ME/CFS Clinical Diagnostic Criteria Worksheet - Page 1

Name _____ **Date**_____

☐ 1. **Fatigue:** Patient must have a significant degree of new onset, unexplained, persistent or recurrent physical and mental fatigue that substantially reduces activity level.

☐ 2. **Post-Exertional Malaise and Fatigue:** There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional fatigue and/or malaise and/or pain and a tendency for other associated symptoms within the patient's cluster to worsen. There is a pathological slow recovery period – usually 24 hours or longer.

☐ 3. **Sleep Dysfunction:*** There is unrefreshed sleep or sleep quantity or rhythm disturbance such as reversed or chaotic diurnal sleep rhythm.

☐ 4. **Pain:** * There is a significant degree of myalgia. Pain can be experienced in the muscles and joints and is often migratory in nature. Often there are significant headaches of new type, pattern or severity.

☐ 5. **Neurological/Cognitive Manifestations:** Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances-e.g., spatial instability, and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory-e.g., photophobia and hypersensitivity to noise-and/or emotional overload, which may lead to "crash"[1] periods and/or anxiety.

☐ **6. At Least One Symptom from Two of the Following Categories:**

☐ **Autonomic Manifestations:** orthostatic intolerance-NMH, POTS, delayed postural hypotension, vertigo; light-headedness, extreme pallor; nausea and IBS; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmia; palpitations, and exertional dyspnea.

☐ **Neuroendocrine Manifestations:** loss of thermostatic stability-subnormal body temperature and/or marked diurnal fluctuation, sweating episodes, recurrent feeling of feverishness and cold extremities; intolerance to heat and cold; marked weight change-anorexia or abnormal appetite; loss of adaptability and tolerance for stress, worsening of symptoms with stress and a slow recovery.

☐ **Immune Manifestations:** tender lymph nodes, recurrent sore throat and flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

☐ 7. **The illness persists for at least six months in adults.** It usually has a distinct onset,**although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

1. "Crash" refers to a temporary period of immobilizing physical and/or mental fatigue.

* A small number of patients have no pain or sleep dysfunction but no other diagnosis fits except ME/CFS. The diagnosis is ME/CFS if these patients have an infectious illness type of onset.

Exclusions: Rule out active disease processes that explain the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction with patient history, physical exam laboratory testing or imaging. These include: Addison's disease, Cushing's syndrome, hypothyroidism, hyperthyroidism, iron deficiency, iron overload syndrome, other treatable forms of anemia, diabetes mellitus, cancer, treatable sleep disorders including upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyosistis, and polymyalgia rheumatica; neurological disorders such as MS, Parkinson's disease, myasthenia gravis and B12 deficiency; infectious diseases such as TB, chronic hepatitis, Lyme disease, AIDS; primary psychiatric disorders and substance abuse. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if the patient meets the criteria otherwise.

Co-Morbid Entities: Fibromyalgia syndrome, myofascial pain syndrome, temporomandibular joint syndrome, irritable bowel syndrome, interstitial cystitis, irritable bladder syndrome, Raynaud's phenomenon, prolapsed mitral valve, migraine, allergies, multiple chemical sensitivities, thyroiditis, sicca syndrome, depression, Hashimoto's, etc. Such co-morbid entities may occur in the setting of ME/CFS. Others such as IBS may precede the development of ME/CFS by many years, but then become associated with it. The same holds true for migraines and depression. Their association is thus looser than between the symptoms within the syndrome. ME/CFS and FMS often closely connect and should be considered to be "overlap syndromes".

Idiopathic Chronic Fatigue: If the patient has unexplained prolonged fatigue but has insufficient symptoms to meet the criteria for ME/CFS, it should be classified as idiopathic chronic fatigue.

_____ Patient meets the criteria for ME/CFS

_____ Patient meets the criteria for Idiopathic Chronic Fatigue

Reference: Carruthers, Bruce, et. al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome 2003; Vol. 11(1): 7-115.

_____ _____

Physician's Signature **Date**

Physician's Stamp:

Bateman Horne Center

RESEARCH | CLINICAL CARE | EDUCATION

NASA 10 Minute Lean Test | Instructions for Providers

Orthostatic intolerance (OI) is an umbrella term used to describe abnormal autonomic nervous system response to orthostatic challenge. Orthostatic hypotension (OH), neurally mediated hypotension (NMH) [or neurogenic hypotension] and postural orthostatic tachycardia syndrome (PoTS) are terms used to describe variants of this response. The new evidence-based IOM clinical criteria for ME/CFS establish that orthostatic intolerance is a common and often overlooked feature of illness that is objectively measurable. OI may contribute to dizziness, fatigue, cognitive dysfunction, chest and abdominal discomfort, and pain manifestations.

We recommend that all ME/CFS and Fibromyalgia patients have a NASA 10-minute Lean Test to assess for orthostatic intolerance.

The test will be most revealing if measures that reduce orthostatic intolerance are withheld before testing. For example: limit extra fluid and sodium intake, do not wear compression socks, and alter the intake of medications that might influence the test (see below). These treatments can be resumed after the test. Use continuous monitoring devices when possible.

