FILADELFIA

Adults with epilepsy

– til pædagoger, psykologer, sundheds- og socialfaglige medarbejdere i kommunen

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.

Many people with epilepsy tell us they do not feel understood by their social worker. At the same time, they often find it difficult explaining the problems that epilepsy causes them.

In order to provide good case management 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 people with severe epilepsy. We 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.

76,000 people in Denmark live with epilepsy.

25% of people with epilepsy develop the disease before they reach the age of 15.
25% develop the disease 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. The disease is often long-term and requires medical treatment.

Diagnosis

Epilepsy is typically only diagnosed after two seizures. Some people know the cause of the disease, such as a blood clot, brain trauma or similar. However, for a large proportion of people with epilepsy, the cause is unknown. In recent years, genetic research has led to more people being given a genetic explanation for their disease, but the number of unknown causes is still high.

To make the diagnosis, the person with epilepsy undergoes an EEG examination, which records brain activity. A thorough description of the seizures is crucial for doctors to make the right diagnosis.

Seizures – not just convulsions

Seizures manifest very differently and with varying frequency. Some people experience rare, brief absences in the form of blanking out, 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 part of the brain. 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 people continue what they are 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.

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).

Epilepsy is considered intractable when the person has tried three medications (possibly in combination) and the seizures continue. 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).

Epilepsy surgery

Every year, around 40 people undergo surgery for epilepsy with frequent and severe seizures. 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. For example, the person may have difficulties learning new things, memorising 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 issues with memory.

The patient should expect to be on antiepileptic medication for at least two years after surgery.

> "TWO THIRDS OF ALL PEOPLE NEWLY DIAGNOSED WITH EPILEPSY CAN BECOME SEIZURE-FREE WITH MEDICAL TREATMENT.

Collecting health information

When a social worker collects health information, it is often through medical records or status certificates. It can also be specialised medical certificates.

It can take a long time to investigate a patient before the doctor can make a relevant assessment of their status. This can cause problems because time limits have become shorter in this area with regard to, e.g. sickness benefits. The doctor cannot answer questions about prognosis early on in the process. Nor can the doctor say when the person will be well again. Often the person does not get well again. It is a matter of treating the symptoms, and how well the medication works will differ from person to person. For long periods of time, the doctor will observe how the medication is working. The medication may need to be increased or decreased, or the doctor may choose a new medication. During this period, it is relevant to consider the treatment, the assessment plan, how the treatment is carried out and when it will be relevant to collect further information.

There may be a problem with collecting the information because people with epilepsy are often unable to provide details about their epilepsy themselves. There are a lot of new things for the person with epilepsy and their family to deal with. A life with sudden seizures, cognitive difficulties that the patient often cannot put into words and the family cannot see, and fatigue are just some of the issues that the patient and their family may face.

It can be difficult to understand the doctor's information. For example, if the doctor writes that treatment is possible, this is not the same as saying that the person's health will improve significantly. When a doctor writes that the person's epilepsy is well-treated, it does not necessarily mean that they no longer have seizures. It is about the best possible treatment with as few side effects as possible.

If there is anything you are unsure about, no matter how small, you are always welcome to contact Special Advisory Services for Epilepsy to discuss your case. It's free of charge.

> "COGNITIVE PROBLEMS ARE PROBLEMS WITH, E.G. LEARNING, MEMORY, CONCENTRATION AND STRUCTURE.

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 are difficulties with learning, memory, concentration, structure and other cognitive domains. Executive skills are often particularly affected when a person has epilepsy. That is, the ability to engage in independent, self-directed behaviour that has a clear purpose. 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 any constraints of the particular situation. One example of this is cooking. This involves deciding on a dish, making a shopping list, getting to the supermarket, doing the shopping, following the recipe, etc. It is a long process that we often go through without thinking about it. If you have cognitive challenges, this process can suddenly become difficult.

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 limiting their hours of study or work. Partly to ensure appropriate energy levels throughout the day, and partly to prevent massive 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 are often not made aware of the person's fatigue. It is important to keep an eye out for fatigue because it often plays a big role in relation to the personal resources the person has at their disposal.

Cognitive problems

Memory

- The person forgets appointments, messages and tasks
- May have difficulty learning and remembering new things, but remembers older things better
- May have memory loss for a limited time
- May experience loss of memory of what happened a moment ago, possibly due to absences.

