FILADELFIA

Young people and epilepsy

- for teachers, student counsellors, educational-psychological counselling services, education advisors and local-authority social workers.

Dear Reader,

Special Advisory Services for Epilepsy advises employees in the country's local authorities so we can support people with epilepsy in leading a better everyday life with their disease. With us, advice is free.

In order to provide good case management or support for people with epilepsy, it is necessary to have a basic knowledge of the disease and the difficulties it causes.

We hope this booklet can contribute to your daily work relating to young people with epilepsy. In the following pages, we will introduce you to epilepsy and how the disease affects everyday life.

You can use it as a reference guide. If you have any doubts or questions, you are always welcome to contact us.

Happy reading!

Special Advisory Services for Epilepsy
Filadelfia

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EPILEPSY – A DISEASE OF THE BRAIN

Epilepsy is one of the most common chronic neurological diseases – a disturbance in the brain's electrical signals that causes epileptic seizures. 55,000 people in Denmark have epilepsy.

25% of people with epilepsy develop the disease before they reach the age of 15, and 25% after they reach the age of 65. The disease consists of seizures triggered by the cerebral cortex. The brain's functions break down for a few seconds or minutes. They are restored with greater or lesser speed. The seizures are often spontaneous and therefore hugely stressful for the person with epilepsy and their family. The disease is often long-term and requires medical treatment.

Seizures often mean loss of control, such as a sudden strange feeling in the body, being able to hear but not understand, being able to see but not speak, losing consciousness for a few seconds or having convulsions and waking up confused with an aching body, headache and sometimes involuntary urination. Alternatively, the person may continue doing what they were doing but without being conscious, which can have serious consequences if they work with dangerous machinery, at heights or are responsible for other people.

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Diagnosis

Diagnosing epilepsy can be very difficult. Often, it can be due to birth defects, congenital disorders or malformations. Epilepsy can also be caused by hereditary factors. People can also develop epilepsy as a result of blood clots, tumours in the brain or acquired brain injury.

To make the diagnosis, the person undergoes an EEG examination, which records brain activity and films the seizure.

Seizures – not just convulsions

Seizures manifest in very different ways. Some people have brief moments of unconsciousness, while others have full-body convulsions daily. Seizures can also involve sensory disturbances, motor disturbances or a sudden change in behaviour. In focal epilepsy, the seizure begins in a specific area of the brain, while in generalised epilepsy the seizure involves the entire brain from the beginning. Most people associate epilepsy with convulsive seizures, where the person has spasms throughout the body and is unconscious. There are also seizures that do not involve loss of consciousness. There are seizures where the person continues to do what they were doing. And seizures where the person does something abnormal for the situation, e.g. taking off their clothes, talking nonsense, walking or cycling through a red light, etc.

After the seizure

Once the seizure is over, consciousness may still be affected. This is a reorientation phase. How long the phase lasts differs from person to person. Some quickly regain full consciousness after the seizure, while others may have a prolonged period where consciousness, behaviour, language or contact with others remain affected.

Treatment

The treatment of epilepsy is primarily medical. Two thirds of people with newly diagnosed epilepsy become seizure-free with medical treatment. The aim of the treatment is to achieve fewer seizures while minimising side effects. The most common side effects are fatigue, dizziness, decreased or increased appetite, changes in behaviour and mood, and memory, learning and attention problems. It is important that the person with epilepsy is offered specialised investigation and treatment to improve their quality of life and reduce side effects.

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Treatment takes a long time. Sometimes it can be lifelong. If the epilepsy is difficult to treat, it means big changes in the person's everyday life. Check-ups, diagnostic assessments and hospitalisations – sometimes far from home – may be necessary.

If medication does not work as intended, the doctors may offer treatment with diet, surgery or vagus nerve stimulation (VNS). One third of people with epilepsy continue to have seizures.

Epilepsy is considered intractable when the person has tried three medications (possibly in combination) but the seizures persist. Early intervention makes a difference. The longer that treatment with medication is delayed, the greater the risk of it not working. If the person does not take their medication, it increases their risk of having seizures and developing status epilepticus, which can lead to permanent functional impairment. The risk of sudden unexpected death in epilepsy (SUDEP) also increases.

Facts

Status epilepticus
Status epilepticus is defined as persistent or repeated epileptic seizures lasting more than 30 minutes where the person does not regain consciousness between seizures.

SUDEP
When a person with epilepsy dies suddenly and with no known cause, it can sometimes be due to sudden unexpected death in epilepsy (SUDEP).

Surgery

Every year, around 40 people with intractable epilepsy undergo surgery. It is a precondition for surgery that the epilepsy starts in a localised area of the brain so that the surgeons can remove the area without destroying too much healthy brain tissue.

Assessment for surgery is a long, thorough and demanding process – both physically and mentally.

It is important that the person with epilepsy, their family and social workers have a realistic expectation of what changes surgery can bring about. If the person's functional ability is impaired before surgery, they should expect it to remain impaired afterwards. In some cases, functioning will be further impaired. It depends on where in the brain the surgeon operates and how much tissue is removed. The young person may have difficulty learning new things, remembering things and finding the right words. The possibilities for rehabilitation are limited. Many people report that the increased quality of life that often comes with fewer or no seizures far outweighs any difficulties with memory. The person should expect to be on antiepileptic medication for at least two years after surgery.

COGNITIVE PROBLEMS AND FATIGUE

Epilepsy can cause cognitive problems – even if there are no seizures. The nature and extent of the problems relate to the type of epilepsy, frequency of seizures, medication, how long the person has lived with epilepsy and other health conditions, including any psychiatric comorbidity, congenital or acquired brain damage, etc. Cognitive problems mean that the person may have difficulties with, for example, learning, memory, concentration and structure.

Executive skills are often affected. This covers the person's ability to set a goal, independently plan how that goal is to be achieved, take action, and continuously and flexibly evaluate and adjust behaviour/efforts in relation to the plan and the constraints of the particular situation. A person's ability to inhibit an immediate response, take initiative, exercise emotional control and be aware of their own social behaviour are part of the executive functioning. The ability to manage and maintain attention and working memory also fall within the executive domain.

