

**Objective:** Alberta clinicians will have the information and tools necessary to detect key symptoms of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and manage these symptoms over the long term.

**Target population:** Adults and children

**Exclusions:** None

## RECOMMENDATIONS

### PRACTICE POINT

*Although there is currently no definitive test or validated tool to diagnose ME/CFS or single proven treatment, symptoms consistent with ME/CFS can be identified and managed successfully within the primary care setting.*

## SUGGESTED ASSESSMENT AND DIAGNOSIS (SEE [ALGORITHM](#))

- ✓ A validated, sensitive and specific tool (Canadian consensus) is suggested for use. This tool is most specific in differentiating ME/CFS from psychiatric conditions and making a diagnosis. See [Table 1](#) – Validated ME/CFS Symptom Checklist.

ME/CFS Symptom Checklist	
Symptoms	Description of Symptom
<b>Pathological fatigue</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	A significant degree of new onset, unexplained, persistent or recurrent physical and/or mental fatigue that substantially reduces activity levels and which is not the result of ongoing exertion and is not relieved by rest.
<b>Post-exertional malaise &amp; worsening of symptoms</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	Mild exertion or even normal activity is followed by malaise: the loss of physical and mental stamina and/or worsening of other symptoms. Recovery is delayed, taking more than 24 hours.
<b>Sleep problems</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	Sleep is un-refreshing; disturbed quantity – daytime hypersomnia or nighttime insomnia and/or disturbed rhythm – day/night reversal Rarely there is no sleep problem.
<b>Pain</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	Pain is widespread, migratory or localized: myalgia; arthralgia (without signs of inflammation); and/or headache – a new type, pattern or severity Rarely there is no pain.
<b>Two neurocognitive symptoms</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	Impaired concentration, short term memory or word retrieval; hypersensitivity to light, noise or emotional overload; confusion; disorientation; slowness of thought; muscle weakness; ataxia.
<b>At least one symptom from two of these categories:</b> a) <b>Autonomic</b> Yes <input type="checkbox"/> No <input type="checkbox"/>  b) <b>Neuroendocrine</b> Yes <input type="checkbox"/> No <input type="checkbox"/>  c) <b>Immune</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	a) Autonomic: Orthostatic intolerance – neutrally-mediated hypotension (NMH); postural orthostatic tachycardia (POTS); light headedness; extreme pallor; palpitations; exertional dyspnea; urinary frequency; irritable bowel syndrome (IBS); nausea
	b) Neuroendocrine: Low body temperature; cold extremities; sweating; intolerance to heat or cold; reduced tolerance for stress; other symptoms worsen with stress; weight change; abnormal appetite
	c) Immune: Recurrent flu-like symptoms; sore throats; tender lymph nodes; fevers; new sensitivities to food, medicines, odors or chemicals

Table 1: Validated ME/CFS Symptom Checklist

## SYMPTOM MANAGEMENT

### GENERAL PRINCIPLES AND CONSIDERATIONS

- ✓ Acknowledge the legitimacy of the condition and respect the patient’s lived experience as an important first step to successful management of ME/CFS. Often patients are more ill than they look.