Concentration

- The person may lose the thread
- May be restless
- Cannot always concentrate on what they are doing
- Can possibly only keep one thing in their mind at a time
- Can get confused in crowded places, such as shops and social settings
- Does not necessarily remember things they read

Overview, planning and initiative

- The person may not be able to fully grasp the course of the day
- Finds it difficult keeping track of appointments
- Often tries to juggle too many things at once
- Does not always manage to finish tasks
- May find it hard to muster the energy to get started.

Fatigue, stamina and responsiveness

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

Understanding the disease and changes in behaviour

- The person may overestimate what they can do
- May appear unconcerned
- Does not necessarily feel sick
- Does not experience the progress they have made
- Can be highly self-absorbed and forget to consider others
- May violate codes of general behaviour
- Can be very impulsive and cannot wait
- May forget to take their medication.

Emotional factors

- The person is prone to cry involuntarily
- May have a tendency to laugh in inappropriate situations
- May experience changes in temperament, such as becoming easily agitated or irritable
- May become indifferent to themselves and their situation
- May become sad, resigned and depressed
- May find it difficult to empathise with others
- May lack confidence, have 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.

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 determine the areas in which the individual needs help. A number of studies suggest that cognitive difficulties may already be present at the onset of epilepsy, and perhaps even before. The person with epilepsy should therefore be aware of any cognitive difficulties already present at the time of diagnosis. There is a risk of underreporting of any cognitive difficulties from both the person with epilepsy and their family. This may be partly because the person with epilepsy perceives the cognitive difficulties as challenges they have always faced and therefore also lived with, and partly because the person may lack the language to adequately express and describe the cognitive difficulties. Finally, any difficulties may be hidden because the environment around the person has compensated for them.

Seizure-free does not equate to problem-free.

Neuropsychological examination

The primary purpose of a neuropsychological examination is to assess a person's cognitive functioning based on knowledge of the relationship between brain functioning and disease in relation to behaviour, thoughts and emotions. Cognitive functioning reflects an individual's personal resources and any challenges in areas such as thought, problem-solving, learning and memory, and can be affected by, among other things, epilepsy.

The examination is usually based on a preliminary conversation with the person regarding their past and current level of functioning and any perceived difficulties, as well as available medical records and other documentation relating to previous examinations and actual testing of cognitive functions. A neuropsychological examination will often take place in a quiet, private examination room with structured alternation between conversation and paperwork.

As cognitive functioning can be negatively affected by the presence of psychiatric symptoms, including symptoms of stress and depression, it may be relevant as part of a neuropsychological examination to determine whether, in addition to cognitive difficulties, there are psychiatric symptoms that may be affecting overall functioning.

The purpose and content of a neuropsychological examination can vary depending on the type of disease, the patient's life circumstances and the questions that are sought to be answered.

A neuropsychological examination may include the following:

- An assessment of the person’s overall learning ability and level of functioning in various cognitive domains, such as memory, attention, language and problem-solving.
- An assessment of the correlation between the perceived difficulties, the test results obtained through examinationand the person’s disease.
- A description of the person's overall personal resources and challenges, as well as any support needs and relevant compensatory strategies.
- A description of any other factors that may affect the person’s overall coping ability and quality of life and indicate the need for further investigation.

Because a neuropsychological examination is conducted one-to-one in a highly structured and private setting, it can help determine a person's cognitive resources under optimal conditions. However, this also means that issues such as distractibility, complex task accomplishment and fatigue cannot always be demonstrated in the examination context. It can therefore be useful to supplement a neuropsychological examination with practical tests or the gathering of information about the person's level of functioning in, for example, education/training and work contexts, as well as in everyday life to obtain the most accurate picture of the person's overall level of functioning. This can lead to recommendations that will support the person in a job or other compensatory measures that can help them to lead a normal everyday life at home. This help could be support in creating structure, understanding and acting on communications from public organisations, managing finances, etc.

MENTAL HEALTH ISSUES IN EPILEPSY

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 are more likely to experience anxiety, 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 fear of developing various cognitive problems that could 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 seen 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 diagnosis. The fear of being discovered having a seizure is a major concern for a lot of people. 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. Isolation can therefore serve as a tool for enduring life and reducing anxiety.

However, untreated depression and anxiety have an impact 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.

Loss of work identity

When epilepsy strikes a person of working age, when job, family and friends have often become established, work identity can be severely affected. Likewise, work identity can be affected when the effects of years of epilepsy and treatment begin to take their toll. Many people with epilepsy therefore struggle to maintain their job or profession, often to the detriment of family, friends and leisure interests. But often also at the cost of more seizures because people with epilepsy deplete the personal resources available to them during the course of the day. It is often difficult for this target group to accept the disease and the difficulties that come with it.

