



EDS ECHO SUMMIT

FATIGUE

CAUSES AND MANAGEMENT
SATURDAY OCT 21, 2023



EDS ECHO SUMMIT SERIES

ECHO SUMMIT: FATIGUE **CAUSES AND MANAGEMENT**

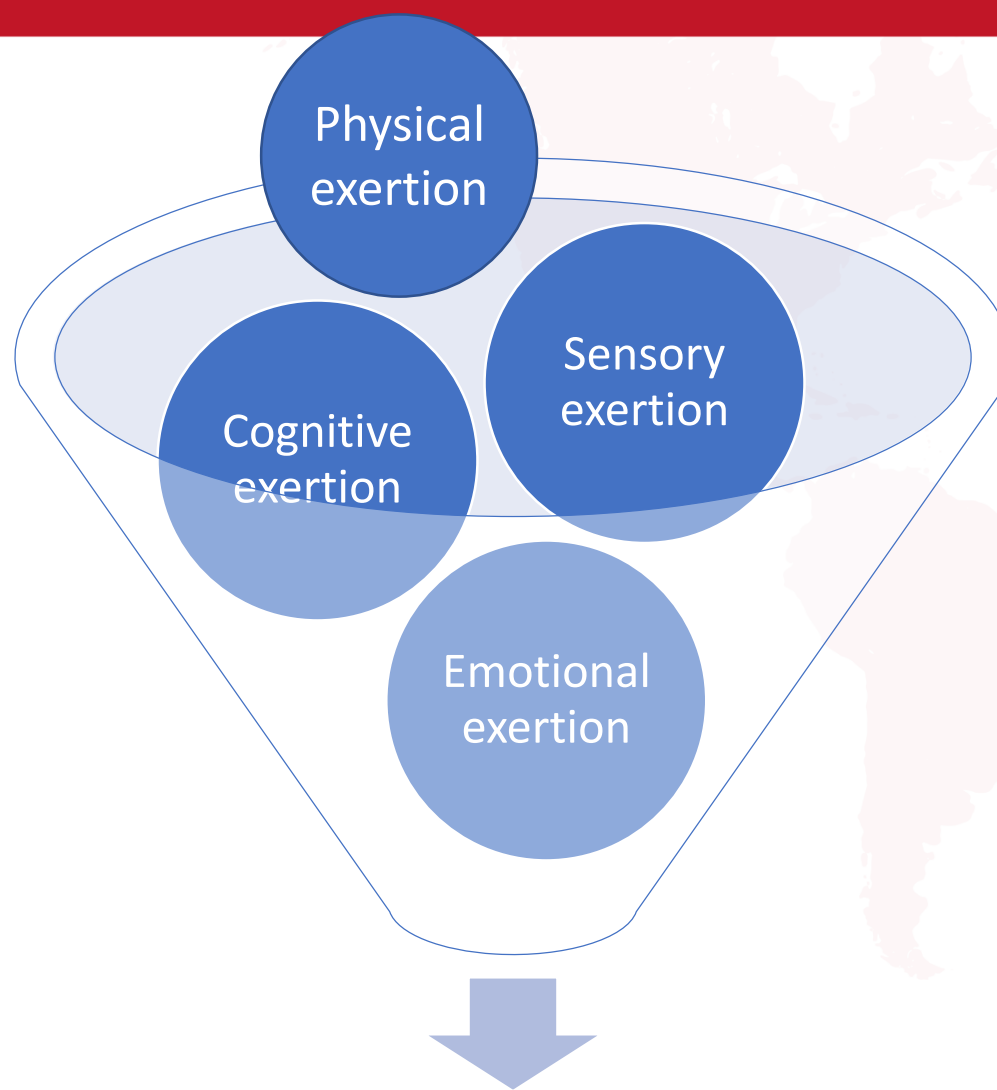
PRESENTATION

Pacing, Exercise, and Managing Daily Activities

SPEAKER

Emily Rich, MOT, OTR/L
Tucson Medical Center

Types of Energy



Overall Energy Demand



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TLDR

(At least) 3 types of energy play into our overall energy capacity.

