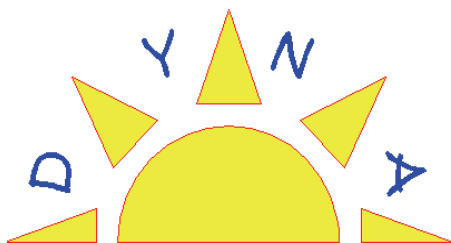


Your Friend or Classmate is Diagnosed With Dysautonomia: A Guide to Understanding



Dysautonomia Youth
Network of America, Inc.

“ A Ray of Hope ”

Purpose

This brochure is designed to provide information and promote understanding to young people who have a friend or a classmate afflicted with a dysautonomia condition.

Peer relationships are especially impacting and essential during our childhood, adolescent, and teen years. Friends and a happy social life contribute to a healthy identity. Medical research shows that people who have friends tend to be happier, healthier, and live longer than those who don't. Friendship has numerous physical and spiritual benefits and is a true blessing.

The experience of an illness is a time when people find out who their real friends are. Sometimes friendships do not have the strength to endure the extra stress of an illness. Other times the illness is what cements a more solid friendship that will last a lifetime. We hope the information provided here will help friends maintain their friendships despite the undeniable difficulties faced by the impact of illness. This booklet will give friends and classmates some general information, suggest some strategies for renewal and growth that will benefit the relationships, and help everyone deal better.

Take a little time to read this booklet and then take a little more time to communicate with your friend or classmate. To begin your communications you will find a handy list included in this material. Please feel free to visit our website, watch our informative video, and contact our office for additional information on dysautonomia conditions.



Introduction

Your friend has been diagnosed with a complex medical condition that is not well known. He or she is probably going through a difficult and stressful time. Chances are good that you are going through some changes too and that your friendship is experiencing some adjustments.

Illness takes a toll on any friendship. Your response to it defines your character and whether you like it or not—defines the solidarity of the friendship.

Most friends count on each other socially. Suddenly, you may find yourself without your friend at the school lunch table, left without a science lab partner, or sitting alone at the school football game. You miss your friend and no doubt, your friend deeply misses you too. You are both worried, you are both dealing with a loss, and you both need extra support right now. Make sure that you talk to your parent(s), guardian(s), school guidance counselor or a teacher if you need a little extra support.



“A faithful friend is the medicine of life.”



What is Dysautonomia?

Dysautonomia (dis-auto-no-me-ah): If you can pronounce this diagnosis, congratulations! Dysautonomia is a medical term used for a group of disorders that involve a dysregulation of the autonomic nervous system (ANS). Dysautonomia conditions can have complicated and often invisible symptoms that are not always obvious to the casual observer. Every individual with a dysautonomia condition has a unique medical situation and a different combination of symptoms.

The autonomic nervous system controls all of the unconscious functions of our bodies (the functions that *automatically* happen and that we never think about). A few things controlled by the ANS are heart rate, blood pressure, digestion, respiration, pupil dilation and constriction, blood vessel dilation and constriction, sensory regulation, and body temperature. As you can imagine, when the ANS doesn't work properly, the body and the person suffer.

Your friend's body is having to use extra energy to do simple things now. It is utilizing its limited resources in an attempt to compensate for the malfunction. Along with other symptoms, your friend probably gets fatigued more easily now, and he or she may become quickly exhausted from all this extra *invisible* work.

Your friend will need to make some adjustments in order to allow their body time to heal. They will probably rest more often and they may take longer to regain their energy after an activity or social event. Schoolwork and extracurricular activities may need to be modified. They may not have as much time to spend with you right now, but it is important that you still stay connected. Not only does having friends make people feel happy, but having good friends promotes healing.



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.



Will my Friend be Okay?

Many doctors at well known universities and hospitals are working very hard to better understand and treat the various dysautonomia conditions. Medical advances are being made everyday.

You will need to recognize that there is no “quick cure.” Your friend may be given medications to help him/her with symptoms. Depending on which condition he or she has things like physical therapy may be recommended to prevent muscle deterioration. They may consult with a chronic illness counselor to help with the stress and life style impact.

