



Massachusetts ME/CFS & FM ASSOCIATION

EDUCATION, SUPPORT & ADVOCACY SINCE 1985



New Jersey ME/CFS Association, Inc.

DBA New Jersey Chronic Fatigue Syndrome Association, Inc. 501(c)(3) not for profit

Maria Vera Nunez, M.D., M.S.

***A whole-person health approach to Myalgic
Encephalomyelitis/Chronic Fatigue Syndrome – Lessons
for Post-COVID conditions***



Sunday Conversations

with MassME

June 19, 2022



Housekeeping

- We respect your privacy
- Please stay muted
- Put questions/comments in the chat
- A recording of the main presentation and Q&A will be posted

We cannot answer questions related to your personal or any specific, medical condition.

The information in this presentation is for educational purposes only. Please consult with your physician or other healthcare provider in matters pertaining to your medical care.

The presenters remarks are their own opinion, and do not represent the views or opinions of Massachusetts ME/CFS & FM Association or the New Jersey ME/CFS Association.





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Featured Speaker



Dr. Maria Vera-Nunez, MD, MS

Board-certified Internal Medicine and Integrative Medicine physician, Certified Functional Medicine Practitioner, MS in Medical Informatics

Assistant Professor at NSU's Neuro-Immune Institute for 7 years

Currently: Attending physician at the Whole Psychiatry and Brain Recovery Center in Maryland; Research Assistant Professor at the Medical University of South Carolina

Founding member US ME/CFS Clinician Coalition



Also participating:

Kenneth Friedman, PhD, Host

Kailey, a person with ME



Your Host – Kenneth J. Friedman, Ph.D.

- Father of a child with ME/CFS
- Former Medical School Professor (Physiology (NJMS - UMDNJ))
- Currently Adjunct, Associate Professor of Medicine (SOM Rowan University)
- Academic interest in ME/CFS since my daughter become ill - the mid-1990's
 - Co-Author of three, ME/CFS diagnosis and treatment manuals
 - (Former) Member of the CFSAC 2004-2007 (Research, Education Subcommittees)
 - Organizer and Participant of the NIH CFS State of Knowledge Workshop 2022
 - Guest edited 3 themed, ME/CFS, medical journal issues: *Frontiers in Pediatrics/Neurology; Medicina; Healthcare*
- Current Interests:
 - Reclassifying chronic illnesses precipitated by infection – PAPIS (Post Active Phase of Infection Syndromes (Examples include ME/CFS, PASC, and chronic Lyme)
 - Developing a PAPIS Topical Collection in the journal *Healthcare*



Whole-person health

- Look at the person as a Whole
 - Clinical symptoms
 - Behavior
 - Social/environment
- Switching focus from disease to
 - Restore and promote health
 - Prevent disease

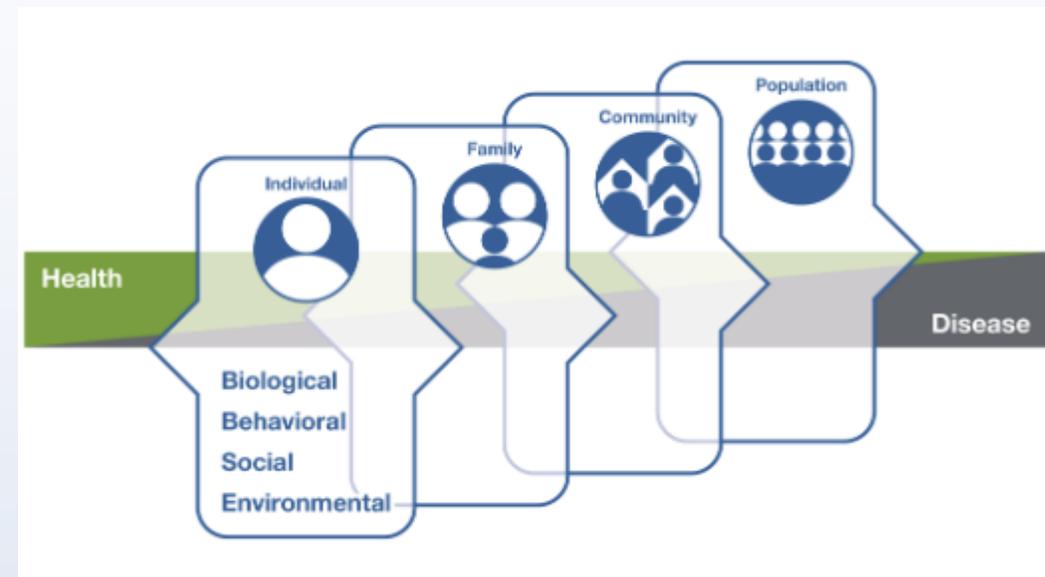
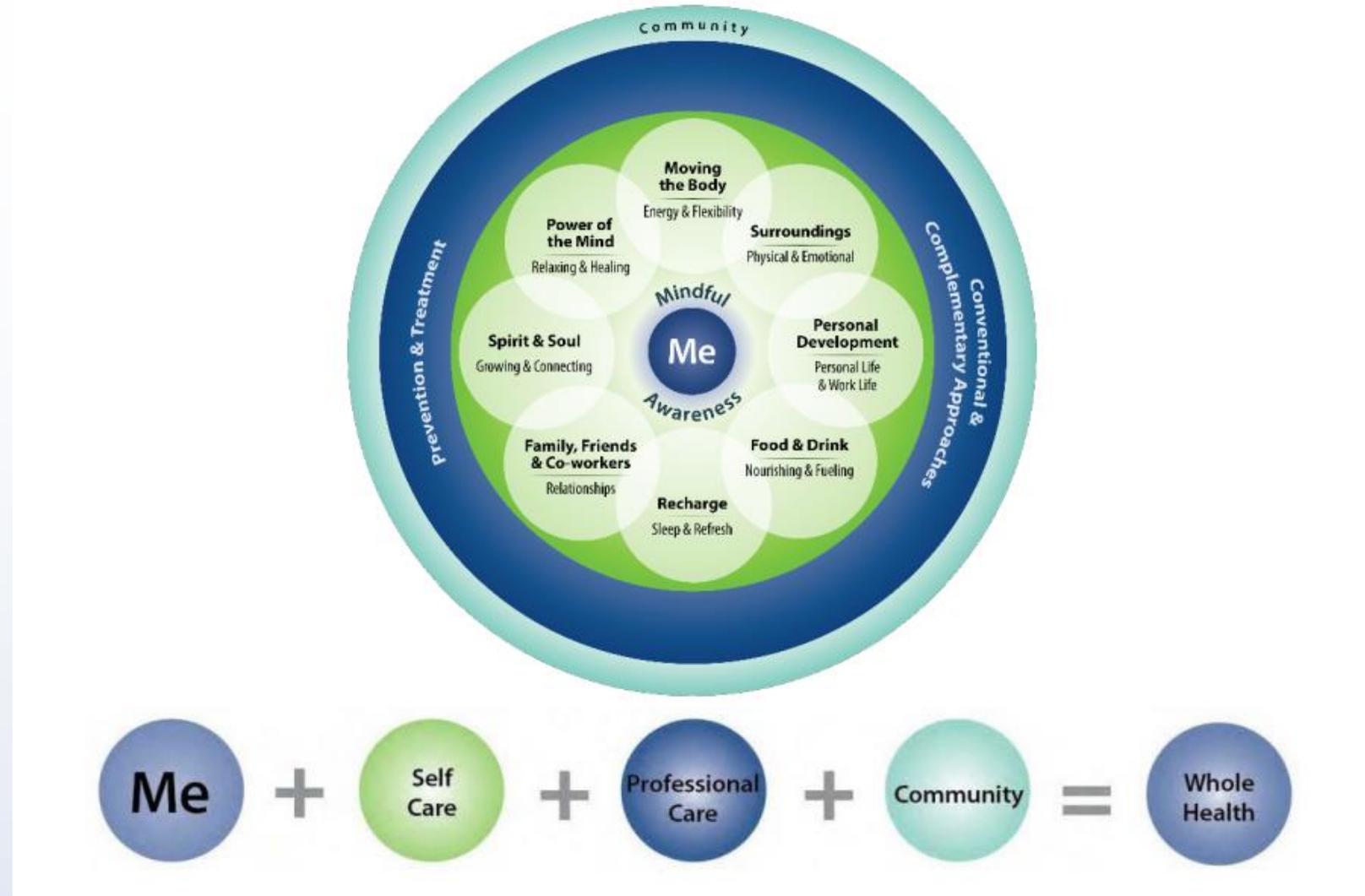


