

# Tour around Caroline's lavender land



MEET THE WORLD OF EPILEPSY

PATRONAT MERYTORYCZNY





The publication is financed by the European Commission within the Erasmus + Program.  
The publication has been funded with the financial support of the European Commission.  
The publication reflects only the views of its authors and the European Commission and the Erasmus +  
Program National Agency are not responsible for its essential content.

FREE PUBLICATION



**EPISCHOOL**

let's overcome the barriers together!

AUTOR TEKSTU:

KATARZYNA KLIMOWICZ:

KOREKTA TEKSTU:

MARZENA DOBOSZ

OPRACOWANIE GRAFICZNE I SKŁAD:

RENATA MIANOWSKA GRAFITARIUM.PL

ILUSTRACJE:

MICHAŁ STRZEŻEK

WARSZAWA 2017



## Why was this brochure developed?

I'm 16 years old. Soon before the holidays I got to know that a new colleague, the daughter of my parents' acquaintances, was going to join my class. They lived in another town until now and I have never met them before.

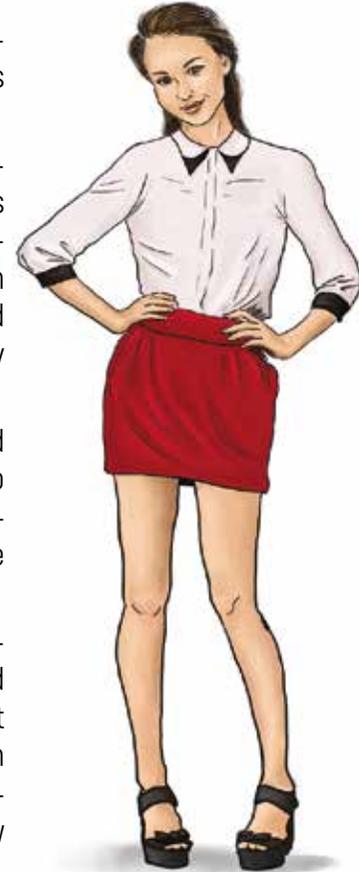
My parents decided that relocation of their acquaintances was a good reason for our families to get closer. And for sure it would be easier for Caroline to join the class at the beginning of the school year knowing somebody already. I met Carol in June and in July we were already good friends. She turned out to be a very nice and sensitive person, but a little shy. She had her hobbies she liked to talk about – criminals, paragliding and aerobics.

The last one was close to me too. After holidays we were planning to go to the classes together.

Caroline's passion was Ludwik van Beethoven's work. As for me – her admiration of his person and his music was a little bit exaggerated – especially that I was not interested in classical music. At that time, however, I did not know yet that there was one more, very important reason for that fascination.

I really liked that girl, but nothing suggested that the most interesting thing was still to come and that we would be joined by something else, something that would cause some confusion.

One beautiful July day we went for a walk round the town. Unexpectedly, Caroline grabbed my hand and cried. After a while I realized that she was lying on the ground and moving in a strange way, her body was twisting in different directions. I completely did not know





what to do. I started screaming. After a while a few gaping onlookers gathered around us, which threw me off balance even more.

– Help! – I shouted as loud as I could.

Finally, a man ran up to Caroline and did some things with her. He said to me:

– Easy, I know what is going on. Call her parents.

At first I did not get it. I was looking as I was hypnotized at my friend still wriggling on the pavement. I felt she could not control this. Her mouth was foaming. Her eyes filled me with fear. Her eyeballs were turned up high as in a horror. I started trembling myself. I thought a similar thing would happen to me. Then the taxi driver repeated:

– Come on girl, call her parents, and now maybe first call 112!

His decisive tone brought me out of stupor. I followed his order.

When I looked at what was going on I felt fear though I have no idea what I was I was afraid of most then. Caroline? That she could hurt herself? Or the people standing around, mostly thoughtlessly staring at my colleague? I felt enormous helplessness and weakness. I was standing as paralysed with emptiness in my head.

Then there was even more fuss and everything was happening as in a kaleidoscope. The ambulance arrived quite quickly and they took Caroline, but her parents did not come. Apparently, they were to go directly to the clinic where the girl was taken. At a certain point, I stayed alone in the street and the helpful man asked:

– Are you all right? How are you feeling? I promised the paramedics that I would take care of you. My name is Matthias.