Fatigue + Daily Life

Impact of Fatigue (in postural orthostatic tachycardia syndrome (POTS))

V. Strassheim et al.

Autonomic Neuroscience: Basic and Clinical 215 (2018) 56–61



Fig. 1. Symptoms described by those with PoTS as consequences of their fatigue.



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TLDR

Fatigue essentially
affects every aspect of
daily life

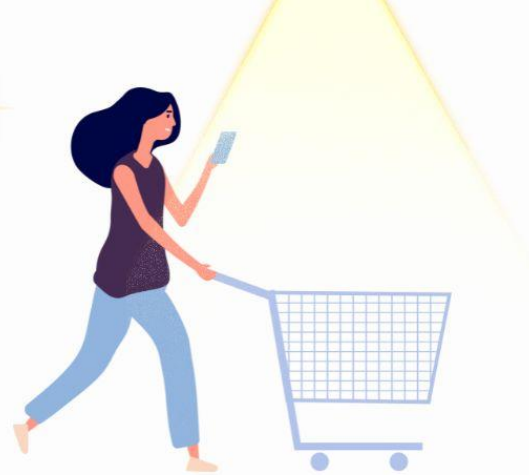
Example



Meal plan + shopping list



Drive to store



Shop



Distressing phone call



Hurridly leave store



Settle distressed child



Exhaustion



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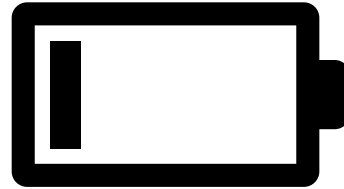
TLDR

Daily life presents all types of energy demands each day

Pacing

A way of approaching

- An activity or task
- A morning
- A day
- A week
- ...life



A frustrating, exhausting, and often impossible task

Something that should be learned and practiced in community, with support

One tool, but should only be one of *many* tools in your box



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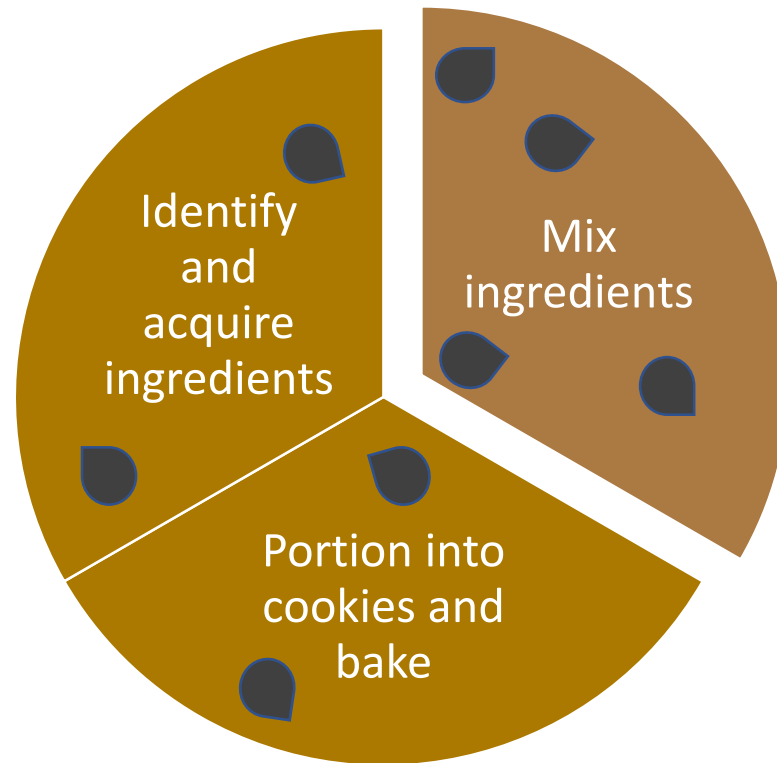


TLDR

Pacing is one tool that can decrease energy demands in daily life and should be implemented with the help of others.

Pacing a Task

Making Cookies



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TLDR

Take the activity one "chunk" at a time and rest between steps.