Executive functions come into play in particular in new and unfamiliar situations. School lessons, everyday activities and socialising place high demands on executive functions. Support is often needed if the person with epilepsy is to create overview and structure not just at home, but also in education/training and work.

People with epilepsy can have severe problems with mental fatigue. It is therefore important for them to make allowances in everyday life by taking frequent breaks and possibly limiting their hours of study or work. Partly to ensure appropriate energy levels throughout the day, and partly to prevent incredible fatigue and stress from causing more seizures. It is not a matter of physical exhaustion, but rather a case of 'battery empty' – the person cannot do any more even if they want to. Local-authority social workers often overlook fatigue in people with epilepsy. However, it is often fatigue that prevents a person from utilising any cognitive resources.

Cognitive problems

Memory

- The person forgets appointments, messages and tasks
- Has difficulty learning and remembering new things, but remembers old events better
- Experiences memory loss for a limited period of time
- In some cases, forgets what happened just a moment ago.

Concentration

- The person loses the thread
- Becomes restless
- Cannot concentrate on what they are doing
- Can only keep one thing in their mind at a time
- Gets confused in crowded places, such as shops and social settings
- Does not remember things they have read.

Overview, planning and initiative

- The person cannot fully grasp the course of the day
- Finds it difficult keeping track of appointments
- Tries to juggle too many things at once
- Fails to get tasks done
- Struggles to get round to starting something.

Fatigue, stamina and responsiveness

- The person takes a long time completing tasks
- Cannot be bothered finishing things
- Has reduced responsiveness
- Finds that things they used to do without thinking about it now require all their energy
- Finds that weaknesses, such as language difficulties, become more apparent when fatigue sets in.

Understanding the disease and changes in behaviour

- The person overestimates what they can do
- Appears unconcerned
- Does not feel sick
- Does not experience the progress they have made
- Is highly self-absorbed and forgets to consider others
- Violates codes of general behaviour
- Is very impulsive and cannot wait.

Emotional factors

- The person is prone to cry involuntarily
- Tends to laugh in inappropriate situations
- Experiences changes in temperament, such as becoming easily agitated or irritable
- Becomes indifferent to themselves and their situation
- Becomes sad, resigned and depressed
- Finds it difficult empathising with others
- Lacks confidence and has a low sense of self-worth.

If a person experiences any of the above symptoms, it can have an impact on their everyday life in education/training and work, as well as in social relationships.

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Assessing cognitive problems

It is crucial to have the person's cognitive problems assessed by a neuropsychologist who is familiar with epilepsy. The cognitive problems can have an impact on work. Some people with epilepsy struggle to complete a full day's work, manage specific tasks or simply do their job.

A neuropsychological examination can help to determine the areas in which the person needs help and to identify potential jobs or education/training.

What is a neuropsychological examination?

A neuropsychological examination describes psychological functions based on knowledge of the connections between brain processes and psychological functions. The examination identifies both weaknesses and strengths, and can include one or more of the following:

- Describing the current consequences of a known brain injury or disease
- Distinguishing between different brain disorders or between the consequences of a neurological injury/disease and pre-existing psychological problems
- Creating a plan for treatment/rehabilitation and light work
- Assessment of social impacts, such as coping ability and compensatory measures.

A neuropsychological examination is conducted one-to-one. It is a highly structured investigative tool. It is not always possible to get a picture of how the person acts and functions in everyday life. The examination should therefore be supplemented with practical tests or similar that can provide a picture of how everyday activities are performed.

It is essential to examine limitations and personal resources. This can lead to recommendations that can support the young person in education/training or work, or in their own home. Compensatory measures can help the young person to lead a normal everyday life, e.g. support them with creating structure, understanding communications from the authorities, managing finances, etc.

MENTAL HEALTH ISSUES

More than half of all people with epilepsy will experience an issue with their mental health at some point in their lives – usually it is short-term. People with epilepsy have a significantly higher prevalence of anxiety disorders, depression, schizophrenia-like psychoses, attention deficit hyperactivity disorder (ADHD), cognitive problems, and suicidal thoughts and attempts than the general population.

25% of people with epilepsy experience significant daily stress related to seizure anxiety and various cognitive problems that can affect their education/training or work, as well as their social relationships.

Anxiety and depression regularly occur in tandem, but often it is the depressive symptoms that are evident in the form of reduced desire, energy and interest. Self-esteem is often lowered, and there is less enthusiasm for life's challenges.

Some people with epilepsy also have cognitive problems (e.g. reduced initiative, overview and fatigue), which means that depression can be misinterpreted, and vice versa.

Many people with epilepsy do not want to talk about their disease. Many find it difficult to accept it themselves. The fear of being discovered having a seizure is a major concern for some. They may also suffer from panic anxiety. For some, the anxiety manifests as a constant tendency towards worry, tension and low self-esteem. Young people with epilepsy in particular develop social phobia, because they are afraid of having seizures in front of others, etc.

Untreated depression and anxiety have an influence on seizures. Worry and stress can trigger a seizure. The fear of having a seizure in itself can get in the way of an active and outgoing life.

It is important that the person with epilepsy is assessed by a doctor or psychiatrist if there is a suspicion of depression and anxiety.

A new identity with epilepsy

For some people, epilepsy is associated with a loss of dreams and identity. If a young person feels different from their peers, it can affect their self-image.

Young people affected by epilepsy in their teenage years may for a period of time want to live life as if nothing had happened to them, as some of them cannot comprehend having a chronic condition that requires daily medication. It can be difficult to accept the changes in everyday life caused by seizures, and the cognitive problems can be stressful. The young person may become fatigued faster than before, with the result that they cannot do the same things as before. The young person may not be able to socialise with friends due to fatigue or fear of having seizures.

