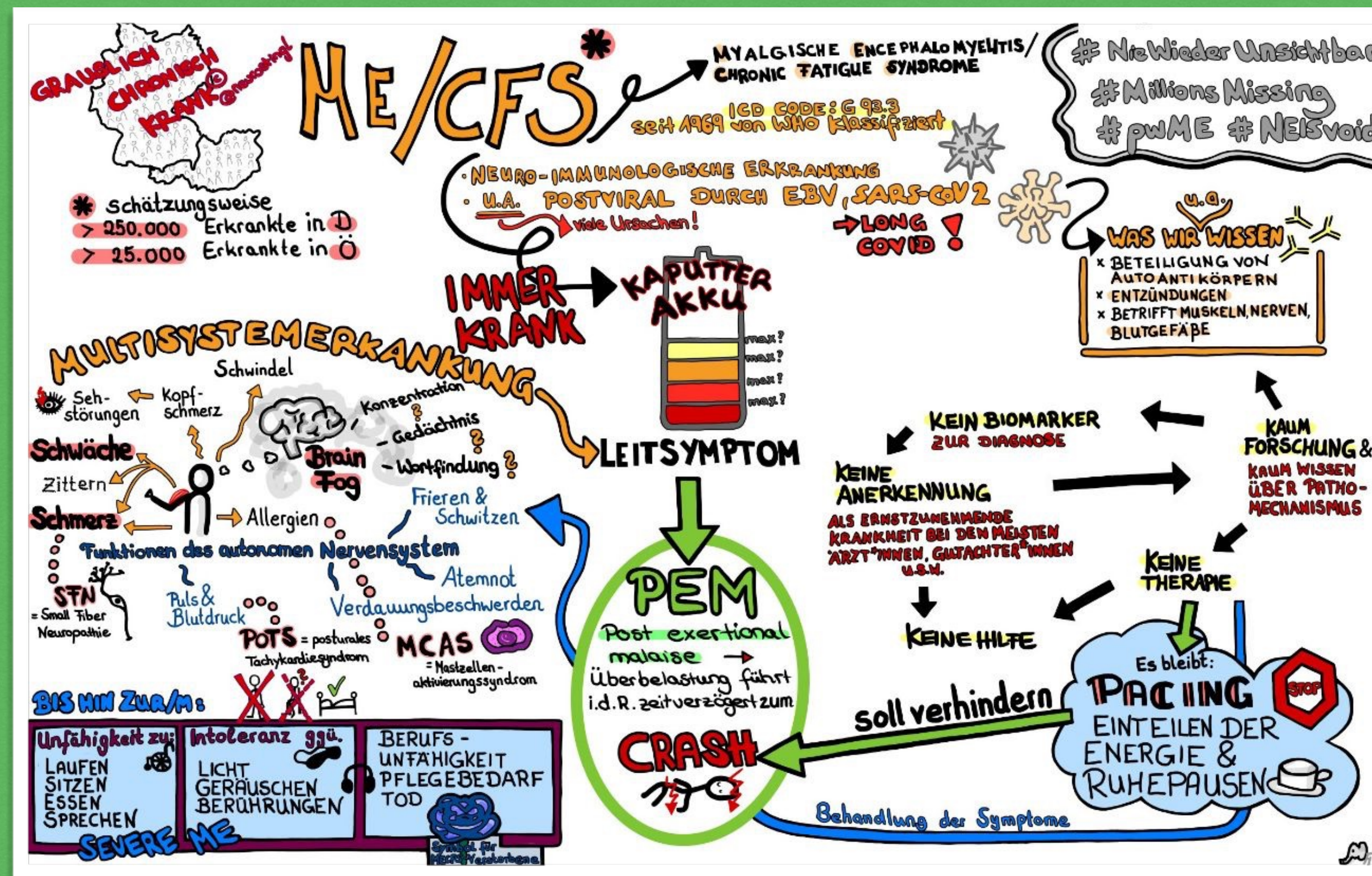


Psychological Support in ME/CFS



Bettina Grande

Berlin, 12.05.23

- **Psychotherapy** and **psychosomatic** rehabilitation have **no curative effect** in the treatment of ME/CFS
- **Mobilisation** in psychotherapy and **rehabilitation** beyond the stress limit may lead to **permanent damage (GET)**
- Nevertheless: Patients suffer severely and their well-being would benefit from **psychotherapeutic support**

Which psychotherapeutic approach is suitable to serve this need?

