## PATIENT INFORMATION BROCHURE ON

## **NEURALLY MEDIATED HYPOTENSION AND ITS TREATMENT**

Neurally Mediated Hypotension Working Group Johns Hopkins Hospital Revised October 1995

This document has been prepared for those who have requested further information about neurally mediated hypotension.

\_What Is Neurally Mediated Hypotension?

Neurally mediated hypotension is also known by the following names: the fainting reflex, neurocardiogenic syncope, vasodepressor syncope, the vaso-vagal reflex, and autonomic dysfunction. Hypotension is the formal medical term for low blood pressure, and syncope is the term for fainting.

Neurally mediated hypotension occurs when there is an abnormal reflex interaction between the heart and the brain, both of which usually are structurally normal.

\_When Does Neurally Mediated Hypotension Lead To Symptoms?\_

Neurally mediated hypotension occurs in susceptible individuals in the following settings:

\* after prolonged periods of quiet upright posture (such as standing in line, standing in a shower, or even sitting up for long periods),

\* after being in a warm environment (such as in hot summer weather, a hot crowded room, a hot shower or bath),

\* after exercise,

\* after emotionally stressful events (seeing blood or gory scenes, being scared or anxious).

\* some individuals get symptoms soon after eating, when blood flow has shifted to the intestinal circulation during the process of digestion.

We are all susceptible to NMH, but each person's susceptibility is affected by his or her genetic makeup, dietary factors, psychological make-up, and acute triggers such as infection. The clinical problem of NMH occurs when there is early triggering of this reflex.

\_How Does Upright Posture Lead To These Problems?\_

After a normal individual stands up, blood pools in the legs through the effect of gravity. To compensate for the lower amount of blood returning to the heart immediately after standing, the body has a surge of adrenaline (epinephrine). This adrenaline surge leads to a faster heart rate and to more vigorous heart beats (a familiar feeling we all experience when we are frightened, for example). The faster heart rate and more vigorous heart contractions allow the reduced amount of blood returning to the heart to be pumped more efficiently to vital organs (especially the brain).

In individuals with neurally mediated hypotension, there is a "miscommunication" between the heart

and the brain. Just when the heart needs to beat faster, (to pump blood to the brain and prevent fainting), the brain sends out t he message that the heart rate should be slowed down, and that the blood vessels in the arms and legs dilate. These actions take even more blood away from the central part of the circulation where it is needed. In response, individuals feel lightheaded or may faint because not enough blood is getting to the brain. Fainting is helpful, in that it restores a person to the flat position, removing the pooling effect of gravity on the blood, and allowing more blood to return to the heart.

Following the lightheadedness or syncope, most individuals feel tired and their mental abilities are somewhat foggy.

\_Which Symptoms Can Be Caused By The Neurally Mediated Hypotension?\_

Recurrent lightheadedness and fainting are common symptoms, as is an unusual difficulty with prolonged fatigue after a modest amount of physical activity. This post-exertional fatigue can last 24-72 hours, and interferes with many daily activities.

We have also observed that chronic fatigue, muscle aches (or fibromyalgia), headaches, and mental confusion can be prominent symptoms of neurally mediated hypotension even in individuals who do not faint. The mental confusion takes the form of difficulty concentrating, staying on task, paying attention, or finding the right words. Some describe being in a "mental fog." It appears that as long as the fainting reflex is activated whenever the person stands or sits upright for a period of time, then the blood pressure is improperly regulated, and these symptoms are the result.

\_How Is Neurally Mediated Hypotension Diagnosed?\_

Neurally mediated hypotension cannot be detected with a routine blood pressure or heart rate screening. A device called a tilt table is the only known means of diagnosis.

Many people with neurally mediated hypotension develop adaptations to keep from fainting, such as sitting or lying down when they get lightheaded or tired, but the tilt table test prohibits them from performing those natural defenses. As a result, lightheadedness, nausea, and fainting often occur to patients during the tilt table test. Fatigue and malaise often occur for a few days after the test is performed.

\_What Causes Neurally Mediated Hypotension?\_

The answer to this question isn't well understood at present, but we suspect neurally mediated hypotension has genetic origins in many people, because it is not uncommon for us to find several individuals with neurally mediated hypotension in the same family. No gene for this condition has been identified. It is likely that we all could develop neurally mediated hypotension provided that the conditions were sufficiently severe: for example, if we did not take in enough fluids or salt, were subjected to extremely prolonged periods of upright posture, or to very warm environments. The reflex response which results in lowered blood pressure may simply occur at an earlier point in some individuals.