Symptom	Suggested Management: Pharmacotherapy/Non-pharmacotherapy Approaches
<b>Pathological fatigue</b>	<p>There are two evidence-based interventions for fatigue. There is active debate among experts as to the better approach.</p> <ul style="list-style-type: none"> <li>• Pacing: identifying one’s energy at a given time and adapting activity level to energy level. If using this approach see <a href="#">complete guideline</a> Appendix A – Activity Log. There is less chance of symptom setback associated with pacing.</li> <li>• Graded exercise: gradually increasing activity level over time. If using this approach, careful monitoring is required as the patient can have a debilitating symptom setback if they inadvertently exceed their energy envelope too often or too severely.</li> </ul> <p>Using both interventions is possible by incorporating pacing within a graded exercise regimen.</p>
<b>Post-exertional malaise (PEM) &amp; worsening of symptoms</b>	<p>Same as above.</p>
<b>Sleep problems</b>	<ul style="list-style-type: none"> <li>✓ Use typical sleep hygiene principles (see <a href="#">Myhealth Alberta</a>).</li> <li>✓ Consider and if necessary prescribe sleep medication (see Appendix B in the <a href="#">complete guideline</a>).</li> <li>✓ Refer to sleep specialist if a primary sleep disorder is suspected (one or more sleep disorders are present in 20% of cases).</li> </ul>
<b>Pain</b>	<ul style="list-style-type: none"> <li>✓ Identify the types of pain.</li> <li>✓ Suggest using pacing activity log (See Appendix A in the complete guideline).</li> <li>✓ Assess the patient’s need for and use typical pain medications.</li> <li>✓ For fibromyalgia pain consider treatment options suggested in 2012 Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome (<a href="http://fmguidelines.ca/?page_id=21">http://fmguidelines.ca/?page_id=21</a>).</li> <li>✓ For migraine/headache see guideline for <a href="#">Primary Care Management of Headache in Adults</a>.</li> </ul>