Pacing a Week

Weekly Schedule without Pacing

Monday

- Rest
- Romance movie night

Tuesday

- Dentist appointment
- Physical therapy appointment
- Cardiology appointment

Wednesday

- Grocery shop
- Meal prep 3 recipes
- Exercise

Thursday

- Study for 1 hour for test
- Examine finances
- Dinner with in-laws

Friday

- Rest



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TLDR

Pacing is less effective by putting all activities of the same type on the same day and resting completely on other days.

Pacing a Week

Weekly Schedule using Pacing Strategies: Cognitive

Monday

- Grocery shop
- Meal prep 1 recipe

Tuesday

- Cardiology appointment
- Examine finances
- Dinner with in-laws

Wednesday

- Meal prep 1 recipe
- Study for test 30 minutes
- Romance movie night

Thursday

- Study for test 30 minutes
- Physical therapy appointment
- Meal prep 1 recipe

Friday

- Dentist appointment
- Exercise

TLDR

Spreading cognitive tasks throughout the week with rest breaks between can decrease energy demands.



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Pacing a Week

Weekly Schedule using Pacing Strategies: Physical

Monday

- Grocery shop
- Meal prep 1 recipe

Tuesday

- Cardiology appointment
- Examine finances
- Dinner with in-laws

Wednesday

- Meal prep 1 recipe
- Study for test 30 minutes
- Romance movie night

Thursday

- Study for test 30 minutes
- Physical therapy appointment
- Meal prep 1 recipe

Friday

- Dentist appointment
- Exercise

TLDR

Spreading physical tasks throughout the week with rest breaks between can decrease energy demands.



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Pacing a Week

Weekly Schedule using Pacing Strategies: Emotional

Monday

- Grocery shop
- Meal prep 1 recipe

Tuesday

- Cardiology appointment
- Examine finances
- Dinner with in-laws

Wednesday

- Meal prep 1 recipe
- Study for test 30 minutes
- Romance movie night

Thursday

- Study for test 30 minutes
- Physical therapy appointment
- Meal prep 1 recipe

Friday

- Dentist appointment
- Exercise

TLDR

Spreading emotional tasks throughout the week with rest breaks between can decrease energy demands.



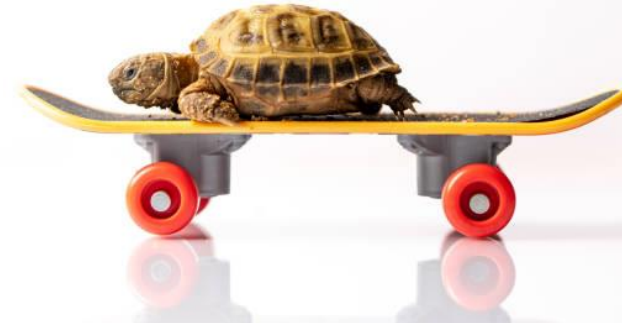
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What else does Pacing Mean?

- Rest between and during activities
- Alternating activities demanding upper and lower body endurance
- Scheduling recovery time without devoting entire days to inactivity
- Prioritizing
- Energy conservation
 - working smarter, not harder



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TLDR

Pacing yourself includes a variety of strategic methods to regulate exertion. It may be a way to manage symptoms and may or may not result in increased energy capacity.

Energy Conservation



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Pacing

- Checking account analogy
 - overdraft fees
- Battery
- Spoon theory



The Spoon Theory

DYSAUTONOMIA INTERNATIONAL
AWARENESS ADVOCACY ADVANCEMENT

The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.

 get out of bed	 bathe	 make & eat a meal	 go to work/school
 get dressed	 style hair	 make plans & socialize	 go shopping
 take pills	 surf the internet	 light housework	 go to the doctor
 watch TV	 read/study	 drive somewhere	 exercise

The Spoon Theory was written by Christine Miserando, which you can check out on her website www.butyoudontlookssick.com.

www.dysautonomiainternational.org



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TLDR

Identifying a common language to explain daily fluctuations in energy levels can help with communicating needs and challenges to loved ones and peers.

How do we Define Rest?