One of the most common, and treatable problems identified in those with neurally mediated hypotension is a low salt (sodium) intake in the diet. Salt helps us retain fluid in the blood vessels, and helps maintain a healthy blood pressure. Salt has received bad press in the last couple of decades because a \_high\_ salt diet in some individuals with high or high-normal blood pressure can contribute to further elevations in blood pressure, and thereby to heart disease and strokes. This has led to general health recommendations to "cut down on salt." As we are finding, this general recommendation isn't right for all people.

An average blood pressure is 120/70, and a blood pressure is considered elevated if it is above 140/90. For individuals with neurally mediated hypotension, some of whom have low or low normal blood pressure (with systolic blood pressures [the top number] being between 90-110), a low salt

intake may be unhealthy, and may move them from feeling good to developing the symptoms of fatigue and lightheadedness described earlier.

In experimental work earlier this century, severe short term salt depletion led to fatigue and mental dulling in the adult research subjects.

\_How Is Neurally Mediated Hypotension Treated?\_

Neurally mediated hypotension is most often treated with a combination of increased salt and water intake in conjunction with drugs that regulate blood pressure. Some drugs work by allowing the kidneys to retain sodium and others block the body's response to adrenaline, which can kick-start the blood pressure abnormality. In addition, it is important to review your current medications with your doctor to ensure that these medications do not include drugs or vitamins that have the potential to make neurally mediated hypotension worse.

We want to emphasize, however, that the treatments require persistence, commitment and the willingness to try several possible drugs and combinations over an extended period of time. Because there is a risk of serious side effects with some of the drugs such as elevated blood pressure, elevated sodium levels, lowered potassium levels, or depression, careful monitoring by a physician is required.

Your treating physician should work with you to determine the best possible combination for your personal situation. In general, however, the first step in treating this problem is to increase fluid intake. We cannot stress this enough. Our patients who have discovered the importance of drinking fluids regularly throughout the day seem to do better than those who don't take this task seriously.

For those who have been on a low salt intake we recommend an increase in the amount of salt they add to their food. The Appendix to this document contains a list of high salt foods, but specific foods are now conveniently labeled with sodium content for you to check. For some mildly affected individuals, an increased intake of salt and fluids may be all that is needed. Most of those with chronic fatigue syndrome and more severe symptoms require one of several medications in addition to the increased salt and fluid intake.

To be successful, though, the increased salt intake must be accompanied by a sufficient increase in the intake of water and other fluids (minimum of 2 liters of fluid per day). The Appendix also describes some of the drugs used for treating neurally mediated hypotension.

\_Does Treatment Cure The Problem?\_

It needs to be emphasized that, when successful, the medications for neurally mediated hypotension do not \_cure\_ the problem. Rather, they help control symptoms. When medications are stopped and when salt intake is reduced, symptoms frequently reappear. Many of the adolescents and adults with the problem also have symptoms resurface or worsen at busy or stressful times (making an oral presentation in class, having company over for Thanksgiving, rushing for a meeting on a hot day and forgetting to drink). Many women describe a worsening of symptoms in the days around the start of a menstrual period.

The question of what happens over the long term has not been adequately studied, and the optimal duration of medical treatment is still being worked out. Unfortunately, despite appropriate doses of the available medications for neurally mediated hypotension, some individuals with abnormal tilt table tests do not experience an improvement in symptoms, and some are intolerant of the medications. This emphasizes the need for more research on this problem. Many women who have NMH describe an improvement in symptoms when they have been pregnant, and often describe pregnancy as the time when they felt "the best ever." The improvement may be due to an expansion of blood volume that occurs with pregnancy.

\_What Other Things Can I Do To Get Better?\_

Where practical, avoid circumstances which might bring on symptoms. For example, shop at non-peak hours to avoid long lines. Take shorter showers and baths and aim for a cooler water temperature. Avoid saunas, hot tubs, and lying on a hot beach. Avoid standing still for prolonged periods in hot environments, and on very hot days. Flex your leg muscles and shift your weight when you are standing still. You may also want to avoid alcohol because it often leads to dilation of the veins, and this can "steal" blood away from the central circulation. Most with neurally mediated hypotension are guite intolerant of alcohol.

We have adopted the recommendation from the literature on the related problem of orthostatic hypotension to elevate the head of the bed slightly (10-15 degrees, a position that appears to help the body retain fluid at night rather than lose fluid into the urine. Depending on one's level of comfort with this form of dress, waist-high support hose can prevent some of the excessive pooling of blood in the legs (knee-high support socks may not work as well).

Again, we want to emphasize strongly that a key part of the therapy is to increase fluid intake. Those who force themselves to drink extra fluids every couple of hours seem to do better than those who aren't as serious about increasing their fluid intakes. Keep in mind that prolonged periods of sleeping (more than 12 hours) may interfere with your ability to attend to your fluid needs on as regular a basis as would be ideal

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