Many young people with epilepsy struggle to maintain status, good grades, friendships, control of their life, etc., which is often to the detriment of family, friends and leisure interests, but may also cause more seizures because the individual's personal resources become depleted. It is often difficult for this particular group to accept epilepsy and the difficulties that come with it. They have often functioned perfectly normally before the epilepsy struck.

Friends and barriers

We hear about lonely and socially isolated young people with epilepsy who are struggling to make and maintain friendships. Epilepsy is taboo. Some people do not tell their friends about the disease. Many hide their disease and problems. Young people often do not consider or acquire an understanding of the problems that epilepsy can cause, which can affect their social interactions and prevent them making and maintaining friendships.

Fatigue can be a barrier to having friends and engaging in social activities. Young people with epilepsy, even those who do not have seizures, can experience incredible fatigue at the end of the study day, leaving them drained of resources to participate in social activities. Weekends are often spent recovering from a study week and getting ready for a new one.

Difficulty concentrating, staying focused and keeping up with conversations involving lots of people can all be very taxing for young people with epilepsy who have cognitive difficulties. The young person may find it difficult socialising and actively participating in conversations for extended periods of time. This can prevent them from participating in larger groups or gatherings, as it is too onerous and they do not get anything out of the interaction. Some need more time to respond and by the time they have an answer or want to contribute to the conversation, it has already moved on to another topic.

It is not just the young person with epilepsy who may be afraid of having a seizure while socialising with friends – their friends may also be afraid that the person will have a seizure. It can be hard to deal with a drastic change in someone's personality during a seizure or having to deal with a change in behaviour. If the young person is not open about their epilepsy, friends or classmates will not get the information they need. They may only experience the seizures. This may result in the young person not being invited along next time through fear that they might have a seizure.

Many people with epilepsy also refrain from attending parties because they do not want to risk having a seizure in the bar, for example. The fear of seizures when socialising or the fear of not being able to participate in conversations due to cognitive difficulties can therefore prevent some young people from attending events where there are lots of people.

Substance misuse

Epilepsy can change the life a person knows and the dreams they have for the future. Some lose friends because they cannot do the things they used to do. This can lead to a feeling of not being in control of their life and a sense of dependency on others, which increases the risk of the person misusing substances.

Substance misuse can also have physiological causes, for example, if epilepsy makes the person more impulsive. We hear of young people who find that cannabis makes them calmer and more focused. Here it is important to investigate whether the young person may need medication that can provide the same calm. Low self-esteem or depression as a result of epilepsy can lead to substance misuse.

How the misuse affects the young person with epilepsy varies. But it often enhances a mood. Some of the effects of epilepsy can be difficult to distinguish from the effects of misuse. The person with epilepsy may often be late and not get things done that they promised. They may lose track of things and find it hard to remember and react.

It is important to discuss the misuse. In our experience, the young person often needs to be able to see the benefits of stopping the misuse; that they do not need to numb the pain but instead dare to believe that life can be lived with the epilepsy. It is often found that an investigation of the effects of epilepsy (e.g. cognitive), counselling and support measures are key elements on the path away from misuse towards the establishment of realistic frameworks and requirements that the young person can manage. This is of great importance for the person stopping their misuse.

55,000
people have epilepsy
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LIVING WITH AND ACCEPTING EPILEPSY

Epilepsy is a disease that can occur at any point in life. For most people, it is a chronic disease that has to be lived with and treated for life. The timing of the onset of the epilepsy has a significant impact on the acceptance of the epilepsy. If the epilepsy occurs in childhood, the young person has often known nothing else. If the epilepsy occurs later, for example, when a young person is choosing an education/training or has established a family, job, etc., it can be more difficult to accept.

Acceptance of epilepsy

There is no set list for how and what a young person needs to learn in order to accept their epilepsy. Nor when they should learn it.

How young people cope with the diagnosis differs greatly and can relate to how the epilepsy affects the person, as well as the person's network and upbringing.

Many people do not always know what it is they need to accept because they are not clear about the difficulties they are facing. The invisible difficulties (cf. later section) are often insidious – unlike seizures, which are mostly visible.

Focus on the visible

The visible symptoms that often appear first are seizures. Following the onset of the epilepsy, it is typically generalised convulsive seizures that appear in the beginning. Treatment is then initiated to stop the seizures. The cause of the seizures is not eliminated with medical treatment, so the seizures will recur if the medication is stopped or if the person does not take their medication correctly. When one type of seizure is treated, another type of seizure may emerge that also needs to be treated, possibly with a different type of medication. Seizures are often a predominant feature of life for the person with epilepsy and their family. There is a lot of focus on seizures in the healthcare system and in the local-authority system, and very little focus on the invisible consequences.

Living with seizures

If the young person continues to have seizures, they need to learn to live with them. That is easier said than done and will often be a long-term process requiring specialised help, such as rehabilitation or psychoeducation. We often see that the seizures start to control the young person's life. This means that the fear of when the next seizure will occur controls the young person's actions. For example, the young person will isolate themselves, refrain from attending social gatherings, not use public transport, etc. In some cases, there may be a mismatch between the degree of fear of seizures and the actual seizures. It may be the fear of seizures that isolates the young person and not the seizures themselves. In this situation, specialised help is needed.

If the seizures are violent or involve actions that may be perceived as inappropriate in the given situation (e.g. drooling, removing clothes, talking nonsense, grabbing other people), there is a high risk of the young person isolating themselves through fear of seizures. Support for the individual in the form of practical help and accompaniment will be needed, as the fear is real.

Understanding epilepsy

For some young people with epilepsy, there may be certain seizure triggers, such as lack of sleep, stress, alcohol, etc. It is important to avoid such triggers. The seizure triggers are often highly individual. Specialised help may be needed to identify them.

If a young people's personal resources become depleted due to seizures, fatigue or cognitive difficulties, a social care needs assessment may be required, for example, in a local-authority setting. The assessment can provide insight into what adaptations are needed to achieve balance in the personal resources the young person has available for education/training, home and leisure respectively. If the young person's energy becomes depleted, the risk of seizures increases.