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Factors Contributing to Energy Levels

Sleep

Pain severity

Self-efficacy

Satisfaction with
management &
treatment

Participation in
relationships &
community

Orthostatic
dizziness

Perceived extent
of joint
hypermobility

Physical activity



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TLDR

8 factors have been identified as highly contributing to levels of fatigue in EDS and HSD

Krahe et al., 2018
Voermans et al., 2010

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TLDR

Sleep and Pain will
be covered later in
this summit by other
speakers

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Self-Efficacy Concerning Fatigue

Self-efficacy

definition: an individual's **belief in [their] capacity** to execute behaviors necessary to produce specific performance attainments

American Psychological Association



Self-efficacy concerning fatigue

definition: a sense of control over fatigue symptoms

Voermans et al., 2010



So, just believe you can do it and then you can!

... but it's not quite that simple, is it?



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TLDR

A person's belief about their ability to control fatigue symptoms may affect their levels of fatigue

Self-Efficacy Concerning Fatigue

- How do we use this information?
 - not encouraging false hope of magically having tons of energy
 - but living with chronic illness can feel overwhelming and out of our control
- Counseling/ therapy for chronic illness may be helpful
- Study using a positive psychology intervention (PPI) program in EDS
 - when people were able to choose the PPIs they were most interested in, they saw greater positive affect and life satisfaction as well as decreased fatigue
 - not toxic positivity, not dismissing daily challenges
 - mindful awareness, future orientation, and gratitude practices
- Potentially contributing to the autonomic nervous system...



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TLDR

Consider how having a mindful awareness and looking for “the good” might contribute to improved energy levels and autonomic nervous system regulation



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Focus on what you can do,
rather than what you can't do.

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Satisfaction with Medical Management and Treatment Options



- Identifying optimal team members
 - willing to learn
- Self-advocacy
- Support groups



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TLDR

A supportive team, or even one member of a healthcare team can greatly maximize success with managing fatigue and increasing function.

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Participation in Relationships and Community

- Assistive tools
 - mobility devices if increase function and participation
- Sensory regulation
- Identify new activities of interest that meet your current level of abilities
- Explore groups for socializing such as Meetup.com or online condition-specific support groups (e.g., Facebook)
- Potential to improve coping with condition



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TLDR

Participating in relationships and community can be an essential and often missing part of fatigue-management.

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Orthostatic Dizziness



Fluid + sodium increases blood volume – the amount of blood circulating.

- 100+ ounces of fluid
- sodium varies (4-12 grams)
- caffeine considerations



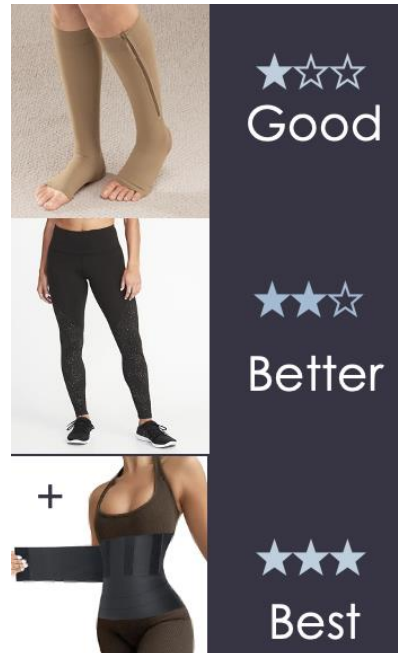
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TLDR

Sodium, fluid, and compression (ideally waist high + abdominal binder) can decrease orthostatic symptoms, thereby helping fatigue.



Compression garments promote blood circulation and minimize pooling:

- ideally waist high + abdominal
- options for assistive devices to decrease effort required for donning & doffing
- 20-30 mmhg compression or greater

Orthostatic Dizziness

Elevating head of bed by 4-6 inches

- cinderblocks, bed risers, or a full-length wedge
- fluid retention overnight



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TLDR

Elevating the head of the bed for sleeping and implementing counterpressure maneuvers while standing still may decrease orthostatic symptoms.