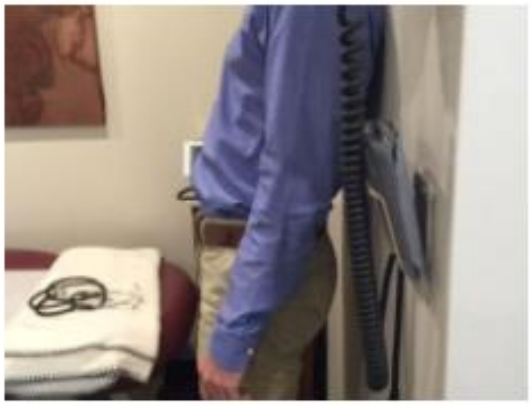
Ask the patient to remove shoes and socks and lie down on a bed or exam table in supine position. After patient has been lying quietly 5-10 minutes, record blood pressure and pulse. Repeat a minute later. If repeat vitals are not similar, retake until two consecutive vital readings are relatively consistent. The goal is to determine the average resting supine blood pressure and pulse.

Next, ask the patient to arise and stand straight while leaning against the wall; only their shoulder blades should contact the wall, their heels should be approximately 6" from the wall. Coach patient to relax as much as possible. Once the patient is leaning against the wall, start the timer and record the first standing blood pressure and pulse. Repeat blood pressure and pulse measurements every minute for the next 10 minutes. Instruct patient not to talk and chat, except to report symptoms, and to resist moving feet or shifting weight. Observe patient for lightheadedness or signs of pre-syncope and stop the test if the patient is about to faint. Observe skin and extremities for swelling or changes in color and temperature. Assess cognition. Include any comments/patient symptoms as applicable. A template that can be used to record blood pressure and pulse follows on page 2.

General test preparation instructions, directed by provider, adjusted as appropriate for each patient.

- Limit water/fluid intake to 1000 mL for 24 hours before the test
- Limit sodium intake for 48 hours before the test
- Do not wear compression socks or clothing on the day of the test
- Withhold medications, supplements, or substances that might affect blood pressure or heart rate, with timing based on the drug half-life and patient safety.

- Examples:
  - midodrine or Northera
  - fludrocortisone
  - beta blockers such as propranolol, metoprolol or atenolol
  - stimulants such as methylphenidate, dexadrine or caffeine
  - tricyclic antidepressants (TCA)-- amitriptyline, doxepin or cyclobenzaprine
  - SNRI's such as Cymbalta or duloxetine
  - tricyclic antidepressants (TCA)-- amitriptyline, doxepin or cyclobenzaprine



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Orthostatic Vital Signs/The NASA 10-minute Lean Test

	Blood Pressure (BP)		Pulse	Comments
	Systolic	Diastolic		
Supine 1 minute				
Supine 2 minute				
Standing 0 minute				
Standing 1 minute				
Standing 2 minute				
Standing 3 minute				
Standing 4 minute				
Standing 5 minute				
Standing 6 minute				
Standing 7 minute				
Standing 8 minute				
Standing 9 minute				
Standing 10 minute				

*The NASA 10-minute Lean Test is a variant of a test used by NASA researchers to test for orthostatic intolerance[1]; it reduces muscular influences on venous return, a major cause of variability in orthostatic testing. Passive stand testing has been validated as an equivalent or superior measure of orthostatic intolerance as compared to head-up Tilt Table tests[2,3].

[1] Bungo, M. W., Charles, J. B., & Johnson Jr, P. C. (1985). Cardiovascular deconditioning during space flight and the use of saline as a countermeasure to orthostatic intolerance. *Aviation, space, and environmental medicine*, 56(10), 985-990.

[2] Shvartz, E., Meroz, A., Magazanik, A., Shoenfeld, Y., & Shapiro, Y. (1977). Exercise and heat orthostatism and the effect of heat acclimation and physical fitness. *Aviation, Space, and Environmental Medicine*, 48(9), 836-842.

[3] Hyatt, K. H., Jacobson, L. B., & Schneider, V. S. (1975). Comparison of 70 degrees tilt, LBNP, and passive standing as measures of orthostatic tolerance. *Aviation, Space, and Environmental Medicine*, 46(6), 801-808.

Bateman Horne Center

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About the Bateman Horne Center

Our Mission:

Empowering Patients, Advancing Research, and Improving Clinical Care for all those impacted by ME/CFS and Fibromyalgia

Formerly the Fatigue Consultation Clinic (FCC) and the Organization for Fatigue & Fibromyalgia Education & Research (OFFER), the Bateman Horne Center of Excellence (BHC), was formed in 2015 as a 501(c)3 nonprofit organization.

We envision a world where patients with ME/CFS and Fibromyalgia are readily diagnosed, effectively treated, and widely met with empathy and understanding. BHC is led by Dr. Lucinda Bateman and Suzanne D. Vernon, Ph.D., who bring more than 40 years of combined experience and leadership to treating patients and advancing research in the areas of ME/CFS and Fibromyalgia.

Lucinda Bateman, MD | Founder & Chief Medical Officer

Dr. Lucinda Bateman completed her BS and MS at Brigham Young University (BYU), attended the Johns Hopkins School of Medicine, returned to the University of Utah for Internal Medicine residency, and became certified by the American Board of Internal Medicine in 1991. She started a small private group practice in 1991 and practiced General Internal Medicine until 2000.