The Psychotherapeutic Approach When Working with ME/CFS Patients

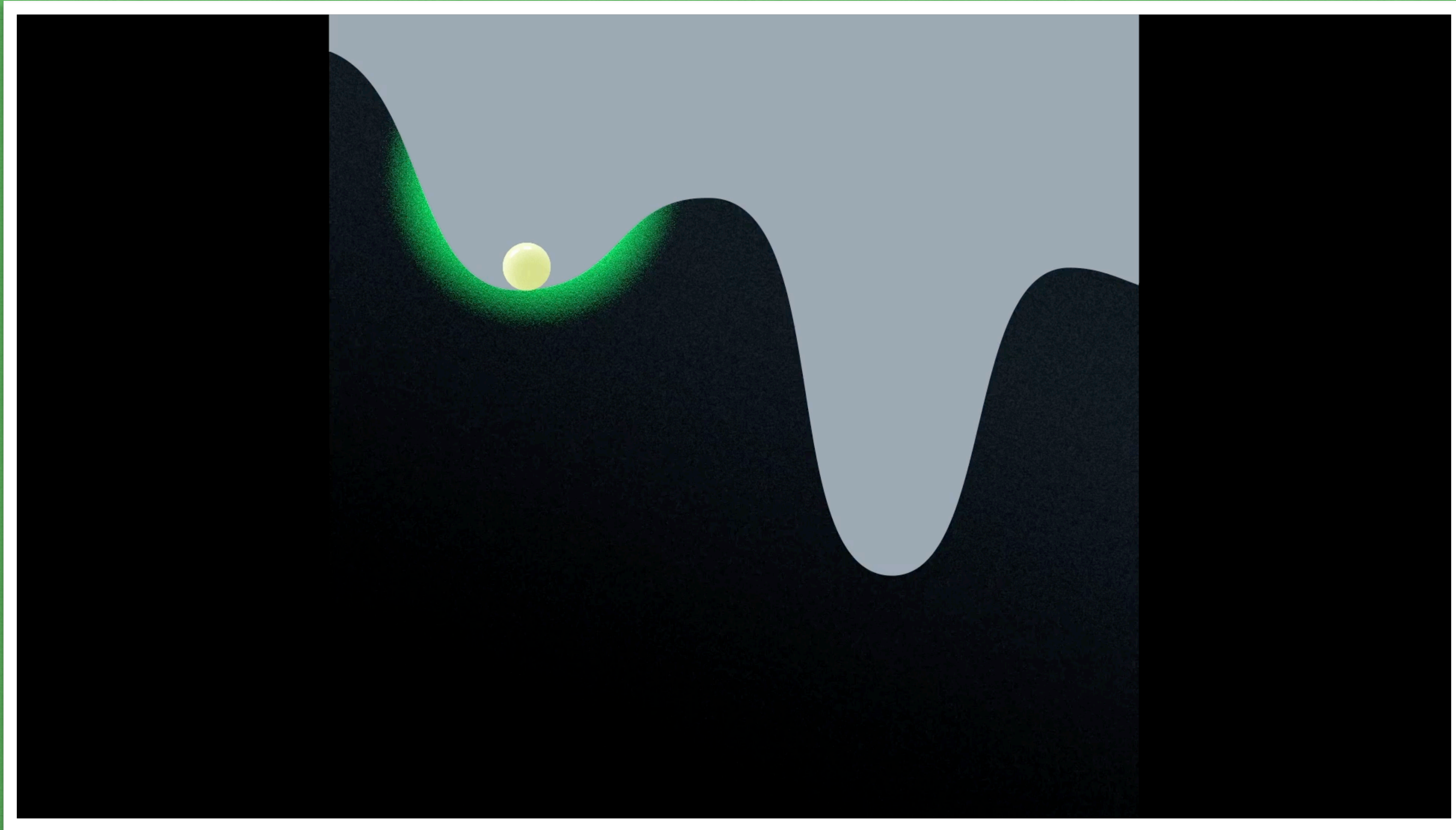
1. ME/CFS is a **physical illness** and curative treatment must therefore be physical
2. Post Exertional Malaise (**PEM**) is the cardinal symptom of ME/CFS which warrants tailored psychotherapeutic attention
3. The understanding of **Pacing** as a method of the best possible control of symptoms and crashes