Friends and barriers

We often hear about lonely and socially isolated people with epilepsy who are struggling to make and maintain friendships.

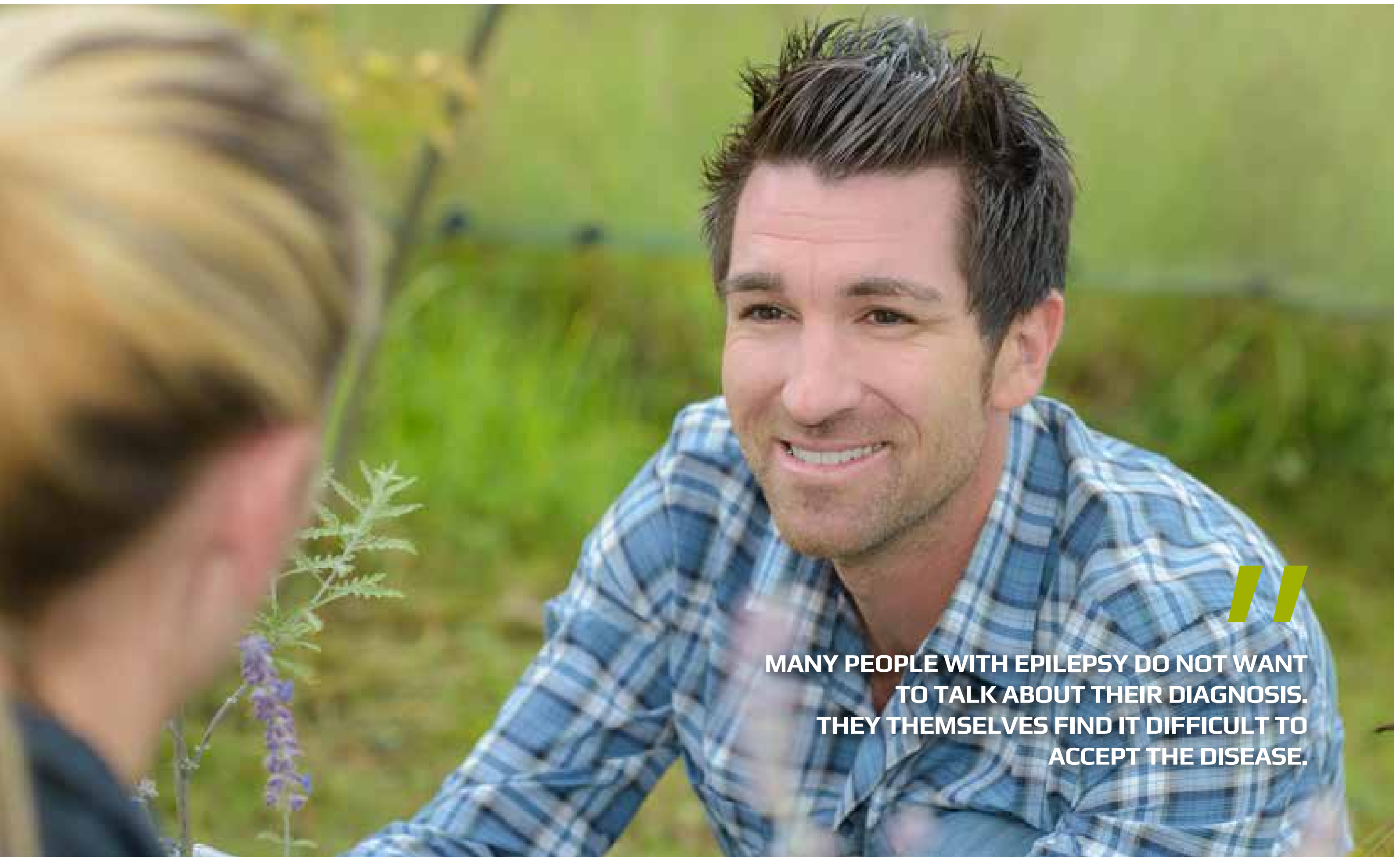
Epilepsy is a taboo disease. Some people do not tell friends and colleagues about their disease. Many hide their disease and problems. They often do not address or understand the problems epilepsy can cause, which can affect social interaction.

Fatigue can be a barrier to having friends and engaging in social activities. Many people with epilepsy, even those who do not have seizures, can experience massive fatigue at the end of the working day, leaving no personal resources to participate in social activities. Weekends are often spent recovering from a working 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 people with epilepsy who have cognitive difficulties. The person may have difficulty socialising and actively participating in the conversation for longer 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 person with epilepsy who may be afraid of having a seizure when 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 person is not open about their epilepsy, their friends or colleagues will not get the necessary information about their epilepsy. They may only experience the seizures. This may result in the person not being invited out next time through fear that they might have a seizure.