During this time, she proctored many students as Adjunct Volunteer Clinical Faculty for the University of Utah, including nurse practitioners, physician assistants (PA), medical students and residents, and was active on the staff at LDS Hospital. She was awarded Teacher of the Year four times while teaching in the Utah PA (Physician's Assistant) program. In 2000, she was one of three Utah internists chosen by her peers in Top Doctors, a national publication.

Throughout her career, Dr. Bateman's interest has become more focused on the diagnosis and management of unexplained chronic fatigue, ME/CFS and FM, inspired by the silent suffering of her sister, Shauna Bateman Horne.

Since starting the Fatigue Consultation Clinic in 2000, Dr. Bateman has evaluated and followed more than a thousand patients with chronic fatigue conditions. She has lectured extensively on issues relating to chronic fatigue syndrome and fibromyalgia. She has served on the boards of the Easter Seals of Utah, The International Association of Chronic Fatigue Syndrome (IACFS/ME) and The CFIDS Association of America. She co-founded the non-profit, OFFER (The Organization for Fatigue and Fibromyalgia Education and Research) to encourage the sharing of information with patients and medical providers and foster cooperative research efforts aimed at understanding the cause(s) of and developing treatments for ME/CFS and FM. This goal led to the recent merge of OFFER Utah and the Fatigue Consultation Clinic to the Bateman Horne Center.

To see Dr. Bateman's bibliography of published journal articles, visit:
http://www.ncbi.nlm.nih.gov/myncbi/collections/bibliography/46470176/?reload=publicURL

DSQ PEM Questionnaire

Cotler, J., Holtzman, C., Dudun, C., & Jason, L. A. (2018). A brief questionnaire to assess Post-Exertional malaise. Diagnostics, 8(3), 66. https://doi.org/10.3390/diagnostics8030066

Appendix A

For each symptom below, please circle one number for frequency and one number for severity: Please complete the chart from left to right.

Symptoms	Frequency: Throughout the **past 6 months**, **how often** have you had this symptom? For each symptom listed below, circle a number from: **0 = none of the time** **1 = a little of the time** **2 = about half the time** **3 = most of the time** **4 = all of the time**					Severity: Throughout the **past 6 months**, **how much** has this symptom bothered you? For each symptom listed below, circle a number from: **0 = symptom not present** **1 = mild** **2 = moderate** **3 = severe** **4= very severe**				
1. Dead, heavy feeling after starting to exercise	0	1	2	3	4	0	1	2	3	4
2. Next day soreness or fatigue after non-strenuous, everyday activities	0	1	2	3	4	0	1	2	3	4
3. Mentally tired after the slightest effort	0	1	2	3	4	0	1	2	3	4
4. Minimum exercise makes you physically tired	0	1	2	3	4	0	1	2	3	4
5. Physically drained or sick after mild activity	0	1	2	3	4	0	1	2	3	4

For each question below, choose the answer which best describes your PEM symptoms.

6. If you were to become exhausted after actively participating in extracurricular activities, sports, or outings with friends, would you recover within an hour or two after the activity ended?	Yes				No	
7. Do you experience a worsening of your **fatigue/energy related illness** after engaging in minimal physical effort?	Yes				No	
8. Do you experience a worsening of your **fatigue/energy related illness** after engaging in mental effort?	Yes				No	
9. If you feel worse after activities, how long does this last?	≤1 h	2–3 h	4–10 h	11–13 h	14–23 h	≥ 24 h
10. If you do not exercise, is it because exercise makes your symptoms worse?	Yes				No	

Appendix B

DSQ-PEM Scoring

Scoring Step 1

Items 1–5: A frequency and severity score of 2, 2 on any items 1–5 is indicative of PEM.

Scoring Step 2

Items 7, 8: Either item 7 or 8 must have an answer of yes to indicate an ME and/or CFS dx.

Item 9: A response of >14 h is needed to indicate an ME and/or CFS dx.

Items 6, 10: Neither item indicates an ME and/or CFS diagnosis, but provides a description of patient PEM for clinical evaluations.

INESSS
LE SAVOIR PREND FORME

April 2023

AIDE-MÉMOIRE

SUPPORT FOR PEOPLE WITH MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME (ME / CFS)

Click on the underlined words for more details, and on tabs to navigate

This aide-mémoire is intended for health and social services professionals who work with people with myalgic encephalomyelitis / chronic fatigue syndrome. It has indicative purposes and does not replace the judgment of the clinician. This document was developed based on a systematic review of clinical practice guidelines and the experience of Québec stakeholders who contributed to its development. For more information, visit the Publications section of inesss.qc.ca bsite.

GENERAL INFORMATION

- ME / CFS is a chronic and complex condition for which there is no known treatment.
- The clinical presentation is variable and functional independence may be affected to different degrees - e.g., the person could:
  - be able to perform activities of daily living (ADLs - e.g., feeding, dressing, hygiene) and instrumental activities of daily living (IADLs - e.g., cleaning, meal preparation, shopping), but require accommodations to study or work;
  - requiring assistance with ADLs and IADLs and being unable to study or work;
  - depend on others for ADLs and unable to perform IADLs, study or work.
- Management central component is energy management. It allows to:
  - respect the energy envelope;
  - limit the occurrence of post-exertional malaise and asthenia;
  - stabilize health status and help prevent its deterioration;
  - promote an improved quality of life.

Energy management requires adaptation of clinical practice.