Image source: NIH website – National Institute for Complementary and Integrative Health

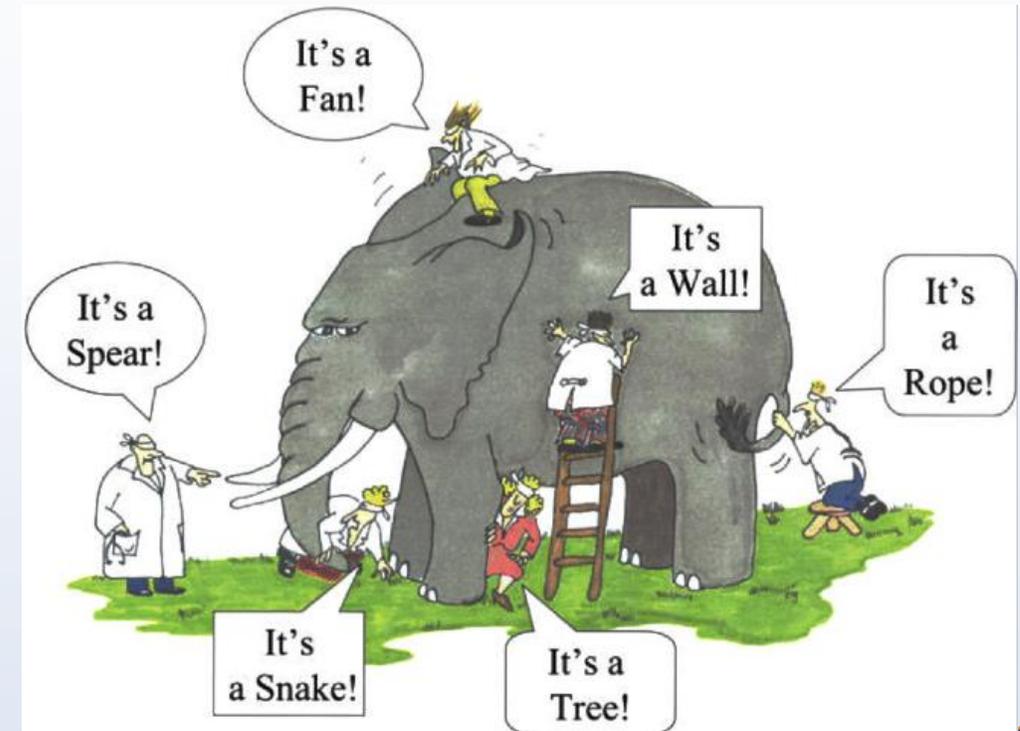
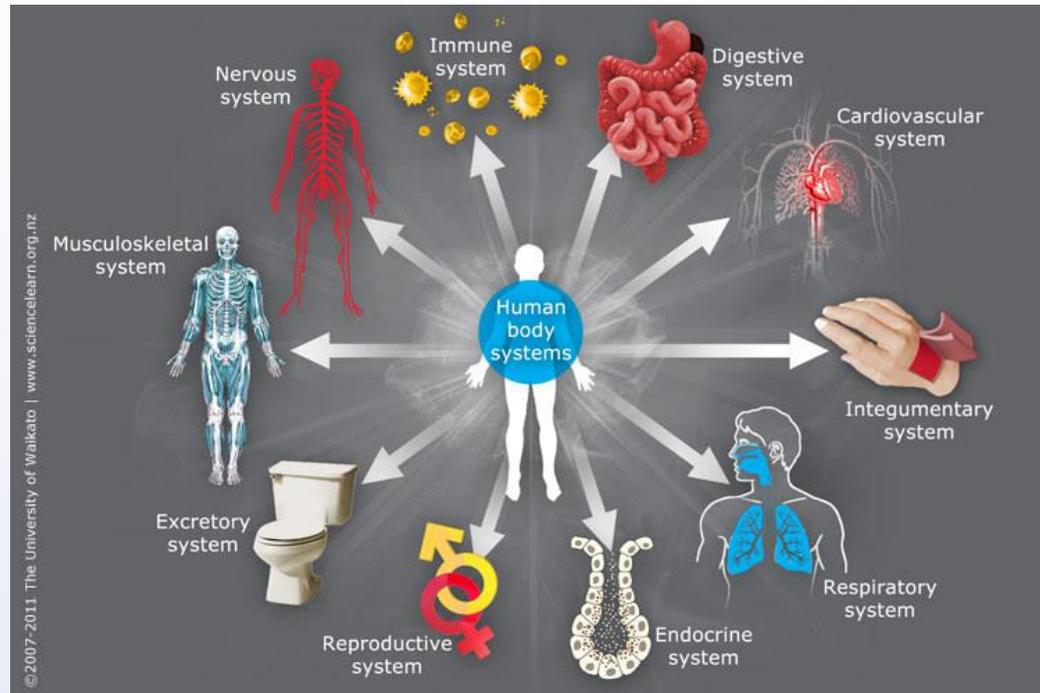
Whole health