– Yeah, I guess so. What happened here? What happened to her?

- She had an epileptic seizure. You didn't know she was ill, did you?
- No. I had no idea – I whispered.
- How long have you known each other?
- Only for a month – I was still shocked.
- This may explain why you don't know anything. People suffering from epilepsy find it difficult to tell others about their illness and what is more to talk about it.
- But if I had known, it would be easier for me to help her. I ran totally scared and I think I'm ashamed – I said with anger.
- Ignorance is not a reason for being ashamed, but for making up for education gaps. You are a young person. You did not have to know. It is adults who have to take care of such a person. They should have told you about the illness of your colleague and teach you what you can do in such a situation – Mr. Matthias said calmly. – Besides, I don't know if you noticed, but I was the only person who helped your colleague in this situation – he added.
- That's right. It's terrible that it is like this – I said still furious, but also scared.
- It's rather a standard. Of course the level of knowledge in the society is rising, but it's going on slowly – the man said.
- Is it always necessary to call an ambulance in such situations? – I asked deciding to take a chance and make up for gaps in my knowledge.
- No. In most cases it's necessary to take care of proper body position and safety around. However, epilepsy seizure of your colleague lasted longer than 5 minutes, so I asked you to call the ambulance. I also saw your helplessness. I preferred to take care of this.
- How did you know what to do at all? – I asked.
- I'm a taxi driver, I can give first aid. I simply did a course.

- Can I do such a course? – I got interested.
- I think that yes. I know that there are first aid courses organized at schools.

After a while he added:

- Listen, I have to go back to work. Will you manage? I suggest going back home.

At this moment my mobile phone rang. It was mum who got to know what happened and was worried about me.

- Yes, thank you. I'll be all right – I said after finishing the conversation. – I've arranged with mum that I'm going back home. It's not far – I added.
- This is my visiting card. If you have any problem, call me.

When I got back home my fury burst. I shouted at my parents in high dudgeon and angry that they did not tell me anything.

- I understand your anger sweet heart, but we couldn't talk about Carol's illness against the will of

her parents and they wanted to wait with this for some time. Caroline has seizures very seldom – once every 2-3 months. We were to talk about that this week, altogether.

- Is it seldom? – I asked surprised.

Our conversation continued for a long time. My parents called Mr. Matthias and thanked him for his help on behalf of themselves and Caroline's parents.

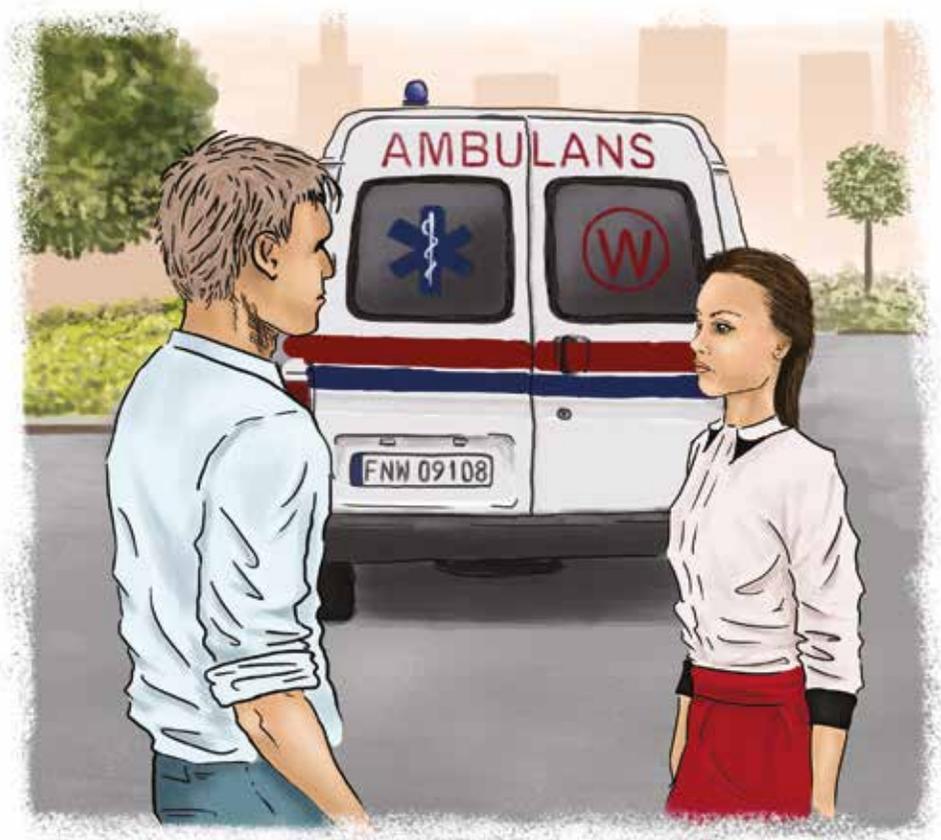
With my parents' advice I decided not to call Caroline yet, although I wanted very much. I only sent her a text message: I HOPE YOU ARE OK. IF YOU WANT TO TALK OR MEET, I'LL BE HAPPY TO DO IT. I THINK ABOUT YOU. AND I ATTACHED A HEART. My mum convinced me that in such situations ill people react in different ways – some need relationship with other people, others not. We have to respect their will, but it's good to signal that we are ready for contact. This convinced me, but I wanted to call Caroline at once very much. I was worried about her. I imagined how she had to feel right now, how difficult this experience must be for an ill person. I really wanted



