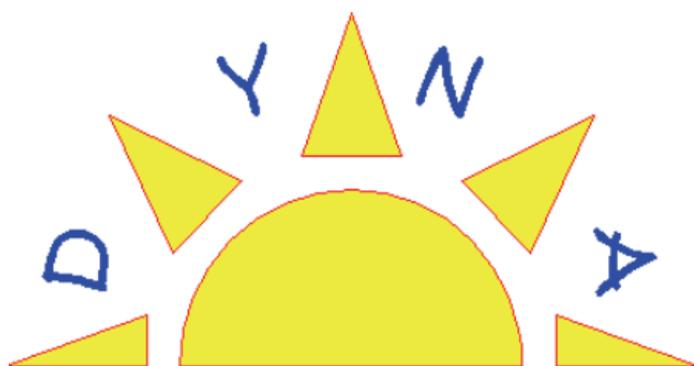
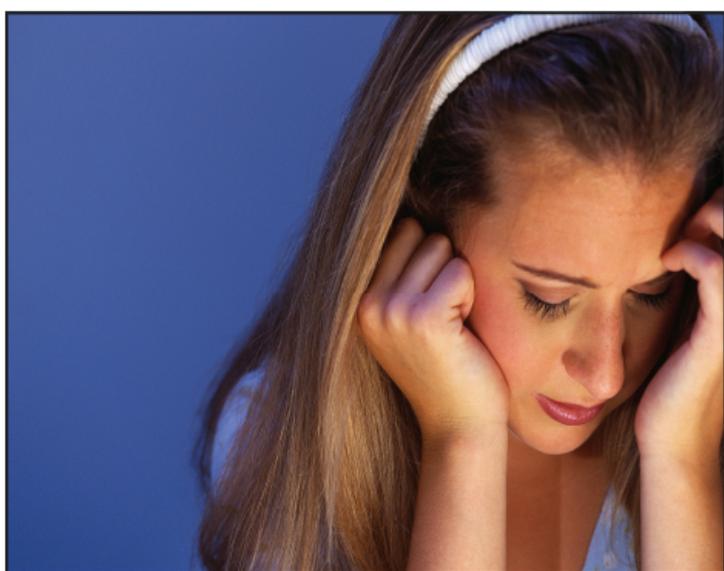


Educating the Dysautonomia Student: An Introduction for Teachers And Other School Personnel



Dysautonomia Youth
Network of America, Inc.

“ A Ray of Hope ”

Purpose

The purpose of this booklet is to guide parents, physicians, teachers, and education professionals toward creating a successful and supportive education for the student afflicted with a dysautonomia condition. By providing a platform for discussion, comprehension, and compassion, all those involved in the education of the impacted student will be better equipped to create a productive learning environment.

This booklet starts by providing a general explanation of dysautonomia conditions, their physical, social and emotional effects, and further suggests points upon which productive conversations can begin. A successful educational plan will pay special attention to individual circumstances as they are raised by the student and his or her parents. In doing so, conditions that might cause additional physical distress and further compromise the student's well-being can be avoided, reducing the chances of short and long term health implications.

Despite the challenges that dysautonomia conditions often impose, creating an individually tailored educational management system can often be profoundly successful. Yet success stories can only be achieved when students, parents, medical and education professionals work together and communicate openly.

Please feel free to visit our website www.dynakids.org, watch our informative video, and contact our office for additional information on dysautonomia conditions.



Introduction

Wouldn't it be ideal if all young people could enjoy consistently good health and smooth adjustments during their school years? Unfortunately, thriving in the school environment can be a challenge for students diagnosed with various dysautonomia conditions. That's why it is so important for teachers and other school personnel to understand these complex invisible medical conditions. Such understanding will help provide the support and encouragement that may make all the difference in the student's life.

The symptoms of dysautonomia conditions are usually "invisible" to the untrained eye. The child may often appear to be as healthy as those around him. The manifestations are occurring internally, and although the symptoms are diagnosed and verified medically, they are often not visible on the outside. Symptoms can be unpredictable, may come and go, appear in any combination, and may vary in severity. Often patients will become more symptomatic after a stimulus, stressor, or physical activity. Patients may find themselves involuntarily limiting their life-style activities in order to compensate for the conditions.