The invisible difficulties

Even if a young person does not have seizures, it does not always mean they are healthy. Epilepsy can cause cognitive problems, such as fatigue, slower pace, etc., cf. earlier section. In our experience, frequent seizures, especially generalised tonic-clonic seizures (GTCSs), can in time lead to cognitive difficulties, so focusing on reducing the frequency of seizures is a high priority. Once a young person has started to experience cognitive difficulties due to epilepsy, the lost functions cannot be retrained. So there is a need to compensate. Often the young person is unaware of the difficulties because they occur over a number of years. Often those around them notice difficulties and loss of function in the young person first. Family and past or present teachers, social educators and trainers can all help in identifying loss of function. The young person will unconsciously compensate for the lack of personal resources by cutting back on, e.g. leisure activities. Young people who live alone and do not have to consider anyone but themselves will often have a life where they struggle to cope with their studies/training and have to sleep the rest of the day to gather energy for the next day.

Living with the invisible difficulties

It is important to identify the invisible difficulties of the young person and pass on this knowledge to the young person and their family. This can give the person an understanding of where the invisible limits are so that they can help manage their own personal resources. This is especially important if the invisible difficulties are causing more frequent seizures or there is a fresh onset of seizures after the person has been seizure-free for a significant period of time. It is important to teach the young person to set limits for themselves, but it is also important that professionals know those limits so that the young person is not put under unnecessary pressure.

What is needed for a person to be able to accept their epilepsy?

It is important to know exactly what it is that a young person with epilepsy has to accept. In the case of newly diagnosed epilepsy, the social worker, youth guidance adviser or student counsellor should wait for the treatment to be established before drawing conclusions about functional ability and possibly enquiring about the prognosis. When a doctor establishes intractable epilepsy, this is where the acceptance of the epilepsy must begin. There may be a need for specialised help in the form of psychological support or a rehabilitation programme.

For a person to understand and accept their condition, it is important for them to know what type of epilepsy they have. It is about both the visible difficulties (seizures) and the invisible difficulties. Some people with epilepsy have watched recordings of themselves having a seizure to take away the mystery. Not everyone, however, as seizures can be so severe that this would cause fear. This is therefore done in consultation with the treating doctor.

Understanding the invisible difficulties requires further assessment, for example, by a neuropsychologist, preferably with knowledge of epilepsy.

55,000 people in Denmark have epilepsy. Yet many feel alone with the disease.

Talking to others who also have epilepsy can be very rewarding for young people. However, this can be difficult to arrange in practice because many people with epilepsy do not feel sick and do not see a need to meet with others in the same situation.

There are a few people who will not accept their epilepsy and the difficulties it causes, regardless of what they have learnt about their disease. For these people, time and personal experience will often provide a basis for acceptance.

Why is it so vital to accept the epilepsy?

If the epilepsy is difficult to treat, the young person has reduced personal resources. However, the level of reduction differs from person to person. Many people with epilepsy feel that the disease controls their lives, which can lead to more seizures, incredible fatigue, psychological comorbidity, etc. It can be a struggle to manage everyday life in terms of work, education/training, family and social life.

If a young person accepts the epilepsy and its limitations and learns to manage their personal resources appropriately, they will often find that they gain control of their epilepsy. It is therefore a matter of helping the young person with epilepsy to recognise their limits in terms of pressure, stress, fatigue and seizure triggers. This knowledge can contribute to increased control over the frequency of seizures and thus a greater sense of control overall.

However, the young person's acceptance makes no sense if their studies or work are not aligned to their personal resources, e.g. through reduced hours or modified work tasks. It is important to involve professionals in the local authority or educational/training institution.

Special Advisory Services for Epilepsy is happy to discuss the difficulties.

CHALLENGES IN COPING WITH LIFE

For some young people, accepting life with epilepsy can be difficult. Their parents have played a very active role in their lives, compensated, helped enormously in making room for adolescent life, and given reminders about things like medication and safety precautions. It can be a big upheaval for a young person with epilepsy to go from being a pupil in folkeskole (primary and lower-secondary school) and living at home to being a student on a youth education programme and possibly living away from home. It is also a period in the young person's life that is influenced by their own experiences and thoughts, and by the demands of their surroundings, such as the responsibilities for tasks and life that come with being an adult.

Acceptance and coping do not come overnight or from an admonishing finger. It is often a natural process built on personal experiences of ups and downs, defeats and gradual maturing that is the basis for being able to accept or simply cope with life with epilepsy.

> "FOR SOME YOUNG PEOPLE IT CAN BE DIFFICULT TO ACCEPT LIFE WITH EPILEPSY.

PROBLEMS WITH EDUCATION/TRAINING

Young people with epilepsy have dreams and aspirations for education/training like everyone else.

However, they cannot become a police officer, train driver, commercial driver or sailor. They cannot do military service either.

It is important to carry out an individual, specific assessment of the young person's education/training possibilities, taking into account the epilepsy and its psychosocial impact.

If the young person has seizures that come without warning, seizures that affect consciousness or seizures involving convulsions, we do not recommend education/training or jobs that involve working at heights, dangerous machinery or responsibility for other people.

Some education/training programmes and jobs can be hindered by a driving ban.

Some young people with epilepsy start their dream education/training programme and after a time have to drop out. We meet young people in our advisory work who have flitted in and out of education/training, which has affected their belief in their abilities. Some of these young people have been interpreted as lazy or disengaged. They were not lazy, but rather had cognitive problems that prevented them from keeping up with the programme. They did not undergo a cognitive assessment, which is important if relevant measures are to be implemented to keep them in a programme. Absences due to seizures, hospitalisations and mental fatigue can also be factors that affect the young person's retention in a programme.

Many of the young people we meet in our advisory work have been subjected to greater demands than they could handle. It is therefore important to know what level the young person needs to be met at and can handle in order to strengthen their self-image and be able to initiate the right help.

Choice of an education/training programme – light work

It is important to ensure that the effects of seizures and cognitive problems are taken into account in the education/training programme the young person chooses, and that the necessary support can be put in place.

