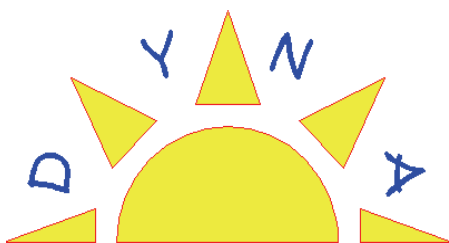
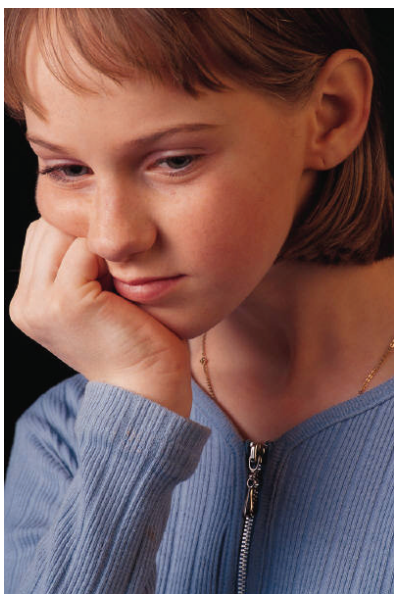


You Have Been Diagnosed with a Dysautonomia Condition



Dysautonomia Youth
Network of America, Inc.

“ A Ray of Hope ”

Your Journey Begins

Living with a medical condition can be stressful and challenging for anyone, but it is especially hard for young people diagnosed with a dysautonomia condition. You are taking an unplanned journey into uncharted territory. With the right resources, you will discover treasures despite hardships.

Obviously, it takes time to adapt to having an illness and to find ways to happily live your childhood in spite of it. It is especially hard to adapt when you are young because everyone else seems to know what is best for you. You may often feel that you have no control over your own life. You probably feel that you have lost your balance in more ways than one!

Over time, most young people diagnosed with dysautonomia conditions adapt, come to terms, and even THRIVE. Playing an active role in your medical care and in your future will help you to progress forward and will enable you to be better prepared to face the journey ahead of you.

Most childhood dysautonomia cases medically improve given time, and many will recover. However, it can sometimes be a long, hard journey. Lucky for you, it has been documented that youth with dysautonomia conditions tend to be highly intelligent and are traditionally high achievers. They often become outstanding adults and make valuable contributions to society. You have a very bright future ahead of you!

DYNA can help guide you through your journey. Make sure that you talk to your physician about your individual case. Please review our web site www.dynakids.org for more information, and feel free to contact our office for assistance.



The Future is Yours

- **It is important to recognize that there are many types and sub-types of dysautonomia conditions. There are also various degrees of each condition.** Just like with every other medical condition, it is completely normal for patients to be afflicted with different levels of impact. Each patient will respond uniquely to the available treatment options and various medications. Specific consideration needs to be given to the complete individuality of each case.
- Obviously, at first many patients feel very vulnerable, confused, and worried about their health and their future. Some even feel let down by their bodies. They may feel that they were cheated and they may feel angry at the world. All these feelings are a part of the normal coping process. After the initial shock fades, most young people decide to take action and to learn more about their specific condition. **Knowledge is power!**
- It is easy for a health condition to become the main focus of a person's life. While it is important to understand your illness, receive support, and be involved in organizations like DYNA, it is even more important for you to still be a kid. Remember, having a medical condition is only a part of your life, and your health condition is not "who you are" but "just something you happen to have."
- Adapting to living with a childhood illness takes time, patience, support, creativity and flexibility. Youth living with dysautonomia conditions typically grow to have tremendous perseverance and inner strength. Stand tall and be proud. **The future is yours for the taking!**



What is Dysautonomia?

Dysautonomia is an umbrella term utilized for a dysregulation of the autonomic nervous system (ANS). The ANS is responsible for controlling all the unconscious functions of our bodies (the things we don't have to think about and that just happen automatically). Dysautonomia conditions can effect boys and girls, men and women of any age. It can be present at birth, manifest over a gradual period of time, or appear suddenly. Cases can be very mild to very severe. Dysautonomia conditions may impact your life minimally or radically. The conditions may be acute (lasting a few months to a few years) or chronic (long term). These conditions are unpredictable and can lapse, relapse, and present intermittently. Each case of dysautonomia is unique and must be recognized, respected and treated as such. Your physician is in the best position to assist you with understanding the details of your situation. It is critical that you relay accurate observations to your doctor and are always completely honest with him/her.