Symptoms may require that some children will need placement in homebound teaching programs; others will be able to attend school, often with modifications/accommodations. For the student with dysautonomia, coping with the social isolation that often accompanies the life-style restrictions can be extremely challenging. Supportive efforts should be made to keep the child involved within the school system and connected to peers.



What is Dysautonomia?

Dysautonomia is a medical term utilized for a group of complex conditions that are caused by a dysregulation of the autonomic nervous system (ANS). The ANS regulates all of the unconscious functions of the body, including the cardiovascular system, gastrointestinal system, metabolic system, and endocrine system. A malfunction of the ANS can cause debilitating symptoms and may pose significant challenges for effective medical treatment.

Orthostatic intolerance (the inability to remain upright) is a hallmark of the various forms of dysautonomia. Dysautonomia conditions can range from mild to debilitating and, on rare occasions, can even be life threatening. Each dysautonomia case is unique to that patient and treatment must be individualized. Patients should be evaluated by a physician who is well-versed on the recent treatment modalities.

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. Some of the patients report a sudden development of symptoms after a viral illness, immunization, or trauma. Others may see a more gradual onset. Although very rare, there are children born with tragic non-familial forms of dysautonomia. There is also a distinctive form of dysautonomia called Familial Dysautonomia (FD) that has been identified in individuals of Ashkenazi Jewish extraction.

Dysautonomia conditions are widely unknown to society at large. As a result, most do not realize the effect and impact such conditions have on those afflicted and their families



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.



Helping the Student Thrive



Children require more
than academics
to thrive in school and in life.

It is essential that educators recognize that chronically ill children are socially vulnerable due to the limitations imposed by their illness. Therefore, it is important that school systems take the initiative to keep these children connected to their fellow students in order to provide them as complete a school experience as possible. Educators will need to take extra steps to keep partially or completely homebound students informed about school happenings, activities and events. Simple things such as school newsletters, picture and year book notices, and school announcements are important connections to be sent home on a regular, timely basis. We suggest that a school based counselor, teacher or staff member be assigned the specific responsibility of keeping these students engaged. It is also very beneficial to assign a buddy or another student to assist in this process. Take the time to consider how these students may feel lonely, disconnected, and isolated. Recognize that they are still enrolled in the school and thus still a deserving part of the student body.



Take the initiative to be creative, compassionate, and proactive. Make the effort – have your student body reach out to a schoolmate in need! There is a wide-range of daily in-school activities in which the home-based student can be included, and even the smallest effort can make a big difference. Physicians often note that patients who feel loved and valued thrive better and recover sooner – so maintain a line of communication with your home-bound student

Compassion is the key to making a difference in someone's life.

Contact DYNA to request our brochure:
"Your Friend or Classmate is Diagnosed with
Dysautonomia: A Guide to Understanding."

Patients who feel loved
and valued thrive better
and recover sooner!



Educational Plans

Many educational systems have explored creative ways to accommodate the unique needs of the student afflicted with a dysautonomia condition. It is impossible for DYNA to provide firm guidelines for educating these children, as each situation is individual and each condition has unique variables.

Young people with these conditions do not “give in” gracefully. They tend to be highly motivated and successful students before the onset of the illness. They suddenly find themselves unable to get out of bed in the morning. They may push themselves beyond their comfort levels to please others who have no true understanding of the nature of the illness and who only see someone who visually appears healthy. Dysautonomia children sometimes discover ways to work through an activity via adrenalin and then suffer the risky consequences and set back afterwards. With understanding, support, and compassion from those around them, they will eventually learn to find a balance in their lives through trial and error. They learn to simplify, to appropriately pace themselves, and to respect their limits. These children are often the very best judge of their own limits, and parents, physicians, and educators eventually learn to respect their judgment and accept their input.