General conditions of psychotherapeutic practice concerning the limits of severely impaired patients



- ➔ Video therapy
- ➔ Duration of session
- ➔ Frequency of sessions
- ➔ Short notice cancellations
- ➔ Premature ending of a session
- ➔ Communication via email
- ➔ Content and gravity of the issues addressed

Post Exertional Malaise (PEM)



DIFFERENT TYPES OF EXERTION AND ACTIVITIES THAT CAN TRIGGER SYMPTOMS

Physical activities

- (Getting to) work/ uni/ school
- Doctor's appointments
- A walk
- A massage
- Food: Eating
- Food: Cooking
- Weather/temperature
- Taking a shower
- Brushing your teeth
- Getting out of bed
- Turning over in bed



Mental activities

- Work/ uni/ school
- Doctor's appointments
- Driving a car
- Driving/ walking a different route
- Conversation/ phone call
- Looking at the calendar
- Making decisions
- To be in the supermarket
- Reading, writing
- Watching TV/ listening to radio
- General sensory impact



PEM

Psychological activities

- Work/ uni/ school
- Doctor's appointments
- Psychotherapy
- Loneliness
- Having coped with something
- Not being able to cope with something
- Reciving a love letter
- Negative feedback
- Positive feedback
- *Own* feelings
- Feeling of *other's*



POST Exertional Malaise

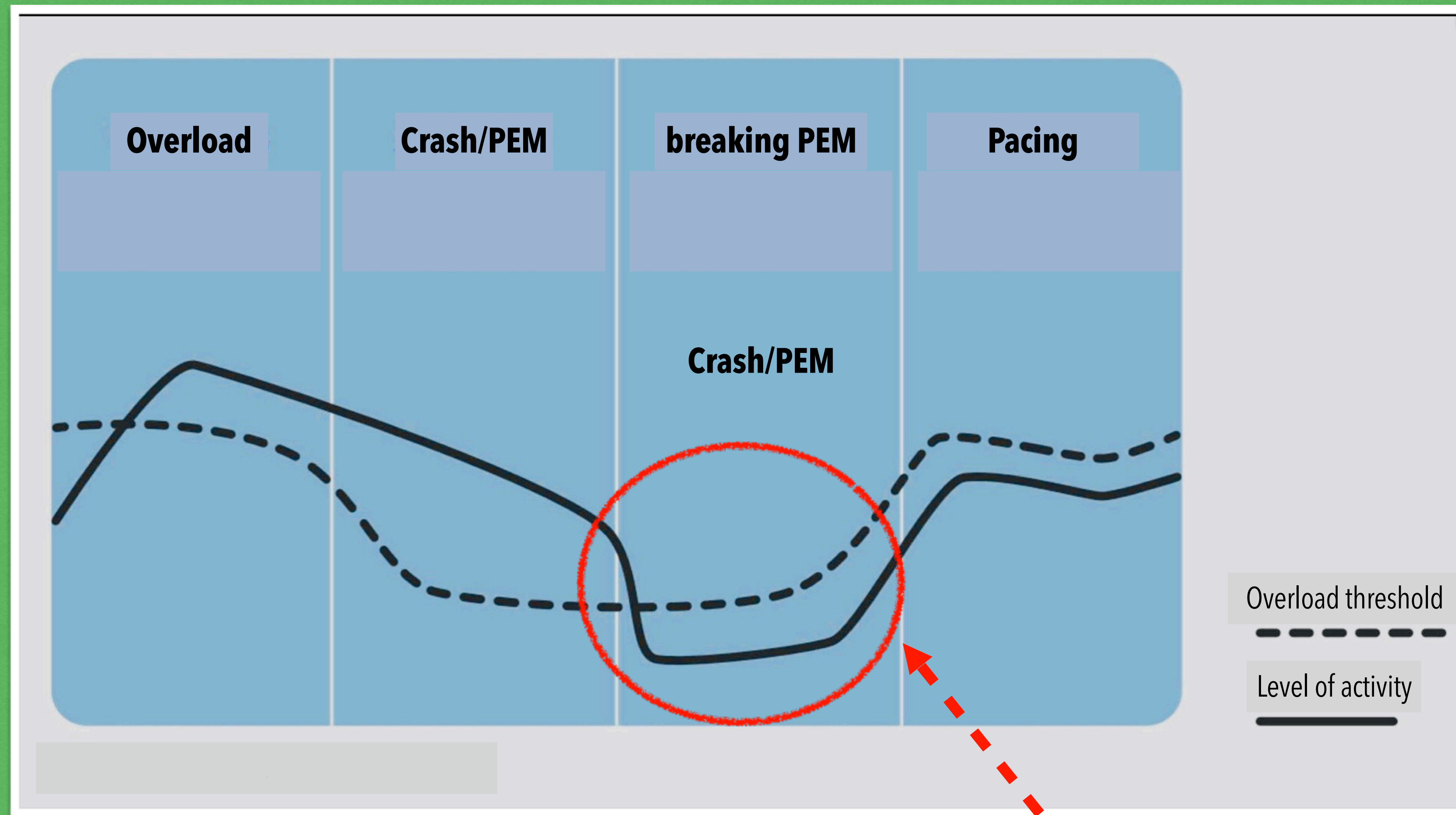
**If I judge from the here and now:
„I feel good and there's still room for improvement",
then this CAN lead to a crash.**