All interactions and interventions must be made with consideration for the energy envelope.	**The person should not be encouraged** to exceed personal limits or engage in activities to increase strength or endurance.
The therapeutic approach must be flexible and personalized.	Physical or cognitive activity/exercise programs or interventions with fixed or continuously increasing duration and intensity parameters **should not be implemented.**

Good to know

- **Asthenia** is an intense fatigue that results in a significant reduction in the ability to perform ADLs and IADLs.
- **Post-exertional malaise** refers to the appearance or aggravation of a group of clinical manifestations that occur following even minimal effort, whether physical, cognitive or emotional.

SUMMARY

Québec

POST-EXERTIONAL MALAISE

CLINICAL MANIFESTATIONS AND EVOLUTION

→ Post-exertional clinical manifestations may affect various systems.

→ The nature and severity of clinical manifestations as well as the evolution of post-exertional malaise may vary according to the type of activities performed, from one episode to another and from one person to another.

CLINICAL MANIFESTATIONS THAT CAN BE OBSERVED DURING POST-EXERTIONAL MALAISE		
Category	**Examples[1] – *non exhaustive list***	
Cardiorespiratory	• Arrythmia • Chest pain • Dyspnea	• Hypotension • Palpitations • Syncope
Cognitive	• Difficulty thinking clearly • Difficulty finding words	• Memory loss • Reduction of attention
Diverse	• Intense fatigue • Flu-like symptoms (e.g., sore throat, painful lymph nodes, fever)	• Non-restorative sleep • Sensation of discomfort when sitting or standing
Musculoskeletal	• Arthralgia • Muscle weakness	• Myalgia
Neurological	• Blurred vision • Difficulty in articulating, pronouncing, expressing oneself • Dizziness or vertigo • Headache • Increased sensitivity to stimuli (e.g., light, sound, touch)	• Neuropathic pain • Paresthesia • Sensation of internal tremors, generally not perceptible from the outside and affecting the lower limbs

1. The information is presented in alphabetical order. Some clinical manifestations may belong to more than one category, but have been placed in only one category.

DISTINGUISHING FROM DECONDITIONING

Characteristics	Deconditioning	Post-exertional malaise
Clinical presentation	• Exercise intolerance. • Reduced ability to perform physical or cognitive activity at the usual frequency, intensity and duration for age, size, gender, muscle mass and cardiovascular capacity.	• Onset or exacerbation of clinical manifestations following previously unproblematic or low-intensity activities. • Intensity of clinical manifestations disproportionate to the activity that caused them (e.g., having to rest after sedentary work). • Onset of clinical manifestations not usually found after exertion in other individuals (e.g., sore throat, difficulty thinking).
Symptoms onset	• During or soon after a physical or cognitive activity.	• Typically a few hours to 72 hours[1] after a physical, cognitive or emotional effort.
Recovery	• Clinical manifestations: - fade with rest or sleep; - usually lasts less than a day.	• Clinical manifestations: - do not go away or only slightly with rest or sleep; - can last for days, weeks or months.

1. Clinical manifestations may occur more rapidly in some people, including those with more severe disease, but scientific evidence is limited.

POST-EXERTIONAL MALAISE ASSESSMENT

- Post-exertional malaise can be evidenced by:
  - questions about what happens after performing activities;
  - documentation of activities and clinical manifestations (type, intensity, frequency and duration) over a one or two week period.
- Identifying post-exertional malaise can be difficult, given:
  - the difficulty in describing them;
  - they may go unnoticed and persist;
  - they may interact with other symptoms.
- Cumulative post-exertional malaise that is not fully recovered may complicate the assessment of post-exertional malaise.
- Smartwatches can help assess activity levels. However, their use has not been scientifically validated.

Examples of questions identifying post-exertional malaise

- What happens when you do or try to do a physical or cognitive activity? What happens afterwards?
- What happens if you try to exceed your limits? What are the consequences?
- Do you avoid or modify any activities because of what might happen if you do them? If so, which ones?
- What activities are you able to do without clinical manifestations? How many activities do you manage to do in a day?
- How long does it take from the time you do an activity to the time you start to feel unwell?
- How long does it take you to recover from an activity?

CHARACTERIZATION OF POST-EXERTIONAL MALAISE AND FOLLOW-UP OF THEIR EVOLUTION

- The characterization of post-exertional malaise is used to monitor its evolution and to assess the effect of interventions and energy management strategies.

Category	Examples of elements that could be documented
Post-exertional malaise onset	• Effect of the following factors on clinical manifestations and energy level: - introduction of activity or increase in its intensity; - presence of sensory stimuli; - proximity to allergens; - change in temperature; - stationary vertical position (sitting or standing). • Type of activity or exertion that triggers the onset or worsening of clinical manifestations, including their intensity.
Post-exertional malaise episode	• Time to onset or worsening of clinical manifestations. • Clinical manifestations that appear or worsen. • Duration of post-exertional malaise / recovery time. • Impact on level of independence and performance in performing ADLs, IADLs, and studies and work (e.g., postponing or avoiding an activity, absenteeism).
Avoidance of post-exertional malaise	• Strategies used to complete activities or continue with studies or work. • Activities that the person is able to perform without post-exertional malaise. • Treatments or activities that limit post-exertional malaise.

Good to know

- **Keeping an activity log is useful for monitoring**, but can be a significant effort and more difficult for people with a low threshold for post-exertional malaise. Therefore, the activity log could be kept for short periods or intermittently.
- Some individuals may prioritize studies or work at the expense of ADLs, IADLs, and leisure time, and then subsequently collapse and present difficulties in other aspects of their lives (e.g., managing family life).