Many people also refrain from attending parties because they do not want to risk having a seizure, perhaps in the middle of a conversation, and ruining the party. The fear of having a seizure while socialising or the fear of not being able to participate in conversations due to cognitive difficulties can therefore prevent some people from attending events where there are lots of people.



> "MANY PEOPLE WITH EPILEPSY DO NOT WANT TO TALK ABOUT THEIR DIAGNOSIS. THEY THEMSELVES FIND IT DIFFICULT TO ACCEPT THE DISEASE.

LIVING WITH EPILEPSY

Epilepsy can occur at any point in life. For many, it will be a chronic and long-lasting disease that they will have to live with and receive lifelong treatment for. There are both visible and invisible difficulties that a person with epilepsy and their family must learn to live with and navigate in everyday life.

The timing of the onset of epilepsy has a significant impact on the changes it can cause in everyday life. If the onset of epilepsy was in childhood, the person has often known nothing else and their daily life and personal resources will be adapted accordingly.
If the onset of epilepsy is in adulthood, it can cause significant changes. It could be an educational/training situation that needs to change, a change of job due to seizures, or family life that is affected to varying degrees.

There is no set list for how and what a person needs to learn in order to live with their epilepsy. Nor when they should learn it. How an individual copes with the onset of epilepsy differs from person to person. It may be related to how the epilepsy develops and affects the person´s situation, the network around the person and the person's upbringing.

The visible difficulties

The visible symptoms are mainly seizures. Following onset of the epilepsy, it is typically generalised convulsive seizures that appear in the beginning. Following diagnosis, treatment is 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, for some people 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 often a lot of focus on diagnosing and treating seizures on the part of the healthcare system and very little on other issues.

Living with seizures

If the treatment does not work and the person continues to have seizures, they have to learn to live with the seizures. This will often be a long-term process requiring specialised help, such as rehabilitation. We often see that seizures start to control a person's life. This means that the fear of when the next seizure will occur controls the person's actions. For example, the 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, especially if the seizures are mild and infrequent. Here it is the fear of seizures that isolates the person, 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 (e.g. drooling, removing clothes, talking nonsense, grabbing other people), there is a high risk of the 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.

Seizure triggers

For some people, certain factors can trigger a seizure. It could be lack of sleep, stress, alcohol, etc. It is vital that the person is aware of their epilepsy and, to the extent possible, tries to avoid behaviour that could trigger a seizure. Often, specialised help is needed to identify what factors may be contributing to an increase in seizure frequency.

If the individual´s personal resources become depleted due to seizures, fatigue or cognitive difficulties, there is an increased risk of them having a seizure or having more seizures. In this type of situation, a social care needs assessment may be required, for example, in a local-authority setting. The assessment can provide an insight into what adaptations are relevant to achieve balance in the person's life. It can be assessed, for example, whether there is a need for special support programmes in education/training, at work or at home.

The invisible difficulties

Even if a person does not have seizures, it does not always mean they can be considered healthy. Epilepsy can cause cognitive problems, such as attention problems, learning difficulties, slower pace, fatigue, etc., cf. earlier section. Frequent seizures, especially generalised tonic-clonic seizures (GTCSs), can in time lead to cognitive difficulties, so focusing on reducing the frequency of seizures is obviously a high priority. When a person has been experiencing cognitive difficulties due to epilepsy for many years, the lost functions cannot be retrained. There will be a need to compensate for these to a greater or lesser extent.

Often the person is unaware of the difficulties because they occur over a number of years. Frequently those around them notice the challenges in the person first. Family and past or present work colleagues can be good sounding boards for identifying loss of function. The person will unconsciously compensate for the lack of personal resources by cutting back on, e.g. leisure activities.

People who live alone and do not have to consider anyone but themselves will often have a life where they use all their personal resources carrying out their work/study/training and have to sleep the rest of the day to gather their energy for the next day. Some people spend the whole weekend relaxing to be ready for the next week's work/study/training, but without fully recharging their batteries.

Living with invisible difficulties

It is important to identify the invisible difficulties of the person and pass on this knowledge to the 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 person to set limits for themselves, but it is also important that professionals know those limits so that the person is not put under unnecessary pressure.

What is needed for a person to be able to navigate life with epilepsy?

