



Building your PEM Toolkit Webinar Session Community Voice

What words do you use to describe PEM?

- The hangover
- Post-exertional exacerbation of symptoms
- Crash or flare up
- Payback
- Crashed Like walking through sand
- Hell Feel like I've been hit by a truck ;)
- Comatose state
- Beetrooted (Rooted was swearing to my mum)
- No more spoons
- Rules every moment of my life
- Sat on by a cow
- Going into hibernation
- Someone turned up the gravity
- Legs burning with lactic acid
- It is no way to live
- "A flu plus the worst hangover you've ever had"
- Killed my power switch
- Tissue hypoxia
- Exhausticated
- Head about to explode
- Like 1000 pirhanas attacking me from the inside
- A full drain of energy, pain, and weakness
- Wrecked
- Soul tired
- Not able to think straight at all
- Just finished a run of night shift with no sleep
- My body is on fire
- Flat like a ribbon
- Marrow sucked out of my bones
- Completely debilitated
- Like a brick wall falling on me and not being able to move or think or talk

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Question 2: How do you nurture yourself through PEM symptoms?

- Drop everything and go to bed.
- Plenty of hydration.
- Minimal light & sound.
- No phone calls.
- When extreme - complete darkness, like when dealing with a migraine.
- Use icepacks for pain.
- Audiobooks in bed and a diffuser with my favourite oil blends
- If I can go outside I sit in garden and watch birds, but usually it is just laying in bed watching tv shows, try to pick light ones When only mild - listen to podcasts PJ days - watching repeats (so I don't have to follow the plot) When in severe state nurture is a dark room, a comfortable bed and an eye mask
- Horizontal and self-talk mediation
- I live in bed and have a close, intimate relationship with my sleep mask.
- When moderate. Looking at nature
- Taking my children to the park and watching them have fun and lots of laughter, even if it is only for a short time
- Sensory aids - noise cancelling headphones, black out curtains, etc. Lots of bed time.
- Dark room, lying flat ...boring!!
- No audio/video/TV.
- Completely stop everything, complete rest, quiet, deep breathing
- Snuggles with my 2 fur babies, curled up in bed.
- Curtains drawn
- Bed, warm hat and under the doona. Cut all out for a while and hope I can rise again soon
- Eye mask, earplugs, soft voices from carers, minimal conversation, limit screen time,
- help with brushing teeth (e.g. spit cup so don't have to walk to bathroom)
- Nothing day.
- Lie horizontal.
- No expectations.

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Question 2 Continued: How do you nurture yourself through PEM symptoms?

- Allow myself to rest on the couch without being guilty that I'm not doing anything
- Eye mask, headphones, curtains shut, windows closed.
- Noise reduction headphones if you can pull the \$\$ together.
- Rest when I get tired... even if I'm half-way to the bedroom door on the way to the
- toilet, if I get tired on the way, I'll stop and even lie down on the floor till I feel rested
- more..
- Need to get horizontal ASAP
- Uber eats and scrolling in the phone
- Resting in bed reading, listing to music or watching tv listening to podcasts spoiling
- myself with dark chocolate and my teddy bed. have just bought a pair of noise
- cancelling headphones.
- Order food when I can't stand up to cook for kids
- Lie down. No verticality allowed!
- Yes. Being horizontal is so urgent.
- In bed, eye mask, quiet dark room no people oil burner soft ambient sounds
- Pee jars - no walking to the toilet!!!

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Question 3: If you could provide one piece of advice to a person who is newly diagnosed with ME/CFS, what would it be?

- Do not push yourself
- Do not try and push through When in doubt, lie down!!
- BED is my BEST FRIEND!
- Pacing! Listen to your body!!
- Pace more than you think you need to PACE yourself!
- Don't push through Rest.
- Rest like your health depends on it because it does. Slow down as much as possible.
- Ask for help.

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Question 3 Continued: If you could provide one piece of advice to a person who is newly diagnosed with ME/CFS, what would it be?

- Learn about pacing.
- Don't doubt you have CFS when you feel 'normal'
- Do not push.
- You'll regret it.
- Listen to your body and don't lose hope.
- Check your thyroid function
- Please know you're not alone, look for support, support is out there
- Learn as much as you can about ME/CFS
- Give yourself a break and learn to listen to your body.
- What's your body trying to tell you?
- Aside from not pushing and rest, advocate for yourself with doctors until someone listens
- Yep. Stop pushing.
- Listen to your body
- Don't push loved ones away
- Listen to your body
- Exercise is a no-go and it is ok to perish.
- Believe in yourself and your understanding of your own body
- Be honest with your family and friends so they can learn to support you
- Learn to stop... why sit when you can stand... why stand when you can lie down...
- There is not one single solution, don't wreck yourself trying to find it
- If orthostatic symptoms are debilitating - get a referral to a Cardiac
- Electrophysiologist to get objective evidence
- Keep an energy emergency fund
- Learn what your PEM symptoms are so you know your warning signs to stop Rest until you're bored out of your skull. If rest was an olympic sport, go for gold
- Don't feel guilty for resting. Find a supportive GP.
- pace as much as possible rest as much as possible ignore when people tell you to
- exercise more
- You can't 'beat it'
- STOP, REST....ignore medical advice to do more.

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Question 3 Continued: If you could provide one piece of advice to a person who is newly diagnosed with ME/CFS, what would it be?

- Make sure anyone advising you, Drs included, know what ME is!
- Find laughs - TV, You Tube, cartoons, etc!
- Triage your needs and abilities
- You can't outrun this illness. Listen to your body.
- Prioritise! What's essential, and what can wait?
- The 'Spoons' story is a good one to share with others...
- Take charge of your own health.
- Join a support group (ME support group)
- Link your loved ones with Emerge Australia.
- Help them understand
- Don't push it - You know your body BETTER than anyone else.
- Keep records - useful when talking to doctors and when trying to remember what worked.
- Journal your days.
- Help you learn and see your triggers savers tools
- Don't think toooooo much. It won't help!!
- Try to make your environment as nice as possible for you Check out Workwell Foundation resources regarding not going over your Anaerobic Threshold - Pacing Using Heart Rate Monitoring
- Clear out all the clutter in your life, this includes negative people or anything or
- anyone that doesn't support you
- Record all your doctor's visits
- Pace, learn about ME/CFS, find a knowledgeable doctor, understand your PEM cycle
- and baseline
- Accept where you are but understand you won't be there forever.
- If you have orthostatic intolerance - do the Lean test (Lucinda Bateman explains
- how). As well as collecting the heart rate and blood pressure data take photos of
- your feet when lying down and at the end of the Lean test. The photos of blood
- pooling show that something is going wrong. Good evidence when the medical
- profession doubts you and your data.