- What is important for the patient?
- Goals of care



Source: US Department of Veterans Affairs – Whole health <https://www.va.gov/wholehealth/>

Why apply a whole person approach to ME/CFS care?



Integrative Medicine

- Patient-centric focus:
 - Health needs
 - Preferences

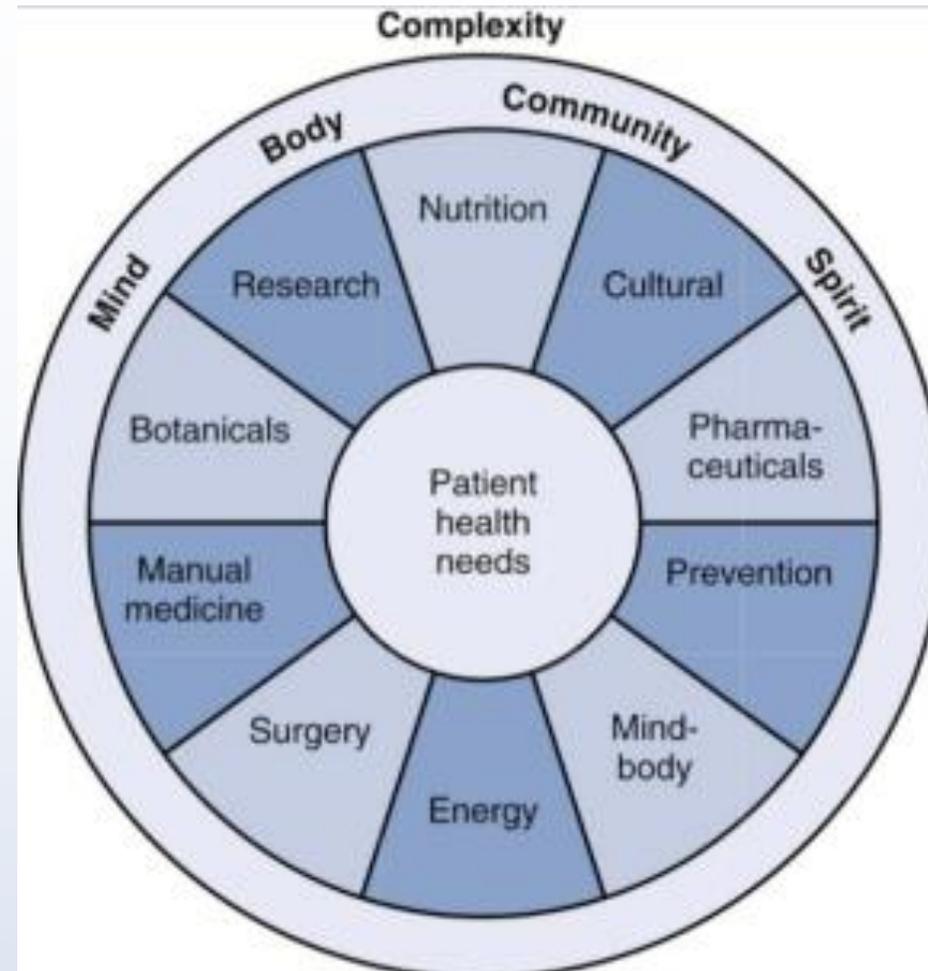
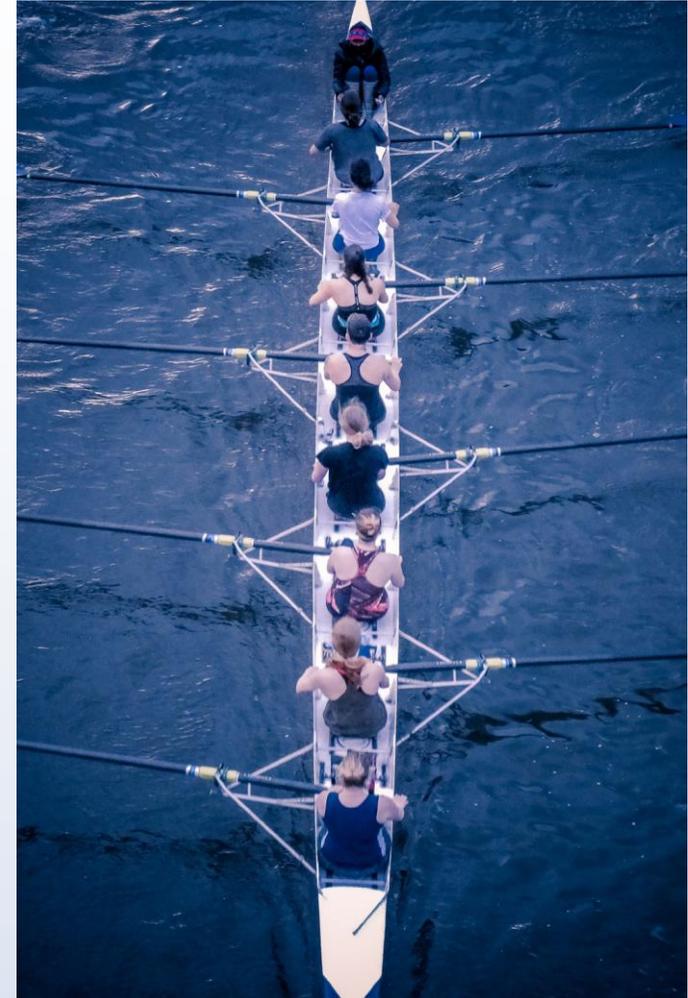


