



## ZENTRUM FÜR POSTINFEKTÖSE MULTISYSTEM-ERKRANKUNGEN

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

### **Parent Information: What You Should Know**

We understand how challenging it is when your child suddenly becomes severely limited by Long COVID, ME/CFS, or Post-Vac Syndrome – and at the same time, you're left waiting for a specialist appointment. One thing is most important: You are not alone. And even now, there are meaningful steps you can take to support your child and prepare well.

### **Documenting Symptoms – with an Eye on Delayed Reactions**

Keep a simple symptom diary. Note:

- Which symptoms occur
- What time of day they are most intense
- How activity impacts the symptoms

Important to know:

In ME/CFS, Long COVID, or Post-Vac, symptoms often appear with a delay – for example, 24 to 48 hours after physical or mental activity. This reaction is called post-exertional malaise (PEM). It can be triggered by even small activities – a short walk, a visitor, or a school task.

That's why it's important to look back at the days before a flare-up: What happened? Was there physical or emotional stress?

You can also record:

- What foods were eaten?
- Any intolerances or unusual reactions?
- How was sleep?
- Were there any emotional or social stressors?

This information can later support medical assessment – and help you better understand the condition.



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### **Nutrition & Gut Health: Supporting the Body Gently**

A balanced, anti-inflammatory diet can ease the body's burden during this difficult time. While not a cure, it can be a vital puzzle piece in the healing journey.

Gut health is especially important: It plays a key role in immunity and nutrient absorption. Many children experience digestive symptoms or food intolerances. Gentle, nutrient-rich foods – tailored to your child's tolerance – can help reduce irritation and improve well-being.

Try to avoid highly processed foods, artificial additives, fast food, and sugary products. Instead, focus on natural, easily digestible meals in small portions throughout the day.

Tip: The Instagram account [@ngk\\_ernaehrung](https://www.instagram.com/ngk_ernaehrung)

### **Adjusting Activity – Pacing Starts at Home**

Balance activity and rest carefully. Overexertion – physically, mentally, or emotionally – can lead to long-term setbacks. Start practicing “pacing” now – a mindful way to manage energy. You can find an introduction on our website [www.zpims.net](http://www.zpims.net)

### **Involve School & School Psychology**

Speak with your child's school early – even without a confirmed diagnosis. Many educators respond with understanding when informed in time. Use the Long COVID guidelines from the Joint Federal Committee (G-BA) or resources from the Federal Ministry of Health. If you have one, bring a medical certificate. Contact with the school psychologist, guidance counselor, or special education services can also help initiate necessary adjustments. A video for teachers (in German) is available here: [https://youtu.be/Qc\\_JKyL-F20](https://youtu.be/Qc_JKyL-F20)

### **Use Pediatric or Family Medical Support**

If possible, involve your child's pediatrician or family doctor. Even basic testing – like lab work, heart rate, EKG – can be valuable. You don't need to push for a full diagnosis immediately. Good documentation and steady support already make a difference.



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Additionally, we recommend registering your child with a specialized Post-COVID clinic. These centers offer targeted diagnostics and therapies for children and teens with Long COVID, ME/CFS, or related conditions.

A key contact is the growing PEDNET-LC network – the Pediatric Network for Care and Research of Post-Acute COVID-19 and Similar Syndromes.

More info: [www.pednet-lc.de](http://www.pednet-lc.de)

### **Inform Yourself – Clearly & Trustworthily**

While you're waiting for medical appointments, building knowledge can be empowering. Understanding helps – in conversations with doctors, teachers, and others.

Recommendation: Visit the YouTube channel of NichtGenesenKids e. V. You'll find expert talks by Dr. Diego Schmidt on ME/CFS, Long COVID, pacing, nutrition, and care – especially for parents and caregivers of affected children and adolescents. <https://youtube.com/playlist?list=PLfp5Z2DO5q5rR2Hvt72TLpCNCn2Pitf21&feature=shared>. Take time for these materials – even small steps in understanding can bring more clarity and confidence.

### **Connect with Other Parents – Share & Support**

Talking with others in the same situation is not just informative – it's emotionally relieving. You are not alone.

We recommend:

- [NichtGenesenKids e. V.](#)
- Parent Initiative ME/CFS Munich

These networks offer exchange, practical advice, and everyday support.

### **Apply for Care Level & Assistive Devices**

If your child needs significant support at home, apply for a care level through your health insurance's long-term care division. This can provide financial support, household help, or respite care.



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Assistive tools like wheelchairs, noise-canceling headphones, or light protection can help daily life. Talk to your pediatrician or GP and request a prescription if needed.

### **And Finally**

You don't have to do it all at once. What matters is this: You're already helping by being attentive, by being there.

We thank you for that – and we look forward to welcoming you at ZPIMS.

Warm regards,

Your ZPIMS Team