**I notice I'm already reaching my limits:
Danger of PEM is now particularly high -
but at the same time it is not certain.**

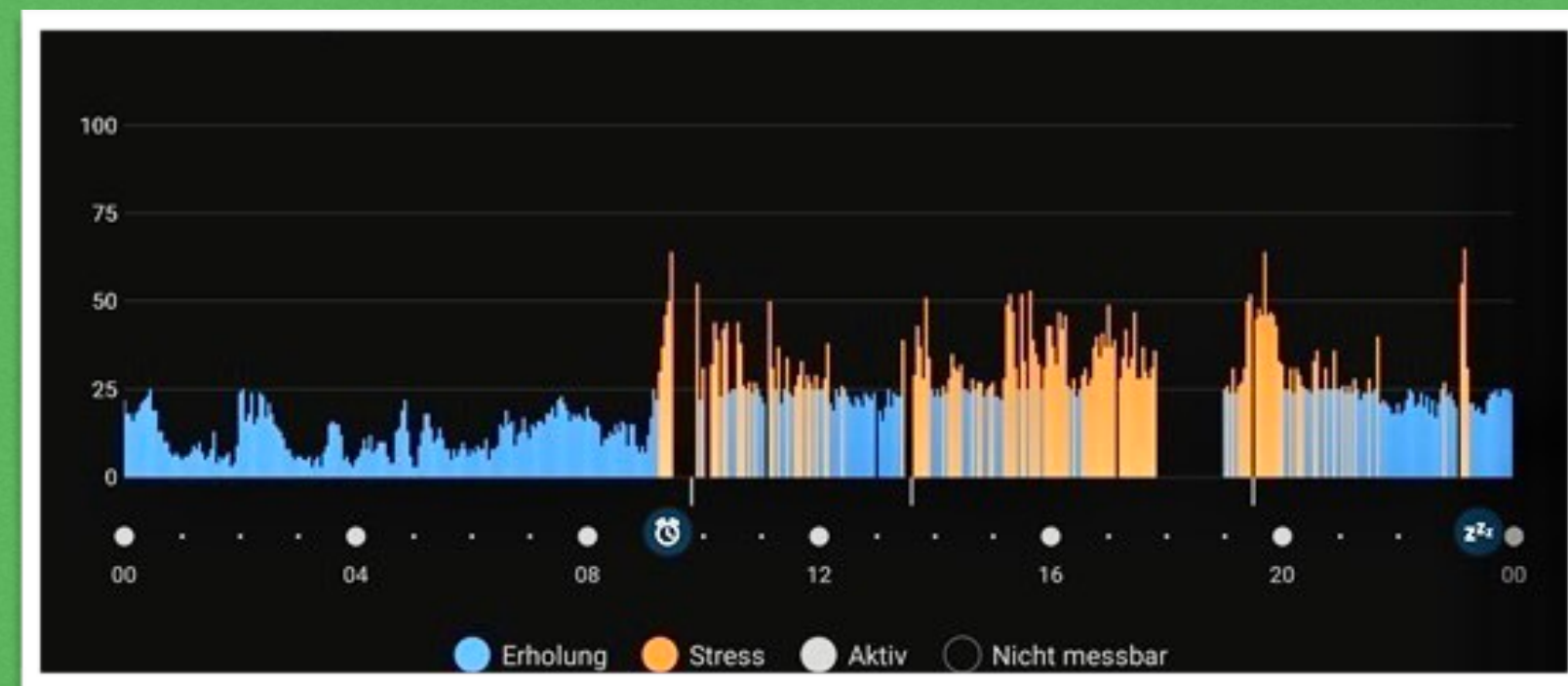
„Can it really be that yesterday's phone call triggered this deterioration?“