It is important to know what it is that a person with epilepsy has to learn to live with and what can be eliminated through treatment. In the case of newly diagnosed epilepsy, it is important for professionals to wait for the treatment to be established before drawing conclusions about functional ability and possibly enquiring about the prognosis.

When the treating epilepsy doctor determines that the epilepsy is difficult to treat, the focus should be on identifying any social problems that may be due to the epilepsy. There may be a need for specialised help in the form of psychological support or, for example, a rehabilitation programme or an assessment of functional ability.

Knowing the person's specific type of epilepsy is the first step in understanding the disease. It is about both the visible seizures and the invisible difficulties. Some people with epilepsy may benefit from watching recordings of themselves having a seizure to take away the mystery. For some people, however, watching themselves having a seizure can cause fear rather than bringing any benefit. This should therefore be done in consultation with the treating doctor and nurse.

Understanding the invisible difficulties requires further assessment, for example, by a neuropsychologist, preferably with knowledge of epilepsy.
According to figures from the Danish Health Authority, 76,000 people in Denmark were living with epilepsy as of 2023. Yet many people feel alone with the disease and the problems it causes. Talking to others who also have the disease can be very rewarding for people with epilepsy. 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 very few people who will not acknowledge that they have epilepsy and the difficulties it causes, regardless of what they have learnt about their disease. Time and personal experience will often form the basis for recognising and managing epilepsy and reduced resources differently.

Why is it so important to manage epilepsy?

If the epilepsy is difficult to treat, many people will have reduced personal resources. However, the level of reduction will vary greatly from person to person.

Many people 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 person recognises the epilepsy and its limitations and learns to manage their personal resources appropriately, they will often find that they are now in control of their epilepsy. It is therefore about helping the person to recognise their limits in terms of pressure, stress, fatigue and other factors that can trigger seizures. This knowledge can contribute to increased control over the frequency of seizures and thus a greater sense of control overall.

However, the person’s own efforts in terms of energy management make 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 that professionals in, for example, the local authority or educational institution are involved.

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

> MANY PEOPLE FEEL THAT THE DISEASE CONTROLS THEIR LIVES.

JOB-RELATED PROBLEMS

People with epilepsy are excluded from jobs such as pilot, train driver or ship's captain. In addition, there are some fields of work in the grey zone, but where health determines whether a person can become, for example, a police officer or do military service. There are other professions that also require good health.

Most other jobs require a reasonable assessment of what type(s) of seizure a person experiences, what work functions need to be performed in the specific position and whether the position involves a risk of the person harming themselves or others.

The nature of the seizures can affect the specific work functions that the person will perform. In particular, loss of consciousness during a seizure can entail a risk, both in relation to dangerous machinery, but also in a job where the person has responsibility for other people. That is why it is crucial to get a thorough description of the seizures, including whether the person can feel a seizure coming on or if it comes suddenly and without warning. It is important to get a description of what happens before, during and after a seizure. Furthermore, the nature of the seizure must be related to the current job and work functions.

In addition to seizures, a person with epilepsy may generally have reduced personal resources compared to others. This can be due to the seizures, the side effects of medication, cognitive difficulties and mental fatigue. This means that a person with epilepsy may be seizure-free but still have great difficulty performing a job under normal conditions.

Identifying difficulties often requires specialised knowledge and experience of the consequences of epilepsy. Often, local-authority social workers have not encountered many people with epilepsy. It can be difficult to identify in a conversation with the person what protective measures are necessary, as the person is not always aware of their own difficulties and limitations.

Some people use a lot of mental resources following a conversation and may leave a meeting without saying what is on their mind. Memory problems and difficulty maintaining an overview of a potentially complex case process can contribute to the person not necessarily being able to pass on relevant information to various organisations.

Some people may need to take home a short summary of the conversation, as they may find it difficult to remember the content and arrangements later on.

Taking time off sick

People with epilepsy are generally no sicker than anyone else. But they may have days off sick due to seizures and hospital outpatient appointments. The employer can get compensation according to the Section 56 agreement. Read more at Borger.dk

We find that many people with epilepsy get by in the labour market like everyone else. However, some people suddenly start experiencing seizures. From living a normal life with their epilepsy, the person can no longer cope at work and goes on long-term sick leave. The focus here is very much on the medical treatment, namely trying to reduce the number of seizures by adjusting the medication. This can mean waiting time in relation to an increase or decrease in medication. There may be side effects from the medication, which means trying another medication or several medications in combination. Sick leave can be prolonged due to hospitalisations, seizure investigations, adjustments of medication or special programmes to assess the person's functional ability or how they are managing their epilepsy.