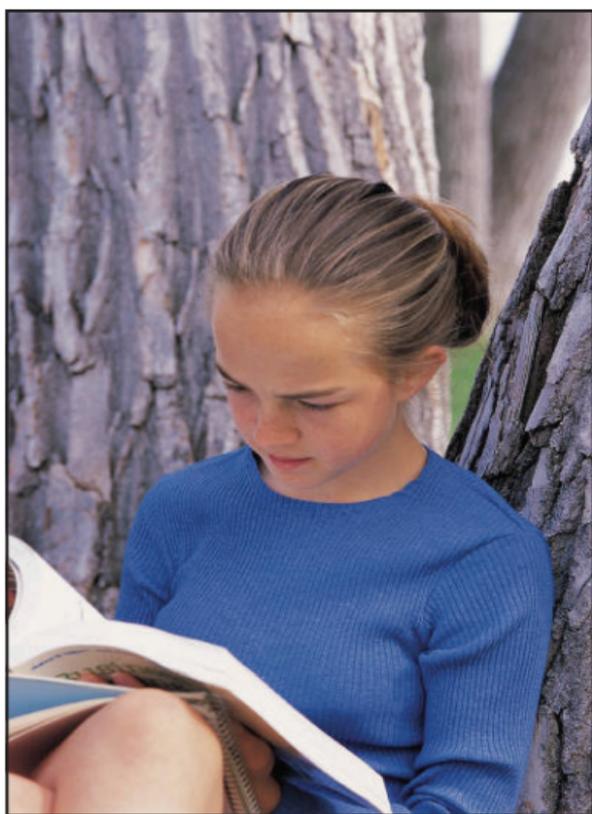
All educational plans must allow for flexibility as the symptoms are often inconsistent and the conditions are noted to wax and wane. Often a medical decline occurs late fall and continues into spring. However, it should be noted that each patient has his own unique presentation and no two patients are the same.



Instructional Options

- Full Homebound Instruction provided by the county for health impaired students.
- Partial School Days and Partial Homebound Instruction.
- Full School Days with various educational accommodations.
- Full School Days with no accommodations (only recommended for very mild cases).

Dysautonomia conditions have unique features that make educational accommodations a continuous necessity, rather than a static process. Educational plans often require frequent revision. Allow for flexibility and accept the unpredictable nature of the conditions.



Educational Considerations

- Open and supportive communication between parents, child, medical and educational professionals is absolutely essential. A common, respected understanding for the illness is the only way that a sound foundation can be established.
- Remember that children with an illness are still normal children. They also come from normal families. They are just dealing with a very difficult and abnormal medical situation.
- Teachers and school staff should demonstrate flexibility in respecting the student's perspective in judging his or her own capabilities. Teachers need to weigh their expertise in understanding the actions of "normal" students and then determine the tolerance needed for kids that "look normal" but have an invisible chronic illness that is not well understood.
- Recognize that dysautonomia students often have a limited window of opportunity when they are feeling well enough to complete school work. Prioritize instruction, utilize the student's limited energy on the essentials.
- "Brain fog" and forgetfulness are an often occurring problem with these children and may present a source of frustration for the student. Concentration may suffer due to lack of blood flow. Comprehension, deduction, and memory storage / retrieval may be impacted. Curriculum may need to be adapted to meet the student's individual range. This is not unlike children with other special learning needs.
- The school system should be aware that the illness often produces frequent absences. Proper planning and understanding is vital so such absences do not unfairly prejudice the student.



- Being a homebound student with a documented medical condition does not mean that the student cannot participate in school activities or have a social life. It is important for these students to remain connected with society. Chronically sick children still need social lives and have a right to be out in public when physically capable.
- When an educational plan involves more than one teacher, coordination between teachers is essential to avoid overloading the student.
- Take into consideration that some students may have a low tolerance of laboratory smells and other substances.
- In some cases noise and light sensitivity may pose a challenge.
- Water is essential and should be allowed at all reasonable times. Frequent salty snacks may be necessary.
- Bathroom privileges may need to be modified. We recommend a permanent hall pass be issued to the student.
- If available, an extra set of books should be provided to keep at home.
- A companion may be needed to help with book bags etc.
- Taking the stairs may not always be possible for the student. Consider passes for the elevator.
- Walking long distances to lockers may not always be possible. Utilize a locker in the vicinity of the student's classes.