ENERGY MANAGEMENT

ENERGY ENVELOPE AND POST-EXERTIONAL MALAISE ONSET

- The energy envelope is the amount of energy available to carry out activities. Its size is specific to each person. However, it can vary from day to day and be modulated by various factors, including health status.
- In general, performing ADLs, IADLs, social or leisure activities, and studying or working will result in energy expenditure, while sleep, rest and eating will result in energy gain.
- People with post-exertional malaise have a smaller than average energy envelope and generally use more energy to perform their activities.
- The accumulation of activities performed and energy consuming factors result in the expenditure of available energy. The point at which the available energy is fully expended is the threshold for post-exertional malaise.

FACTORS THAT CAN AFFECT THE AMOUNT OF ENERGY AVAILABLE IN ME / CFS	
Energy expenditure	**Energy gain**

• Other acute illness (e. g., cold)
• Non stabilized comorbidity
• Environmental factors (e. g., proximity of allergens, change of temperature or season changeover)
• Performing activities that require an effort[1]:
  - **physical:** brushing teeth, dressing, showering, drying hair, walking, climbing stairs, doing laundry, etc.;
  - **cognitive:** listening to music, watching television, reading, writing, working on the computer, driving, etc.;
  - **emotional:** interactions with others, bereavements (e.g., difficulty returning to previous activities or to work or school), stressful events (e.g., insurance claims, arguments, or illness of a loved one), happy events (e.g., holiday, birth), etc.;
• Sensory stimuli (e.g., sound, light, touch)
• If presence of autonomic-like clinical manifestations:
  - Postprandial state[2]
  - Upright position (sitting or standing) - worse if stationary
	• Food intake
	• Rest
	• Sleep
	• If presence of autonomic-like clinical manifestations:
	  - Autonomic nervous system regulation strategies (e.g., lying down)

1. Some activities may require more than one type of effort, but they are placed in one location.

2. The state resulting from the ingestion and digestion of a meal.

Good to know

- The amount of energy required to perform an activity varies depending on the type of activity, its duration, intensity, environment, energy level in the bank, attitude at the time of doing the activity, or the way the activity is performed.
- A warning symptom may occur when some of the available energy is spent (e.g., headache, sore throat, increased sensitivity to stimuli, difficulty speaking, palpitations or irritability).
  - The warning symptoms are similar to the clinical manifestations of post-exertional malaise and share the same variability.
  - Rest before or at the onset of the warning symptom may decrease the amount of rest required and prevent the occurrence of post-exertional malaise.

ENERGY MANAGEMENT STRATEGIES

→ **Energy management strategies are day-to-day measures that allow for as many activities as possible without exceeding the energy envelope.**

Energy management strategy	Facilitators
Adapting activities: • modify environments and activities to make them easier to complete; • breaking down large tasks into smaller ones. **Modulating the rhythm of activity and rest periods:** • determine the physical, cognitive and emotional effort thresholds that trigger post-exertional malaise; • adjust the intensity of activities and plan alternating periods of activity and rest so as not to exceed the effort thresholds found. **Planning the activities:** • spread activities over days or weeks; • perform energy-intensive activities during the periods when energy is highest; • set aside time for energizing activities within the energy envelope (e.g., hobbies, sitting outside, any activity that brings pleasure and satisfaction). **Prioritizing activities:** • prioritize activities; • conserve energy for meaningful activities; • recognize and limit energy-consuming activities.	• Plan rest periods first and activities later. • Plan break and rest periods each day. • Leave time for the unexpected. • Alternate tasks (e.g., easy vs. difficult, physical vs. cognitive). • Stop an activity before you are very tired, before a warning symptom appears or as soon as it appears. • Ask for help with some tasks and delegate others. • Choose activities so that they do not exceed the amount of energy available for the day and do not take up energy for the following days (e.g., spoon theory[1]). • Limit sensory stimuli. • Control autonomic-like clinical manifestations, if applicable. • Control environmental factors (e.g., ambient temperature and proximity of allergens). • Agreeing to adjust standards (e.g., tolerating less than perfect cleaning or having someone else make the meal).

1. The spoon theory comes from an essay in which a person with a chronic illness explains the fatigue caused by her condition and the choices she must make on a daily basis. The spoon represents one unit of energy. Each person has a unique amount of spoons. Each activity consumes a different amount of spoons per person.

① **The principles of supporting the person in energy management are:**

- **encourage the person to respect his or her limits** and not to encourage him or her to make efforts / activities to increase his or her strength or endurance;
- **to ensure that the person is supported in the dosage of effort required** for each of his or her activities and for all of them so that the energy expended does not exceed the energy envelope.

→ **Rest periods are essential for good energy management**, but:

- prolonged periods of complete rest should be avoided as much as possible;
- the goal is not to sleep, as prolonged naps can cause sleep inertia and interfere with nighttime sleep.

→ **Optimal energy management** may take some time to learn as it involves a process of trial and error. In addition, adjustments are required based on changes in health, medications, unexpected events and the addition of activities to the routine.

→ Some people may become hypervigilant about their symptoms and tend to overly restrict their activities.

