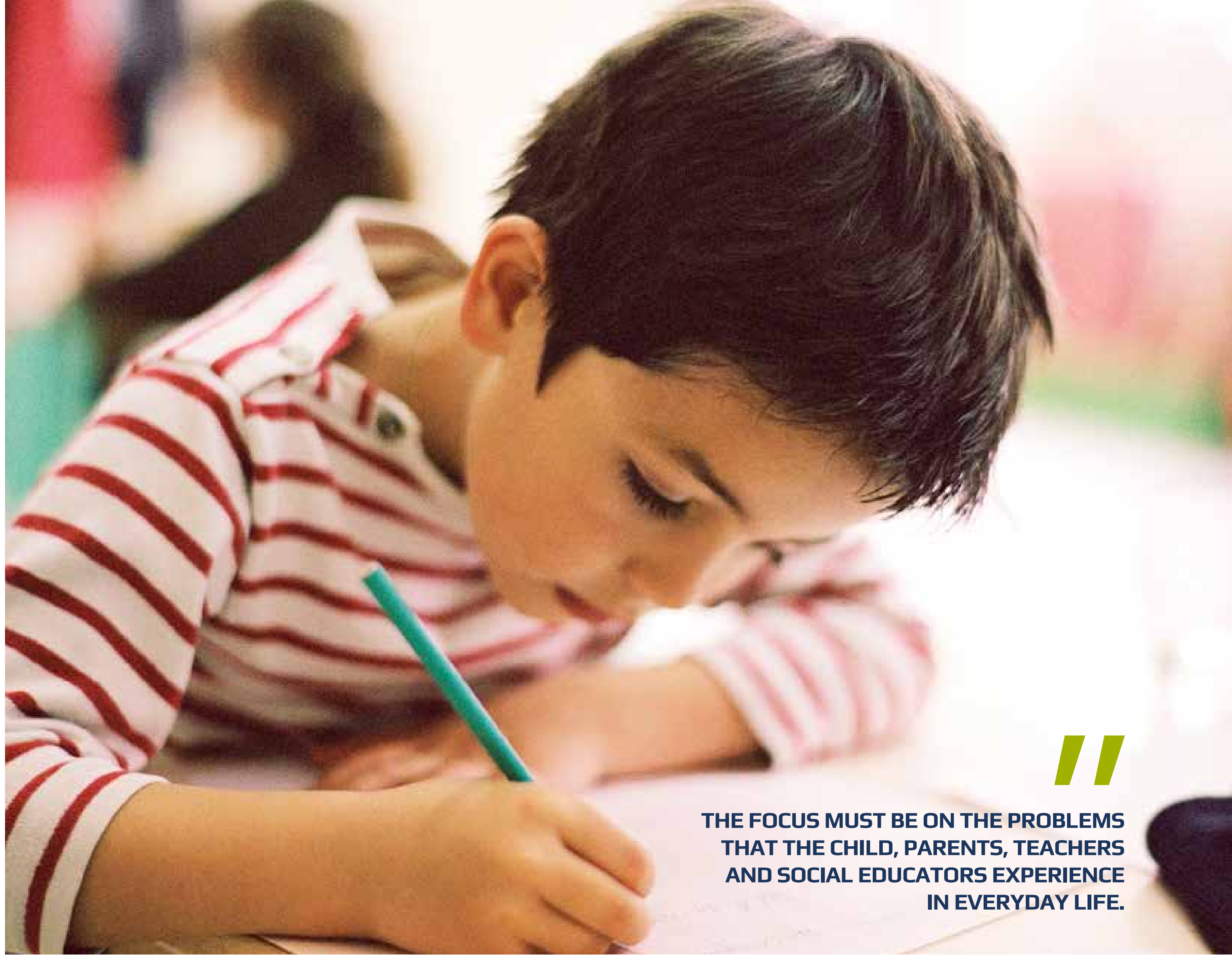
**When advising on physical activity choices for people with epilepsy, a distinction can be made between:**

- Activities with no restrictions, e.g. walking, jogging, general aerobic exercise
- Activities with restrictions that require safety precautions, e.g. a helmet, life jacket or partner
- Activities that should be discouraged, e.g. climbing, hang gliding, diving, motorsport

All advice should be given on the basis of an individual assessment. The individual child’s doctor/nurse should therefore be consulted.

