

After Your Diagnosis

Living with Myalgic Encephalomyelitis



We're Here for You

Facing a diagnosis of a complex, chronic illness can be overwhelming and a relief at the same time. Relief because now you have a name for your complex symptoms. In addition, there are symptomatic treatments that your doctor can recommend and steps that you can take to make your illness more manageable. The goal of this booklet is to help make life more manageable by providing you with practical information that will help you live better with your illness.

Learn About ME/CFS

- ▶ What is ME/CFS?: A combination of myalgic encephalomyelitis and chronic fatigue syndrome
- ▶ ME - myalgic encephalomyelitis meaning: myalgic - muscle, encephalo - brain, myelitis - inflammation of the spinal cord
- ▶ ME is a complex systemic disease
- ▶ Most individuals with ME experience a sudden onset of the disease after an acute illness
- ▶ Symptoms may relapse and remit throughout the day or remain nearly the same for months, years, and up to a life-time
- ▶ Approximately 30% of individuals with ME are bedbound and experience a severe illness that requires extensive help with daily living



Primary Symptoms

- ▶ Profound fatigue
- ▶ Post exertional malaise PEM, a worsening of symptoms after minimal physical or mental exertion.
- ▶ Cognitive impairment or difficulty with short term memory or word retrieval
- ▶ Disordered sleep
- ▶ Flu-like illness with tender lymph nodes, sore throat, headache, etc.

Other Physical Symptoms

- ▶ Gastrointestinal distress
- ▶ New onset or severity levels of allergies in food, medication, and the environment
- ▶ Frequent persistent infections or reinfections (altered immunity)
- ▶ Difficulty remaining in an upright position, racing heartbeat, feeling faint (dysautonomia)
- ▶ Sensory sensitivities

Comorbid Conditions

- ▶ Fibromyalgia
- ▶ Irritable bowel syndrome
- ▶ Ehlers–Danlos Syndrome (EDS)
- ▶ Mast Cell Activation Syndrome (MCAS)
- ▶ Dysautonomia
- ▶ Multiple chemical sensitivities
- ▶ Autoimmune diseases
- ▶ Prolapsed mitral valve
- ▶ Migraines
- ▶ Reactive depression

Dysautonomia

Refers to problems with the autonomic nervous system (ANS). The ANS controls involuntary body functions including your heartbeat, breathing, and digestion. Many of the symptoms one experiences with ME, can be attributed to dysautonomia such as feeling faint, inability to maintain an upright position, racing heartbeat, low blood pressure, difficulty breathing, constipation, bladder problems, etc. To learn more about dysautonomia visit: my.clevelandclinic.org.

It's Up To You

There are areas in your life that you can control despite your illness

- ▶ Learn about the disease process
- ▶ Choose a care-partner to help support you.
- ▶ Decide how to best discuss your illness with your family members
- ▶ Plan your work and social activities to avoid PEM
- ▶ Create a medical support team with your primary doctor to aid you through the challenges of your illness



- ▶ Give yourself permission to mourn the loss of your previous level of health
- ▶ Acknowledge the limits your illness places on your health and energy levels
- ▶ Seek professional support to help you cope with your illness
- ▶ Talk with your care-partner about your feelings
- ▶ Encourage your family to express their concerns with you

Accepting Your New Reality

- ▶ Give yourself permission to take time to heal, but realize **YOU ARE NOT YOUR ILLNESS**
- ▶ Create a plan for your daily activities that allows for rest and healing.
- ▶ Discuss your specific needs for help with activities that have been your responsibility
- ▶ Discuss your limitations and specific needs with the rest of your family
- ▶ Adjust your daily activities so that you stay within your energy envelope, and avoid a crash (PEM)





This information was prepared by Annette Whittemore and reviewed and approved by Dr. Kenny De Meirleir. WPI is proud to be a source of information about ME/CFS. Our comments are based on professional advice, published experience, and expert opinion. This booklet is not intended to replace a doctor's care.

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