It is therefore essential that the youth guidance adviser has a good basis for assessing the young person's challenges and possibilities.
If the young person has trouble learning from written materials and instead learns best by being shown, then the choice of education/training needs to be in a more practical direction.

Working in a shop may seem straightforward, but it can be inappropriate for some people if seizures might occur during working hours. It also depends on the employer's attitude to seizures and the type of seizure.

Working in a kindergarten can also be problematic for some people if there is a risk that they might have seizures in front of the children, have cognitive problems and therefore cannot remember messages from parents, or cannot keep track of what is going on in the room due to the noise and commotion.

Youth guidance and student counselling

It is necessary that the student counsellor is informed about the impact of the epilepsy so that specific guidance can be given on the possibilities and barriers in relation to the desired programme.

It is important that the young person, together with the student counsellor, considers whether the subject of the programme, e.g. carpentry, is realistic in the long term: The young person may be able to complete the programme, but in the event of a seizure there might be consequences for their driving licence, work functioning, etc. that require them to find an alternative job or field of work.

It is important to discuss the risk and possibilities in the event of absence. The tendency to fatigue should be discussed, as it needs to be taken into account when planning education/training, as well as the possibility of, for example, taking the programme over a longer period of time.

The location of the education/training institution and travel time should also be considered, as this can be a significant factor in a young person's ability to complete a full day of study.

Completion of education/training

If a young person has executive problems, they may need help with the overview and structure of assignments and projects and with any reading lists. It may be relevant to apply for support for extra examination time and extended study time. In our experience, many young people benefit from having a study support tutor, perhaps for an hour a week, to help with structure when completing assignments or prioritising any reading lists. Extra time may be needed for exams, as the stress of having to perform in exams can be stressful for the young person. It can trigger seizures. It is recommended that exams should not be too close together, as this can also put pressure on the young person and cause more seizures.

Project/group work

Some young people with epilepsy will find it difficult to participate on an equal footing with other students in project/group work due to the cognitive challenges they face. For example, fatigue, reduced work pace and the need for help with structure and planning. It is therefore important that the tutor and study group are informed about the special conditions that the young person with epilepsy needs in order to be able to contribute to the group work.

If the young person is open about their needs and challenges, they will often not feel excluded from group/project work.

Sickness absence

Young people with epilepsy are generally no sicker than other young people. However, they may have sickness absence due to seizures and in connection with hospital outpatient appointments.

In our advisory work, we find that many people with epilepsy manage their education/training like everyone else, but may suddenly experience an increase in seizure frequency or even seizure breakthrough. From having lived a normal life with epilepsy, the young person is no longer able to cope with their studies and has long-term sickness absence. There is a lot of focus on medical treatment, namely trying to reduce the frequency of seizures by adjusting medication. This can mean waiting time in relation to an increase or decrease in medication. Side effects may mean trying another medication or multiple mediations in combination with each other. There may be waiting time in relation to going into hospital for seizure classification, adjustments of medication or special programmes to assess the person's functional ability or how they are managing their epilepsy. All factors that can prolong the time off sick and thus the period of absence from studies.

It can be stressful for the person not knowing whether they can return to their training team or class, or whether they will have to postpone their studies indefinitely. For some people, it is clear that seizures are triggered by the number of hours in the week, assignments or exams. It can also be the prioritisation of leisure activities or concerns about their own situation.

Part-time jobs

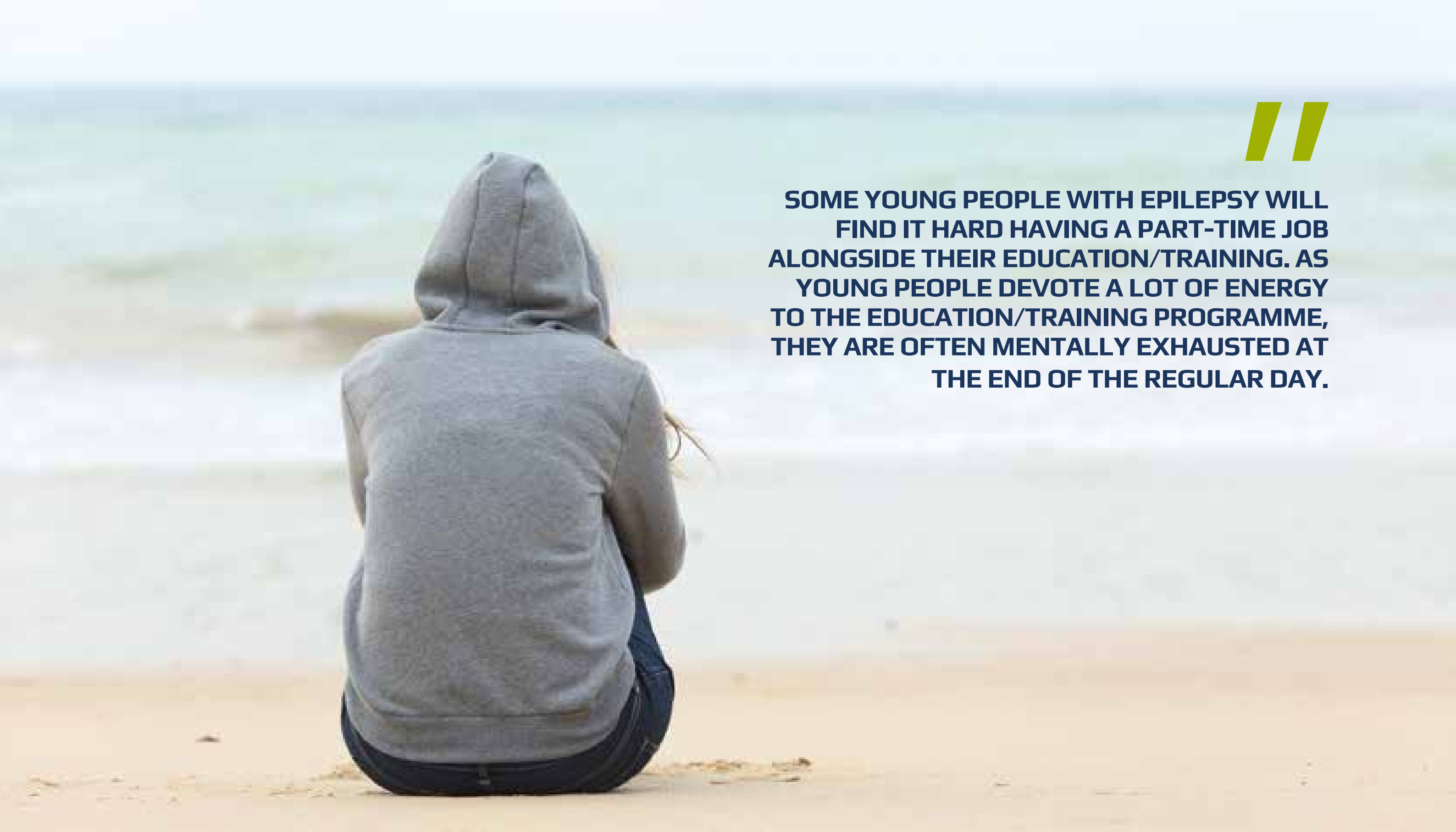
Some young people with epilepsy will find it hard having a part-time job alongside their education/training. As young people devote a lot of energy to the education/training programme, they are often mentally exhausted at the end of the regular day. Some young people do not have the personal resources to spend time with their friends or engage in leisure activities. They spend weekends and holidays catching up on academic work that they have not quite got to grips with or building up mental resources for the week ahead.