Image source: Rakel, 2018 – Integrative Medicine. Fourth Ed.

Healthcare team for ME/CFS

- Create a partnership
- Empower the patient/caregivers
- Team effort!
 - Clinical provider
 - Nutritionist
 - PT/OT
 - Psychologist
 - Acupuncturist/Massage therapist
 - Health coach



Functional Medicine

- Finding the underlying mechanism
 - Antecedents
 - Triggers
 - Mediators
- Personalized healthcare plan

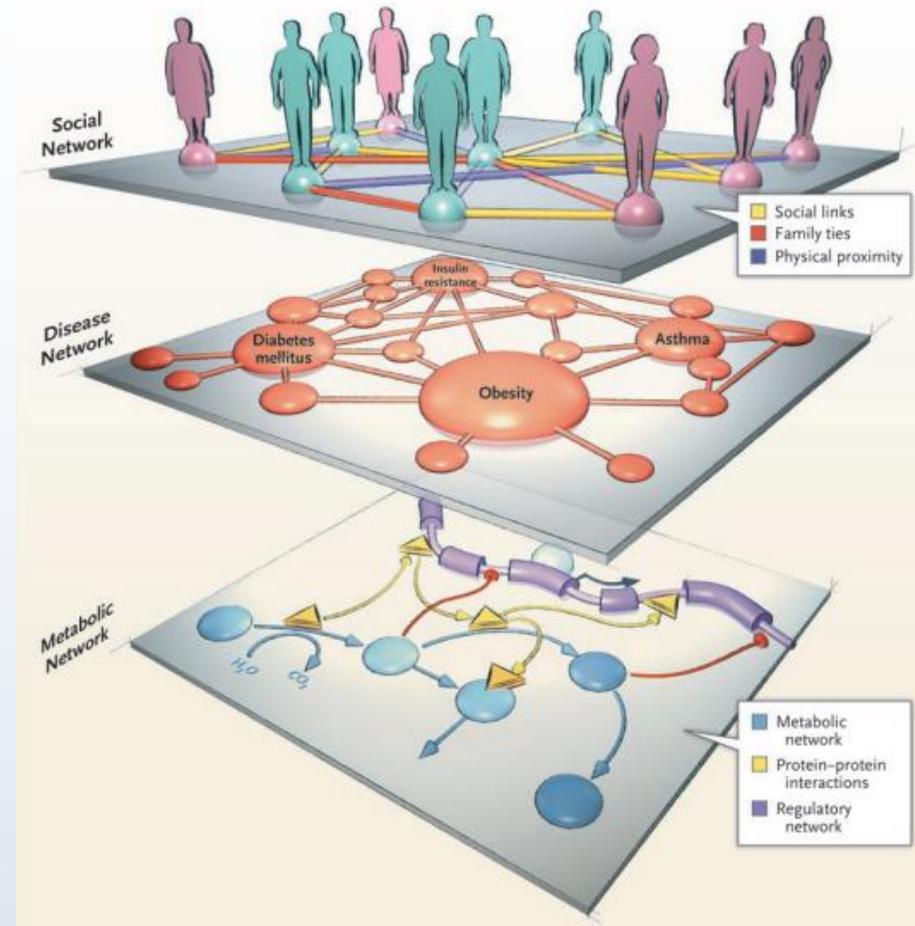


Image source: Barabasi, A. 2007. New England Journal of Medicine. 347:404-407

ME/CFS lessons that may apply to Post COVID Conditions



Foundation - Lifestyle

1. Nutrition
2. Stress management
3. Sleep
4. Activity/exercise
5. Relationships - connection



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Nutrition

Patients with ME/CFS are at risk of nutrient deficiencies:

- Long-term use of medications
- Gastrointestinal problems (reduction of beneficial bacteria or increase of potentially pathogenic bacteria, SIBO)*
- Dysautonomia (motility issues, nausea, reflux, gastroparesis, abnormal digestive enzyme release)

* Kirchgessner, The role of microbiota and potential for dietary intervention in CFS A. H. Stanton, Editor. 2016, Elsevier: London, UK.