You will need to recognize that medications will not "cure" your condition, but can provide a degree of symptom control. Communicate closely with your doctor regarding any side effects you may experience from your medications. Often patients stop taking a beneficial medication because of a temporary side effect that would have resolved with time. Remember to always obtain your information from reliable, reputable and informed sources.

Life-style modifications/adaptations are a crucial factor for you now. You will need to be flexible. Dysautonomia conditions tend to fluctuate and be unpredictable in specific symptom occurrence, intensity, and frequency. Patience will become your best friend.



What are the Symptoms?

TACHYCARDIA (FAST HEART RATE)

BRADYCARDIA (SLOW HEART RATE)

ORTHOSTATIC HYPOTENSION (LOW UPRIGHT BLOOD PRESSURE)

ORTHOSTATIC INTOLERANCE (INABILITY TO REMAIN UPRIGHT)

SYNCOPE AND NEAR SYNCOPE (FAINTING)

SEVERE DIZZINESS

EXCESSIVE FATIGUE

EXERCISE INTOLERANCE

MIGRAINES / HEADACHES

GASTROINTESTINAL ISSUES

NAUSEA / DIARRHEA / CONSTIPATION

INSOMNIA

JOINT / MUSCLE PAIN

JOINT HYPERMOBILITY

MUSCLE WEAKNESS

MENSTRUAL IRREGULARITIES

SHORTNESS OF BREATH

THERMOREGULATORY ISSUES

ANXIETY

LOW MOOD

TREMULOUSNESS

FREQUENT URINATION

COGNITIVE IMPAIRMENT (BRAIN FOG)

VISUAL BLURRING OR TUNNELING

SEIZURES / CONVULSIONS

- Each dysautonomia condition has its own set of symptoms that apply.
- Each patient will experience different degrees of symptoms and have various systems impacted.
- Like all medical conditions, patients are afflicted to a different extent.
- Each case is unique unto itself.



What Do I Call It?

No doubt you will be confused by the medical terminology that you will hear. You sure are not alone! The doctors can't seem to make up their minds on what to call conditions that are caused by a *dysregulation of the autonomic nervous system*. DYNA uses the term *Dysautonomia*, but your physician may not. The term utilized for these conditions is not what is important to us right now. We will let the docs deal with that problem! Call it what you will—we just want to help the kids who have it.

Remember, don't get hung up on the name game. Don't start accumulating and fixating over various medical terms. Don't assign an individual diagnosis to each symptom you may experience. It is typical to have "combo platters" of various conditions and symptoms with dysautonomia. Just saying you have dysautonomia works fine!

The following diagnostic terms may be issued to children with forms of dysautonomia:

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Neurocardiogenic Syncope (NCS)
- Neurally Mediated Hypotension (NMH)
- Vasovagal Syncope
- Post-Viral Dysautonomia
- Non-Familial Dysautonomia
- Generalized Dysautonomia
- Familial Dysautonomia (FD is a distinctive form of dysautonomia that has been identified in individuals of Ashkenazi Jewish extraction.)



Tips From DYNA Kids

- Drink lots of water frequently and add extra salt to your diet.
- Keep a “grab bag” with you that includes water, salty snacks, and chocolate.
- Plan ahead! If you know your body will be facing a stress, load up on fluids and salt ahead of time and also during the stressor.
- Get plenty of sleep regularly and stick to a schedule. One “all nighter” can do you in!
- Don’t leave your assignments until the last minute. Be prepared.
- Take frequent breaks.
- Listen to your body signals and respond accordingly.
- Slowly work up your tolerance to being upright.
- If you get dizzy—squat, lie down, or sit in a chair with your feet elevated.
- Recliners are great!
- Avoid standing or sitting for prolonged periods. Curl your toes, cross your legs, and tense your leg muscles to compensate.
- Avoid hot water! Try cool showers and baths.
- Avoid heat! Also, avoid extremes in temperature. Even in the winter the cold can be hard on your system.
- Avoid long periods of intense concentration. Concentration lowers blood pressure. Drink and consume salty snacks while doing school work and taking tests. Take frequent breaks.
- Avoid public places during flu season. Speak to your doctor about getting a flu shot.
- Consult your doctor before taking over the counter cold medications.
- Persistence and determination will pay off in the end. Stick with the program. Keep the faith! Things will improve once your treatment gets started.