to support her and show her that I was thinking about her.

This experience moved me very much and most of all I was still ashamed that I knew nothing about this illness. However, I remembered Mr. Matthias' words and I decided to make up for the gaps in my knowledge as soon as it was possible.

Surfing on the net, and also browsing through pages of different publications, I managed to access different information. I wasn't able to understand everything – epilepsy is a complicated brain illness and a brain is a complicated device – but I gathered as a whole what I managed to get, found possible to understand and important to know.



I developed a short, brief information base I intended to address to my peers. I simply thought that it might be worth to popularize such knowledge, especially among people in my age. As I learnt, not many adults know how to deal with the above described situation, so what can be expected from a teenager. And as my grandpa says: 'as the twig is bent.....'

I also hoped that my work would appear helpful for Caroline when she joins our class. I was convinced that pupils would learn about her illness and at the same time would get a piece of information on it as well as on how to help an ill person, which would be easier for everyone. I also knew that I could rely on help of our class teacher

who can communicate with us in an excellent way and is our authority. He for sure will support Caroline and me.

After a few days from July adventure Caroline got on touch with me and invited me to her.

I was very happy because of this. I had a feeling that I already had a lot of theoretical information, but I lacked a conversation with somebody with real needs, who is struggling with this illness.

I was extremely stressed before this meeting. I feared it would be difficult for us to talk and I also wasn't sure what to say. For sure I wanted to tell her about my research and show its effect.

I entered Caroline's house indecisively. When I saw her smiling face I immediately felt better.

- Hi, how are you feeling? – I asked.
- Already fine – she smiled. – You must have got scared... – she added quietly.
- I'm not going to lie that I did not. I was frightened.

Seeing my friend's sad face I added:

- This situation taught me, however, not only how little I, but also adults know about your illness.
- Yeh, I know. I'm sorry I didn't tell you – she answered with sadness in her voice.
- I'm not going to hide that I was very angry about this, however when the emotions fell, I understood that maybe you did not want to talk about it. I don't feel offended by this at all. I think it's very difficult to cope with such an experience.

After a while she continued:

- I'd like to share my findings with you. – Caroline looked at me with interest. – For the few days when we did not see each other I collected some information about epilepsy and I decided to develop an information brochure on it for our peers. I'm curious what you think about it. Would you like to look at it?

Caroline was evidently surprised. I was happy because of this.

- - Wow, yes, with pleasure! – she finally said. – I'm impressed. I'll be honest – Carol hesitated – I thought you would never come to me again ...
- Well, I sent you a text message – I answered surprised.
- Yes, but... – I felt it was difficult to speak for her – I was worried that you wrote like this, because maybe your parents asked you to write so...
- How could you think so?! – I felt a little bit offended, but after a while I added – I understand that you probably have such experience...
- Yes, a little bit... I know that seeing a person in epileptic seizure may be shocking and you may be afraid – she smiled. – Show me the brochure. I'm very curious of it.

I was waiting for Caroline's verdict under tension.

