

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](https://inesss.qc.ca) website.

## 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.**

<ul style="list-style-type: none"> <li>✔ <b>All interactions and interventions</b> must be made with consideration for the <a href="#">energy envelope</a>.</li> <li>✔ <b>The therapeutic approach must be flexible and personalized.</b></li> </ul>	<ul style="list-style-type: none"> <li>✘ <b>The person should not be encouraged</b> to exceed personal limits or engage in activities to increase strength or endurance.</li> <li>✘ Physical or cognitive activity/exercise programs or interventions with fixed or continuously increasing duration and intensity parameters <b>should not be implemented.</b></li> </ul>
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### 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.

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# 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 <sup>1</sup> – <i>non exhaustive list</i>
Cardiorespiratory	<ul style="list-style-type: none"> <li>• Arrhythmia</li> <li>• Chest pain</li> <li>• Dyspnea</li> <li>• Hypotension</li> <li>• Palpitations</li> <li>• Syncope</li> </ul>
Cognitive	<ul style="list-style-type: none"> <li>• Difficulty thinking clearly</li> <li>• Difficulty finding words</li> <li>• Memory loss</li> <li>• Reduction of attention</li> </ul>
Diverse	<ul style="list-style-type: none"> <li>• Intense fatigue</li> <li>• Flu-like symptoms (e.g., sore throat, painful lymph nodes, fever)</li> <li>• Non-restorative sleep</li> <li>• Sensation of discomfort when sitting or standing</li> </ul>
Musculoskeletal	<ul style="list-style-type: none"> <li>• Arthralgia</li> <li>• Muscle weakness</li> <li>• Myalgia</li> </ul>
Neurological	<ul style="list-style-type: none"> <li>• Blurred vision</li> <li>• Difficulty in articulating, pronouncing, expressing oneself</li> <li>• Dizziness or vertigo</li> <li>• Headache</li> <li>• Increased sensitivity to stimuli (e.g., light, sound, touch)</li> <li>• Neuropathic pain</li> <li>• Paresthesia</li> <li>• Sensation of internal tremors, generally not perceptible from the outside and affecting the lower limbs</li> </ul>

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	<ul style="list-style-type: none"> <li>• Exercise intolerance.</li> <li>• Reduced ability to perform physical or cognitive activity at the usual frequency, intensity and duration for age, size, gender, muscle mass and cardiovascular capacity.</li> </ul>	<ul style="list-style-type: none"> <li>• Onset or exacerbation of clinical manifestations following previously unproblematic or low-intensity activities.</li> <li>• Intensity of clinical manifestations disproportionate to the activity that caused them (e.g., having to rest after sedentary work).</li> <li>• Onset of clinical manifestations not usually found after exertion in other individuals (e.g., sore throat, difficulty thinking).</li> </ul>
Symptoms onset	<ul style="list-style-type: none"> <li>• During or soon after a physical or cognitive activity.</li> </ul>	<ul style="list-style-type: none"> <li>• Typically a few hours to 72 hours<sup>1</sup> after a physical, cognitive or emotional effort.</li> </ul>
Recovery	<ul style="list-style-type: none"> <li>• Clinical manifestations:               <ul style="list-style-type: none"> <li>- fade with rest or sleep;</li> <li>- usually lasts less than a day.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Clinical manifestations:               <ul style="list-style-type: none"> <li>- do not go away or only slightly with rest or sleep;</li> <li>- can last for days, weeks or months.</li> </ul> </li> </ul>

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	<ul style="list-style-type: none"> <li>• Effect of the following factors on clinical manifestations and energy level:                             <ul style="list-style-type: none"> <li>- introduction of activity or increase in its intensity;</li> <li>- presence of sensory stimuli;</li> <li>- proximity to allergens;</li> <li>- change in temperature;</li> <li>- stationary vertical position (sitting or standing).</li> </ul> </li> <li>• Type of activity or exertion that triggers the onset or worsening of clinical manifestations, including their intensity.</li> </ul>
Post-exertional malaise episode	<ul style="list-style-type: none"> <li>• Time to onset or worsening of clinical manifestations.</li> <li>• Clinical manifestations that appear or worsen.</li> <li>• Duration of post-exertional malaise / recovery time.</li> <li>• Impact on level of independence and performance in performing ADLs, IADLs, and studies and work (e.g., postponing or avoiding an activity, absenteeism).</li> </ul>
Avoidance of post-exertional malaise	<ul style="list-style-type: none"> <li>• Strategies used to complete activities or continue with studies or work.</li> <li>• Activities that the person is able to perform without post-exertional malaise.</li> <li>• Treatments or activities that limit post-exertional malaise.</li> </ul>