The length of a sickness absence will be completely different from person to person.

The person will often feel caught between:

- their employer, who wants them back at work
- the local authority, which wants the person to be in work
- the epilepsy, which the person themselves may feel powerless to do anything about
- the healthcare system, which wants the person to take things easy until the change of medication is in place.

Being off sick can be very stressful for a person with epilepsy, especially when it is not possible to put a date on when they will be able to return to work.

Naturally, a health assessment has to be carried out to consider the medical treatment and whether any changes need to be made. However, sometimes it can also be beneficial to look at the person's everyday life. Have things changed at work? New tasks, a new colleague or boss can lead to changes in structure and routines that can cause stress for the person with epilepsy. Sometimes it is changes in the home: moving house, divorce or some other factor can affect the emotional state of the person and potentially make demands on their personal resources.

Job-seeking

Should the job-seeker disclose their epilepsy to the employer? When should it be done? What happens if they do not? The answers to some questions are to be found in the legislation. There are some professions that people with epilepsy are specifically excluded from. Other fields of work require good health or a health assessment prior to training/work, such as military service, the police, etc. Consider the functions of the job in relation to the epilepsy, e.g. skilled trades or professions where the person has responsibility for other people, such as nursing, care and early years education.

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. This applies to both young people and adults with epilepsy. For example, some people are only diagnosed with epilepsy after working in a certain field for many years.

The responsibility for disclosing epilepsy lies with the job-seeker. It is important for the person to understand what kind of seizures they have and how they manifest. Is help needed after a seizure and are the seizures compatible with the job functions? Are there other issues, such as needing more time for instruction in a task or needing the instruction to be given in a certain way? Being nervous about having seizures during working hours can be a significant stress factor if the employer/colleagues are not informed about the epilepsy. This in itself can contribute to an increased risk of seizures.

Assessing personal resources – can the person work full time?

Most people with epilepsy want to manage by themselves and be self-reliant. It is often a very difficult situation for a person with epilepsy to admit that they do not have the personal resources for a regular job if they are also going to have a life outside of work. We see a lot of people in our advisory work who are hanging on to a job because they do not want to lose it. They may use twice as many personal resources as a colleague without epilepsy to do the same job. This can lead to incredible fatigue after a day's work, trigger seizures and have a major impact on the person's ability to engage in social relationships, family life and other daily tasks.

We also see a lot of people with epilepsy who do not feel understood by the public authorities because they look normal and may have managed by themselves and been in full-time employment for many years. Many people do not have seizures but still have great difficulty coping with work and daily life due to fatigue and cognitive difficulties.

In our experience, various employment assessment programmes, including work placements, focus a lot on working ability alone, while less attention is paid to whether at the end of the working day the individual has the personal resources for ordinary tasks such as shopping, cooking, socialising, etc. Many people with epilepsy experience incredible fatigue, use up all their energy at work and often have to spend the rest of the day (and perhaps several days) recovering and getting ready for the next working day. If the person has close family who have an abundance of personal resources, they will often try to compensate by taking on most of the practical everyday tasks to relieve the burden on the person with epilepsy. This can put a lot of strain on the family, but also on the person with epilepsy, who does not necessarily benefit from an increase in their own personal resources and in many cases becomes highly dependent on family while their difficulties and inadequate personal resources remain invisible to everyone else.

More than many others, people with epilepsy therefore need to prioritise which activities they spend their personal resources on during the day. Many need advice and support to structure and maintain energy for the whole day. When a work placement is initiated to determine a person's work capacity, it is therefore important to take into account their overall personal resources and not just focus on their ability to do a job. Many people with epilepsy do not know their own personal resources and limitations.

Epilepsy can affect a job, but a job can also affect epilepsy.

PROBLEMS IN EVERYDAY LIFE

Living independently

Young people and adults alike can struggle to have enough personal resources to manage their daily lives. Many may be exhausted after a day of education/training or work and may not have the personal resources to participate in the same activities as others. This can include social networking, doing homework, shopping, cooking, participating in leisure activities, etc. Often, this will lead to them opting out of the least necessary activities, which can result in social isolation.

Successful independent living often requires the person to be able to manage, plan and organise their daily life. Many people with epilepsy struggle to manage, plan and organise, making even small everyday tasks seem overwhelming and exhausting. For many, it can be difficult to admit not being able to do simple tasks, and it can be hard asking for help. In this situation, social-educational support may be needed.