Job-seeking/work placements

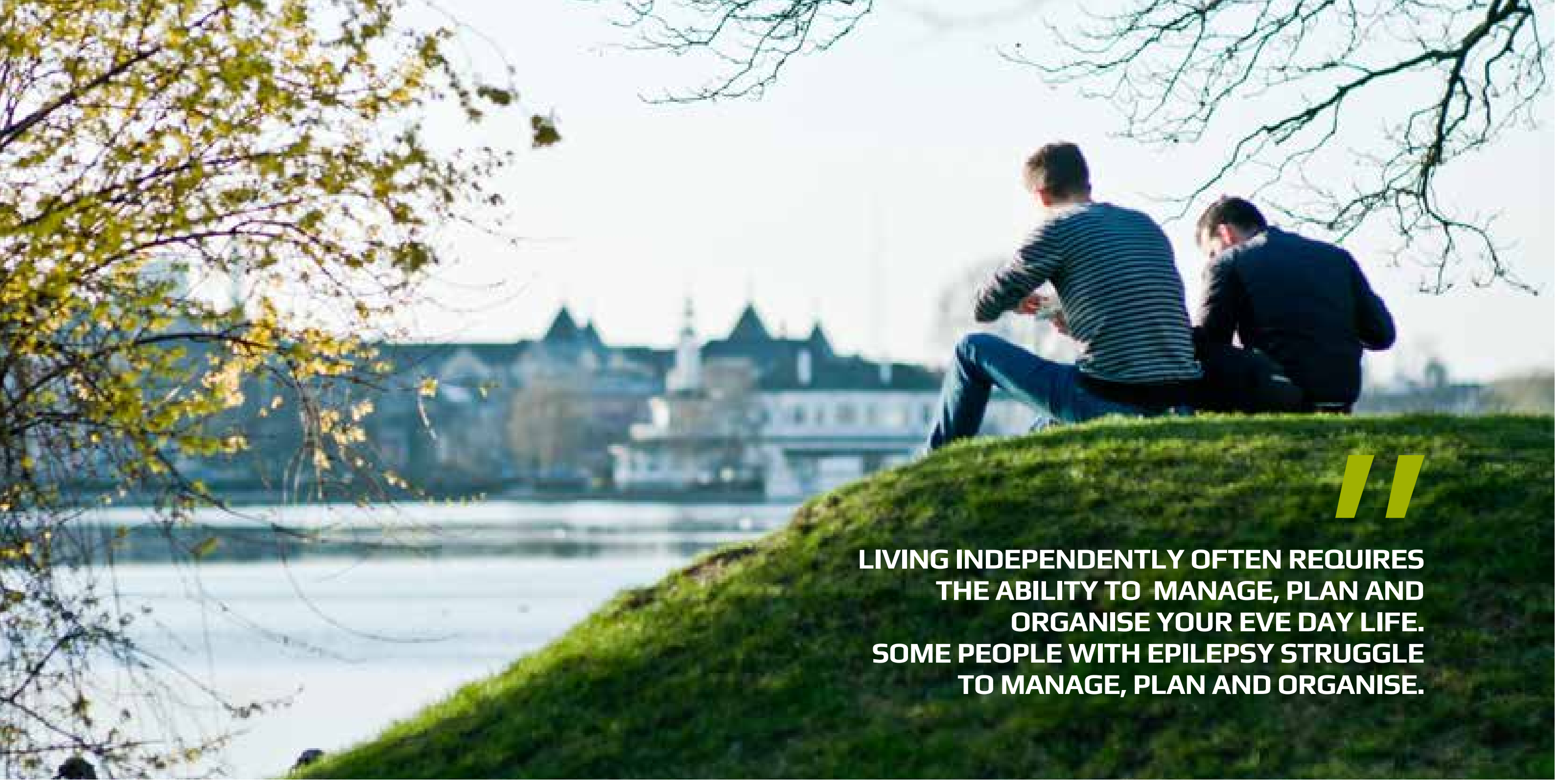
We meet many people in our advisory work who do not disclose their epilepsy to a future employer. "I simply wouldn't get the job," is the reason given. It is important to engage in dialogue with the young person and help them reflect on the functions of the job in relation to their epilepsy. For example, there may be an insurance-related aspect that makes it necessary to inform the employer.