### 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 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
<ul style="list-style-type: none"> <li>• Other acute illness (e. g., cold)</li> <li>• Non stabilized comorbidity</li> <li>• Environmental factors (e. g., proximity of allergens, change of temperature or season changeover)</li> <li>• Performing activities that require an effort<sup>1</sup>:                             <ul style="list-style-type: none"> <li>- <b>physical</b>: brushing teeth, dressing, showering, drying hair, walking, climbing stairs, doing laundry, etc.;</li> <li>- <b>cognitive</b>: listening to music, watching television, reading, writing, working on the computer, driving, etc.;</li> <li>- <b>emotional</b>: 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.;</li> </ul> </li> <li>• Sensory stimuli (e.g., sound, light, touch)</li> <li>• If presence of <a href="#">autonomic-like clinical manifestations</a>:                             <ul style="list-style-type: none"> <li>- Postprandial state<sup>2</sup></li> <li>- Upright position (sitting or standing) - worse if stationary</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Food intake</li> <li>• Rest</li> <li>• Sleep</li> <li>• If presence of <a href="#">autonomic-like clinical manifestations</a>:                             <ul style="list-style-type: none"> <li>- Autonomic nervous system regulation strategies (e.g., lying down)</li> </ul> </li> </ul>

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
<p><b>Adapting activities:</b></p> <ul style="list-style-type: none"> <li>• modify environments and activities to make them easier to complete;</li> <li>• breaking down large tasks into smaller ones.</li> </ul> <p><b>Modulating the rhythm of activity and rest periods:</b></p> <ul style="list-style-type: none"> <li>• determine the physical, cognitive and emotional effort thresholds that trigger post-exertional malaise;</li> <li>• adjust the intensity of activities and plan alternating periods of activity and rest so as not to exceed the effort thresholds found.</li> </ul> <p><b>Planning the activities:</b></p> <ul style="list-style-type: none"> <li>• spread activities over days or weeks;</li> <li>• perform energy-intensive activities during the periods when energy is highest;</li> <li>• set aside time for energizing activities within the energy envelope (e.g., hobbies, sitting outside, any activity that brings pleasure and satisfaction).</li> </ul> <p><b>Prioritizing activities:</b></p> <ul style="list-style-type: none"> <li>• prioritize activities;</li> <li>• conserve energy for meaningful activities;</li> <li>• recognize and limit energy-consuming activities.</li> </ul>	<ul style="list-style-type: none"> <li>• Plan rest periods first and activities later.</li> <li>• Plan break and rest periods each day.</li> <li>• Leave time for the unexpected.</li> <li>• Alternate tasks (e.g., easy vs. difficult, physical vs. cognitive).</li> <li>• Stop an activity before you are very tired, before a warning symptom appears or as soon as it appears.</li> <li>• Ask for help with some tasks and delegate others.</li> <li>• 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<sup>1</sup>).</li> <li>• Limit sensory stimuli.</li> <li>• Control <a href="#">autonomic-like clinical manifestations</a>, if applicable.</li> <li>• Control environmental factors (e.g., ambient temperature and proximity of allergens).</li> <li>• Agreeing to adjust standards (e.g., tolerating less than perfect cleaning or having someone else make the meal).</li> </ul>

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.

