

POTS/Dysautonomia Treatment Plan

RECOMMENDATIONS:

1. Goal of at least 80 ounces of fluids per day of mainly water; spread throughout the day
2. Add salt to foods and have two snacks with salt daily
3. Try the compression stockings, see below
4. Recognize your symptoms and sit/squat/lie down to avoid passing out
5. Your urine should be clear during the day if you're drinking enough fluids
6. Goal of being physically active EVERY day, start slowly
7. Try elevating your head at night by 4-6 inches (put blocks under the bed frame) to see if this helps with the morning dizziness
8. Drink water and have something salty about 30 minutes before getting out of bed in the morning, if your dizziness is worse in the morning

If you don't have MyChart, please sign up for this, we prefer this route of communication with patients. Please see the code on this print-out or go to uwhealthmychart.org. This should not be used for urgent concerns.

If lab results were ordered, you should expect a call or mychart within 3 days, call if you haven't heard from us. 608-263-6420, option 2.

POTS EXPECTATIONS FOR RECOVERY AND TREATMENT

POTS and dysautonomia can cause many symptoms that can affect your daily life, which can be very frustrating. It can take a long time (sometimes months) to figure out what type of treatments and medications can improve your symptoms. Please be patient as we work with you to figure out what will help you return to your normal activities. If you have started a new medication, it can take a lot of time (sometimes weeks) to know if this medication will help.

In a study done at Mayo Clinic, 86% of patients have minimal symptoms 5 years after their POTS diagnosis, so there is hope that you will feel better!

DEFINITIONS AND COMMON SYMPTOMS

POTS - postural orthostatic tachycardia syndrome (fast heart rate and dizziness while upright)

Dysautonomia or autonomic dysfunction - the autonomic system of the body not working correctly

While dysautonomia symptoms can affect many parts of your body, these symptoms are not life-threatening. If you have urgent concerns about your symptoms, you may need to be seen in urgent care or the emergency room.

The autonomic systems is responsible for many things in the body, so when this isn't working correctly, there can be many resulting symptoms. Here are common symptoms:

- Dizziness/lightheadedness
- Fatigue
- Fast or abnormal heart rates
- Fainting
- Inability to exercise as you used to be able to do
- Brain fog (mental cloudiness/inability to concentrate well)
- Headaches
- Stomach symptoms: Abdominal pain, vomiting, nausea, diarrhea, constipation, early fullness

- Sensitivity to hot or cold
- Purple and splotchy arms and legs (venous pooling)
- Abnormal sweating - too much or too little

If you have bothersome headaches or stomach symptoms, please contact your primary care provider and they will contact me if needed. Sometimes referrals to our Headache Clinic and/or GI clinic may be needed.

FLUIDS

Increased fluid intake is one of the MOST important things to do to help your symptoms of POTS. This increases the amount of fluid in your body, making it easier for your blood to get to your head to help you feel less dizzy. You will not necessarily feel thirsty, but it's still important to keep drinking until you reach your daily goal of fluid intake.

You should drink at least 80 ounces of water throughout the day, more if it's hot outside or you're doing sports or exercise. This should be mostly water, some non-fat milk, and a maximum of 8 oz. of juice or sports drinks daily is fine to include. There are apps that can help you track your fluid intake and remind you if you're not drinking enough. Try the Plant Nanny app (free)!

SALT

Many people try to avoid extra salt in food. Most people need about 2300 mg of sodium daily. In people who get lightheaded, dizzy, or have POTS (postural orthostatic tachycardia syndrome), adding salt can sometimes help with their symptoms. Salt and sodium are often used in place of each other, but are different. One gram of salt has about 388mg of sodium.

A guideline is to aim for a total of 1 tsp of salt in the morning and 1 tsp in the early evening.

How can I add salt to my diet?

- **Sprinkle salt on your favorite foods.** 1/4 teaspoon of salt has 575 mg of sodium.

Try adding ¼ teaspoon of salt to:

- o Sliced cucumbers or tomatoes
- o Watermelon wedges
- o Sliced apple or banana with peanut butter
- o Scrambled eggs
- o Air-popped popcorn
- o Edamame (soy beans) or kale chips made with soy sauce

Choose salty drinks, aim for 80 oz. of fluids everyday. Fluids with extra salt are: tomato juice, tomato soup or warm broth. Drinks high in electrolytes, such as low calorie G2™, Powerade Zero™, and Propel™, can also be helpful (limit to 8 to 12 ounces per day). Make water your number one drink.

