Date: Aug 3, 2021

Clinical Protocol: Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

PREAMBLE

- There is currently no cure for ME/CFS; there is not even an effective treatment that targets the underlying illness itself. Treatment is focused on symptom reduction and self-management.
- The symptoms of ME/CFS can be broadly divided into 5 categories:
  - Fatigue (both physical and mental), with post-exertional malaise
  - Pain
  - Neurocognitive symptoms
  - Sleep disturbance
  - Other symptoms (e.g., palpitations, temperature instability, etc.)
- No one treatment (so far) targets all types of symptoms
- Pain is treated with the same protocol as FM and Chronic Pain in Related Disorders Protocol
  - There is up to ~ 60% overlap with ME/CFS and FM
- Please note that there is a Primary Care Toolkit to help you implement an individualized patient plan.

1. PATIENT EDUCATION

- Incorporated into multiple offerings (e.g., handouts, videos and web-based resources)
  - ME/CFS Patient Resources
- Incorporated into group educational activities
- "Family and Friends" sessions

  Check the website under the News and Events

2. ACTIVITY MANAGEMENT

- Offered in group setting sessions with PT and OT
  - Patients with ME/CFS are encouraged to pace themselves and keep activities within their tolerance limits
  - Formal exercise can be considered if the energy envelope permits and does not cause post-exertional malaise
- More information about pacing

3. SLEEP

- Sleep disturbance is a major component of ME/CFS
- See Sleep Protocol for details

4. DIET

- Offered in group sessions with dietitian
- Many patients benefit from a low-inflammatory diet
- The major emphasis, however, is a healthy diet

5. ALTERNATIVE AND COMPLEMENTARY THERAPIES

- Offered in group sessions with our naturopath

- Some agents are crossing into mainstream medicine and may be worth trying:

5.1 Co-enzyme Q

- 200 mg TID

5.2 D-Ribose

- 5 g TID

5.3 Magnesium Malate

- 250 mg QID

5.4 Vitamin D

- 2000 IU daily

6. PSYCHOLOGICAL AND BEHAVIOURAL THERAPIES

- Incorporated into group sessions
- For patients waiting to get into our program, on-line courses are available

7. INTERVENTIONS

7.1 Trigger Point Injection, etc.

- Maneuvers that target muscular trigger points, lengthen muscle contractures, and release painful scars and other connective tissue restrictions
- For example:
  - Myofascial release
  - Trigger Point Injections
  - Nerve blocks
- Check availability in the community:
  - Change Pain Clinic: http://www.changepain.ca
  - Muscle MD Clinic: http://musclemd.ca
  - Myo Clinic (Victoria): http://www.myoclinic.ca
  - Other practitioners across the province

7.2 Acupressure

- Offered as part of our group activities.

8. MEDICATIONS

8.1 Pain Medications

- For ME/CFS patients with significant myalgias or overlap with FM, see the FM and Chronic Pain in Related Disorders protocol.

8.2 Iron

- Iron helps with fatigue in patients with ferritin below 50
- Need to watch for constipation (especially IBS-C)
- May need to add PEG +/- Milk of Magnesia (see IBS protocol)
- Patients unable to tolerate oral iron, may need IV replacement

- The rule of thumb is that the easier the iron is on the stomach the less bioavailable iron there is
- New guidelines suggest that iron should not be taken every day (or multiple times a day) as it decreases absorption. The current recommendation is to only take iron every 2nd day on an empty stomach with acid (e.g., Vitamin C or orange juice)

8.2 A Ferrous fumarate

- Available OTC
- High amount of iron
- Very effective, but less well tolerated
- 300 mg (one capsule) every 2nd day; each capsule contains 100 mg elemental iron

8.2 B Ferrous gluconate

- Available OTC
- Less iron than fumarate but somewhat easier on the stomach
- Effective, better tolerated than fumarate
- 300 mg (one tablet) every 2nd day**;** each tablet contains 35 mg elemental iron

8.2 C Iron polysaccharide

- Available OTC
- Although it contains the highest amount of elemental iron and is well tolerated, it is not usually effective at repleting iron stores.
- 150 mg daily (as elemental iron)

