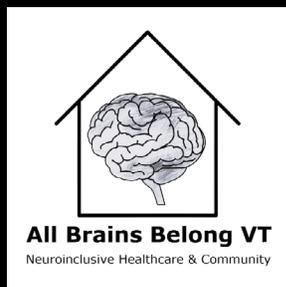


Exploring ENERGY Equilibrium Strategies for Individuals who Experience Post Exertional Malaise (PEM)*

Autism Level UP!
All Brains Belong VT



**The considerations offered in this support are not medical advice and do not replace medical interventions prescribed by a care team.*

PEM is:

- the hallmark symptom of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and also common in presentations of long COVID and fibromyalgia.
- a depletion of energy in the body at a physiological level.
- a worsening of symptoms (e.g., fatigue, cognitive dysfunction, sleep abnormalities, pain, etc.) that occur after minimal physical activity. Minimal physical activity encompasses things like sitting upright and walking household distances. Symptoms are often experienced as extreme fatigue and flu-like symptoms with onset 12-72 hours after exertion.
- most often associated with physical exertion but can be triggered by cognitive exertion and also intense emotional and/or sensory experiences.

PEM is not:

- fleeting.
- a little tired.
- something a nap can fix.
- in someone's head.

PEM and Regulation

PEM impacts participation and engagement in Activities of Daily Living (ADLs) due depleted energy stores. While it is common to assume that people experiencing low energy need to power up their energy by using regulation strategies to support engagement, this is not advised for individuals who experience PEM. For individuals who experience PEM expending energy in an attempt to increase energy can make symptoms worse and lead to all-encompassing energy crashes.

For individuals who experience PEM the maintaining of an energetic equilibrium is critical to functioning, engagement, and protective for the prevention of crashes. Strategies used to help achieve Energy Equilibrium may be best conceptualized as maintenance strategies and often involve passive sensory regulation strategies / input (i.e., strategies that do not requires extensive energy expenditure to realize their benefits). Energy Equilibrium Strategies may also include centering practices and environmental strategies.

As you explore this resource, keep in mind that medical management of neuroimmune conditions is complex. Some strategies in this resource may not work for you, and that's ok. Some strategies listed here may layer on top of each other, to “unlock” improvement. We encourage you to partner with your medical team to work through these strategies together.

[Here is a resource](#) for initiating these conversations with your primary care team. It is also included at the back of this resource.

General Recommendations for Exploring ENERGY Equilibrium Strategies

Do:

- Recognize that context matters. Existing in supportive, less taxing contexts when possible is desirable. Consider the following contextual domains:
 - Nutrition / hydration
 - Exercise
 - Rest
 - Meaningful and safe connections to others
 - Opportunity for connections to nature
 - Making changes in these areas may not always be possible for a host of reasons. But, keeping them on the radar screen as factors influencing PEM experience and the effectiveness of ENERGY equilibrium strategies is worthwhile. We have included some additional information related to these areas starting on page 12 if the topic is of interest to you.
- Break down strategies/tasks into chunks. Engage in explicit pacing during activities. If you think you are going slow, go slower! Take breaks.
- Consider modification of activities to remove the strain of working against gravity. For example, if dancing is a joyful activity for you. Think about moving your arms and legs in time with music while lying down. Being upright can be extremely fatiguing.
- Recognize that movement or a strategy may feel good in the moment, but it also drains energy. Consider working at 50% of what you think your capacity is, even if you are feeling strong and energetic.
- Monitor for signs of over exertion. Respect these signs and stop activity. Record your experiences for future reference.
- Take the needed time to recover if you are actively experiencing PEM or an energy crash.

Do Not:

- Push through. Pushing through will cause damage to your mitochondria and prolong recovery time.
- Try all of the strategies listed in one go. The suggestions that follow are meant for consideration over time.

Exploring Energy Equilibrium Strategies

The following ideas are offered as examples of Energy Equilibrium Strategies to try over the course of time. This is not an exhaustive list. You are encouraged to add your own ideas in the blank rows.