- Good work! It's a really valuable piece of information. – Caroline was evidently excited. – I also have something – she took a piece of paper out of her desk. – Look, this is a list of known people

with epilepsy. One day I searched the Internet to find such information when I got to know that Ludwig van Beethoven suffered from it.

- I see, now I understand why you are so interested in his person – I laughed warmly satisfied with my finding.

Caroline also had fun that I was such a 'detective'. It was wonderful to laugh together.

- Carol, we need to add this list to my, no – I corrected myself – our brochure. But – I paused – I think it still lacks the basic issue.
- What exactly?
- How you, I mean, ill people manage such a situation. What do you feel and, what is a very important information for me, how can you be helped? Can we talk about this?
- Hm, but what do you want me to say? – Carol hesitated.
- As I said, I think it's a very difficult experience,

but in fact I don't know anything about it, because I'm not ill. I'm curious how you feel with this and what you experience.

My friend was evidently surprised.

- I'm not used to talking about it so openly... - she hesitated.
- When it appeared that I was ill, at first there was mistrust. I thought that maybe my first seizure was a reaction to something else. After a number of examinations, however, it appeared that it wasn't. Then I got furious, angry with the fate, with my parents - although it's not their fault - that it happened like this. And then I started being afraid that I wouldn't manage this.

I often feel helplessness, because



even despite best efforts, I cannot prevent it.

I saw that Caroline found it difficult to talk about it. I tried only to listen and not to urge her.

- Well, there were also unpleasant experiences in my previous school - she said and she hung her head - that's why together with my parents we decided that I would change my school. This coincided with searching a new job by my father and this is how it came to our relocation.
- What happened in your school?  
- I couldn't refrain from asking.
- It happened that I had a seizure and most of the students took it badly and they cringed away from me.



I was moved by what I heard. That day I spent a few hours at Caroline's. We had a long talk about her illness and her expectations from others connected with her situation.

I also found out that people suffering from epilepsy can often predict their seizure, but unfortunately only for a few seconds before it. Then they feel precisely the symptoms preceding the seizure. If the people from the surrounding know about the illness, they can also observe the symptoms. These are in many cases nausea, stiffening, dizziness, abdominal or throat pressure, strange auditory, sensory or smell sensations. All these phenomena warning of a seizure are called 'aura'. If others notice the symptoms of 'aura' they can help – even if they keep the ill person's head to prevent their sudden fall to the ground resulting with serious injuries.

I asked Caroline what she was afraid of in the new place and with new people. She said that in such situations she is always afraid of the reaction of others

to her illness, that people would cringe away from her – which she already experienced – or that they would laugh at her or joke. As she also experienced – she cannot always rely on adult people's help as they also often have no idea how to behave. The seizure can be caused by different situations she cannot prevent. Therefore Caroline is often afraid that stress often resulting from social relationships may cause epilepsy seizures or may have influence upon her learning, headaches or fatigue.

There was one more issue bothering me and one day – despite concerns – I decided to ask Caroline about it.

- *Carol, we were to go to aerobics together...* – I started shyly.
- *Yes* – she looked at me questioningly.
- *You know..., I wonder if you can...* – I felt foolish. Despite so many conversations I didn't know how to say it.
- *Listen, I can do sports. Of course there are disciplines which are not recommended for people*

suffering from epilepsy, but generally sport is advisable.

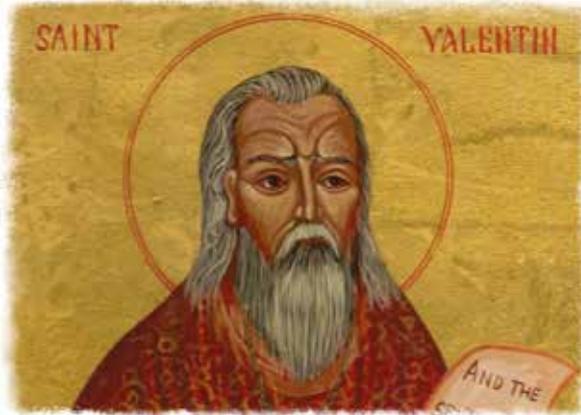
- It's super – I breathed a sigh of relief.
- You see, I can do aerobics and I will go to it with pleasure, but it is much worse with my beloved paragliding. For now my parents said they would not agree to it. Too much risk. Maybe in some time I will be able to fly with a trainer.
- It would be great. Besides, you are going to be of full age and you will be able to decide yourself.
- Well yes, but I also have to take the responsibility of myself. The fact that I decide does not mean the end of the illness. Now I'm learning how to live with it and accept my limitations, also in order to take decisions good for my health in the future. I'll be with the illness for the whole life.