### Facts

- Children do not want to feel different because of illness and do not want to be treated differently.
- The days should be as similar as possible.
- Physical activity is important for people with epilepsy.
- Many children with epilepsy need to take breaks or have short rests during the school day.
- Some children with epilepsy experience incredible fatigue.
- Speak slowly and use simple phrases that are not abstract and do not contain irony.
- Praise should be specific. Experiencing success is important.
- Fatigue is not just ordinary tiredness, but a more exhausting and intense tiredness that requires lots of breaks to recharge.
- Pay attention to whether the child changes over a longer period of time.



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THE FOCUS MUST BE ON THE PROBLEMS THAT THE CHILD, PARENTS, TEACHERS AND SOCIAL EDUCATORS EXPERIENCE IN EVERYDAY LIFE.

## PRACTICAL ADVICE FOR EDUCATIONAL-PSYCHOLOGICAL COUNSELLING SERVICES

**It is important to strike the right balance between making demands and protecting children with epilepsy to best support their academic development.**

The type of support that children need varies. The focus must be on the problems that the child, parents, teachers and social educators experience in everyday life. Problems related to the child’s academic development, emotional and behavioural development, social skills and degree of cognitive difficulties.

If the class has pupils with general or specific learning difficulties, as many children with epilepsy do, it can be extremely difficult for the individual teacher to offer differentiated teaching within the framework of the normal classroom. Children with epilepsy will often therefore need extra support.

In general, parents often believe it is best for their child to attend the nearby folkeskole (primary and lower-secondary school), which can give the child a normal life in terms of school and leisure time with their classmates.

Consider a special class or special school. All too often we see children being moved down a grade or repeating a school year due to the academic and social difficulties that they face. In some cases, further investigation of the child’s difficulties will be necessary. This could be in the form of a school/pre-school observation or a neuropsychological examination.

Pay attention to whether the child changes over a longer period of time. In so doing, distinguish between physical, behavioural and emotional reactions. Often there will be a mixture of several different reactions.

# PRACTICAL ADVICE FOR LOCAL-AUTHORITY SOCIAL WORKERS

**The financial strain caused by epilepsy often leads parents to seek financial support to cover additional expenses or compensation for lost earnings. Often, talking to parents reveals that their problems or challenges are much more complex.**

Epilepsy can be a very disruptive disease for the child, parents and siblings. The disease can also place great demands on other people in the child's everyday life.

In order to form an overview and initiate a holistic intervention for these families, it is therefore important that the social worker obtains relevant information not just from the parents, but also from the doctor, the school/kindergarten, the educational-psychological counselling service, etc.

### It is important to get information on the diagnosis and prognosis as well as:

- How does the diagnosis affect the child's functional ability?
- How does the medication affect the child, e.g. fatigue, etc.?
- How does the epilepsy affect the family's everyday life, e.g. in terms of work, socially and physically?

### For the school or daycare institution, it is important to describe the child's day-to-day life in school or daycare:

- Does the child have absences from school or daycare and to what extent?
- Does the child have daytime seizures?
- Are the parents contacted and do they collect the child?
- Does the child become fatigued during the day?