It is the responsibility of the person with epilepsy to disclose their disease. It is important for the person to consider what seizures they have and what they look like. Is help needed after a seizure and are the seizures compatible with the job that the person is applying for? Are there any other issues, such as needing more time for instruction in a task or needing the instruction to be given in a particular way?

Worrying about seizures during work hours can be a significant stress factor if the person has not informed their workplace about the epilepsy. That strain in itself can contribute to an increased risk of seizures.



> **"SOME YOUNG PEOPLE WITH EPILEPSY WILL FIND IT HARD HAVING A PART-TIME JOB ALONGSIDE THEIR EDUCATION/TRAINING. AS YOUNG PEOPLE DEVOTE A LOT OF ENERGY TO THE EDUCATION/TRAINING PROGRAMME, THEY ARE OFTEN MENTALLY EXHAUSTED AT THE END OF THE REGULAR DAY.**



> LIVING INDEPENDENTLY OFTEN REQUIRES THE ABILITY TO MANAGE, PLAN AND ORGANISE YOUR EVE DAY LIFE. SOME PEOPLE WITH EPILEPSY STRUGGLE TO MANAGE, PLAN AND ORGANISE.

PROBLEMS IN EVERYDAY LIFE/AT HOME

Moving away from home

Many questions arise when young people with epilepsy leave home. Young people often do not see this as a problem and want to be independent and manage for themselves like other people. Family often find it difficult to let go because they are worried about whether the young person can cope and manage their epilepsy.

Moving away from home means the young person has to manage everything, from dealing with the authorities to the practicalities of home life, such as laundry, cooking and finances.

In our advisory work, we find that young people with epilepsy can have difficulties managing on their own. They may be exhausted after a day of study or work and may not have the personal resources to do what other people do. This could be socialising, doing homework, shopping, cooking, participating in leisure activities, etc. Often the least necessary things, such as leisure interests and friends, are not prioritised.

Living independently often requires the ability to manage, plan and organise daily life. Some people with epilepsy find it difficult to manage, plan and organise. Small everyday tasks can seem unmanageable. It can be difficult to admit not being able to do simple tasks, and it can be hard asking for help.

In the worst case scenario, it can mean that the young person with epilepsy becomes so stressed that it results in seizure breakthrough or an increase in seizures. Some drop out of the education/training programme because they cannot live independently and study at the same time. Weekends are used to recover and recharge for a new week. Others move back in with their parents until the situation is back under control or until the education/training programme has been completed.

Filling out a seizure diary can be difficult if the young person does not notice their seizures. Some people may have difficulty remembering to take their medication, in which case measures should be put in place wherever possible to ensure that the medication is taken. An app can help, while others rely on personal assistance because they do not remember that their phone has alerted them to take their medication.
Some parents have concerns about whether it is safe for the young person to live alone, for example in an efterskole (residential school), hall of residence or apartment. A treating doctor should be involved. The doctor will be able to advise on the need for emergency pull cords or buttons, supervision, personal alarm devices, etc., especially if the young person is at risk of SUDEP.

Parents as teammates or opponents

Worried parents often ask for help for the grown-up child who is really struggling. They may feel vulnerable discussing it. Parents talk about the young person's fatigue after studying, problems keeping it together, participating in everyday activities or having the personal resources for physical interaction. They may observe the young person withdrawing from social situations and not attending parties due to fatigue or fear of seizures.

It is important to consider the following factors when talking to parents. They are the young person's knowledge bank when it comes to epilepsy, but they also have the baggage of the emotional experiences.

As parents of an adolescent with newly diagnosed epilepsy, they may have the same emotion as if their child had developed epilepsy as a toddler. Grief over lost dreams on behalf of a child can dominate parents' everyday lives.

If the first seizure involved convulsions, most parents will be anxious. They thought the young person was going to die. It is harrowing to stand there, look on and maybe not be able to do anything other than call for an ambulance. Many parents will be worried that there will be another seizure. For some parents, the anxiety subsides once treatment begins and is effective. Other parents, however, live in constant fear of the next seizure.

If the epilepsy proves difficult to treat and there are a lot of seizures, the family may be in a more or less constant state of crisis for many years.

Epilepsy can cause emotional and practical problems in the family:

- Fear about seizures, the young person's development and the future
- Shame about the seizures, the disease and the young person's behaviour
- Changing daily and life routines
- Difficulty being around the young person to keep an eye on them
- Sleep problems due to nocturnal seizures
- Changing care patterns and requirements.

Epilepsy often has social costs. Some families become afraid to let the young person do things the way they used to. They change habits for the young person, and also for the rest of the family. The changes can cause limitations in the family's social life, and they can become socially isolated.

Friends and family may step away because they do not understand the changes happening to the family. Many struggle to cope with or understand the disease. Especially for the group of young people who develop epilepsy as teenagers, we hear about a lack of understanding – both on the part of the young person, but also the parents, who question their abilities and way of bringing up the young person – the fact is that the young person looks exactly the same as before the epilepsy.

Sometimes unhelpful patterns will emerge in the family, such as overprotection of the young person, lack of boundary-setting and mollycoddling.

PRACTICAL PROBLEMS WITH EPILEPSY

Driving ban

The rules on obtaining a driving licence and driving bans in connection with newly diagnosed and pre-existing epilepsy are clear. Please refer to the Danish Patient Safety Authority's 'Guidelines on health requirements for driving licences' and consult with the treating epilepsy doctor.

Anyone can depend on a driving licence for education/training and work placements. It is a big problem when someone loses the possibility of holding a driving licence. Alternative driving options should therefore be considered, such as a moped 30 (maximum speed 30 kilometres an hour), carsharing with friends or public transport.

Public transport and epilepsy

Some people with epilepsy have a fear of seizures. The nature of the seizures and the loss of control can discourage the young person from using public transport, which can make it difficult being in the labour market. It is not just the frequency of seizures that determines the level of anxiety, but rather how the attacks manifest. Some people have seizures when they wake up. Many have major issues with mental fatigue and may fall asleep on the bus or train, so the risk for them is that they might have a seizure upon waking up or falling asleep. For some people, finding their way around train and bus timetables is a major task due to cognitive issues.