8.2 D Iron sucrose

- IV iron, usually administered in a medical short stay unit
- Not offered at CCDP
- 300 mg over 3 hrs x 3 doses (1 – 2 weeks between doses)
- Ferritin falsely elevated (often above 100) for a few months

8.3 Modafinil

- Helps with mental alertness/brain fog and may give the sense of increased energy
- We do not use this medication very often given that many of our patients have anxiety and autonomic dysfunction; modafinil can make these worse
- Also, the false sense of increased energy is at risk of pushing patients beyond their energy envelope and causing crashes of symptoms (post-exertional malaise)
- Start 100 mg daily
- May increase to 200 mg daily
- Watch for anxiety, insomnia, and adrenergic side effects

8.4 SNRI

- Helps with pain and some of the unexplained symptom category
- See the FM and Chronic Pain in Related Disorders protocol for prescribing instructions

- **ASSESS AND TREAT COEXISTING DISORDERS**
- Treatment protocols are available on our website
- Central Sensitivity Syndromes include:
  - IBS
  - Migraine
  - Tension Type Headaches
  - POTS

- Multiple Chemical Sensitivities
- Interstitial Cystitis
- Pelvic Pain Syndromes
- Irritable Larynx Syndrome
- Restless Leg Syndrome
- Non-cardiac Chest Pain
- Temporomandibular Disorders
- Myofascial Pain Syndrome
- Central Abdominal Pain Syndrome
- PTSD

9. ASSESS AND TREAT FOR COEXISTING ANXIETY AND MOOD DISORDERS

- Referral to psychiatrist for selected patients

11. HORMONAL ISSUES

- Testing
  - TSH is part of the screening blood work for new patients
  - AM cortisol can be ordered as a second-line test if hypoadrenalism is suspected
  - Patients requiring anything beyond this, should be referred to endocrinology
- Non-Addison adrenal issues
  - Some patients show abnormal diurnal variation in cortisol levels; the issue is one of dysregulation rather than deficiency. Also, some patients may get a diagnosis of "adrenal fatigue" from a naturopath (or self-diagnosed)
  - Currently there is no evidence that patients who do not demonstrate adrenal insufficient by validated tests such as ACTH stimulation test, CRH stimulation test and Insulin Tolerance Test (ITT) would benefit from active glucocorticoid replacement
  - The Clinical Advisory Committee believes that the potential harm would greatly outweigh any perceived benefit by patients
- Patients with normal TSH, low T3, or low T4
  - These findings are analogous to those seen in "sick euthyroid" patients
  - Currently, there is no role for the administration of exogenous thyroxine to these patients. Extrapolating from this approach, CCDP patients with similar thyroid function test findings would not be given thyroid replacement therapy
- Growth Hormone
  - Lower levels of IGF-1 /GH have been reported in some patients with fibromyalgia, a condition related to ME/CFS.
  - Although growth hormone replacement has been explored in small series, the potential benefit of GH replacement long-term clearly is outweighed by the risks and cost
- Hormone Replacement Therapy (HRT) for women
  - Some patients with have abnormal level of sex hormones. The relevance is not known
  - Further referral to subspecialists is required for these patients.
- Androgen replacement in men
  - Androgen replacement therapy may be indicated for those with symptoms and who have a confirmed diagnosis of hypogonadism (decreased free testosterone levels below the normal values).

  - However, ongoing use of androgen replacement is similarly associated with the risk of cardiovascular disease and prostate disease.
  - The use of ART should not be routine in men with hypogonadism without a further assessment of patient risks from these sex-hormone replacements.
  - Further referral to subspecialists is required for these patients.
- Patient with diabetes insipidus-like symptoms
  - If patients are suspected to have diabetes insipidus based on a history of unexplained polyuria and polydipsia in the absence of diabetes of mellitus, they should be referred to an endocrinologist for consideration of a water deprivation test.
  - There is currently no logistic support at BCW's to safely perform a water-deprivation test.
- Melatonin assessment
  - The Endocrinology panelist members are unaware on the implications of melatonin assessment on the health of patients.

12. CO-INFECTIONS

Insufficient evidence for routine use of antivirals and antibiotics

Patient Resources
http://www.bcwomens.ca/health-info/living-with-illness/chronic-fatigue-syndrome-(me-cfs)