MYALGIC ENCEPHALOMYELITIS
USING A PULSE OXIMETER

Heart rate (HR) numbers outside of typical readings is often an indicator of post-exertional neuroimmune exhaustion (PENE) or impending PENE. Recording HR and oxygen can provide your doctor with objective measurements to better understand ME and PENE.

> *"PENE is characterized by a pathological low threshold of physical and mental fatigability, exhaustion, pain, and an abnormal exacerbation of symptoms in response to exertion."*
>
> (ME IC Primer pg 2)

Adequate rest is important to minimize PENE. The amount of rest needed varies for each person. Severe ME patients often cannot rest enough to lower HR or avoid PENE.

Recording HR and oxygen levels on the chart provided on page 4 in this handout can help find baseline readings for rest, during activity, and post-activity. This specific information can help medical professionals better understand that typical measurements for HR and oxygen may not apply to patients with ME and help them recognize the unique aspects of ME. Because PENE may be delayed by 24 to 72 hours, it is important to record readings over at least a few weeks to show patterns of delayed reaction.

Examples:

- A person with ME may typically show 99% oxygen level but during PENE it may be lower.
- Typical resting HR may be in the 50s or 60s, but during PENE (or going into PENE) the resting HR may be much higher.

A benefit of knowing your baseline is when readings show a change it is an indication that aggressive rest may be needed to minimize even more exacerbation of symptoms.

TIPS FOR MEASURING OXYGEN:

- Dark nail polish may interfere with the meter's reading.
- Typical normal is about 95% or above and below 90% is considered low.

IMPROVING OXYGEN INTAKE:

Dr. Paul Cheney gives the following tips for improving oxygen intake in people with ME.

- Inhale through your nose for four seconds.
- Hold your breath for seven seconds.
- Exhale through tightly pursed lips, creating "back pressure," for eight seconds.
- Do this eight times, twice a day, every day.

See details in "DR. CHENEY: Increase Your Oxygen Intake" by By Carol Sieverling HERE.

NOTE: Many patients with ME do not tolerate added oxygen. "ME patients cannot deal with increased O2 throughput (required to make energy via aerobic metabolism) and therefore their bodies restrict it to prevent oxidative damage." https://mdwme.blogspot.com/2013/04/dr-paul-cheneys-latest-observations.html

Information provided is not to be considered as medical advice.

TIPS FOR MEASURING HEART RATE:

- Estimating HR limit or safe zone is difficult. A suggestion from Mark VanNess of Workwell Foundation is to use 15 beats per minute (BPM) above resting HR. See the PACING video here: https://workwellfoundation.org/educational-videos/
- Typical HR during the day for a healthy person is listed as between 60 and 100 BPM.
- It is important to take multiple measurements at rest and during activities over several days to find a baseline.
- Avoiding HR outside of safe zone can help minimize PENE.
- Elevated HR at rest may be an indicator of PENE and indicate rest is needed.
- By recording morning resting HR over time, patterns can be seen to watch for PENE as well as a way to monitor baseline HR to watch for improvement or deterioration.
- **Pacing by Numbers: Using Your Heart Rate To Stay Inside the Energy Envelope** discusses importance of recording morning heart rate. http://www.cfsselfhelp.org/library/pacing-numbers-using-your-heart-rate-to-stay-inside-energy-envelope/
- An increase of more than 30 BPM within 10 minutes of standing can be an indicator of postural orthostatic tachycardia syndrome (POTS) and should be noted for referral to a dysautonomia medical professional. (See info at www.dysautonomiainternational.org & http://standinguptopots.org)

UNDERSTANDING HEART RATE ISSUES IN ME

From the ME IC Primer:

- "A heart rate monitor can assist in keeping cardiovascular responses below the anaerobic threshold." (pg 15)
- Resting heart rate is elevated in pwME. (pg 3)
- Low blood volume can lead to elevated heart rate. (pg 18)
- Elevated heart rate may be connected to orthostatic intolerance. The IC Primer (pg 18) lists the following possible pathological components.

  - **cerebral hypoperfusion**
  - **dehydration**
  - **decreased cardiac output**
  - **reduced circulating red cell count**
  - **reduced plasma volume**
  - **reduced ability of the blood to carry oxygen to the brain**
  - **decreased venous return**
  - **neck problems**
  - **medication**
  - **low ADH**
  - **CNS disorder.**

Links to the ME IC Primer in multiple languages at: www.me-international.org/primercheat-sheets

Find information for non-pharmaceutical and pharmaceutical recommendations for managing orthostatic intolerance on page 18 of the IC Primer.

While most pulse oximeters do not have the capability to beep to warn when going out of a set range, it can be worn during activity to check HR in order to help avoid exceeding safe zone. More sophisticated HR monitors will beep and can provide heart rate variability which may provide useful information.

LEARN MORE AT THESE LINKS:

- **Video with Mark VanNess from the Workwell Foundation** explains the science behind the danger for people with ME to do activity outside their safe threshold. https://www.youtube.com/embed/FXN6f53ba6k

- **Cardiopulmonary responses to exercise in an individual with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome during long-term treatment with intravenous saline: A case study.** *"IV saline may promote beneficial effects for cardiopulmonary function and symptoms in people with ME/CFS, which should be the focus of formal study."* https://workwellfoundation.org/wp-content/uploads/2020/08/Davenport-et-al-2020_Cardiopulmanary-responses-to-exercise-in-MECFS-with-IV-saline_A-case-study.pdf

- **Blunted heart rate and implications for pacing in ME/CFS** *Chronotropic incompetence (CI) – the inability of the heart to keep pace with increased activity – is common in myalgic encephalomyelitis (ME/CFS)* https://chronicallycaroline.com/2020/08/29/blunted-heart-rate-and-implications-for-pacing-in-me-cfs/

- **ME Cardiologist Handout can be found at:** https://www.me-international.org/primercheat-sheets.html which includes information about heart abnormalities found in ME. This handout also includes more HR and BP tracking forms.

- **Evidence of altered cardiac autonomic regulation in ME/CFS – A systematic review and meta-analysis (2019)**
  "The differences in HR parameters identified by the meta-analysis indicate that ME/CFS patients have altered autonomic cardiac regulation when compared to healthy controls. These alterations in HR parameters may be symptomatic of the condition."
  https://journals.lww.com/md-journal/Fulltext/2019/10250/Evidence_of_altered_cardiac_autonomic_regulation.36.aspx

More information can be found at www.ME-International.org on the patient resources page.

NAME _____ DATE _____

CHART TO FIND BASELINE HR & OXYGEN LEVELS

Having ME will make it difficult to take a daily measurement,
so filling in what you can when you can is a good goal.

RESTING HR & OXYGEN READINGS TAKEN FIRST THING IN MORNING

	MON	TUE	WED	THU	FRI	SAT	SUN
HR/OX							
HR/OX							
HR/OX							
HR/OX							

HR/OX DURING & AFTER ACTIVITY

DATE/TIME	ACTIVITY	FUNCTION LEVEL (SYMPTOMS)	HR/OX

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