In the worst case scenario, it can mean that the person with epilepsy becomes so stressed that seizures recur after a long period without seizures or there is an increase in the number of seizures. Some people take sick leave from work or have no social life outside of work because their free time is spent recovering.

Living independently may also make it difficult for the person to fill out a seizure diary if the person does not notice their seizures.

Partners of people with epilepsy

For a person with epilepsy, having a partner can be a good thing. It can be reassuring for them to have someone to take care of them in the event of a seizure. The partner can help manage daily life if it is difficult for the person with epilepsy. The partner can also accompany the person with epilepsy at various meetings with the authorities.

But being the partner of a person with epilepsy can be very stressful. So stressful, in fact, that the partner can develop symptoms of post traumatic stress disorder (PTSD).

We see worried people with epilepsy asking for help for their partners. Many people with epilepsy can see that their partner is struggling, but it can often be difficult to talk about.

It is important for a professional to know how a partner is affected in day-to-day life so that the professional can help the person with epilepsy become an equal partner in the relationship.

Many partners are not always aware of the demands they may be making of the person with epilepsy because many people with epilepsy want to contribute on an equal footing and therefore do not always speak up. However, the energy and personal resources of the person with epilepsy can fluctuate from day to day, and especially over time. So, sometimes we find that partners can actually be making too many demands. Many people with epilepsy experience a decline in personal resources over the years, and it can be difficult for partners to come to terms with the fact that they cannot do the things they used to. It could be a matter of memory problems or fatigue.

Partners of people with epilepsy are important resource persons, both for the person with epilepsy and as important sources of information for the healthcare system and others who need knowledge about functional level, seizure phenomena, etc. So, it is important to ask a partner about the situation. Because they have a wealth of knowledge about the person's epilepsy, and that makes them a great resource. They can contribute to the assessment of epilepsy and functional ability. They often see what the person with epilepsy does not see.

Children of parents with epilepsy

It is essential that professionals working with a person with epilepsy also consider the person's children and how they are affected in everyday life.

It can be difficult for children of parents with epilepsy to understand and accept the disease. Personality and behaviour can change with the disease.

Loss of control, uncertainty about when the next seizure will occur, personality changes before, during and after a seizure, cognitive difficulties and fatigue can all affect children of parents with epilepsy.
Children may find it stressful having to cope in a family that can be overshadowed by epilepsy's unpredictability and loss of control. Children are constantly on high alert, wondering when mum or dad will have the next seizure. And what they should do to help?

If children have witnessed seizures, many questions may arise: "*Is mum or dad in pain during a seizure?*" or "*Can mum or dad die during a seizure?*" The questions can be many and highly relevant.

A child can easily feel guilty and perhaps ashamed of their father or mother's epilepsy. Children can also consider it a big responsibility having to take care of a sick parent or do all the practical things around the home, such as shopping, cooking, cleaning and looking after younger siblings if mum or dad is exhausted. In these situations, where children become 'parents to their parents', there is no room to be a child and this will inevitably affect the child later in life. As a child, it can be difficult to fully understand epilepsy.

Children may not bring friends home from school because it can be embarrassing if mum or dad has one of their strange seizures, or they want to spare mum or dad the strain of having guests in the home as it tires them out. The child may not make play dates or participate in leisure activities because they have to go home and look after mum or dad.

Studies show that children can cope with a lot of difficult things if they have someone around them who can support them in understanding and talking about the difficulties. It can be difficult for parents to tell their children the right things. The information should be appropriate to the child's age and level, and can usefully be provided by the professionals when the parents go for outpatient appointments.

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'.

Public transport and epilepsy

Many people with epilepsy have seizure anxiety for good reason. The nature of the seizures and loss of control can deter people from
using public transport.

If the person has regular seizures, they can sometimes find it hard getting to work. It is not just the frequency of attacks that determines the severity of the anxiety, but rather how the attacks manifest. In addition, there can be major issues with mental fatigue. Some people may fall asleep on the bus or train, and finding their way around train and bus timetables can be a difficult or impossible task due to cognitive issues.

A CHILD CAN EASILY FEEL GUILTY AND
MAYBE ASHAMED OF THEIR FATHER'S
OR MOTHER'S EPILEPSY.