Yes. You must now learn how to pace yourself!

WHAT DOES PACING MEAN?



PHYSICAL STRESS LEVELS REPRESENTED BY THE HEART RATE VARIABILITY AT ME/CFS



Stress levels on a relatively good day with **activities below** the stress limit



Stress levels **after** exercise, on a day **without any activity**

PEM/
Crash

IS PACING THE SOLUTION?

"I'm already hardly doing anything!"

PACING is a challenge:

Sunday Reflection

#MECFS, PEM: If I could control my desire to take action, pacing myself would be much simpler. I often wake up with numerous ideas and plans for the day, but end up crossing most of them out as the consequences of overexertion would be too painful to bear.

You can't get anything done without undoing yourself."
#PEM

Yes, you always have to be cautious about curbing your own euphoria - although I'm aware that my complaints may seem trivial in comparison. For many of us living with ME/CFS, basic activities such as simply standing, speaking, or holding objects have become impossible, and even being online can be a challenge.

There's also no sense of satisfaction even when you've accomplished something. Quickly wiping down the sink in the bathroom is not the same as having a clean and tidy bathroom as a result of hard work. I really miss that feeling.

Exactly. You have to make so many compromises with the demands you place on yourself. I don't feel like myself anymore. Being myself is not possible with ME/CFS and PEM. Having a sparkling clean home was once the reward for a job well done. Now, there's no reward, only punishment: crashing instead of satisfaction.

I find this especially difficult in conversations. I get so excited about reconnecting with people and seeing some friends again. I hate that it's never possible to just let go and enjoy the moment.

