



ZENTRUM FÜR POSTINFEKTÖSE MULTISYSTEM-ERKRANKUNGEN

Individualized medicine for children, adolescents, and adults
with ME/CFS, Long COVID, Post-Vac & related conditions

What is ME/CFS?

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) is a serious, complex condition that can profoundly impact the lives of children and adolescents. It affects multiple systems in the body – including the nervous, immune, and circulatory systems – and presents with a wide range of symptoms that vary greatly from child to child.

How ME/CFS Appears in Children and Adolescents

Some children develop ME/CFS following an acute infection such as COVID-19, Epstein-Barr virus (mononucleosis), or other viral or bacterial illnesses – and in rare cases, following vaccination. Others have no clear triggering event. What they have in common is a growing inability to tolerate physical, cognitive, and social exertion – often to a dramatic degree.

Core Symptoms

1. Severe Exhaustion (Fatigue)
This goes far beyond normal tiredness and cannot be relieved by rest or sleep. Even minor efforts – like holding a short conversation, eating a meal, or exposure to light – can worsen the fatigue.
2. Post-Exertional Malaise (PEM)
PEM refers to a worsening of symptoms after physical, mental, or emotional effort. Uniquely, these reactions often appear 24–72 hours later, not immediately. Even small activities – a short walk, background noise at school, reading a text – can trigger a crash. During PEM phases, symptoms intensify: exhaustion, pain, nausea, circulatory issues, or new symptoms such as flu-like feelings, trembling, extreme sensitivity to light or sound, or complete functional shutdown. These episodes can last days or even weeks – making even small actions impossible. In severe cases, the baseline health condition may deteriorate permanently. Protecting against overexertion is critical. Learning to recognize and respect personal limits – through a method called Pacing – is the key to avoiding relapses.
3. Cognitive Impairments (“Brain Fog”)
Many children report difficulty concentrating, memory problems, slower



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thinking, or trouble absorbing or processing information – even in familiar settings.

4. Circulatory Problems and Exercise Intolerance

Many children with ME/CFS experience orthostatic intolerance – meaning they feel worse when sitting or standing for too long. Symptoms include dizziness, palpitations, or weakness. A common related condition is POTS (Postural Orthostatic Tachycardia Syndrome). In POTS, standing up causes a rapid increase in heart rate – often more than 30 beats per minute, or above 120 bpm in adolescents – along with dizziness, shaking, or faintness. Symptoms usually improve when lying down. Even simple tasks like showering or standing in line can be overwhelming. Gradual posture changes, good hydration, and activity pacing can help.

5. Sensory Sensitivities

Many affected children are sensitive to light, sound, touch, or smell. A normal classroom or supermarket can become overwhelming.

6. Pain

Headaches, muscle aches, stomach pain, and joint discomfort are common. Some children also describe burning sensations on their skin or limbs.

7. Sleep Disturbances

Sleep problems are frequent – but highly variable. Some children wake frequently, others feel unrefreshed despite long sleep. Some can only sleep during the day, while others struggle to sleep at all. Sleep-wake cycles may shift, making school attendance difficult.

Highly Individual Expression

While key symptoms like fatigue, PEM, circulatory issues, and brain fog are typical, ME/CFS affects each child differently. Some experience severe pain; others do not. Some sleep excessively; others hardly at all. Co-conditions like POTS or food intolerances vary.

What matters most: don't compare your child to others. Instead, observe what they need and how their condition evolves. Symptoms may shift over time or new ones may appear.



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Course and Prognosis

ME/CFS follows an individual and often unpredictable course. Some children stabilize over time through pacing and medical support. Others face long, difficult illness trajectories with setbacks. Overexertion – through school pressure, sensory overload, or inappropriate therapies – can lead to deterioration.

Early recognition, protection, and pacing are crucial for a more stable or even improving outcome.

What Helps?

A Supportive Network

Because ME/CFS is often misunderstood, informed and compassionate people are key: physicians, teachers, family members, and peers all need to understand the condition.

Sensory Protection and Energy Management

Pacing – respecting personal energy limits – is central. Calm environments, flexible routines, and lowered expectations can support stability.

Being Believed

Many children and teens with ME/CFS are dismissed or told their symptoms are “just psychological.” But for them, it's essential to hear:

You are seen. You are believed. This is not your fault.

Where to Find Help and Information: the websites of NichtGenesenKids e.V.

(www.nichtgenesekids.de)