SENSORY

LOW MOTION / NO MOTION STRATEGIES

Proprioceptive Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Weighted blanket						
Laying on back with legs up on the wall						
Squeeze hands						
Hug from trusted human						
Massage from trusted human						

Vestibular Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Rocking chair						
Touch toes while seated						
Swivel in office chair						
Gentle head turns and tilts						
Riding in a car or a wheelchair with assist of trusted human						

Tactile Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Rub different textures (e.g., mermaid fabric, silk, Velcro, etc)						
Heating pad						
Ice pack						
Stroke / pet / touch trusted human or pet						
Light, rhythmic touch provided by trusted human						

Visual Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Kaleidoscope						
Lava lamp						
Stim screen on phone / tablet (explore decreasing blue light and brightness in settings)						
Watch moving water, flame, wind in trees						
Light blocking eye mask						

Taste Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Warm beverage						
Cold beverage						
Spicy food						
Sweet food						
Sour food						
Salty food						
Bland food						

Smell Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Essential oils						
Coffee						
Perfume / scent of trusted human						
Scent of pet						
Nature						

Listening Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Music						
Brown noise						
Nature sounds						
Voice of trusted human (may be recorded)						
Podcast / Audiobook						

CENTERING ACTIVITIES

Activities	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Mindfulness/Meditation https://www.freemindfulness.org/download						
Non-Sleep Deep Rest https://www.youtube.com/watch?v=r17gxZQ0i48						
Tapping https://www.youtube.com/watch?v=Sqe3h3l8a7w						
Breathwork https://www.youtube.com/watch?v=tbMK48EoaBA						
Reiki with trusted partner						
Coloring/sketching						
Ritual (e.g., coffee making)						
Grounding (bare feet in grass)						
Humming						

ENVIRONMENTAL STRATEGIES

Environmental Strategies/ Considerations	Energetic Experience			Likability		
	Steady	Improved	Drained	Yuck	OK	Awesome
Pets						
Presence of trusted human						
Access to comfort object						
Small space						
Wide open space						
Outside						
Inside						

A few thoughts on food, diet and lifestyle to help mind your mitochondria:*

Before making any changes to supplements or nutrition, we recommend consulting with your personal medical team. The following is for educational purposes only and is not medical advice.

There is no one-size-fits-all diet for curing chronic fatigue, PEM, long-covid, nor any inflammatory or autoimmune condition. However, most inflammatory conditions share some common characteristics. Research finds that the mitochondria of people with inflammation and autoimmune conditions look like they are mitochondria belonging to someone twice the actual age of the individual. Mitochondria are the powerhouses of the cell and literally create energy for the body, but their ability to create energy is hindered in inflammatory conditions! Repairing mitochondrial health can be critical to healing for many people.

What vitamins, minerals, nutrients, foods and supplements are good for mitochondrial health? Find foods you are willing to eat and/or supplements that are high in the following:

- B Vitamins (especially B1, B2, B3, B5, B6, B12)
- Coenzyme Q10
- L-Carnitine
- Iron
- Zinc
- Copper
- Selenium
- Creatine**
- Taurine

Lifestyle Synergy:

- **Exercise:** Stimulates mitochondrial biogenesis. But, this is a delicate balance for those with PEM, as any exercise can trigger extreme fatigue and create further damage. If you chose to explore this are consider the low motion strategies offered in this support.
- **Nutrition:** Explore nutritional strategies with your health care professional.
- **Sleep:** Necessary for mitochondrial repair and function.
- **Avoid toxins:** Mitochondria are vulnerable to heavy metals, pesticides, etc.
- **Sunlight and Red light (and the absence of man-made blue light)**
- **Temperature:** Explore using hot or cold showers depending on preference to support mitochondria and energy.

In addition to foods that support energy production...

It is important to note that while food can be an amazing source of medicine, it can also be an inflammatory toxin. A person's body's response to a particular food is often individualized. One person's body may perceive a food as a threat and mount an inflammatory response, while another person's may not. As such, we encourage you to discuss your diet and nutrition with your healthcare team if this is an area of interest to you.

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***Creatine may not be safe for all people—be sure to consult with your medical team before considering.*

Want to know more about ME/CFS, Long COVID, MCAS, etc.?

Check out All Brains Belong VT's resource - Everything is Connected to Everything: Improving the Healthcare of Autistic & ADHD Patients at <https://allbrainsbelong.org/all-the-things>



All Brains Belong VT
Neuroinclusive Healthcare & Community

Dear Primary Care Clinician,

Your patient has accessed this document through “**Improving Healthcare for Autistic & ADHD Adults**,” a project created by All Brains Belong VT and sponsored by the Organization for Autism Research and by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under the Autism Intervention Research Network on Physical Health (AIR-P) grant.

This educational project consists of multiple sets of resources for patients and primary care clinicians related to the **constellation of related neuroimmune conditions commonly experienced by autistic and/or ADHD adults**. This content merges available evidence-based practice and patient focus group input. The clinician guide was peer-reviewed by a group of primary care physicians.

Your patient is not under our medical care. The purpose of the patient education component of this project is to empower patients to discuss this information with you as their primary care clinician.

For evidence-based information created for healthcare professionals, please visit <https://allbrainsbelong.org/clinician-resources> or use the QR code below.

Sincerely,

Melissa Houser, M.D.
Executive Director, All Brains Belong VT

