

NEURO-CARDIOGENIC SYNCOPE

Patient Information

Neurocardiogenic Syncope, Postural Orthostatic Tachycardia Syndrome (POTS), Dysautonomia, and Vasovagal syncope all can refer to the same phenomenon. Despite what name they go by, the cause and treatment are essentially the same, and for practical purposes, not worth differentiating. Below, they will all be referred to as Neurocardiogenic Syncope.

Neurocardiogenic syncope is most commonly discovered in adolescents and in older adults. It is essentially a failure of the brain and the cardiovascular system (blood vessels) to adequately communicate and respond to each other. This is not a "heart problem" or "heart defect". Because of the way people are made, it is "easiest" for blood to pool in the extremities. It requires "work" (messages sent by the brain, contraction of blood vessels pumping of the heart) to send blood to our heart and brain. There are a number of forces that work against blood returning to the central part of the body (vital organs and brain): gravity, amount of fluid in the vessels, dilation of the vessels, neurotransmitters (chemicals in the brain that allow nerves to communicate) available to convey messages from the brain and even barometric pressure. In addition, people who have this diurese urinate or lose body water more than they should. This leaves less fluid in the blood vessels.

For most people, this process of returning the blood to the central part of the body works efficiently and without our notice, just like breathing. When this process does not work well, symptoms can be experienced such as: dizziness, lightheadedness, fainting, headache, neck/back pain, visual disturbances, difficulty breathing, chest pain, heart racing, sweating, feeling too hot or too cold or rapid swings in body temperature, nausea, abdominal pain, GI problems, muscle aches or pains, fatigue, depression, inappropriate or exaggerated emotional responses, to name a few.

Unfortunately, it is not obvious from looking at someone that they have this. Because there are so many factors that affect blood return to the central organs, an affected person may be fine one moment and have significant trouble the next. Also, if someone has had this condition for a long time, they may not know that what their body does is abnormal - sort of like not noticing when your eyesight slowly decreases.

Many people who have this have been told that they are "crazy" because a doctor cannot find anything physically wrong to explain a symptom that they are having (i.e. no infection to explain fatigue, or nothing wrong with their abdomen to explain severe pain). Many doctors do not know about this condition because it was not well understood until 1989, and at that time, only the most severe cases were identified - those people that passed out frequently. Now we know that you have this condition even if you do not pass out.

Some people get Neurocardiogenic syncope abruptly in their teenage years and it leaves just as abruptly. Some people have this "forever" but the symptoms wax and wane, so that you are not always symptomatic and do not always require treatment. For some, Neurocardiogenic syncope is hereditary and for others it is not. Do not be surprised if someone else in your family has some of the same symptoms you do. Not everyone has this to the same degree. It can range from very mild to completely incapacitating (bed ridden). There is nothing that anyone did to "cause" this and nothing that could have been done to prevent getting it. It just is.

There are objective ways to identify this condition besides symptoms: changes in blood pressure and/or pulse between sitting and standing (stress of gravity), and a tilt table test. The tilt table test provides prolonged gravitational stress to the cardiovascular system and eliminates some of the ways that the brain counteracts those stresses. The patient's blood pressure and pulse, as well as other indicators and symptoms, are monitored during this test.

Treatment consists of understanding the problem, salt, fluid, caffeine, and prescription medications. Knowing that you have this condition and what makes the symptoms better or worse is the most important step. Physical illness, psychological stress, allergies (histamine causes blood vessels to dilate), dehydration, and barometric pressure changes (including flying or high altitude), make symptoms worse.

Position is important because of gravity. You will have fewer symptoms when sitting or laying down than when standing. If still symptomatic laying down, get your legs higher than your heart (prop them up on a pillow or the arm of the couch). Moving your muscles helps, too, because this squeezes the blood vessels and helps return the blood to the brain. (This is why many of us sway, wiggle, or squeeze our calves when standing). Good cardiovascular health is important, too; it will decrease symptoms. Regular aerobic exercise should be done for 40 minutes at least three times a week, when it can be done without creating symptoms. Take warm or cool showers/baths instead of hot. When you are hot, the blood vessels in your arms and legs dilate in order to cool you down. Dilated blood vessels keep more blood away from your central organs and make you more symptomatic. If you sleep without clothes on, you will have less trouble with temperature swings at night.

People with Neurocardiogenic syncope need much more fluid and salt every day than "normal" people (*who need > 64 oz. per day*). When feeling symptomatic, even more fluid and salt is needed. Fluids are important so that there is enough volume in the blood vessels to make it to the brain. It is like trying to fill a sink without having a stopper in the drain. It can be

done, but it takes A LOT of fluid. Salt helps keep fluid in the blood vessels longer. Caffeine raises the blood pressure to help get the blood back to the brain. If you have a normal heart and kidneys, extra salt and caffeine cause NO problems, and, in fact, will HELP you A LOT. When you are symptomatic, sit down and drink a can of pop or gatorade and take some salt. In 15 minutes, although your symptoms will not be completely gone, you will feel much better. The sooner you treat your symptoms, the easier it is to make them go away. The longer you ignore them, the harder it is to get rid of them (it will take A LOT more salt, fluids and caffeine). The way you get the salt, fluids, and caffeine down is less important than that you do. You can drink Mountain Dew, eat potato chips, and M&Ms or you can drink water and eat salt out of your hand. Your choice, JUST DO IT! Some tips from those with daily experience:

- Of the sports drinks, Gatorade has the most salt.
- A salt packet added to 20 oz. of Gatorade or pop does not change the taste.
- Keep an "emergency kit" with you at all times (salt packets, chocolates).
- Carry (and drink) fluids with you at all times.
- Plan ahead: if you know something is going to happen that will give you more symptoms (storm, standing in line, allergies), salt and fluid load ahead of time and also during the stressor.
- Do not overdo it; plan time to take care of yourself and get enough sleep.
- When your allergies are acting up, take an antihistamine (even if it doesn't help your nose), to block the histamine effect of the allergic response.
- Ask someone else to give you feedback - it is usually obvious to others that we are symptomatic before we recognize it (we get cranky and pale).

Several medications can be prescribed and these will be tailored to your needs:

Florinef: This is an alpha-adrenergic receptor sensitiser, which means that it helps the blood vessels return the blood to the brain. It is taken twice a day and takes up to 2 - 3 weeks to see its full effect. People who do not have a good intake of potassium may require a supplement.

SSRI: This is a group of medications which help the Serotonin balance in the brain. Serotonin is a neurotransmitter in the brain - it controls: blood pressure, heart rate, body temperature, menstrual periods, etc. Many people with Neurocardiogenic syncope do not have adequate stores of Serotonin. These medications restore that balance. SSRI's include: Serzone, Zoloft, Prozac, Paxil, and Effexor. You may have heard of these medications being used to treat depression. This is NOT why you would be receiving these medications. These medications are taken once or twice daily, and may take 4 - 6 weeks to see their full effect. They are started at low doses and increased as indicated.

Ritalin / Proamitine: Ritalin and Proamitine work by causing vasoconstriction (squeezing of the blood vessels). Proamitine does not have the stimulatory effect on the brain that Ritalin does. For those that have trouble with memory / concentration (also a symptom), the Ritalin can be very helpful. It is not given in as high doses as that used for people with Attention Deficit Disorder though. Ritalin and Proamitine have a quick onset of action and are short acting. This means that they start working

within 30 minutes of the time that you take it and stop working in 4 hours. They are commonly prescribed to be taken when you get up and then every 4 hours for a maximum of 3 doses /day (Ritalin) or 4 doses/day (Proamitine). Ritalin is not taken after 4 p.m. because it may keep you awake at night. Proamitine is not taken after 8 p.m. An example of a dosing schedule would be 8 a.m., 12 noon, 4 p.m. (Ritalin) or 8 a.m., 12 noon, 4 p.m., 8 p.m. (Proamitine). The advantage of these medications is that you receive quick relief; and if you miss a dose, it does not have any consequence except that you may be symptomatic until you remember to take your pill. (If you miss a dose of Florinef or SSRI, it will decrease your blood level and it will take awhile to get back to the right blood level.) So you can sleep in on the weekend and just take your first pill when you get up. For those of you who have a hard time getting out of bed, taking your Ritalin or Proamitine 30 minutes before you want to get up will make the process easier.

Biofeedback is also a treatment option. You can train your blood vessels to constrict when you want them to and return the blood to your brain. Ibuprofen has some activity against Neurocardiogenic syncope. For this reason, if you can tolerate Ibuprofen, this is a better choice for aches and pains than Tylenol.

Motivation is critical. When we HAVE to do something important, our adrenaline kicks in and helps control our symptoms. Once you are up, active, and out of the house, you are less symptomatic because of the adrenaline and your muscles are helping return blood to your brain. When we are very symptomatic, we do not feel well enough to motivate ourselves to get up/drink/salt/caffeine. It is easier to give in to feeling horrible, and lay on the couch, and feel like we cannot get up to drink, etc. It is important to plan reasons to leave the house everyday ahead of time; things you cannot "weasel" out of if you are feeling under the weather.

Neurocardiogenic syncope can be controlled. The more quickly you learn to recognize your symptoms and treat them appropriately, the quicker you will feel better (it takes A LOT of salt and fluid). Medication will be added to control your symptoms, it does take time to see the effects of medication, so be patient. You have had this for awhile, and it cannot be controlled "overnight". Even when you are under good control, you may have occasional "bad days" when you will need to use LOTS more salt/fluids/caffeine than usual. This happens to all of us. Take them in stride, it does not mean that you are having a relapse.

Initially, your follow-up appointments will be scheduled as often as a medication adjustment can be made. The treatment goal is for you to be able to aerobically exercise for 40 minutes three times a week without symptoms (not just get off the couch without symptoms). At that point, your follow-up visits will be changed to every 6 months, and after one year we will try to take you off your medication.

If you pass out, you may not drive a car until you have not passed out for 6 months (you may also need a repeat tilt table test) and your physician completes a form for the Bureau of Motor Vehicles.