- Classroom temperatures may dramatically impact the child. While the overall needs of the class are primary, recognition that a warm environment can compromise these students is needed.
- Remaining upright may exacerbate symptoms. Standing in line, fire drills, outside assemblies and other such events may require special accommodations so the student is not standing upright or in the heat for long periods.
- Sitting too long and prolonged concentration can lower blood pressure. These children should stretch their legs periodically and take breaks when needed.
- Consider plans of action for fire drills, bomb threats, and lock downs. Plan for unexpected situations in which the student's health may pose significant obstacles and be prepared for such emergency situations. Have extra medication on hand, extra fluids, and salty snacks. Assign a staff member to be responsible for the student in a crisis.
- Allow the student to maintain possession of his or her own cell phone (turned off) for emergency use.
- Routine tests and exams present practical problems. Special testing concessions may need to be made, but should not be viewed as "favoritism".
- State and standardized tests may be best issued at home and divided over a period of time in order to allow the student adequate recuperation time.
- Keeping the frequently absent or homebound student in contact with his or her school peers can be a tremendous help emotionally.
- Exercise intolerance may require elimination of PE from the student's individual curriculum.



- Avoid unnecessary exposure to viruses or germs. Consider sending the nurse to the student for administration of medication.
- Arrange for a quiet private area, such as the library, where the student can rest when symptomatic.
- Rumors often surface among the other students regarding a fellow student's medical condition. Therefore, it is best to communicate and educate classmates about dysautonomia. Children have a great capacity for understanding when treated like adults and dealt with in a mature manner. This is especially important for a classmate who "appears" to be healthy, but has a chronic illness. Ostracism can happen quickly if the school officials or staff present an ill-informed, skeptical attitude.
- This illness was not always taught in medical school or nursing school. While medical specialists in the field of dysautonomia are familiar with the varied and complex symptoms associated with this condition, many others are just starting to gain exposure to this illness. It would be unproductive to expect school health officials to understand and interpret this complex condition. A patient approach through open discussion with the student about his or her unique medical situation and the distribution of appropriate literature is the most effective way to increase awareness of dysautonomia and create a productive, comfortable environment for life and learning.



The Goal

A chronic illness can have a diverse set of effects on a child's life. Due to the daily management of their illness, most children with dysautonomia conditions automatically reevaluate and reprioritize their lives. They learn how to self-manage their illness and live as full a childhood as possible. They learn to cope with their symptoms, and they learn to face the physical and the psychosocial consequences of the illness. Family members, teachers, physicians, and community support personnel can all play a vital role in helping them lead full, well adjusted, and happy lives.

We all have a lot to learn about dysautonomia conditions, and the children who suffer from it have the most to teach us.



Children who have dysautonomia struggle with some of the most basic functions that healthy people take for granted, beginning with getting out of bed in the morning. Each day and each moment bring new and unexpected obstacles. Yet, despite the betrayal of an uncooperative body, these young individuals face life with profound courage and incredible strength.



Awareness

Schools can play a significant role in helping students with dysautonomia obtain a proper diagnosis and receive qualified medical treatment. The school nurse, teachers, and staff members often notice sudden changes in the student. A formerly active, alert student may begin to display fatigue, dizziness, tachycardia, brain fog, exercise intolerance and a notably pale translucent complexion. The knowledge obtained by having one student within the school system diagnosed often promotes awareness that leads to future children being diagnosed sooner and obtaining proper medical care from a qualified and informed medical specialist.

Informative Video Lecture

Features DYNA Lectures conducted by the leading physicians in the pediatric dysautonomia field.

Price \$25.00 check or money order to: DYNA

Mail to: DYNA Video Orders
1301 Greengate Court
Waldorf, MD 20601

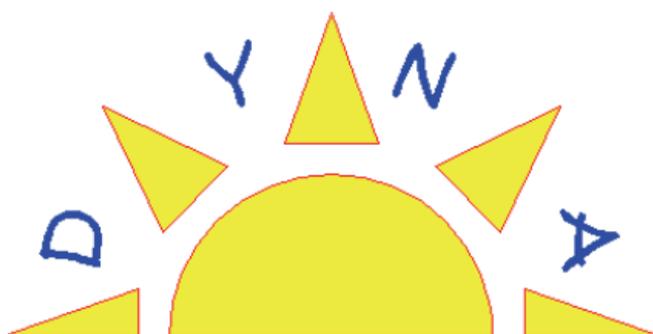
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The only thing predictable about dysautonomia
is that it is unpredictable.

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