POINTS OF ATTENTION FOR PROFESSIONALS

Epilepsy in everyday life

- How often does the young person have seizures?
- What type(s) of seizure do they experience?
- How is the young person affected before and after a seizure?
- Does the young person need to rest afterwards, and for how long are they affected?
- Is the young person anxious or externalising before a seizure?
- What can trigger a seizure?

Cognitive problems

- Does the young person have problems remembering, learning – visually or linguistically?
- Can the young person remember information from lessons, take notes and understand content?
- Does the young person learn better from doing things in practice rather than theoretical teaching?
- Can verbal messages be remembered?
- Does the young person have the personal resources to get their homework done?
- Can the young person create the necessary structure and maintain an overview of tasks, reading lists, etc.?
- How many hours can the young person last without getting exhausted?
- Are any special aids or setups needed for the young person to learn best, such as headphones or a particular seat?

Socialising with others in the class

- What is best for the young person at breaktimes – being alone or with others?
- Does the young person need to be alone at breaktimes due to fatigue?
- Does the young person use headphones/computer/mobile phone to recharge mentally?
- Does the young person have the personal resources to socialise after school?
- Does the young person have the personal resources for anything other than the education/training programme?

Facts about young people with epilepsy

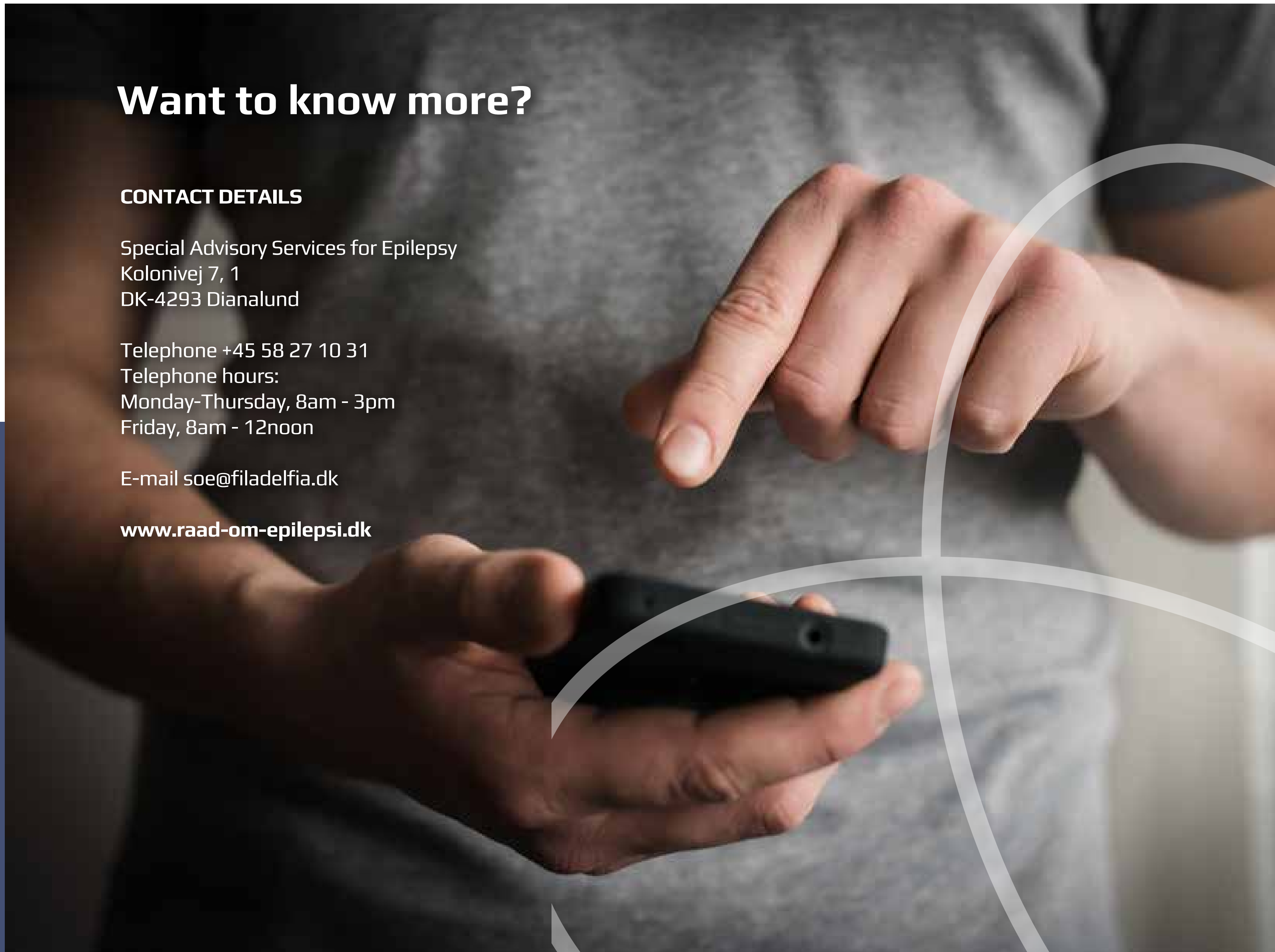
- More than half of all people with epilepsy will experience an issue with their mental health at some point in their lives.
- For some people, epilepsy is associated with a loss of dreams and identity.
- Epilepsy is taboo.
- It is important to have a discussion about the risk of substance misuse and the consequences.
- Even if a young person does not have seizures, it does not always mean they are healthy.
- It is essential to teach the young person to set boundaries for themselves.
- Many young people with epilepsy feel alone with the disease and the problems it causes.
- Young people with epilepsy have dreams and aspirations for education/training like everyone else.
- Having to perform well in exams is stressful for young people with epilepsy. It can trigger seizures.
- It is the responsibility of the person with epilepsy to disclose their disease.

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 assess, 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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