- The following can help support energy management:
  - explanations of post-exertional malaise and how to avoid it;
  - importance of slowing down;
  - tips on recognizing and managing exertion (e.g., Borg scale);
  - information on warning symptoms and support in identifying them;
  - support for self-monitoring of clinical manifestations and for implementing energy management strategies;
  - advice and assessment of the need for home adaptation or access to home care services, technical aids, mobility aids to promote energy conservation;
  - promoting the adoption of healthy lifestyle habits to enable optimal functioning.
- **The effect of energy management strategies** should be assessed by characterizing post-exertional malaise and not by the intensity of fatigue, since fatigue may be one of the last symptoms to resolve.
  - **Persistence in approach is indicated** if a trend toward improvement in post-exertional malaise is observed (e.g., clinical manifestations that are more spaced out, of less intensity, or of shorter duration).
  - **Stabilization of health status may be slow**; the effect of strategies should be assessed over months or years.
- **If goals are given,** they must be realistic, flexible and personalized. In addition, they should be modulated very gradually.
- **Energy management strategies** should be reviewed regularly as health status and needs change over time.
- Some people with more severe disease are at risk for complications related to immobility (e.g., pressure ulcers, deep vein thrombosis, contractures and osteoporosis). Standard prevention and management practices are applicable, provided they are within the energy envelope.

EXAMPLES OF ELEMENTS THAT CAN PROMOTE ENERGY CONSERVATION

Category	Elements
Environment	• Home adaptations to support participation in ADLs and IADLs • Proximity of controls for light, sound and temperature
Home maintenance	• Assistance or maintenance service for snow removal, cleaning, landscaping, lawn and house work
Mobility	• Motorized wheelchair • Stairlift • Three or four wheelers • Walker with seat
Modification of activities	• Changing position (e.g., sitting, semi-seated or lying down) • Limiting stimuli (e.g., occasional plugs or ear muffs, sleep mask, screen, light screening, dark mode on electronic devices, blue wave blocking glasses, restriction of screen time)
Pauses	• Take sensory breaks (e.g., 5 to 20 minutes) • Take frequent short breaks (e.g., 2-5 minutes)
Personal care	• Bedpan • Shower bench
Relaxation	• Breathing exercises, cardiac coherence, exposure to nature, soft music • Meditation, visualization, centering and anchoring exercises
Rest	• Book one or more days without commitment, the day before an appointment • Lie down for an hour before an activity and also after if it is energy consuming • Take a complete rest (do nothing)
Shopping and groceries	• Online ordering • Prioritize the less busy periods • Shopping assistance
Transport	• Adapted transportation • Parking stickers

POST-EXERTIONAL MALAISE MANAGEMENT

→ Onset of post-exertional malaise:

- is possible and normal even with adequate energy management given the variability in the threshold for post-exertional malaise.

→ The following may help return to stable health status during post-exertional malaise:

- identifying the trigger (e.g., activity of too high intensity, sensory overload, acute illness);
- reducing the level of activity and increasing the frequency and duration of rest periods;
- monitoring the evolution of clinical manifestations;
- waiting for clinical manifestations to resolve and health status to stabilize for a few weeks before attempting to quietly return to the pre-discomfort activity level;
- review of energy management strategies depending on the trigger and intensity of the post-exertional malaise.

INTEGRATION OF ACTIVITIES INTO THE ROUTINE

→ The integration of activities into the routine should be considered on a case-by-case basis if the health condition has been stabilized for several weeks. **It should then be done with caution and in the respect** of the energy envelope.

- Activities should be simple to perform and appropriate to the person's ability, e.g., physical activities as light in intensity as:
- movements in the lying position;
- stretching;
- short walk (e. g., 5 to 15 minutes).

→ The following elements may contribute to the success of integrating an activity into the routine:

- discussing the risks and benefits with the person with the disease;
- planning with the person with ME/CFS: a short, light-intensity activity to start with, with rest periods after the activity;
- flexibility in the integration plan to avoid exceeding the energy envelope;
- gradually increasing the duration or intensity of the activity if health status remains stable;
- reviewing the integration plan and regular follow-up.

Good to know

- ADLs, IADLs, and socialization should take priority over incorporating physical or cognitive activities into the routine.
- Gentle, slow-paced physical activities that combine movement and breathing would be appreciated by people with ME/CFS who have the ability to perform ADLs and IADLs and who enjoyed working out.

FOOD INTAKE

→ Eating can increase the amount of energy available. However, eating and drinking may require a significant effort for some people.

ELEMENTS THAT CAN SUPPORT PROPER NUTRITION AND HYDRATION	
Category	**Elements**
Tips for healthy eating	• Choose nutritious foods and balanced meals that include fruits, vegetables, whole grains and protein-rich foods. • Reduce consumption of ultra-processed foods, foods high in trans fat and saturated fat, added sugars, caffeine[1] and alcohol.
Strategies to facilitate nourishment and hydration in the presence of gastrointestinal events	• Recognize food intolerances and adjust diet as needed (e.g., lactose-free dairy products). • Split meals (e.g., 3 meals and 2-3 snacks). • Have nutritious drinks or snacks. • Choose water to stay hydrated. • Use a straw, spill-proof cups or hydration bags.
Strategies to limit the energy required to feed oneself	• Have assistance with meal preparation. • Prefer food with a softer texture. • Purchase nutritious prepared or semi-prepared foods. • Prepare larger quantities of food when energy is available and store it for future use. • Eat or drink in bed in a sitting position. • Place snacks in an easily accessible place. • Use light-weight utensils and dishes. • Cut food into small pieces. • Split up meal preparation. • Sitting down to prepare meals (e.g., portable cooking surface).