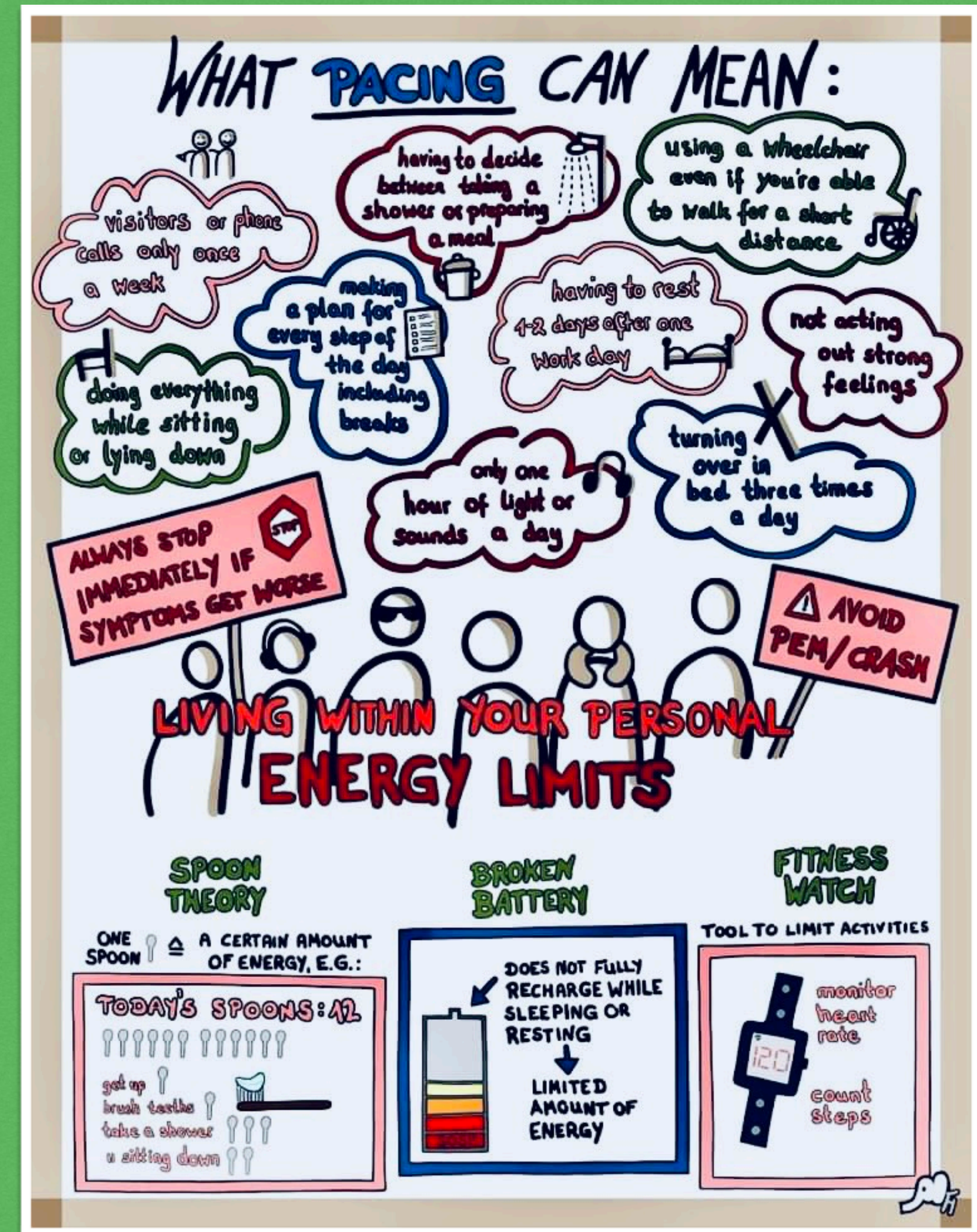
If I don't pace myself carefully and my adrenaline spikes, I can still manage to do quite a bit. It's as if I'm under the influence of drugs - I try to convince myself that things are different now and that I can do them.

WHAT PACING CAN MEAN FOR PATIENTS:

- Limitation
- Self-control
- Renunciation
- Frustration
- Isolation
- Loneliness
- Desperation
- Anxiety
- Depression



Psychotherapy



What is the focus of the psychotherapy?