Marbles and Balance

You may have been told that you have to find a “balance” in your life when dealing with your illness. Well, finding that balance means that you have to manage to juggle all your responsibilities and needs and still be “yourself” in spite of the illness. **YOU ARE STILL YOU!** You are not a dysautonomia youth - you are a youth that happens to have dysautonomia.

You may have heard of people with illness obtaining balance in life by “learning to live with a limited number of marbles in their jar.”

Let’s just pretend that you have a jar of marbles at the beginning of each day. In your jar you have 100 marbles. You use 25 marbles to get through your school work. You use 25 marbles in your friendships and relationships. You use another 25 marbles following your physician’s orders. It takes more marbles to perform all the activities necessary to manage your illness. We haven’t even listed the normal activities of daily living that you must do (bathing, cooking, chores, etc.). And well... by the time we get to your emotional needs, you probably have no marbles left to live with!

As time goes on you get tired of living on the edge with those darn marbles. They start rolling away on useless tasks, and next thing you know you have lost your marbles before the day even starts! No pun intended. You need to gather up your marbles and keep count of them and be selective about using them throughout the day. Save some for the party you may want to attend tomorrow or the friend you may want to invite over this weekend. And remember that homework assignment due on Friday! They are precious marbles you have in your possession – don’t lose them!



The Message Is:

- Live your life on your current terms and not your previous terms.
- Remember that you are about YOU first and not your illness.
- Have patience and allow healing to occur.
- It takes TIME.
- Prioritize your energy usage.
- Stand up for yourself (in more ways than one).
- Play the hand you have been dealt and stop thinking about the hand you wanted.
- Ask for help if you need it!
- Keep your marbles!



Childhood dysautonomia conditions typically (but not always) strike adolescents after the onset of puberty, often after a period of very rapid growth. There is a female to male ratio of 5 to 1.



How Can I Help Myself?

The number one thing you can do to help yourself is to **drink water**. Water is not just a beverage, it is an essential nutrient! Speak with your doctor to confirm the amount he wants you to drink.

Every single day the body recycles the equivalent of forty thousand glasses of water to maintain its normal physiological function. The pattern of water metabolism and its recycling process leaves healthy bodies short of about 6 to 10 glasses of water a day! Your particular body can not tolerate that deficit. Your body probably requires that you drink at least an extra 2 liters a day. You will find this very beneficial to keeping your blood volume up and helping with your symptoms. Think of your body as being like a bucket of water that has a leak in it. You have to constantly add more water to keep it filled.

Just like you should not let your car run out of gas before you fill it up—you should not let your body run out of water. Constantly replenish your body with water! Drink in 8 oz. portions spaced throughout the day. **Carry a bottle with you at all times, and don't just *carry it*—drink it!** Start gradually with this new habit and build up your tolerance to additional water over a few days or you will get an upset stomach. It seems like a lot to drink at first, but if you start drinking when you wake up (put a drink at your bed side table the night before) and continue drinking throughout the day - it really adds up. Measure the amount you consume at first so that you make sure that you are reaching your goal. Soon enough, it will become a life-time habit.

Your body needs, requires, depends, relies, and wants that water! Nothing substitutes for water.



Remember:

- With that extra water you must also increase your salt intake. This will help maintain a normal fluid volume in your blood vessels and will play a role in preserving a normal blood pressure. You can do this by drinking electrolyte solutions or by eating salty snacks such as pretzels.
- When your urine is colorless, you are meeting your bodies water requirements. 😊
- Drinking water 30 minutes prior to meals prepares the digestive tract, and drinking water two and half hours after meals helps complete the process of digestions and can help correct the dehydration caused by food breakdown.
- Caffeinated drinks and tea are acceptable to drink in moderation, but remember they can increase urination so they should not be your major source of fluids. They can also cause an increase in heart rate so they are not encouraged for those who already have an elevated heart rate. Some people do better avoiding caffeine entirely.
- Limit intake of artificial sweeteners; in some people they can promote migraines.
- Avoid alcoholic beverages because they not only lower your blood pressure but they also impair brain function and can interact negatively with your medications.



Add Salt to Life!

Because we know so many youth impacted with dysautonomia conditions, DYNA has learned a great deal. We witness your struggles, challenges, heartbreaks, and yes, blessedly we even witness your success stories -- not just the recovery stories, but also the "finding your inner strength" success stories.

