https://www.laikmetis.lt/kai-nuovargis-tampa-liga-ka-turime-zinoti-apie-letinio-nuovargio-sindroma/

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14 July 2025

## What is ME/CFS?

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a severe, complex, often disabling neurological disease characterised by persistent, physically unexplained fatigue, inadequate response to physical or mental exertion (so-called post-exertional malaise), sleep disorders, pain, and dysfunction of the autonomic and immunological systems.

It is important to understand that this fatigue is not a simple exhaustion that can be overcome with a day off or a good night's sleep. People affected by ME/CFS are often unable to even get out of bed, perform daily activities, or even respond to environmental stimuli - light, sound, smells.

## How many people have ME/CFS?

The World Health Organization recognises ME/CFS as a neurological disease, and scientific estimates put the incidence at around 0.2–0.4% of the total population. This means that between 5,000 and 12,000 people in Lithuania could suffer from ME/CFS.

There is no accurate data in our country, as Lithuania still lacks disease coding, comprehensive diagnostics, and official statistical research. Many people remain undiagnosed or are given inaccurate diagnoses, such as depression, anxiety disorders, or somatoform disorders.

## Main symptoms

The symptoms of ME/CFS are varied and can change from day to day. However, there are some key signs that can help you identify the condition:

- Constant, severe fatigue that does not go away even after a long rest.
- Post-exertional malaise (PEM) is a worsening of symptoms after even minor physical or mental exertion.
- Sleep disorders – poor, unrefreshing sleep, difficulty falling asleep, or frequent awakenings.
- Pain – muscles, joints, head, throat.
- Cognitive disorders – difficulty concentrating, remembering, orientation, impaired speech.
- Cardiovascular problems – rapid heartbeat, orthostatic hypotension (drop in blood pressure upon standing), dizziness.
- Temperature fluctuations, intolerance to cold or heat.

Some people develop the condition after an infection (e.g., a viral infection), while others develop it after emotional or physical shock. After the COVID-19 pandemic, there has been an increase in cases of chronic fatigue becoming part of the “Long COVID” syndrome.

**Diagnostics: a long and difficult road**

Diagnosing ME/CFS is not easy. The disease is currently diagnosed by elimination, which means that other possible conditions that cause similar symptoms (thyroid disease, multiple sclerosis, depression, anemia, etc.) are first ruled out.

There are several officially recognised diagnostic criteria, the most widely used of which are:

- Canadian criteria (2003)
- International consensus criteria (2011)
- CDC (Centers for Disease Control and Prevention) Fukuda criteria (1994)
- IOM (Institute of Medicine, now NAM) recommendations (2015)

Unfortunately, in Lithuania, the diagnosis of ME/CFS is not regulated in detail, and doctors are often not familiar with international criteria. As a result, patients spend years going from specialist to specialist, until they are ultimately misunderstood, the veracity of their complaints is questioned, or they are advised to “just rest” or “change their attitude.”

**Treatment is more about care than cure**

There is currently no cure for ME/CFS. Treatment focuses on relieving symptoms and improving quality of life.

The following methods may be applied:

- Individual activity planning (pacing) is the planning of activities according to energy resources in order to avoid exacerbation of symptoms.
- Cognitive Behavioural Therapy is useful as an adjunct to help manage emotional reactions, but it does not treat the underlying biological illness.
- Sleep hygiene – improving sleep patterns, and if necessary, medication.
- Symptomatic treatment – pain relief, stabilisation of the nervous system, correction of autonomic dysfunction.
- Psychological and social support is especially important for people with chronic illnesses.

The most important thing is not to hold patients responsible for the disease, because it is not a psychological condition, but a neurological dysfunction.

**What is it like to live with ME/CFS?**

Living with ME/CFS is often a complete lifestyle change. Some people become completely disabled, unable to participate in social life, or even unable to take care of themselves without help.

People with ME/CFS often experience social isolation, misunderstanding, and even accusations of faking it. This is especially painful for the families of those affected, as the disease robs them of not only energy but also their former identity, profession, and relationships.

For children and adolescents, the disease can disrupt educational plans, isolate them from their peers, and cause self-esteem problems.

## Situation in Lithuania: challenges and hope

In Lithuania, people with ME/CFS still remain invisible. The disease is not included in the lists of disability assessment criteria, which means that even seriously ill people cannot receive social assistance, personal assistants, or compensation.

Doctors are not trained to recognise ME/CFS, there are no specialised centres or services. The disease is still considered “unclear” by government institutions. And people are left alone.

However, in recent years, the situation has been changing little by little. Non-governmental organisations such as "Independent Living", "Association of Personal Assistants", individual activists and patients themselves have begun to publicise the topic of ME/CFS, talk about early help, demand visibility and rights. The disease is also increasingly being discussed in the world media, and after the COVID-19 pandemic, more funded scientific research has emerged.

## What can we all do?

- To enlighten and enlighten others – not all fatigue is the same.
- Support loved ones diagnosed with ME/CFS – even if the disease is invisible, it is real.
- Encourage politicians and institutions to include ME/CFS in service, support and disability assessment systems.
- Trust patients – they are not looking for attention, they are looking for help.

## Finally

ME/CFS is not “laziness,” not “depression,” not “a made-up syndrome.” It is a real, debilitating disease that has ruined the lives of many people. It must be seen, recognised, treated, and those who suffer from it accepted with respect and understanding.

For now, living with ME/CFS in Lithuania is a story of survival. But every story can change. If we listen, hear, help, and respond, more than one person will be able to say: “I’m not just surviving – I’m living.”