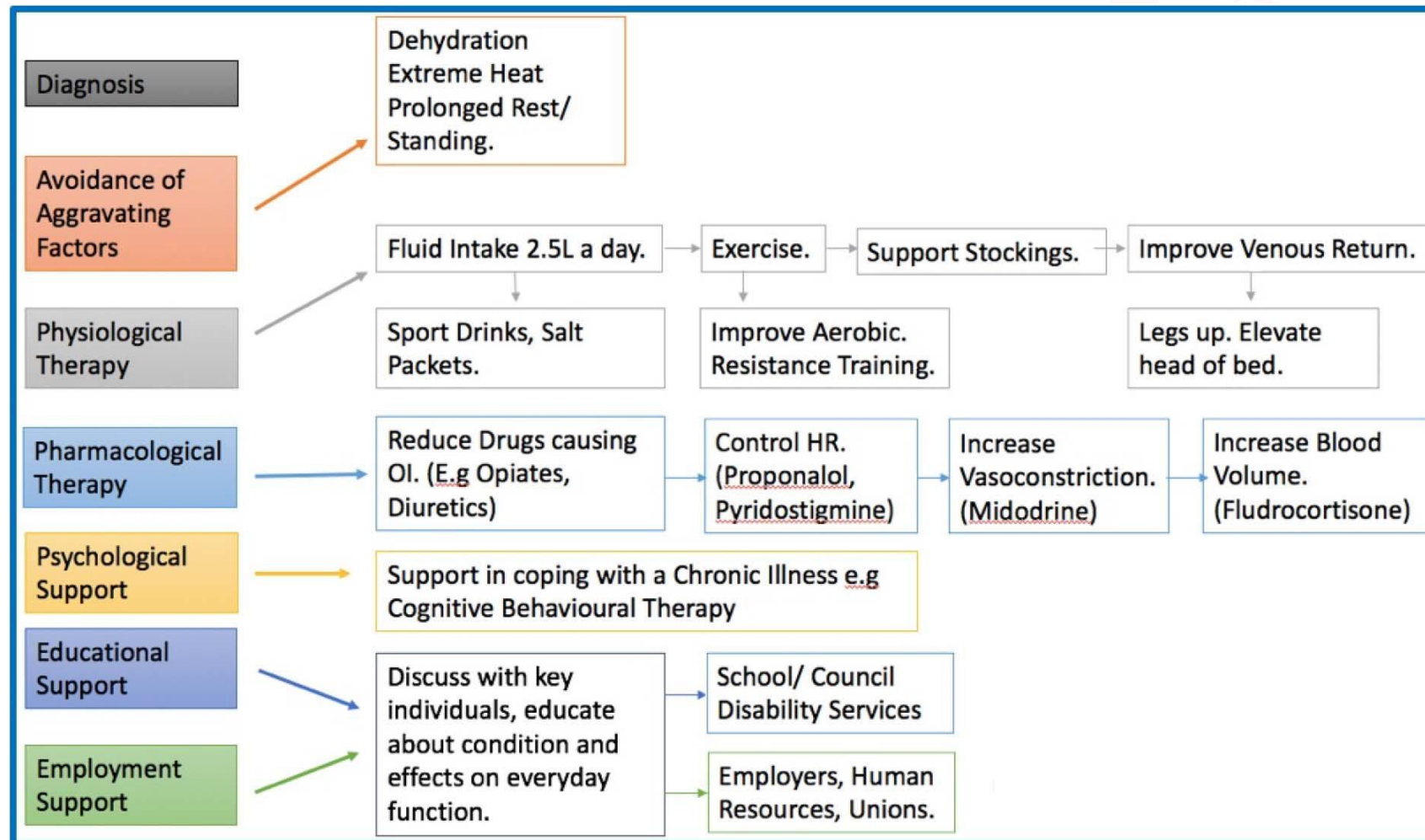
Counterpressure maneuvers help minimize blood pooling

- calf raises
- cross thighs + squeeze
- glute squeezes (buttocks)
- shifting weight to one leg



Orthostatic Dizziness

Newcastle Approach to POTS Fatigue



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TLDR

A multi-pronged approach to managing orthostatic symptoms may include avoiding aggravating factors, fluid, sodium, exercise, compression, medication, psychological supports, and accommodations.