Over time, it appears that most of our members develop a sense of living on a different "level" than they did before they became sick. Initially, they seem to think of the illness as something bad that has happened to them, but then they seem to develop a different awareness than they had before, and start to realize the unique "gifts" that they have gained within this new awareness. It is almost like a blind person who develops an extra sense of his surroundings – it appears that DYNA members, develop a deep sense or inner strength that is a very special and unique gift. Needless to say, the illness itself is still challenging for our members but they learn to deal with it better and they certainly become better people because of it.

Youth have a sense of resilience that most adults are unable to obtain. Youth are more flexible, more adaptable, and more open. Watching DYNA members, we are reminded (and don't laugh at this...okay go ahead and laugh because it is silly) of the old Colonial tradition of dry salt curing meats! Salt them down heavily, let them hang in a dark place and the salt preserves, creates a resiliency, and promotes a special unique long-lasting depth and flavor.

DYNA encourages our members to reach inside and pay attention to this "flavor". Develop it. Nurture it. It is a very blessed gift. **Absorb the salt in your life and hang tight to be cured!**



DYNA

DYNA is a 501 (c)(3) non-profit organization dedicated to serving young people diagnosed with various dysautonomia conditions. DYNA is a dynamic group of positively focused and empowered individuals. Without exception, DYNA members face each day with profound courage and incredible strength. Our members have joined together in an attempt to make a difference in the future. Instead of feeling sorry for themselves, DYNA members are taking action by promoting awareness of these life-impacting conditions and by helping others afflicted with them. You are now a recipient of their efforts.

You can apply to JOIN DYNA (free of charge) via our web site. If you meet the membership requirements and are accepted for membership, you will have the opportunity to find security, hope, and friendship within our organization.

Our website has a wealth of easy to understand information at your disposal. Our "Awareness Series" brochures can help to inform you and educate others about these conditions. You can be confident that the information is current and accurate as we have a Medical Advisory Board with whom we consult regularly. Please note, however, that our resources are purely for informational purposes and are not meant to take the place of professional medical supervision.



DYNA Conference

DYNA holds an annual conference called our “Summer Chill.” This PRIVATE, INVITATION—ONLY event provides a singular resource for DYNA members-in-good-standing, their families, and physicians. The Summer Chill offers DYNA youth members the companionship of understanding friends in a congenial, productive, supportive atmosphere. The event promotes camaraderie, socialization, and interaction among DYNA families and staff. The highlight of the event is our “Goofy Slipper Lecture on Dysautonomia”. This informative lecture provides attendees with the rare opportunity to hear from the field's top-most authorities on childhood dysautonomia conditions. Numerous fun activities exist throughout the event for the children. DYNA is known as a catalyst for promoting dysautonomia awareness and developing better opportunities for accurate diagnosis and improved hope for prognosis. Our Summer Chill event was officially recognized and received the Loudoun Convention and Visitors Association “Humanitarian Award” from Loudoun County, Virginia (a major Washington, DC suburb). This event is supportive, informative, educational and emotionally beneficial.

Video

Our professional video production from the DYNA Summer Chill “Goofy Slipper” Lecture on Dysautonomia is tremendously beneficial to families dealing with dysautonomia conditions. The video features our DYNA members and highly informative lectures conducted by world renowned physicians in the field of dysautonomia. Please refer to our web site www.dynakids.org for



Awareness Series Brochures

DYNA INFORMATIONAL BROCHURES:

Your Pediatric Patient is Diagnosed with
Dysautonomia: A Guide to Understanding
Autonomic Dysregulation

Your Child is Diagnosed With Dysautonomia:
A Resource for Family and Extended Family

Your Friend or Classmate is Diagnosed with
Dysautonomia: A Guide to Understanding

Educating the Dysautonomia Student:
An Introduction For Teachers
and Other School Personnel

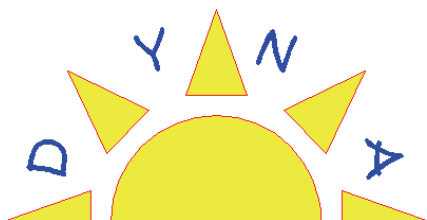
You Have Been Diagnosed With
A Dysautonomia Condition

Special Accommodations Medical Card

Please refer to our web site for information on ordering our materials.

Donations to DYNA, Inc. are graciously accepted and deeply valued. Funds are needed to advance the availability of our informative materials, to continue providing our services, and to move forward with the demanding mission of childhood dysautonomia awareness. No amount is too small to make a difference. Speak with your parents and then refer to our web site for easy access to making a donation in your name.





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Hope gives each of us the courage to face life's challenges, the motivation to move forward, and the strength to go on.

~Barbara Cage

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