### ! 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	<ul style="list-style-type: none"> <li>• Home adaptations to support participation in ADLs and IADLs</li> <li>• Proximity of controls for light, sound and temperature</li> </ul>
Home maintenance	<ul style="list-style-type: none"> <li>• Assistance or maintenance service for snow removal, cleaning, landscaping, lawn and house work</li> </ul>
Mobility	<ul style="list-style-type: none"> <li>• Motorized wheelchair</li> <li>• Stairlift</li> <li>• Three or four wheelers</li> <li>• Walker with seat</li> </ul>
Modification of activities	<ul style="list-style-type: none"> <li>• Changing position (e.g., sitting, semi-seated or lying down)</li> <li>• 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)</li> </ul>
Pauses	<ul style="list-style-type: none"> <li>• Take sensory breaks (e.g., 5 to 20 minutes)</li> <li>• Take frequent short breaks (e.g., 2-5 minutes)</li> </ul>
Personal care	<ul style="list-style-type: none"> <li>• Bedpan</li> <li>• Shower bench</li> </ul>
Relaxation	<ul style="list-style-type: none"> <li>• Breathing exercises, cardiac coherence, exposure to nature, soft music</li> <li>• Meditation, visualization, centering and anchoring exercises</li> </ul>
Rest	<ul style="list-style-type: none"> <li>• Book one or more days without commitment, the day before an appointment</li> <li>• Lie down for an hour before an activity and also after if it is energy consuming</li> <li>• Take a complete rest (do nothing)</li> </ul>
Shopping and groceries	<ul style="list-style-type: none"> <li>• Online ordering</li> <li>• Prioritize the less busy periods</li> <li>• Shopping assistance</li> </ul>
Transport	<ul style="list-style-type: none"> <li>• Adapted transportation</li> <li>• Parking stickers</li> </ul>



## 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	<ul style="list-style-type: none"> <li>Choose nutritious foods and balanced meals that include fruits, vegetables, whole grains and protein-rich foods.</li> <li>Reduce consumption of ultra-processed foods, foods high in trans fat and saturated fat, added sugars, caffeine<sup>1</sup> and alcohol.</li> </ul>
Strategies to facilitate nourishment and hydration in the presence of gastrointestinal events	<ul style="list-style-type: none"> <li>Recognize food intolerances and adjust diet as needed (e.g., lactose-free dairy products).</li> <li>Split meals (e.g., 3 meals and 2-3 snacks).</li> <li>Have nutritious drinks or snacks.</li> <li>Choose water to stay hydrated.</li> <li>Use a straw, spill-proof cups or hydration bags.</li> </ul>
Strategies to limit the energy required to feed oneself	<ul style="list-style-type: none"> <li>Have assistance with meal preparation.</li> <li>Prefer food with a softer texture.</li> <li>Purchase nutritious prepared or semi-prepared foods.</li> <li>Prepare larger quantities of food when energy is available and store it for future use.</li> <li>Eat or drink in bed in a sitting position.</li> <li>Place snacks in an easily accessible place.</li> <li>Use light-weight utensils and dishes.</li> <li>Cut food into small pieces.</li> <li>Split up meal preparation.</li> <li>Sitting down to prepare meals (e.g., portable cooking surface).</li> </ul>
Advice for people who have <a href="#">autonomic clinical manifestations</a>	<ul style="list-style-type: none"> <li>Increase fluid and salt intake in people who do not have high blood pressure, kidney or heart failure, or other contraindications.                             <ul style="list-style-type: none"> <li>Drink frequently &gt; 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.</li> <li>Aim to drink the equivalent of a small glass each time.</li> <li>Add salt to your meal to taste.</li> </ul> </li> <li>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).</li> </ul> <p> <b>Good to know</b></p> <ul style="list-style-type: none"> <li><i>The optimal amount of salt varies from person to person; salt tablets with potassium may be helpful for some people.</i></li> <li><i>Examples of drinks and foods to increase fluid and salt intake: healthy rehydration drinks, tomato or vegetable juices, soups, pickles, olives, salsa, salted nuts.</i></li> <li><i>Alcohol consumption would generally worsen the clinical manifestations.</i></li> </ul>