Orthostatic Dizziness

Managing MCAS-Related Fatigue



Histamine bucket theory
MastCellAction.org

- Manage MCAS through:
 - Minimizing aggravating factors
 - Extreme temperatures or sudden changes in temperature; sun
 - Stress
 - Medications
 - Foods and drinks
 - Mechanical irritation (e.g., vibration)
 - Infections; insect/animal venoms
 - Natural or chemical odors/ scents
 - Excess exercise/overexertion
 - Fatigue
 - Medications
 - Increasing threshold of tolerance



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TLDR

Managing symptoms of MCAS through minimizing aggravating factors, taking medications for MCAS, and increasing the threshold of tolerance may decrease fatigue.

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Perceived Extent of Joint Hypermobility

- Tools to manage hypermobility and provide feedback to joints (proprioception)
- Splints/ orthotics
 - Wearing dynamic fabric orthoses (DFOs) (Higo et al., 2023)
 - Custom foot orthotics
 - Custom made foot orthoses worn for 3 months demonstrated significant improvement in fatigue (Reina-Bueno et al., 2020)
 - Custom-made polypropylene foot orthotics worn for one month led to significantly decrease in pain, health-related quality of life, functional capacity, and fatigue (Maarj et al., 2023)
- Workstation modifications and ergonomics

Wearing DEFO helps postural awareness and alignment



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TLDR

Utilizing devices, ergonomic modifications, and strategic exercises can improve joint position in daily activities.

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Physical Activity

- Essential to identify the best physical activity for you as an individual
- Appropriate physical activity or movement practices can contribute to decreased fatigue and improve energy levels
- Ideal to work with a knowledgeable physiotherapist or occupational therapist
 - at minimum, someone who is willing to learn



RPE Scale	Rate of Perceived Exertion
10	Max Effort Activity Feels almost impossible to keep going. Completely out of breath, unable to talk. Cannot maintain for more than a very short time.
9	Very Hard Activity Very difficult to maintain exercise intensity. Can barely breath and speak only a few words
7-8	Vigorous Activity Borderline uncomfortable. Short of breath, can speak a sentence.
4-6	Moderate Activity Breathing heavily, can hold short conversation. Still somewhat comfortable, but becoming noticeably more challenging.
2-3	Light Activity Feels like you can maintain for hours. Easy to breathe and carry a conversation
1	Very Light Activity Hardly any exertion, but more than sleeping, watching TV, etc



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TLDR

Movement practices have potential to improve fatigue levels and increase energy.

Progress, not perfection

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)

- Neurologic illness characterized by extreme tiredness which is not relieved by sleep or rest
- Often provoked by viral or bacterial infection and believed to target the immune system
- Characterized by post-exertional malaise (aka: PEM or PESE)
 - Fatigue with increased severity; potential delayed onset; prolonged duration; out of proportion to magnitude of stimulus; may include fever, swollen lymph nodes, sore throat, pain, aches
- Suspected link to cervical issues in a percentage of pts
- Graded exercise therapy (GET) is contraindicated in ME/CFS
 - Assess before beginning exercise regimen
 - “Do no harm”
 - Assess and prioritize activities of daily living performance before exercise



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TLDR

Individuals with ME/CFS require a specific, individualized approach which will be different from individuals without ME/CFS.

(Larun, 2019, Cochrane Review)

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Breathing
pattern



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Breathing Pattern

- Breathing is often a contributing factor to energy levels (awake or while sleeping)
- Focus on abdominal or “belly” breathing rather than chest
 - in and out through nostrils rather than mouth
- Go at a pace that is comfortable and at the pace your nervous system needs; no rush
 - work on extending exhale overtime with longer, slower breaths
 - focus on consistency of breathing
 - counting can be helpful
- Gets easier over time; start where you’re at and be consistent
- Utilize apps and websites



Inhale, belly rises
Exhale, belly falls



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TLDR

Breathing patterns may contribute to fatigue; intentional breathing practices emphasizing diaphragmatic breathing through the nose focusing on slow breathing and working to extend the exhale may improve energy levels.