During the next days we met to polish up our brochure. We also made a plan how to prepare the te-

achers and the students to receive it. Although it was difficult, I convinced Caroline that only speaking openly about her illness and treating it as a part of her shall allow her and us to talk about it in a normal way. After different hesitations, she agreed first of all to a conversation with our class teacher – yet before the beginning of the school year – and then planning actions in our class and then maybe even in the whole school. I knew that our class would help us.

14<sup>th</sup> February

is not only St. Valentine's Day

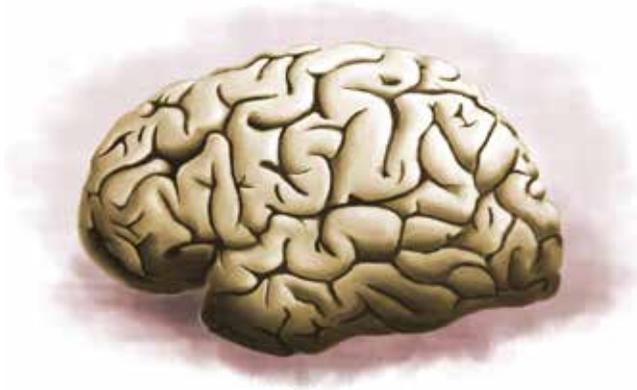


14th February is not only St. Valentine's Day – this day we also celebrate the International Epilepsy Day, since St. Valentine is not only the patron of the people who are in love, but also of those who suffer from epilepsy. In many old paintings we can see the figure of that saint

dressed like a bishop curing the ill people from epilepsy. Today St. Valentine is associated with people who are in love, but in the Middle Ages his name was associated much more with being a patron of epileptics.

In the calendar there is also one more important date connected with epilepsy. *26<sup>th</sup> March* has been the **International Epilepsy (Lavender) Day** for a few years. On this day different kinds of educational events devoted to this illness and possibilities of its treatment take place all over the world. The originator of the 'Lavender Day' is Cassidy Megan from Canada. In 2008 this nine years old at that time girl decided to motivate others to act in order to propagate the knowledge about the illness and overthrowing the myths connected with it. As a sign of solidarity with people suffering from epilepsy, on that day it is worth to use some addition in lavender colour in your outfit. Why lavender? Little Cassidy, as she was struggling with epilepsy herself, drew attention to the fact that this colour is often associated with loneliness and social isolation the ill suffer from – often more than from epilepsy itself.

# Epilepsy - what is it?



Epilepsy is one of the most frequent, the so called chronic, illnesses (an ill person is struggling with it for the whole life) among school age children and teenagers, so among my and your peers.

Its basic symptoms are sudden, uncontrolled and recurring epilepsy seizures during which the ill person falls to the ground and makes a number of uncoordinated and uncontrolled body movements. This behaviour may be by some people associated with an electric shock.

Despite advances in contemporary medicine, most of the reasons for epileptic seizures cannot be defined. The doctors are unable to diagnose its reasons in the case of about 70 % of the ill people.

Epilepsy is not a communicable disease. It's not a mental, but a neurological illness. Epileptic seizure is a temporary brain work disorder which most often, regardless of its degrees, leads to lowering of the fitness of the ill person in everyday life.

No medicine allowing for 100 % cure has been discovered yet. It is only possible to limit the number of seizures and weaken their convulsiveness. People suffering from epilepsy live with uncertainty, in fear, because they do not know when to expect a seizure. The most difficult element of life with epilepsy is lack of the feeling of safety..

# Why do ill people behave like this?

Do you know that in your brain there are discharges all the time?

E.g. when you are reading this brochure, your eyes send to your brain electric impulses and the brain processes single letters into words and comprehensible sentences. The brain using electric impulses sends an order to the muscles when you play the ball, have breakfast or work in the garden.