Enjoy a salty snack. High salt snacks include:

- o Baked potato chips or pretzels
- o Tortilla chips with salsa
- o Cottage cheese with tomato or fresh fruit
- o Beef or turkey jerky
- o Pickles
- o Olives
- o Salted nuts or seeds
- o Raw vegetables with dip

Salt Tablets/Pills

If your dizziness/fainting doesn't improve with salt in your diet, or your provider recommends them, some people can feel better by taking salt tablets or pills.

These can be purchased over the counter. Many pharmacies have salt tablets, 1 gram each. These should be taken with meals (can cause stomach upset), take 1-2 with each meal. Another type is called ThermoTabs, these can be easier on the stomach, take 2 with each meal.

Another type of salt tablet is Vitassium or Salt Stick, these also have other electrolytes. These include some other electrolytes along with sodium chloride (salt). Take 2 tablets with each meal. These can sometimes be better tolerated if the regular salt tablets irritate your stomach.

Nutrition clinics for UW Hospital and Clinics (UWHC) and American Family Children's Hospital (AFCH) can be reached at: **(608) 890-5500**

EXERCISE

Another one of the MOST important thing to help you recover from POTS is exercise. Studies (Dr. Levine) have shows that when people with POTS do a regular exercise routine, they feel much better It can take a while (sometimes months!) before you feel the results of exercise, so don't give up!

Start very slowly, exercise 5 minutes twice per day. Every week increase your exercise time by 3 minutes. Most patients with POTS feel better doing exercises that are recumbent (sitting down, such as using a stationary bike, rowing machine, or swimming).

**For a specific plan for exercise, search for "CHOP POTS exercise", or:
http://www.dynainc.org/docs/chop_modified_dallas_pots_exercise_program.pdf**

SLEEP

Many people with POTS have difficulty sleeping. Here are some things that may help:

- Lower the lights one hour before bedtime
- Do a relaxing activity, such as reading under low light, massage, meditation, yoga, stretching, or a warm bath.
- Turn off the television, computer and video games, and stop cell phone use.
- When it is time for bed, the room should be dark (no night lights) and cool, but not cold.
- Have a consistent bedtime and amount of sleep (10-14 hours for adolescents)

HEAT INTOLERANCE

Many people with POTS have worse symptoms when they're hot. These are some things that may help:

- A cooling vest is a vest with gel inserts that can be cooled in the freezer, then inserted into the vest and worn when it is hot outside. There are also evaporative cooling vests, as well. Patients who cannot tolerate the heat often appreciate these. Some insurance companies may cover these with a prescription. These can be purchased online.
- Frogg Togg towels can also help keep you cool, these can be purchased online

COMPRESSION STOCKINGS

The compression stockings can help symptoms of dizziness/fainting as this can make it easier for blood to return to your head/heart. They are most effective if worn during the day when you're upright, they should be taken off at night. Try them consistently for 1-2 weeks before you decide whether they're helpful or not.

Thigh high or waist high stockings are more effective than knee high stockings. They should have at least 30 mmHg of compression. Some people have tried athletic knee high compression stockings (can be purchased online or from sporting good stores). These often come in more colors/patterns. Although not as strong as medical compression stockings, these can be effective in helping with symptoms in some people.

Please call your insurance and ask where you can get the compression stockings if you would like extra pairs. If you have any questions/issues, please contact our case manager: 608-890-8375.

MEDICATIONS

Some people with POTS will have symptom improvement with the above recommendations. Other people with POTS may need medications along with the above things, to help with their symptoms. Medications that are used to treat POTS in children/teenagers are off-label, meaning the medications are usually used for other purposes, but they're used in people with POTS as the medication effect can help with their symptoms. Commonly used medications are Fludrocortisone (Florinef), Midodrine, and beta-blockers (Atenolol, Metoprolol, Propranolol).

SUPPORT GROUPS/WEBSITES

Patients with POTS often benefit from talking with a counselor/therapist. POTS symptoms can affect many areas of your life and this can be very difficult. Please talk with your doctor/health care provider to discuss this further. If you ever feel very down or depressed, please talk with someone (parents, friends, health care provider).

For more information, we suggest:

- Dysautonomia International: (dysautonomiainternational.org), this site has great resources for patients, friends, and schools
- The Dysautonomia Information Network (www.dinet.org). This site has good descriptions of symptoms and treatments, but is focused on adult patients.
- The Dysautonomia Youth Network of America (www.dynainc.org). This website is especially set up for children, adolescents, and their parents.

As you read this information, please remember that each person's story and situation is unique. Read these for general information, and talk to your provider about your personal specifics.

Call 608-263-6420; Pod 2; with questions or concerns.