Advice for people who have autonomic clinical manifestations	• Increase fluid and salt intake in people who do not have high blood pressure, kidney or heart failure, or other contraindications.
	  - Drink frequently > 2 liters/day: drink more in the morning after a night without drinking (e.g., every hour) and less during the rest of the day (e.g., every 2 hours), drink during and after activity.
	  - Aim to drink the equivalent of a small glass each time.
	  - Add salt to your meal to taste.
	• Lie down for at least 15 minutes after a meal or alcohol consumption for people who do not have contraindications (e.g., gastroesophageal reflux disease).
	Good to know
	- *The optimal amount of salt varies from person to person; salt tablets with potassium may be helpful for some people.*
	- *Examples of drinks and foods to increase fluid and salt intake: healthy rehydration drinks, tomato or vegetable juices, soups, pickles, olives, salsa, salted nuts.*
	- *Alcohol consumption would generally worsen the clinical manifestations.*

1. Coffee intake should not exceed 2 cups per day.

ACCEPTANCE AND ADAPTATION TO LIFE CHANGES

→ The clinical manifestations of ME / CFS are numerous and can be physical, neuropsychological and psychological in nature. In addition, ME / CFS impacts different aspects of life and can particularly:

- generate psychological symptoms;
- have an impact on the couple, family dynamics and relationships with loved ones.

→ **Both the person with ME / CFS and their loved ones may need support.**

→ Compassion, openness, and recognition of the impact of ME / CFS on quality of life promote the person's well-being.

→ The person's need for support from a qualified professional or access to community services to help cope with the burden of the disease should be assessed periodically.

STRATEGIES FOR ACCEPTANCE AND ADAPTATION TO LIFE CHANGES

Category	Strategies
Activities	• Giving oneself permission to ask for help and delegate tasks. • Finding enjoyable, low-stress activities to do with loved ones. • Finding pleasure in activities, even if they are routine or ordinary.
Emotions	• Have realistic expectations. • Develop a sense of satisfaction based on small victories. • Be kind to self. • Normalize the emotions related to the gap between the pre-illness state and the current state. • Live emotions without feeling too guilty.
Lifestyle	• Redefine lifestyle according to physical, cognitive and emotional constraints. • View post-exertional malaise as an opportunity to learn more about limits.
Stress and anxiety	• Reduce stress and anxiety (e.g., breathing exercises, relaxation). • Reduce commitments and stressors.
Support	• Inform people in one's personal and professional environment of the clinical manifestations and their consequences in order to promote adequate understanding and support. • Seek psychological help when needed.

① **People with ME / CFS are more sensitive than average to medications** (e.g., those affecting the central nervous system) and drug interactions. If pharmacological treatment is initiated, it is important that:

- it should be started at a low dose and adjusted slowly to the minimum effective dose;
- close monitoring of its efficacy and safety is carried out.

Support interventions should:

- be aimed at reducing distress associated with the changes imposed by ME / CFS and not be an objective of recovery;
- be adjusted to avoid post-exertional malaise (e.g., shorter or less frequent sessions, long-term goals).

→ Support intervention could include the following:

- an exploration of what the individual knows about ME / CFS;
- information about ME / CFS and correction of erroneous knowledge;
- normalization of emotional responses, considering the clinical manifestations of ME / CFS and their impact;
- clarification and discussion about anxiety and mood changes;
- discussion about energy and symptom management strategies that allow the individual to live with the limitations imposed by ME / CFS.

→ An intervention based on a cognitive-behavioural approach may help some people. It could include the following elements:

- the development of a common understanding between the therapist and the person, regarding the difficulties and challenges faced by the person;
- exploring clinical manifestations and their meaning for the person;
- the development of strategies to promote self-management of clinical manifestations;
- adapting and refining self-management strategies, in collaboration with the person to improve functioning and quality of life;
- regular review of self-management strategies based on changes in clinical manifestations and functioning;
- development of a comprehensive summary that includes a list of the challenges and clinical manifestations presented and the self-management strategies implemented at the end of the intervention.

→ Some people may benefit from other forms of intervention such as acceptance and commitment therapy.

Good to know

- To facilitate the progess of the person, it may be useful to:
  - intervene initially in the mourning of the person he/she was;
  - help the person with ME / CFS move from a mindset focused on the past (e. g., What have I got? Why me?) to a mindset focused on future gains.

STUDIES OR WORK

- Several persons with post-exertional malaise are unable to study or work, even part-time, in particular because of their restricted energy envelope, their cognitive difficulties and the fluctuation of their symptoms.
- Some persons may be able to study or work part-time when they have access to flexible and personalized accommodations.

Good to know

- **Education or work should not be the only activity the persone undertakes.**
  - The achievement of a certain quality of life and a balance between the time allocated to this occupation, the time spent at home and with loved ones, as well as the time allocated to leisure and social activities are desirable.
- **Usual returning to work protocols may contravene energy management** and are therefore inappropriate for people with ME / CFS.
- **A risk of deterioration in health status** and cessation of studies or work is possible if integration is too rapid, even if it is progressive.
- **Disability guidelines and information** should be based on standard practice while taking into account energy management.