People suffering from epilepsy have short disorders of the activity of some nerve cells in the brain, which is accompanied by electric impulses as well. An epileptic seizure takes place when the process is disordered and a group of nerve cells in the brain undergoes too violent discharges. Some of these disorders may lead to occurrence of epileptic seizures.

Therefore association of behaviour of a person suffering

from an epileptic seizure with an electric shock is in a certain sense justified.

You for sure saw warnings on TV screens before some films telling about a possibility of occurrence of strong visual stimuli in the form of a flickering screen. Such information may also appear at some cinemas or discos. They are addressed exactly to people suffering from epilepsy, because in the case of about 5% of patients seizures are caused by certain external conditions, such as flickering of a TV or a computer screen, watching TV in a dark room, disco lights or some computer games.

It happens that temporary loss of consciousness may be erroneously diagnosed as epilepsy seizure. Sometimes strong emotions, hysteria or a tragic message may cause similar symptoms.

## *You can be scared and not understand*

Due to intensiveness of the symptoms in the so called grand mall – exactly the one I was a witness of – and often due to the lack of knowledge of the environment on the illness, people suffering from epilepsy – especially those who happen to have seizures – may be rejected by their environment. Looking at a person in an epileptic seizure we may feel fear and helplessness. If we are not aware of the danger, we may react with laughter or we may think that somebody is playing the fool. An ill person can be taken as a drunk one or being under the influence of drugs or mentally ill.

Mistaking the symptoms in the case of an ill person often causes that they are not given proper aid.



## How to help when an ill person has a seizure

Ignorance and fear may be the source of helplessness, panic and horror, which may intensively disturb giving aid. Therefore, the more you learn today on how to help, the bigger are your chances for successful acting in case of danger.

Always, first of all, look for help of an adult person. So if you see somebody having seizure, first of all say loudly e.g. 'This person is probably having an epileptic seizure. Can anyone help? Is anyone here a doctor?' Remember, you are a teenager and you don't have to deal with such a situation alone. If there are competent people around, let them act.



## *In case of a seizure:*

- Stay calm.
- Give the ill person a possibility to stay in a straightened position – on a bed, on the floor, pavement, lawn, a dry surface would be the best.
- Secure the place where the ill person is lying, e.g. stop the traffic, make some space around the person, take away any objects which might be dangerous for them – sharp, hot, etc.
- Lay the ill person on a side, with their head slightly directed downstairs, which shall enable free saliva escape from the mouth and prevent gagging.
- Provide them with as much space as it is possible and protect them against a possible injury – loosen their collar, take off glasses, chain, back-pack, if only it is possible – place something soft under their head.
- Check the time to know exactly when the seizure started. If it lasts longer than 5 minutes – you have to call an ambulance dialing the emergency number 999 or 112.

*Remember that the listed actions maximize comfort of the ill person, but you may not know how or you may have no chance to do them. You're a teenager.*

## *During a seizure one shouldn't:*

- Use force or try to stop the seizure or limit movements of the ill person, keep their hands or legs.
- Put anything into the ill person's mouth or try by force to open the ill person's tight jaws. It's a very dangerous myth that when we put something between the teeth during the seizure the ill person shall not bite their tongue. We also do not administer any medicines.
- Revive the ill person pouring water on them, giving them smelling salts or tapping their face. You mustn't shake the ill person when the seizure is over or try to wake them up. Sleepiness is a natural reaction of the body after an epileptic seizure and the ill person needs quiet.
- Lift the ill person or carry them during the seizure.

# *How to help an ill person in their peer and school environment as well as everyday life*

Remember that care over a child and providing them with physical and mental comfort is always the duty of adult people. You can, however, take different kinds of actions, which help an ill peer to handle a situation they find difficult.

What can you do knowing that there is a peer suffering from epilepsy in your environment? If only you know about it, first of all let them know it and – if it is so – show your readiness for a conversation on this subject or help. However, remember that it's always the ill person and in the case of a child – their parents – who decide if and how much information

about their illness is to be passed on to other people. This has to be respected.

If your peer, suffering from epilepsy, agrees to some kind of help on your part, you can suggest:

- Accompanying them in their going out to the cinema, to social meetings, going for walks or shopping. Then, having on your mind such a possibility, you can be more alert to signals warning of a seizure, i.e. 'aura'. In many cases these are nausea, stiffening, dizziness, abdominal or throat pressure, strange auditory, sensory or smell sensations.
- Help at the moment of epileptic seizure.
- Help in popularization of the knowledge on the illness and ways of helping an ill person. I hope that my brochure may be helpful in this. It can be copied and distributed. Check if there is a possibility to invite to the school a doctor, a psychologist or a paramedic who could tell about the illness. Engage in organizing such a meeting..