Managing Cognitive Fatigue

- Identify and minimize/avoid triggers
- Cognitive & environmental adaptations
 - e.g., positioning supports, reminders, smart devices/tools
- Supporting routine and good habits
- Considerations for proprioception
 - Braces and orthoses may improve cognitive function
 - decreasing attentional demands (Jensen, 2021)
- Acute water bolus therapy for POTS (Rodriguez et al., 2022)
- Physical exercise
- Taking breaks, minimizing unnecessary information
- Alternating types of tasks
- Consider sensory demands and sensory supports



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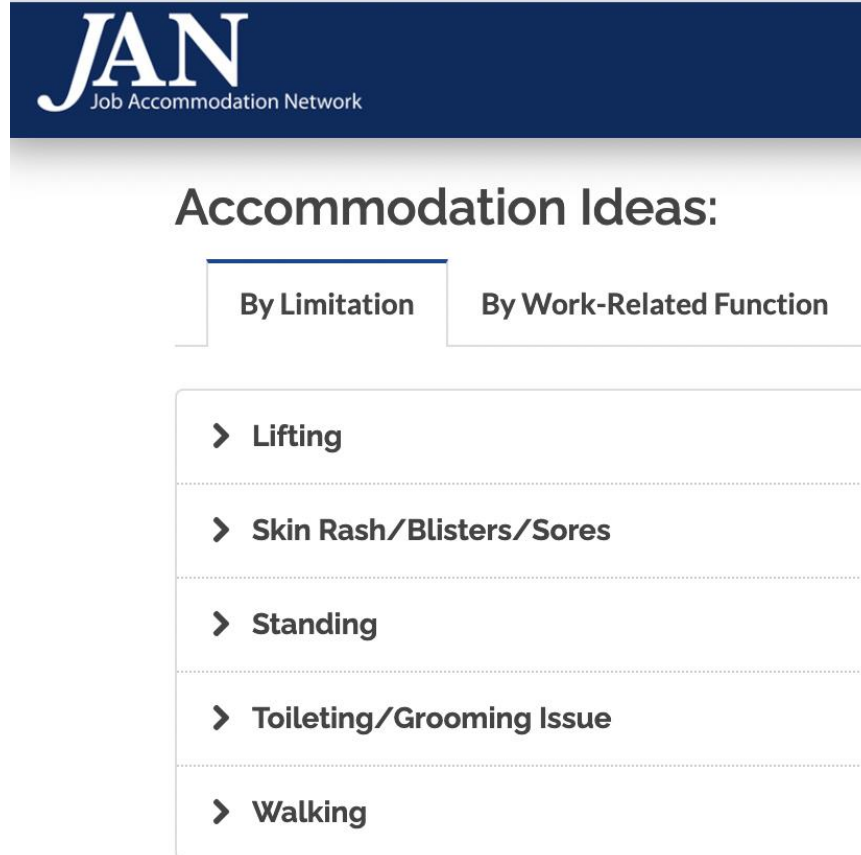
TLDR

Strategies to increase cognitive function and decrease fatigue include minimizing other symptom triggers, compensating, and setting up the environment for success.

(Levine, 2021; Russek, 2015)

Resources for Accommodation

- Job accommodations network
 - AskJAN.org
 - Diagnoses-specific guides
 - EDS
 - Fibromyalgia
 - POTS
 - Symptom-specific guides



The screenshot shows the JAN Job Accommodation Network website. At the top is the JAN logo with the text "Job Accommodation Network". Below the logo is a section titled "Accommodation Ideas:". Under this title are two tabs: "By Limitation" (which is selected) and "By Work-Related Function". Below the "By Limitation" tab is a list of five categories, each preceded by a right-pointing chevron: "Lifting", "Skin Rash/Blisters/Sores", "Standing", "Toileting/Grooming Issue", and "Walking".



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TLDR

The Job Accommodations Network is a helpful resource for searching by diagnosis or by limitation to identify potentially helpful accommodations in work or school settings.

Connect



Website: OTEmily.com



Instagram: EmilyRichOT

YouTube: Oh The pOTsabilities: OT Emily



Spotify: Oh The pOTsabilities



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Thank you
for listening