Nutrition

Patients with ME/CFS are at risk of nutrient deficiencies: .cont

- Dental/oral problems*
- Eating disorders**
- Tube feeding *

* Rowe, P.C., et al., 2017, ME/CFS Diagnosis and Management in Young People: A Primer. Front Pediatr, 5: p. 121

** Pendergrast, T., et al., 2016, Housebound versus nonhousebound patients with ME/CFS. Chronic Illn, 12(4): p. 292-307

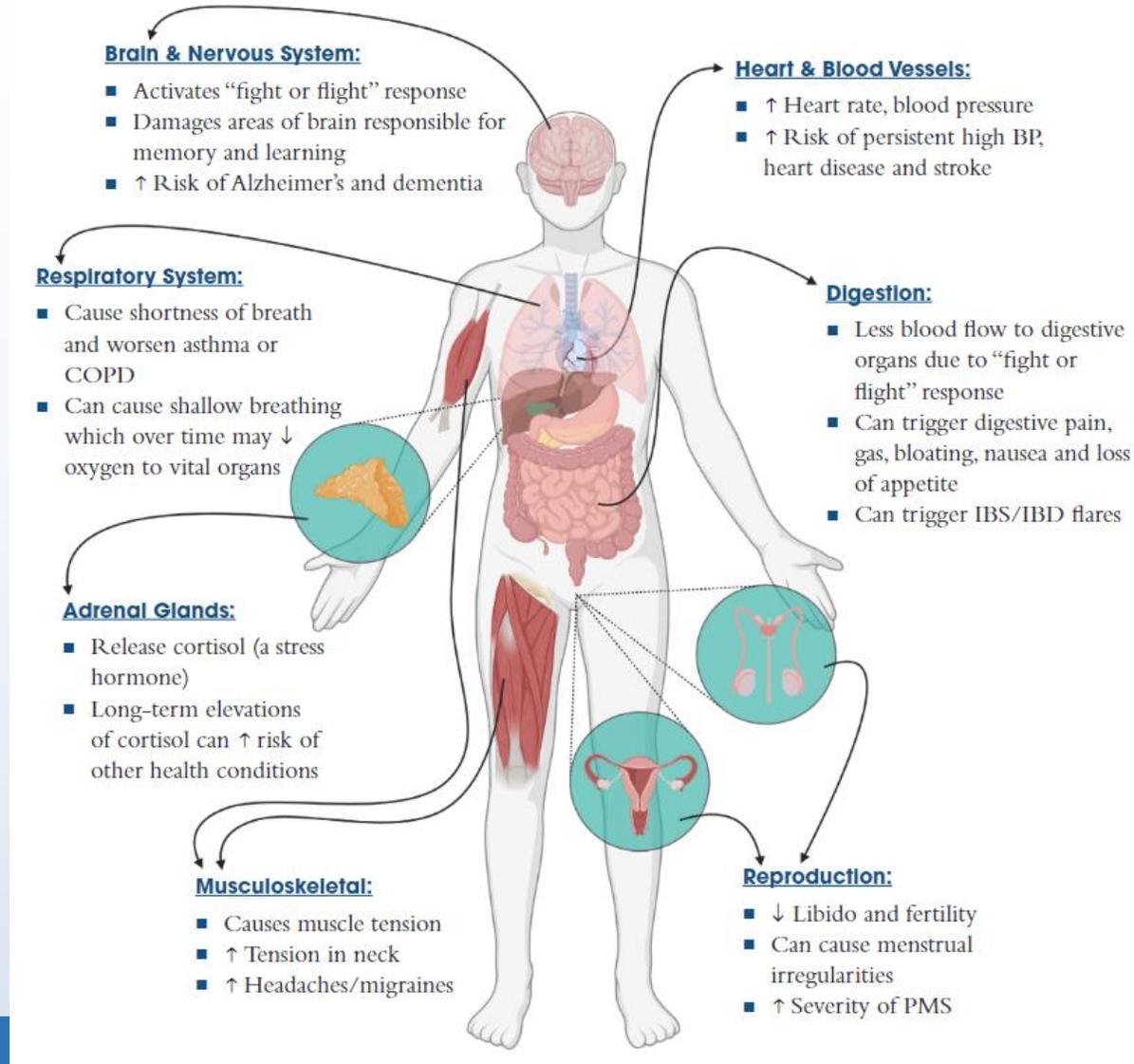


Nutrition

- Multiple nutrient deficits described in patients with ME/CFS
- Discuss with your clinical providers about checking your nutrient levels and adding or adjusting the replacement dose based on the results.

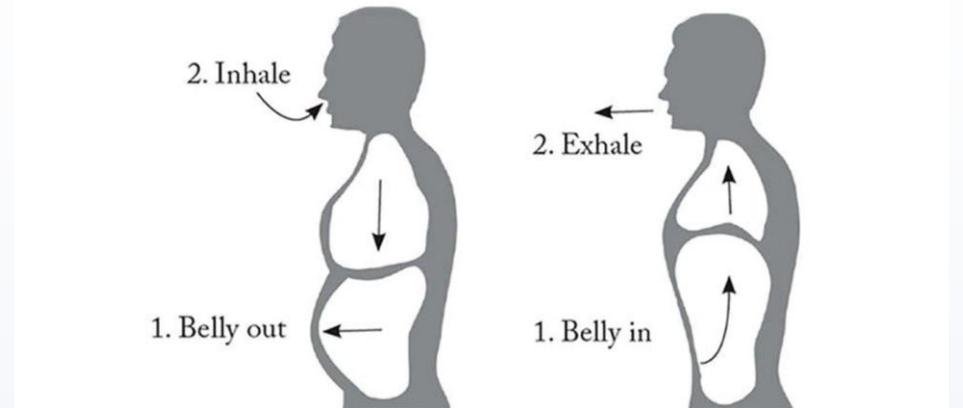


Effects of chronic stress



Stress management

- Diaphragmatic (belly) breathing
- Tai Chi, Yoga
- Mindfulness
- Cognitive Behavioral Therapy
- Guided imagery
- Biofeedback
- Gratitude



Sleep

- Sleep deprivation decreases **glymphatic system** clearance of waste in the brain.