- Interprofessional collaboration and partnership with school workers or with the employer and paying agents is desirable in establishing the required accommodations.
- When an increase in study time or work performance is desired:
  - the individual should gradually simulate his or her living habits and activities in preparation for the desired increase (e.g., wake-up and bedtime, meal schedule, activities similar to the study or work day).
  - integration should be individualized, flexible and very gradual.
- Regular monitoring of the person is necessary, as their needs may change. Coaching is important to determine if:
  - studies or work do not interfere with ADLs and IADLs;
  - accommodations can be improved to promote energy management.
- The person may need support in dealing with:
  - school workers for the resumption of learning-related activities.
  - His / her employer and paying agents for the resumption of work-related activities or in case of disability.

EXAMPLES OF ACCOMMODATIONS PROMOTING ENERGY MANAGEMENT
• Schedule modifications (e.g., part-time, shorter days, flexible hours);
• Possibility of last-minute absences due to the unpredictability of post-exertional malaise;
• Adjustment of curriculum or tasks to be completed;
• Reduced demands or firm deadlines;
• Allowing more time to complete tasks;
• Possibility of taking courses or working online or in a hybrid mode;
• Designation of a quiet place to rest if needed or to do tasks that require more concentration (e.g., taking an exam);
• Allowing the use of headphones or earplugs during exams or individual work;
• Environmental adaptations (in particular physical, logistical, ergonomic);
• Provision of technical aids.

CONSULTATION CONSIDERATIONS

→ Different strategies can be put in place to account for the fact that:

- consultations and interpersonal interactions may require significant physical and cognitive effort and generate an exacerbation of clinical manifestations;
- people with ME / CFS have cognitive difficulties.

STRATEGIES
Conduct of consultations

• Different modalities (e.g., phone, teleconsultation or home consultation).
• Duration adapted to the person's capacity:
  - to allow time for self-expression while taking breaks;
  - to respect the limited energy available.
• Number of visits and frequency appropriate to the person's ability.
• Different position and ability to change (e.g., semi-seated or lying down).
• Reduction of sensory stimuli (e.g., dimming lights, speaking in low voices, comfortable temperature).
• Reduced interruptions (e.g., telephone, pager).

Retention of information and recommendations
• Presence of a close relation to facilitate communication and retention of information. • Transmission of information and recommendations for the person to refer to after the consultation (e.g., handwritten sheet, email, audio or video recording). • Simple, easy-to-understand text.
Appointment management

• Timing of consultations to:
  - reduce waiting time (e.g., first appointment in the morning or afternoon);
  - limit sensory stimuli (e.g., waiting in another room or in the car);
  - coincide with the time when the person's energy level is generally higher.
• Reducing the number of intermediaries for appointment scheduling (e.g., clinician schedules the appointment).
• Exempting cancellation policies to allow for prioritization of energy management.

MAIN REFERENCES

To consult all references: see the report in support of the clinical tools.

APPENDIX

AUTONOMIC CLINICAL MANIFESTATIONS

- **Clinical manifestations of autonomic nature** involve functions controlled by the autonomic nervous system (e.g., heart rate, breathing, digestion, sweating).
- **In the context of ME / CFS**, an imbalance between the functions of the autonomic nervous system, i.e., between the sympathetic and parasympathetic systems, is often mentioned. Orthostatic intolerance is the main term used to refer to this, but other clinical manifestations with an autonomic character can also be observed.
- **Orthostatic intolerance** is a constellation of clinical manifestations that occur when moving from lying or sitting to standing and improve in the supine position (e.g., headache, chest pain, dizziness or lightheadedness, nausea, palpitations, loss of clarity of thought or other cognitive difficulties, sensation of internal tremors, syncope or presyncope, blurred vision or scotomas).

Category[1]	Advice and strategies for people with ME / CFS who have clinical manifestations that are autonomic in nature or suggest orthostatic intolerance
Clothing	• Wear 20-30 mm Hg compression garments (e.g., abdominal girdle or waist-high compression tights). • Wear cooling clothing.
Lifestyle habits	• If possible, engage in light physical activity daily within the energy envelope (e.g., movements lying down, sitting, in the water, or lower extremities toning). • Avoid stress. • Engage in activities that stimulate the vagus nerve or activate the parasympathetic nervous system on a daily basis within the energy envelope (e.g., cardiac coherence, deep and diaphragmatic breathing, box breathing, meditation, relaxation, cold water immersion, cold compresses, listening to relaxing music, spending time outdoors, singing).
Posture	• Sleep on a reclining bed with the head up (reverse Trendelenburg position) increase the inclination very gently to the maximum tolerated (max. 15 degrees). • Adopt postures that improve venous return to the heart (e.g., crossing legs, shifting weight from one leg to the other or heel-to-toe rocking when standing, sitting with knees higher than hips or with knees close to chest, contracting leg muscles before standing). • Change positions frequently to avoid stationary positions. • Avoid standing or sitting for long periods of time. • Avoid sitting with feet dangling. • Avoid getting up too quickly. • Pay attention to posture, in general, and neck posture, in particular.
Temperature	• Avoid hot environments for extended periods of time (e.g., saunas, sunbathing). • Take showers or short duration baths in lukewarm water and finish with cooler water.

1. Advice related to Food intake appears in the corresponding section.

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