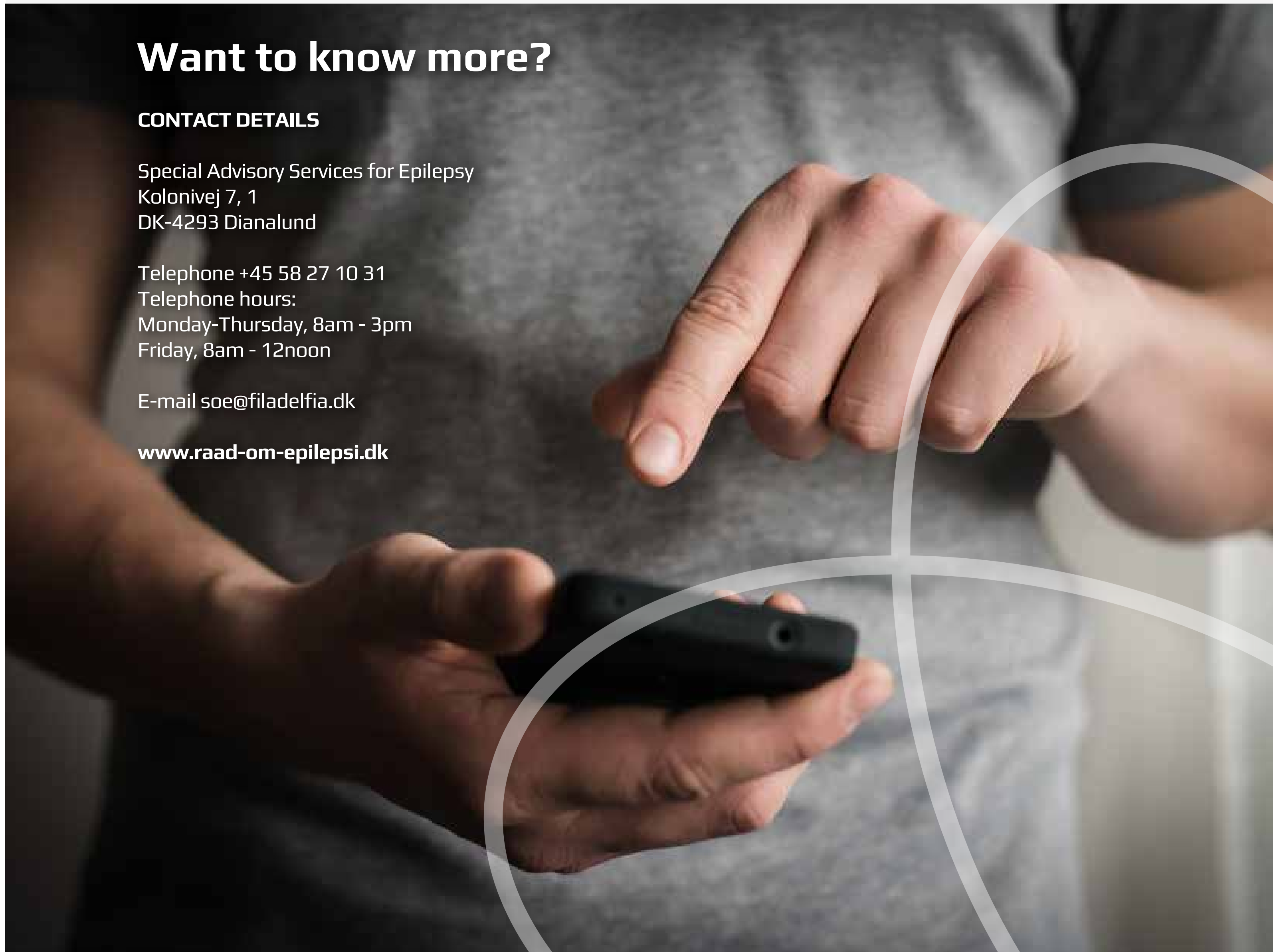
For the educational-psychological counselling service, information about observations or test results can help to determine the child's personal resources and any limitations, as well as what measures and initiatives have already been implemented.

# SPECIAL ADVISORY SERVICES FOR EPILEPSY

Special Advisory Services for Epilepsy, Filadelfia, is part of the Coordination of Special Counselling (KaS) network under VISO 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?

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