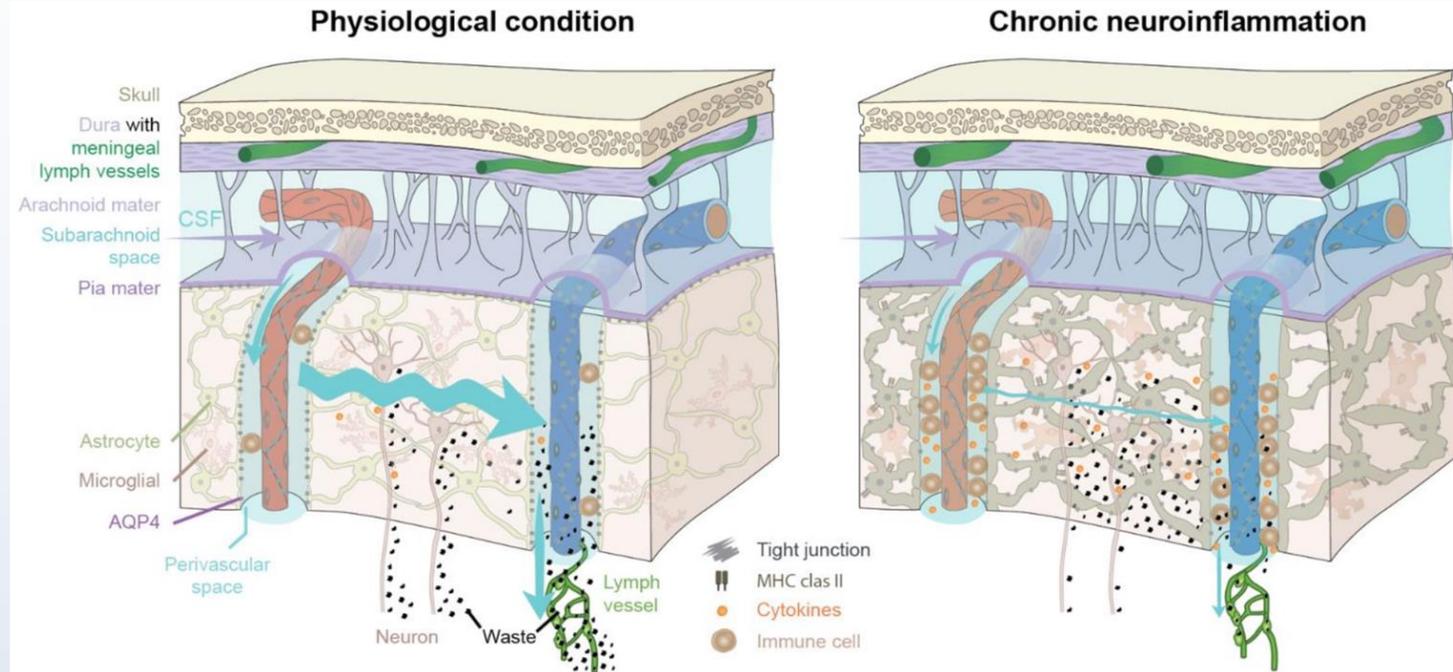


Image source: Mogensen 2021. Int J.Mol. Sci. 22(14), 7491

Sleep

- As much as possible: same sleep and wake-up time
- Avoid stimulant or anxiety-inducing activities close to bedtime
- Avoid LCD screens (laptop, TV, smartphone) or use blue-light blockers (apps, glasses)
- Dark bedroom with a comfortable temperature
- Belly breathing
- If you snore discuss with your clinician home oximetry or sleep study to evaluate for sleep apnea.



Activity/exercise

- Energy conservation
- Keep track of your activities and symptoms
- Activity trackers (steps, heart rate, heart rate variability)
- Decluttering/minimalism

- 1 Learn about your energy reserve/reservoir**
 - Your energy reserve is how much energy you have each day – this will vary so it is best to find your baseline by using an activity and symptom diary. Your “baseline” is what you can do fairly easily on a good day and only just do on a bad day.
 - You should always aim to leave some energy at the end of the exercise – don’t keep going until you feel tired.
- 2 Learn how much energy you have**
 - Your activity and symptom diary should start to show some patterns. You can now reduce or modify your activity levels so that you don’t trigger PESE or “crash”. This will help you find a level of activity you can maintain on both good and bad days, unless you have a relapse. Learn to recognise early signs of PESE and immediately initiate stop, rest, pace to avoid a crash.
- 3 Learn how to use the 4 Ps to help you plan your activities**
 - **Prioritise** what you really need to do in a day or week. Question whether all activities are necessary. Can someone else do it? Can I change the activity so it is easier for me?
 - **Plan** in your main prioritised tasks for the day. Plan in your rest time so the day is paced.
 - **Pacing** – break up your activity into smaller, more manageable tasks with rest breaks.
 - **Pleasure** – spend some energy on things you enjoy to help improve your quality of life.
- 4 Learn how to save energy**
 - Learn to say no.
 - Avoid the temptation to “do just a little more”.
 - Modify your activities to use less energy.
 - Take short cuts and ask for help.
- 5 Learn to rest between activities**
 - Rest means absolutely minimal activity and little or no mental stimulation.
 - During rests avoid activities that can be stimulating, such as TV and social media.
 - Try some meditation and/or breathing exercises instead.