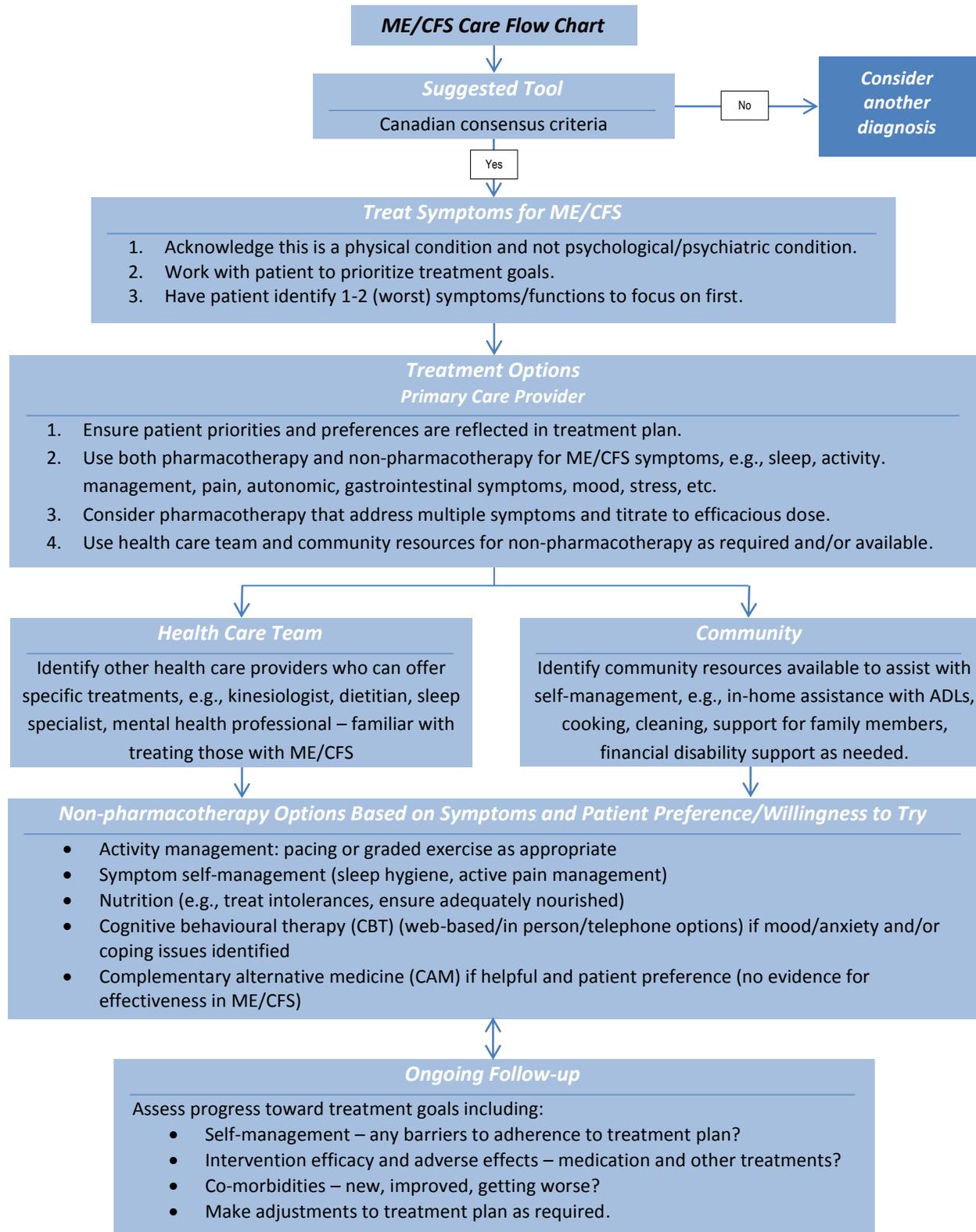
Symptom	Suggested Management: Pharmacotherapy/Non-pharmacotherapy Approaches
<b>Neurocognitive symptoms</b>	<ul style="list-style-type: none"> <li>✓ Pace cognitive tasks similar to pacing physical activity.</li> <li>✓ Plan important tasks for the “best time of day.”</li> <li>✓ Suggest strategies to keep information, appointments and personal items organized such as a “memory book.” Keep common items (keys, glasses, wallet) in a central, consistent location.</li> <li>X Avoid high intensity or multisensory situations or events.</li> </ul>
<b>Autonomic</b>	<ul style="list-style-type: none"> <li>✓ Manage as per usual care.</li> </ul>
<b>Neuroendocrine</b>	<ul style="list-style-type: none"> <li>✓ Manage as per usual care.</li> </ul>
<b>Immune</b>	<ul style="list-style-type: none"> <li>✓ Consider long-term antibiotics, anti-parasitics or antiviral therapy where pathogen(s) can be confirmed by testing (although testing is not easily available in Alberta).</li> </ul>
<b>Sensitivity to chemicals and drugs</b>	<ul style="list-style-type: none"> <li>✓ Patients with ME/CFS often have increased sensitivity to food, chemicals and medications and should avoid these irritants. There is no special diet for ME/CFS.</li> <li>✓ Workplace accommodation is often required.</li> </ul>
<b>Other Symptoms/Co-Morbid Conditions Associated with ME/CFS</b>	
<b>Depression, mood and anxiety disorders</b>	<ul style="list-style-type: none"> <li>✓ Treat and manage co-morbid psychiatric conditions as per usual care. (Note that patients with ME/CFS tend to be more sensitive to medication side effects than primary psychiatric patients.)</li> <li>✓ Suggest evidence-based psychotherapy, e.g., cognitive behavioural therapy, which would be the best fit for those patients who are depressed, anxious or hopeless as a result of their illness and to assist in optimizing self-management. (Note many PCNs in Alberta now offer doctoral level psychologist counselling and/or CBT programs. Physicians should inquire about availability in their PCN.)</li> </ul>

- ✓ Manage children and adolescents with ME/CFS similarly to adults. For additional information see page 29 in [http://iacfsme.org/portals/0/pdf/Primer\\_Post\\_2014\\_conference.pdf](http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf).
- ✓ For more information and a comparison of existing fibromyalgia guidelines see: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3856149>.

## IMPLEMENTATION CONSIDERATIONS

- Specialists can provide the CPG as a resource for primary care physicians if and when patients are referred for ME/CFS.
- The CPG will be shared with Alberta Health Services Health Link as a resource and informing Health Link ME/CFS algorithms.
- The CPG will be circulated for use and information over time to related interest groups by the partners and champions participating in the development of the CPG.
- The CPG will be presented and promoted at events such as grand rounds or medical conferences by physicians participating in the development of the CPG.

# ALGORITHM



These recommendations are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. They should be used as an adjunct to sound clinical decision making.