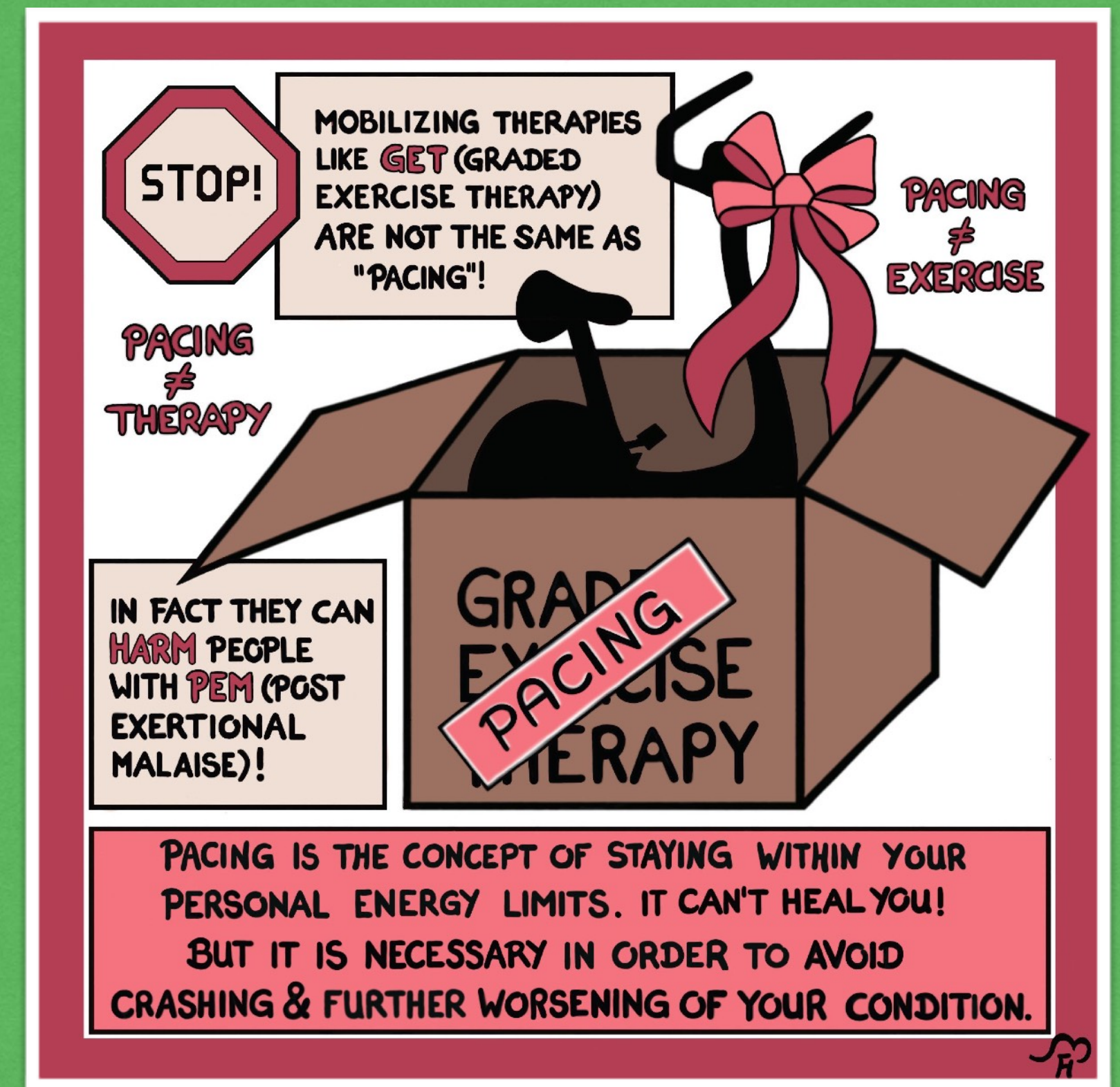
- PEM-analysis: What contributed to the crash?
- What of this could be avoided in the future?
- Self-blame because of crashes
- Practical and emotional consequences of restrictions in everyday life
- How to allocate limited resources
- When to say „no“ to external requirements
- Note these points in the psychotherapy itself



Therapists can accompany and promote this process, but they do not primarily have superior knowledge that would allow them to guide the affected person from „outside“

Key psychotherapeutic elements of working with ME/CFS patients

- Introduction and practice of the principle of pacing
- Dealing with the inner resistance when following the „regime“ of pacing
- Setting boundaries against social pressure
- Existential themes related to severe/ chronic/ debilitating illness



Conclusion

It is much easier to worsen the condition of ME/CFS patients through ambitious psychotherapies than to improve it.

Our goal must therefore be to avoid patients crashing and to help those affected to make the most of the opportunities available to them within their physical limits.

This is what the goal of pacing is!

But please note:

Pacing is often understood as a solution to the problem,
but is itself a **huge problem** and an enormous challenge.

**Psychotherapy can make an important
contribution to dealing with this challenge.**



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SEVERE



VERY SEVERE

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Thank you for your interest and attention!

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