Relationships - Connection

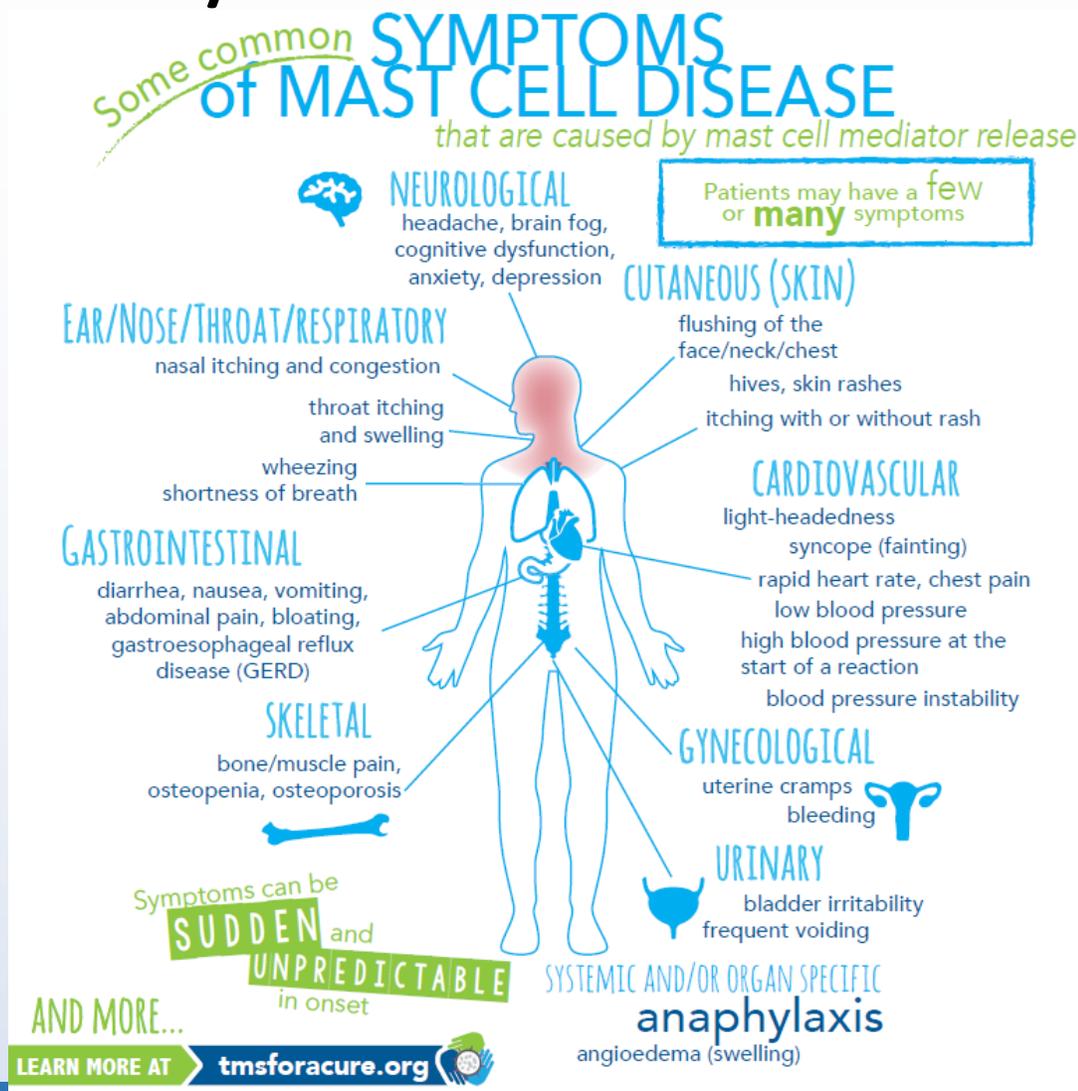
Close relationships

- Decreased risk of heart disease and stroke
- Lower risk of depression and dementia
- Pets
- Nature
 - Dr. Suzanne Simard's book – Finding the Mother Tree



Mast cell activation in ME/CFS

- Increase in mast cells in moderate and severe ME/CFS reported.*
- MCAS may present with symptoms in multiple body systems.



*Nguyen, 2017. Asian Pac J Allergy Immunol. 35(2):75-81



Mast cell activation Post COVID

- Hyperinflammation “cytokine storm” response may be rooted in an abnormal Mast cell response.*
- Observation: Medications with activity on mast cells and mediators have been helpful in Post COVID-19 illness. *

* Afrin, L. 2020. COVID-19 hyperinflammation and post COVID 19 illness may be rooted in MCAS. International Journal of Infectious Diseases 100: 327-332



Mast cell activation Evaluation

- Try to identify triggers.
- Avoid rich histamine foods.
- Discuss with your clinician to complete tests for MCAS

MAST CELL DISEASE COMMON TRIGGERS
These generalized triggers are common, but each patient has their own specific sensitivities.
not just a picnic in the park

Reactions are often **disabling and dangerous.**

Stress Physical, emotional and environmental stress are all major triggers, as is fatigue. Unpredictable symptoms can make living with mast cell disease very challenging!

Medication Get a headache? Careful! Certain medications can be triggering.

Insect Stings & Bites

Specific Foods

Alcohol

Odors

Exercise Even modest exercise can be triggering for some.