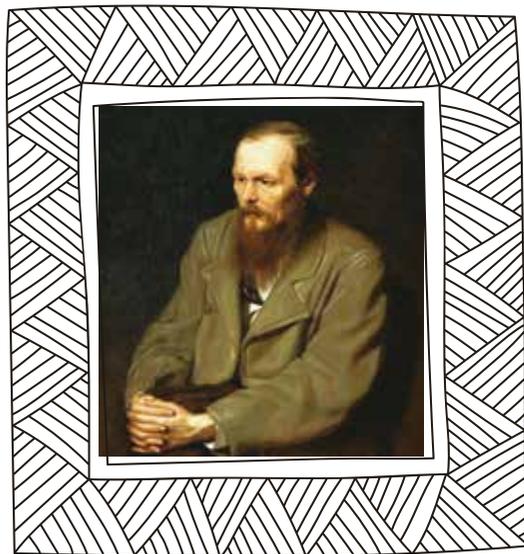


Apart from this you can:

- Make others aware – talk to the boys and girls in the class about the situation of your peer and share your knowledge on the possibilities to help this person with them.
- Make aware and support the ill person in situations where their rights are in danger – when somebody offends them, especially due to the illness, does not help or ignores them. You may print out the United Nations Convention on the Rights of the Child and the Patient Charter and propagate them in the environment in which there is the ill person (posters, leaflets, competitions). This may be useful for everyone.
- Call help in situations in which you know that you won't manage or don't manage (e.g. epileptic seizure, aggression on others' part).
- Inform adults about situations which have already taken place and proclaim that the ill person's rights have been breached

## They also suffered from epilepsy

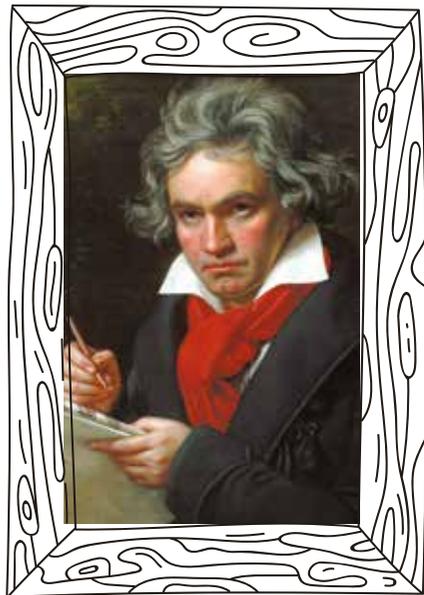
Below there is a list of a few famous people suffering from epilepsy. The list proves that epilepsy does not lower the mental or cognitive ability. Although for sure it causes a number of difficulties and limitations in everyday life, they aren't impossible to overcome in part.



- **Fiodor Dostojewski**  
Russian novelist, among others the author of the 'Crime and Punishment'



- **Julius Caesar**  
the first Roman emperor



- **Ludwig van Beethoven**  
German composer  
and pianist



- **Napoléon Bonaparte**  
French emperor,  
big military and political  
commander



- **Vincent van Gogh**  
Dutch painter

# When to call

## emergency numbers 999 or 112?

- ! When you know that this is the first seizure of the ill person.
- ! When you see that the ill person during the fall suffered an injury you expect to be dangerous.
- ! When within a short time after the first seizure the next ones take place.
- ! When the ill person has problems with breathing when the seizure is over.
- ! When the seizure lasts at least 2 minutes longer than usual.
- ! When the seizure lasts longer than 5 minutes and you don't know how long it usually lasts.

# USEFUL PUBLICATIONS, ADDRESSES AND OTHER INFORMATION

## USEFUL ADDRESSES

- Epilepsy Ireland  
[www.epilepsy.ie](http://www.epilepsy.ie)  
Epilepsy Ireland (formerly Brainwave) is the national organisation supporting and representing people with epilepsy and their families

PATRONAT MERYTORYCZNY