Your friend will have times where they feel well enough to socialize and times where they feel bad again. That is what happens with dysautonomia conditions and many other chronic illnesses. There are often many ups and downs. Patients constantly have to make ongoing adjustments and readjustments in their lives. Often their sense of loss can be overwhelming. With the right support system, things will be much easier. Most patients will learn how to help their body function as well as possible. They will learn how to balance health needs, school obligations, and social desires. Your understanding will make a difference. Remember, your friend is still the same person he or she was before they got sick. Don't treat them like they are different now just because they have a medical condition. Let them know that you care and try your best to be there for them. Pick up that phone and ask how you can help.

Dysautonomia brings special considerations because the conditions are entirely unpredictable and the circumstances are always changing.



TIPS FOR FRIENDS

- Most importantly keep being you—a good friend!
- Try to understand that your friend has a big challenge to overcome.
- Communicate your questions and feelings to each other.
- Give this booklet to your parents—so they can help you.
- Read our web site www.dynakids.org for more information. Be sure to refer to the special section for friends under: “What is Dysautonomia”

Message to Parents of Friend

Your child has a friend or classmate diagnosed with a form of dysautonomia—a serious and chronic health condition. We want you to know, that this condition is definitely not contagious and is usually not life threatening. It can, however, be significantly life altering and very stressful for the patient and the family.

Illness is part of life—a tough part. Unfortunately, many children learn about this life lesson early in life. We recommend that you take this time as an opportunity to discuss such life circumstances with your child. If your child was friends with the ill student, you will want to make sure that they have the emotional support they need. Help them to maintain their friendship. Pick up the phone and call the friend's house and talk to the parents and just offer your concern. This can be a critical time for understanding and growth for our children (and sometimes for us). A caring community truly can make a difference for an ill child and the family. We invite you to visit our website for more information on dysautonomia.



Let's Talk About It

Your friend has an invisible chronic illness. That means other people can't always see what they are dealing with. Sometimes people who don't understand what is going on, gossip and spread rumors. We want you to get reliable information. Please speak directly to your friend or your parents, teacher or counselor. Avoid inaccurate information. Use the next page to begin your communication with your friend. Feel free to contact the DYNA office at 301-705-6995 if you have any general questions about dysautonomia.

DYNA Member Notes to You

I have a form of dysautonomia called:

You can learn more about it at www.dynakids.org

I want you to know: _____

You can call me at: _____

My email is: _____

I am up to seeing visitors.

Please call me soon.





DYNA Friend Information

Please read this booklet and then fill in this page, cut this sheet at the perforation and give it back to your friend, then give the booklet to your parents to read.

Dear _____

From: _____

I am your friend and I miss you. and would like to keep in touch.

I am a classmate and would like to know you better.

I read the literature and understand your medical condition better.

I don't understand.

I want to help you and offer my support. Please tell me how.

I am uncomfortable talking about illness, but I wish you well.

I can't pronounce dysautonomia! GEEZ!

I am available to keep you up to date with school assignments, activities, etc. when you are absent



What is DYNA?

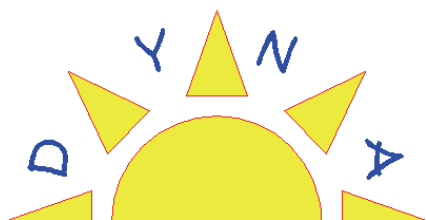
DYNA is a non profit organization established specifically for youth afflicted with dysautonomia conditions.

Along with the leading physicians in the field of childhood dysautonomia and other professionals, we work to support children afflicted with these life impacting conditions. We hold special events for our youth members and provide reliable and accurate medical information on dysautonomia conditions.

Our Awareness Campaign is aimed at promoting additional community understanding of youth diagnosed with dysautonomia and of the impact the conditions have on their lives.

We are able to provide our services because of the kindness of others. If you wish to make a donation in honor of your friend or classmate, please ask your parents or guardian to log on to www.dynakids.org and follow the directions. We will be glad to let your friend know and to list you in our next newsletter.





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Friendship isn't a big thing —
it's a million little things!

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