# Orthostatic Intolerance (OI) Orthostatic Hypotension (OH) Neurally Mediated Hypotension (NMH) Postural Orthostatic Tachycardia Syndrome (POTS)

NMH, OH, POTS and OI are terms used to describe dizziness upon standing, a drop in blood pressure, and/or abnormal heart rate response----either increased or decreased---while in an upright position. While the phenomenon is complex and not fully understood, the usual signals or mechanisms that maintain blood vessel tone, heart rate and contractility while changing positions from lying to standing don't work correctly. This leads to venous pooling, decreased blood return to the heart, and lower cardiac output to the brain and body. Some people are aware of symptoms that occur during the episode, such as dizziness or palpitations (a sensation of increasing heart rate or intensity of each heart beat), and others are not. The body compensates in varied ways for these changes. On occasion, the person actually faints. Others develop rapid heartrate (tachycardia.) NMH, POTS, OH are common manifestations of OI in Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FM).

#### **Common triggers:**

- Prolonged periods of quiet upright posture (such as standing in line, washing dishes, or sitting for long periods)
- Being in a warm environment (such as in hot summer weather, a hot crowded room, a hot bath or shower)
  - Heat dilates blood vessels and also triggers loss of fluid and electrolytes in sweat, since evaporation is a natural cooling mechanism. These combined events may dramatically aggravate symptoms.
- Exercise, or immediately following exercise
- Emotionally stressful events
- Eating, in some individuals, when blood flow has shifted to the intestinal circulation during the process of digestion
- Certain medications

# Symptoms:

- Recurrent lightheadedness and fainting after standing or squatting
- Headaches
- Mental confusion including difficulty concentrating, staying on task, paying attention, or finding the right words
- Chest or abdominal discomfort, nausea
- Cold hands and feet
- Chronic fatigue
- Muscle aches

# Treatments

#### **Orthostatic Intolerance adaptations:**

- 1. Increase daily intake of sodium and water:
  - Drink at least 2 liters of water or other (Eight 8-ounce glasses equals about 2 liters. A large soda bottle is 2 liters). Drinking water alone is not enough. It is important to combine and balance water with salt. Eating salt alone will draw water from cells into the blood stream, causing cell dehydration. Water consumed alone is simply eliminated to avoid dilution of the normal body salts.
    - Minimum of 1 glass with meals, at least 1 glass x 2 at other times, AND 1 glass upon arising in the morning
    - Half of the fluid intake should be composed of an electrolyte drink (e.g. Pedialyte)

# 2. Increase sodium intake

- Salt helps us retain fluid and maintain a healthy blood pressure
- Consume 3- 5 grams (3000-5000 mg) daily (1 tsp = 2.3 gm, 2300 mg)
  - Select foods with high sodium content: canned soups and vegetables, V8, broths, pickles, and additives such as soy sauce and dressings
  - Supplements can help you towards your goal:
    - Over-the-counter sodium chloride salt tablets (0.5 1 gm) may be used but may produce some stomach upset, ALWAYS take with a meal and plenty of water
    - Nuun/Gu tabs found in athletic stores
    - Recipe for "homemade" Pedialyte (make your own variations) 1 liter water
      - 1 tablespoon salt
      - 2-3 tablespoons sugar
      - ½ packet Kool-aid (any flavor) or 1 Tbsp Jello powder

#### 3. Wear compression clothing

- Wear knee high compression socks at a minimum
- Combine knee high socks with tight exercise shorts, compression athletic wear or yoga pants
- Waist-high compression stockings
- These work BEST if put on before getting out of bed and taken off when lying down

# 4. Exercise – reverse deconditioning of the cardiovascular system!

- $\circ$  This may be better tolerated when considering the impact of upright posture
- Take advantage of hydrostatic pressure by exercising gently in deep water or chose exercises that can be done in a supine position to avoid aggravating OI
- o Hydrate well beforehand and wear compression clothing during exercise
- Should include both resistance training + a low level cardiovascular exercise regime:
  - Cardio:
    - Start with a recumbent bike or swimming for 5 to 10 minutes daily
    - Transitioning to upright (challenging gravity) as able
    - Work up to 30 minutes of exercise if possible
    - Short intervals, combined with rest are okay
  - Light weight lifting or strength training focus on resistance training to strengthen leg muscles and abdominal muscles
    - Avoid heavy lifting or exercising in hot, humid environments
    - Afternoon exercise may be better tolerated

# 5. Eat small, but frequent meals

Avoid alcohol in general because it causes vasodilation.
Avoid caffeine or exercise within an hour after a meal

# 6. Possible medications to regulate blood pressure

- **Propranolol** 10-20 mg before bed or two to three times daily (or other beta blockers)
- Fludrocortisone is a drug similar to aldosterone, a hormone made in the adrenal glands that encourages retention of salt and water. One double blind study of CFS patients with NMH showed marginal benefit and some mild adrenal suppression. Light potassium supplementation is advisable, since sodium is retained as potassium is excreted. The effects are helpful but not always sustained.
- Midodrine is a medication that acts on peripheral alpha receptors and increases blood pressure by constricting arterioles (small arteries). It is often helpful for NMH, especially in combination with salt/water loading. The dose range of midodrine is 2.5 to 10 mg three times daily (every 3-4 hours), with the 10 mg being the most effective. It is generally well-tolerated. The most common side effects are tingling or itching in the fingers, toes and scalp from constricted blood vessels as the drug kicks in. But dizziness, fatigue and/or palpitations when then dose is wearing off (when the low blood pressure suddenly returns) about four hours after taking it are common also. It is important to take this medication only when planning to be in an upright position, sitting or standing, for several hours. The last dose should be taken no later than four hours before lying down in bed at night. Blood pressure stabilizes when supine (lying down) and

midodrine is not necessary. Contraindications to midodrine are high blood pressure and previous allergic reaction to the medication.

- **Droxidopa (Northera).** Approved for neurogenic orthostatic hypotension and very expensive. \$15,000/mo
- Pyridostigmine (Mestinon). A medication used to treat <u>myasthenia gravis</u> that blocks the action of <u>acetylcholinesterase</u> and therefore increases the levels of <u>acetylcholine</u>, a neurotransmitter at the neuromuscular junction and of the parasympathetic nervous system. Common side effects include nausea, diarrhea, frequent urination, and abdominal discomfort. Used off-label to treat orthostatic hypotension and POTS. The doses range from 30-60 mg every 4-6 hours to much higher depending on tolerance and response.

#### 7. Maneuvers as needed to address worsening symptoms:

- 1. Rapidly drinking two 8-ounce (500 mL) glasses of cold water can help if done before:
  - Prolonged standing is expected (for example shopping)
  - Any circumstance that may produce symptoms (for example: before a walk, exercise, or taking a shower)
- 2. Postural counter-maneuvers can help prevent fainting
  - Contracting abdominal and buttock muscles for 30 seconds
  - Leg crossing and bending at the waist
  - Raising on toes
  - Isometric contraction of stomach, thigh, and buttock muscles
  - Slow marching in pace
  - o Squat
  - Lie down and elevate feet

#### Web Resources:

- Dysautonomia Information Network <a href="http://dinet.org/">http://dinet.org/</a>
- Dysautonomia International <u>http://www.dysautonomiainternational.org/</u>