Facts about adults with epilepsy

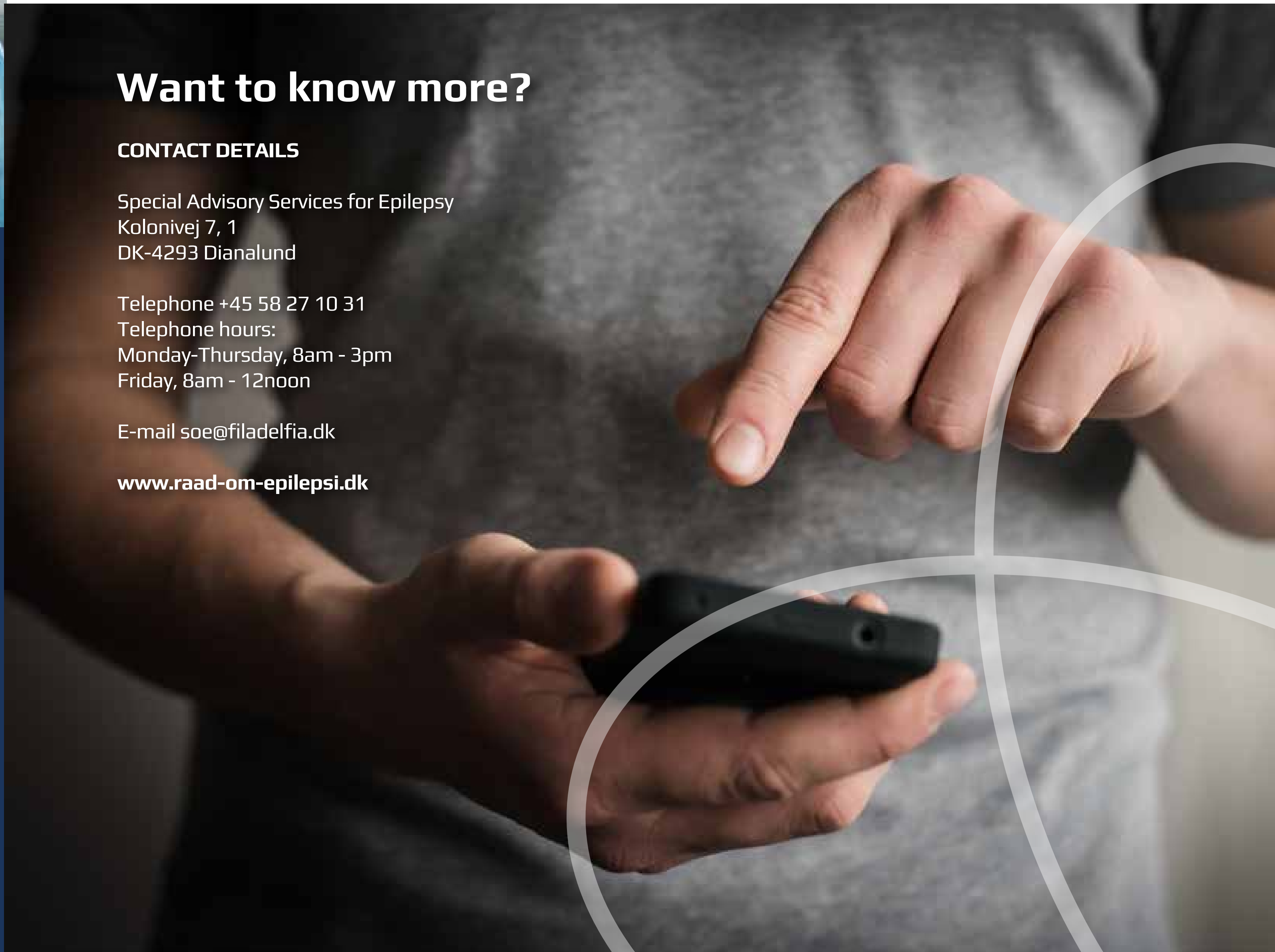
- Many people with epilepsy do not want to talk about their diagnosis.
- Epilepsy is a taboo disease.
- Many people with epilepsy are not even aware of their difficulties.
- Many young people with epilepsy feel alone with the disease and the problems it causes.
- Many people feel that the disease controls their lives.
- Some people with epilepsy may need to take home a short summary of the conversation, as they may find it difficult to remember what was said later on.
- Being off sick can be very stressful for a person with epilepsy, especially when it is not possible to put a date on when they will be able to return to work.
- The responsibility for disclosing epilepsy lies with the job-seeker.
- It is difficult for a person with epilepsy to admit that they do not have enough personal resources for a regular job.
- Many people with epilepsy do not know their own personal resources and limitations.
- It can be difficult to admit not being able to do simple tasks, and it can be hard asking for help.
- A child can easily feel guilty and perhaps ashamed of their father or mother's epilepsy.

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 offer counselling for professionals, citizens and relatives on how to cope with 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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