

Pacing Basics 8

Crash Recovery &
Coping with Setbacks and Relapses

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Overview of Session

Who am I?

Ground rules

“Definitions”

Crash Recovery

Coping with Setbacks and Relapses

End points

A Shrinking Energy Envelope

Shower

Look after cat

Eat

Prepare Food

Socialise with Friends

**Work 5 hours a
day**



PEM is the body's inability to recover normally following physical, cognitive and emotional effort, as well as orthostatic, environmental, and sensory stress. The onset of PEM is often delayed in presentation, occurring 12- 72 hours after the trigger(s), and can last hours to weeks and even months at a time depending on the severity of the energy insult.

Patients experiencing PEM often describe "flu-like symptoms" (profound fatigue, weakness, fever, headache, dizziness, sore throat, chills, muscle and joint pain, enlarged lymph nodes), worsened cognitive symptoms (insomnia, brain fog, word-finding and concentration difficulties), and increased sensitivity to stimuli (noise, light, sound, odor, movement). **Periods of prolonged and severe PEM are referred to as a crash.**

Crashes can vary from person to person and episode to episode. Some may be mild resulting in an inability to carry on with daily activities such as cognitive processing or physical tasks. Others can be so severely debilitating it becomes life-threatening due to the individual's inability to walk, talk, eat, drink, or sit upright.

Once in a crash, the individual **must allow** their body to recover before resuming activities. It is critical to allow restoration and to avoid a repetitive push-crash cycle.




Crash Care Survival Guide v6

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ME/CFS
CRASH
SURVIVAL GUIDE

The Art of Living with ME/CFS



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Relapses and Crashes are often possible and hard to avoid

PREVENT

- Try to prevent crashes with good pacing & rest - this includes trying to manage commitments, plan well etc.
- Some people find their crashes are fairly mild and it's worth them sometimes overdoing it a bit to do things they really want to do. For others that could cause permanent harm

PREPARE

- Preparation for the possibility of crashes depending on your situation. It might be you have a family member who you have trained and shown what help you need
- It might be you have a "survival" bag with supplies you need e.g. easy ways to clean yourself, eat, things to lift your mood if need be, extra clothes so don't need to wash as much etc.
- You might need some money reserves for hired help, not earning money, takeout
- You might have some aids in the house you don't normally use but use them during crashes e.g. communication aids, shower chairs, wheelchairs etc.

ACCEPT

- Mentally prepare so if it comes you are able to do what you need to do to get through it as easily and painlessly as possible
- Even when you make progress crashes can take time to recover from. It can feel like you are back on step 1

When Your Energy Envelope Has Shrunk a Lot?

- Do as little as possible - When whatever you do you are exceeding your energy envelope try to do so by as little as possible
- Focus on rest and high quality rest
- If there is an underlying cause e.g. an infection, can it be treated, can this be waited out?
- Get the help you need
- Readjust goals and aims

When in “Crash” state

- Be kind to yourself - it might be that it is things you did that brought it on, its good to learn from that but first and foremost be kind
- Address environmental issues - Bateman Crash guide talks of “turning down the volume”
- Some people stop being on social media, stop checking emails etc.
- Be patient - it can take a long time, lots of horrible symptoms, often really low quality of life...but it often passes and improves with rest and pacing
- Adapt

Setbacks & Relapses

Causes

- Not pacing/ resting well
- Thought was making more improvements than were
- Had big event felt needed to be part of
- Illness (e.g. other health issues)
- Emotional situation -breakup, argument
- Seasonal issues
- Unexpected situations

- Unknown factors

Coping With Setbacks & Relapses

- Be Kind to yourself
- Try to reduce what you do so you have “energy to spare” or at least not in deficit i.e. acknowledge you have less energy than “usual” and adapt
- Utilise energy saving tips that you cannot always do (e.g. for cost issues, calling in favours, environmental impact etc).
- Setbacks are almost inevitable. Whilst its good to learn from setbacks don't linger on anything that you might do differently next time

Adapting to Setbacks and Relapses

Re-start doing activity diaries

Focus on high quality rest and relaxation if need be

Try to cut down what you are doing if your energy envelope is smaller

Re-assess and re-priorities goals and commitments

Listen to your body and your needs

Accept recovery is not linear

Setbacks are not always fair and are rarely easy

Thank You

Resources

Action For ME Pacing Guide

The Fatigue Book - Lydia Rolley

Watch out for Closed Peer Support Pacing Groups - hopefully recruiting soon

Bateman Horne - Great YouTube videos & Crash Survival Guide

PhysiosforME - good online resources and book out this August

Long Covid Support - A great place to ask questions and share experiences - plus lots of great events and resources