MYALGIC ENCEPHALOMYELITIS
EMERGENCY ROOM INFORMATION

Information compiled from patient input and expert documents to assist patients and caregivers in communicating with medical professionals. Detailed medical information can be found in the Myalgic Encephalomyelitis: International Consensus Primer for Medical Practitioners (2012).

Myalgic Encephalomyelitis (ME) is one of the most complex illnesses wherein multiple body systems are affected and presents with difficult illness-specific biochemistry. ME may be mistakenly diagnosed as Chronic Fatigue Syndrome, Fibromyalgia, and/or POTS. Reactions to suggestions vary. **Patient's input must be valued to prevent harm**.

A cursory online illness overview is unlikely to provide medical expertise sufficient to diagnose or treat someone with ME. ME patients arriving at an ER may be result of downstream effect caused by any of the following underlying multi-system pathophysiology abnormalities. See more information on page 4-6 of the ME IC Primer.

- Neurological abnormalities
- Abnormal sleep patterns
- Cerebral spinal fluid abnormalities
- Central nervous system signal altered
- Immune impairments – decreased NK cell function & Th1 shift towards Th2
- Energy production and ion transport impairments
- Cardiovascular and autonomic impairments
- Endocrine system dysfunction
- Gastrointestinal tract impairments
- Impaired oxygen exchange

Treatment suggestions can be found on page 16 of the ME IC Primer - https://bit.ly/2IX1SHD

Key to proper emergency care, is understanding cardinal symptom **Post Exertional Neuroimmune Exhaustion (PENE).** Sometimes labeled Post Exertion Malaise-PEM. PENE is the exacerbation of all illness symptoms after activity exceeding the energy production window. The cascade of symptoms after even minor activities can lead to symptoms so severe patients seek emergency help. This "crash" is often seen 24-48 hours after activity. The ER visit is likely to induce PENE. Minimizing PENE by treating patients with care can help reduce the likelihood of a return to the ER in the next 48 hours.

INAPPROPRIATE TREATMENT IN ANY MEDICAL SETTING CAN EXACERBATE THIS DEBILITATING DISEASE

PRIORITY for any medical provider to be part of the solution and not part of the problem, is a good understanding of things that will exacerbate the illness. Tips to avoid exacerbating the symptoms of an ME patient: (See IC Primer page 13)

- Activity (including mental) exacerbates all symptoms. **Minimize interaction as much as possible.**
- Elevated heart rate with orthostatic intolerance – inability to stand for length of time. Standing/sitting are outside energy production envelope of most patients. **Many patients MUST recline to reduce PENE. Reclining exacerbates symptoms in some patients.** Seek patient/caregiver input to avoid exacerbating illness. (pg 3)
- Immune system dysfunction causes susceptibility to bacteria and viruses. **Isolate patients.** (pg 8)
- Low blood volume, dehydration and electrolyte imbalance are common - **IV saline helpful to stabilize patients** (pg 18)
- Patients cannot regulate body temperature – **patients may need warming blankets** (pg 3)
- Oxygen levels may look fine, but studies show exchange of oxygen at cellular level is impaired. Patients have high oxidative stress. Listening to the patient is vital to avoid exacerbating the situation. Not all ME patients respond well to oxygen. Oxygen may be helpful or harmful. **Listening to the patient's response to oxygen is important.** (pg 3)
- Cognition issues lead to Impaired concentration, slowed thought, difficulty with word finding and memory lapses. **Clearly written notes with detailed instructions is vital to avoid future ER visits.** (pg 7)
- Overload phenomena - Sensitivity to light, noise, vibration, odor, taste, touch and motion can cause temporary period of immobilizing physical and/or cognitive exhaustion leading to inability to communicate and possible seizures. **Patients usually require darkened and quiet room – avoid exposure to odors including colognes.** (pg 18)
- Patients must avoid unnecessary activity – patients have impaired depth perception, muscle weakness and poor coordination. **Provide wheelchair if requested to minimize risk of falls and avoid PENE.** (pg 7)

- Serious side effects from medications are common. including increased risk of dangerous withdrawal symptoms when trying to stop a medication. **Prescribing lowest dose possible is recommended** (pg 6)
  NOTE: ME patients may experience extreme levels of pain. None of these warnings should limit access to adequate pain treatments.
- Homeostasis is impaired **-** many systems are easily affected so care must be taken to avoid shocking the system. **Start all medications as low as possible and increase very slowly.**
- Paralysis of muscles is seen in ME. Resting muscles is vital to recover function. Patients know their safe limits. **Listen to patients – provide assistance to bathroom – do NOT pressure to move around more than necessary.** (pg 7)
- Anesthesia warning - use following with caution (sparingly) catecholamines, sympathomimetics, vasodilators and hypotensive agents. **Avoid histamine releasing anesthetic and muscle relaxing agents if possible**. (pg 20)
- Surgery – **Pre and post-surgery considerations covered on page 20 of ME IC Primer**

Patients CANNOT exercise safely.
Patients have been harmed by recommendations to gradually increase activity or exercise. Pushing patients to be more active is not recommended. Exercise is contraindicated due to the damaged oxygen exchange and impaired energy production which leads to exacerbation of symptoms. Patients can use muscles for short bursts but the oxygen exchange malfunction leaves muscles starved for oxygen leading to a cascade of symptoms including chest pains and shortness of breath. See Workwell Foundation information: https://bit.ly/2RHw5gm

EXAMPLES OF ISSUES THAT LEAD TO ER VISIT

Pain - Headaches and severe widespread pain can be a downstream effect of several core features of ME. ME pain can reach extreme levels and **may require strong medications to sufficiently alleviate pain**. Research has shown brain inflammation and central nervous damage may be involved. Suicide from unrelieved pain and ongoing suffering from multisystem issues is a significant cause of death in this patient population. (pgs 3, 4 & 5)

Gastro-intestinal tract is affected causing nausea, abdominal pain, bloating and irritable bowel syndrome. Chronic enterovirus of the stomach, intestinal dysbiosis and hypermeable gut should be considered. (pg 6)

Genitourinary issues such as urinary urgency or frequency and excessive urination at night are common. Bladder infections may occur without normal signs such as fever. (pg 18)

Ocular system is affected leading to inability to focus, blurred vision, night blindness and temporary blindness. (pg 7)

Symptoms for medical issues may not present normally - Many patients will not have a fever during infections. Other signs and symptoms normally associated with bacterial or viral infections or other health issues may not be present. Gallbladder issues is one area that may cause illness or GI issues, but does not present with normal symptoms.

UNDERSTANDING ME EXPERIENCE
ME patients suffer a living death that is life changing and, in most cases, lifelong. These patients need to avoid many activities a normal person would undertake, including social interaction. Progression of ME is not well understood but a significant percentage may become so ill as to require a caregiver and a subgroup may require 24/7 care and tube-fed.

IMPORTANCE OF REST

"Those patients who are given a period of enforced rest from the onset have the best prognosis... Those who, on the false assumption of 'neurosis', have been exhorted to 'snap out of it' and 'take plenty of exercise' the condition finally results in a state of constant exhaustion... Any excessive physical or mental stress is likely to precipitate a relapse." Dr. Ramsay stated about ME in 1986

ME has one of the lowest health-related quality of life scores of any disease.

"The condition can be as disabling as multiple sclerosis, rheumatoid arthritis, systemic lupus erythematosus and congestive heart failure." The Health-Related Quality of Life for Patients with ME/CFS (2015)

For detailed information see the International Consensus Criteria for Myalgic Encephalomyelitis and the International Consensus Primer for ME. Links can be found at www.MEadvocacy.org/resources