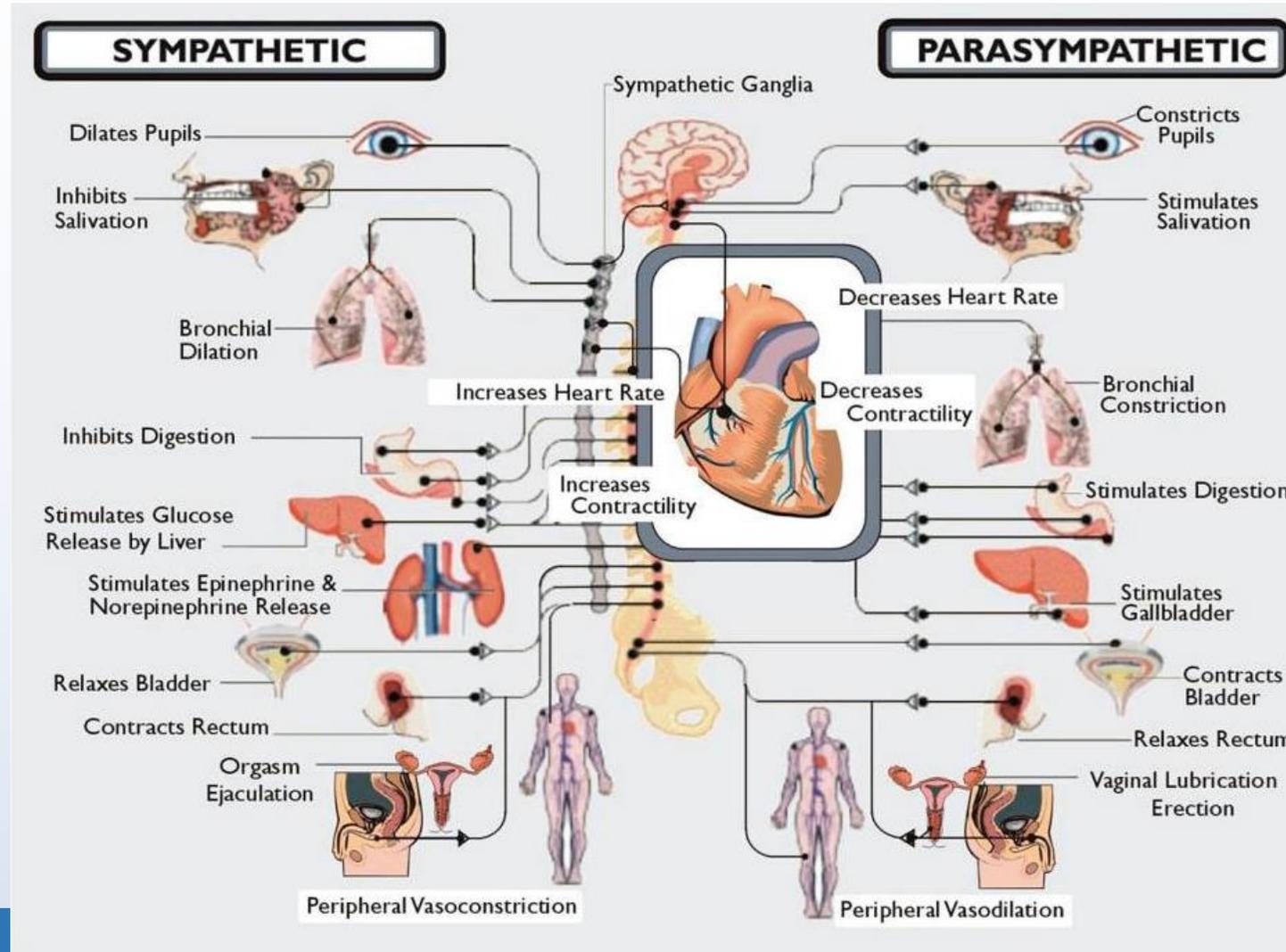
HOT OR COLD Temperatures

And more! Patients can react to a wide range of triggers!

LEARN MORE AT tmsforacure.org

† Jennings S, et al. J Allergy Clin Immunol Pract. 2014;2(1):70-6.

Autonomic Dysfunction



Autonomic dysfunction in ME/CFS

- Small fiber neuropathy*
- Abnormal cardiac filling during exercise **
- Reduced cerebral blood flow ***

* Shoenfeld, Y., et al., 2020, Complex syndromes of chronic pain, fatigue and cognitive impairment linked to autoimmune dysautonomia and small fiber neuropathy. Clin Immunol, 214: p. 108384

** Joseph, P., et al., 2021, Insights from Invasive Cardiopulmonary Exercise Testing of Patients with ME/CFS . Chest. 160(2):642-651

van Campen, C., et al., 2020, Cerebral blood flow is reduced in ME/CFS during head-up tilt testing even in the absence of hypotension or tachycardia: A quantitative, controlled study using Doppler echography. Clin Neurophysiol Pract, 5: p. 50-58



Autonomic dysfunction Post COVID

- Persistent intolerance to exercise and
- Abnormal cardiopulmonary exercise testing*

- Tilt table test reproduced Long COVID symptoms
- Decreased cerebral flow
- Small fiber neuropathy**

* Singh, I., et al., Persistent Exertional Intolerance After COVID-19: Insights From Invasive Cardiopulmonary Exercise Testing. Chest, 2022. 161(1): p. 54-63.

** Novak, P., et al., Multisystem Involvement in Post-Acute Sequelae of Coronavirus Disease 19. Ann Neurol, 2021



Autonomic dysfunction evaluation

- Passive standing test*
- Cardiology evaluation
- Tilt-table test



- Neurology evaluation
- Skin biopsy for small fiber neuropathy**

* Bateman Horne Center – NASA 10-minute Lean test <https://batemanhornecenter.org/nasa-10-minute-lean-test-2/>

** Neuropathy Commons website. Getting a Diagnostic Skin Biopsy. Available from: <https://neuropathycommons.org/get-tested/skin-biopsy>.







***Please join us for a special program
Sunday, August 21, 2022, 4 p.m. EDT***

To join the Sunday Conversations team: volunteer@massmecfs.org



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Thank you!

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