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	<ul style="list-style-type: none"> <li>• Giving oneself permission to ask for help and delegate tasks.</li> <li>• Finding enjoyable, low-stress activities to do with loved ones.</li> <li>• Finding pleasure in activities, even if they are routine or ordinary.</li> </ul>
Emotions	<ul style="list-style-type: none"> <li>• Have realistic expectations.</li> <li>• Develop a sense of satisfaction based on small victories.</li> <li>• Be kind to self.</li> <li>• Normalize the emotions related to the gap between the pre-illness state and the current state.</li> <li>• Live emotions without feeling too guilty.</li> </ul>
Lifestyle	<ul style="list-style-type: none"> <li>• Redefine lifestyle according to physical, cognitive and emotional constraints.</li> <li>• View post-exertional malaise as an opportunity to learn more about limits.</li> </ul>
Stress and anxiety	<ul style="list-style-type: none"> <li>• Reduce stress and anxiety (e.g., breathing exercises, relaxation).</li> <li>• Reduce commitments and stressors.</li> </ul>
Support	<ul style="list-style-type: none"> <li>• Inform people in one's personal and professional environment of the clinical manifestations and their consequences in order to promote adequate understanding and support.</li> <li>• Seek psychological help when needed.</li> </ul>

- ⚠ **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 progress 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 person 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
<b>Conduct of consultations</b>
<ul style="list-style-type: none"><li>• Different modalities (e.g., phone, teleconsultation or home consultation).</li><li>• Duration adapted to the person's capacity:<ul style="list-style-type: none"><li>- to allow time for self-expression while taking breaks;</li><li>- to respect the limited energy available.</li></ul></li><li>• Number of visits and frequency appropriate to the person's ability.</li><li>• Different position and ability to change (e.g., semi-seated or lying down).</li><li>• Reduction of sensory stimuli (e.g., dimming lights, speaking in low voices, comfortable temperature).</li><li>• Reduced interruptions (e.g., telephone, pager).</li></ul>
<b>Retention of information and recommendations</b>
<ul style="list-style-type: none"><li>• Presence of a close relation to facilitate communication and retention of information.</li><li>• Transmission of information and recommendations for the person to refer to after the consultation (e.g., handwritten sheet, email, audio or video recording).</li><li>• Simple, easy-to-understand text.</li></ul>
<b>Appointment management</b>
<ul style="list-style-type: none"><li>• Timing of consultations to:<ul style="list-style-type: none"><li>- reduce waiting time (e.g., first appointment in the morning or afternoon);</li><li>- limit sensory stimuli (e.g., waiting in another room or in the car);</li><li>- coincide with the time when the person's energy level is generally higher.</li></ul></li><li>• Reducing the number of intermediaries for appointment scheduling (e.g., clinician schedules the appointment).</li><li>• Exempting cancellation policies to allow for prioritization of energy management.</li></ul>

## MAIN REFERENCES

To consult all references: see the [report in support](#) of the clinical tools.

## 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 <sup>1</sup>	Advice and strategies for people with ME / CFS who have clinical manifestations that are autonomic in nature or suggest orthostatic intolerance
Clothing	<ul style="list-style-type: none"> <li>• Wear 20-30 mm Hg compression garments (e.g., abdominal girdle or waist-high compression tights).</li> <li>• Wear cooling clothing.</li> </ul>
Lifestyle habits	<ul style="list-style-type: none"> <li>• If possible, engage in light physical activity daily within the <a href="#">energy envelope</a> (e.g., movements lying down, sitting, in the water, or lower extremities toning).</li> <li>• Avoid stress.</li> <li>• Engage in activities that stimulate the vagus nerve or activate the parasympathetic nervous system on a daily basis within the <a href="#">energy envelope</a> (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).</li> </ul>
Posture	<ul style="list-style-type: none"> <li>• Sleep on a reclining bed with the head up (reverse Trendelenburg position) increase the inclination very gently to the maximum tolerated (max. 15 degrees).</li> <li>• 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).</li> <li>• Change positions frequently to avoid stationary positions.</li> <li>• Avoid standing or sitting for long periods of time.</li> <li>• Avoid sitting with feet dangling.</li> <li>• Avoid getting up too quickly.</li> <li>• Pay attention to posture, in general, and neck posture, in particular.</li> </ul>
Temperature	<ul style="list-style-type: none"> <li>• Avoid hot environments for extended periods of time (e.g., saunas, sunbathing).</li> <li>• Take showers or short duration baths in lukewarm water and finish with cooler water.</li> </ul>

1. Advice related to [Food intake](#) appears in the corresponding section.