



ZENTRUM FÜR POSTINFEKTIÖSE MULTISYSTEM-ERKRANKUNGEN

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

Pacing in ME/CFS – A Path Toward Greater Stability

When children and adolescents develop ME/CFS, families are faced with overwhelming challenges. One of the most important strategies in managing the illness is called pacing – an individualized approach to activity and energy management that helps prevent overexertion and reduces symptom crashes (post-exertional malaise, PEM).

This handout explains pacing in accessible language and offers practical advice on how to support your child in daily life.

What Is Pacing?

Pacing means learning to set the right tempo for oneself. It helps identify personal energy limits and organize daily life in a way that respects those boundaries. The goal is not performance improvement – but stability.

Especially in ME/CFS and post-COVID or post-vaccine syndromes, one core symptom is exertion intolerance – where overexertion leads to post-exertional malaise (PEM), often with delayed onset. Even small activities – a walk, a visit, or schoolwork – can trigger significant symptom worsening. Pacing helps to prevent or soften these crashes.

Why Is Pacing So Important?

PEM is the hallmark symptom of ME/CFS. It describes a worsening of symptoms after physical, mental, or emotional effort – typically 24 to 48 hours later, sometimes even after 72 hours.

These crashes are not only distressing but can cause lasting deterioration and push children into a downward spiral. Pacing is the most effective way to break this cycle.

Core Principles of Pacing

The main components of pacing are:

- Prioritize – What absolutely needs to be done today?
- Delegate – What can others help with?
- Modify – How can a task be made less energy-consuming? (e.g., with tools or support)
- Alternate – Mix physical and cognitive tasks to avoid overload.
- Listen – Take early warning signs seriously and build in rest.
- Stop – Be courageous enough to leave tasks unfinished when necessary.



ZENTRUM FÜR POSTINFEKTIÖSE MULTISYSTEM-ERKRANKUNGEN

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

Recognizing & Documenting PEM

Because symptom worsening may be delayed, it's helpful to keep an activity and symptom diary to identify patterns over time.

Record not only physical or cognitive exertion, but also:

- Sleep quality
- Emotional stress
- Sensory input (noise, lights, smells) Even sensory overload – such as loud environments or many simultaneous impressions – can cause overexertion.

You can also track:

- How many visitors were present?
- How long did they stay?
- What was the noise level?
- Was there a school day or stressful test?
- Did your child carry a heavy backpack?

Food intake is also worth noting, as some children develop new food sensitivities.

Remember: Even small events like a short conversation or a change of location can be significant.

Pacing with Heart Rate Monitoring

Some families use heart rate monitors (e.g., smartwatches or fitness trackers) to support pacing by helping detect early signs of overexertion.

However, the commonly cited formula for target heart rate: $[(220 - \text{age}) \times 0.6]$ is not reliable for children as it's based on adult sports medicine.

Instead, a more personalized approach is useful:

- Measure resting heart rate each morning while still lying in bed.
- As a rough guide, an increase of +15 bpm during light activity (without symptoms) can serve as a personal threshold.
- If the resting heart rate is +10 bpm higher than usual on any given day, this may indicate underlying strain – and activity should be reduced.

 **Note:** Heart rate alone doesn't tell the full story. Mental or emotional stress may not cause a spike – but can still be overwhelming. So always pay attention to individual warning signs, not just numbers.



ZENTRUM FÜR POSTINFEKTIÖSE MULTISYSTEM-ERKRANKUNGEN

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

Tip: Many devices allow you to set custom alerts or track trends. Always use them together with a symptom diary – not as a replacement for attentive observation.

The Energy Traffic Light – A Simple Everyday Tool

A visual “energy traffic light” can help communicate your child’s current capacity – to themselves and others. It can even be a collaborative family project and a way for siblings or friends to feel involved.

● Green – Feeling okay, within energy limits. Light activities like brief conversations or small meals are manageable.

● Yellow – Warning zone. Symptoms are emerging, stimulation is adding up. A break is urgently needed.

● Red – Stop. The child is overexerted and needs complete rest.

This tool does not replace medical care but helps guide daily routines. You can make it from cardboard, as a magnetic board, or display it on the bedroom door.

Important: Pacing Is Not a Therapy

Pacing is not a cure, but it is essential to effective illness management. It’s not about pushing limits – in fact, it often helps to do just 50% of what might seem possible.

This approach can help build stability, prevent crashes, and gradually restore quality of life.

You Are Not Alone

Many families are going through similar challenges. Sharing your experience with others can bring both emotional relief and practical insight. We recommend: [NichtGenesenKids e. V.](https://www.nichtgenesenkids.de)