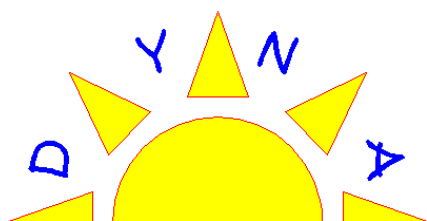


Awareness Series

Awareness Series



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# Educating the Dysautonomia Student: Dysautonomia In The College Setting

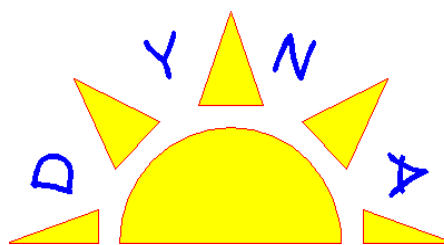


**Special Thanks To:**

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University of Toledo

Department Educational Leadership

“Student Engagement in the College Setting for Students  
with the Hidden Disability of Orthostatic Intolerance:  
How Level is the Playing Field?”



**Dysautonomia Youth  
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“A Ray of Hope”

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## What is Dysautonomia?

Dysautonomia is an umbrella medical term that is utilized for a group of complex conditions that are caused by a malfunction of the autonomic nervous system (ANS). The ANS regulates all of the unconscious functions of the body, including, but not limited to, the cardiovascular system, gastrointestinal system, metabolic system, and endocrine system. Orthostatic intolerance (the inability to remain in the upright position without symptoms) is a hallmark of the various forms of dysautonomia. Dysautonomia conditions can range from mild to debilitating, can be extremely life impacting and, on rare occasions, can also be life threatening.

## An Invisible Disability

Prior to the onset of their illness, most college age students that are afflicted with dysautonomia were very athletically, academically, and socially involved young people.

Researchers from respected medical facilities <sup>(1)</sup> have noted that a majority of dysautonomia patients have hyper-mobile joints, fair skin and long, lean body frames. Thus, in our society, dysautonomia patients tend to have the physical traits that we automatically associate with healthy good looks. **Dysautonomia is an invisible illness.**

Students afflicted with dysautonomia may be experiencing any number of the symptoms listed on the opposite page and yet still appear healthy to the casual observer. Furthermore, these symptoms can be unpredictable, continual or intermittent, appear in any combination, and vary in severity. Students with dysautonomia may face skepticism from uninformed professors, friends, roommates, class mates, and society in general.

<sup>(1)</sup> Autonomics Disorders Clinic—University of Toledo Medical Center, Johns Hopkins Children's Center, Mayo Clinic, National Institute of Health, Children's Heart Institute of Virginia.



## Contact Information

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STUDENT'S NAME

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CELL PHONE NUMBER

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HOME PHONE NUMBER

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EMAIL ADDRESS

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CLASS (AND SECTION NUMBER IF AVAILABLE)

NOTES:

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## Communication is a Must

- Faculty should work with dysautonomia students on a one-on-one basis.
- Open and comfortable lines of communication are essential to a greater understanding of the dysautonomia student's unique medical circumstances and special needs.
- The student afflicted with dysautonomia is the best source of information regarding their condition.
- The student should take an assertive role in communicating with faculty about their disability, adaptations, and accommodations.



Because of the invisibility of the disability, many students may not be given the same consideration for their disability, such as a student with a visible physical disability. It has been suggested that the "playing field" for this distinct cohort of college students is not level.

(Kravetz, 1997).



## What are the Symptoms?

TACHYCARDIA (EXTREMELY FAST HEART RATE)

BRADYCARDIA (EXTREMELY 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

GASTROINTESTINAL ISSUES

NAUSEA

INSOMNIA

SHORTNESS OF BREATH

THERMOREGULATORY ISSUES  
(BODY TEMPERATURE REGULATION/INTOLERANCE TO HEAT)

ANXIETY

TREMULOUSNESS

FREQUENT URINATION

COGNITIVE IMPAIRMENT ("BRAIN FOG")

VISUAL BLURRING OR TUNNELING

SEIZURES

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



## Cognitive Considerations

Students afflicted with dysautonomia conditions may experience periods of hypoxia (low oxygen levels) that can significantly reduce their cognitive capabilities and cause periods of disabling “brain fog” and cognitive impairment.

Alterations in the dysautonomia student’s blood flow and neurotransmitters (brain chemicals such as serotonin, dopamine, and adrenaline), as well as blood pressure and blood sugar all contribute to the cognitive issues associated with these conditions.

Brain fog is typically described as confusion and/or a lack of mental clarity. It can feel like a heavy cloud that reduces visibility or clarity of mind. It can cause patients to experience episodic disorientation, forgetfulness, and feelings of detachment from their surroundings. In severe cases brain fog may even manifest as temporary confusion regarding surroundings and the inability to recall names.

The cognitive impairment that is associated with dysautonomia conditions typically involves difficulties with regard to memory, word finding and word substitution, retrieving and recalling information, multi tasking, problem-solving, attention, and comprehension.



## Immune System

Chronic illness weakens the immune system. Students afflicted with dysautonomia are more susceptible to catching colds/viruses and are at a higher risk for complications.

Illnesses that other college students may consider just a mild nuisance can easily trigger a cascade effect that can cause a serious medical set back to a dysautonomia student.

Communication as to how to best handle flu outbreaks and illness should occur.

## Uniqueness

Students afflicted with dysautonomia are unique among themselves. It should be noted that individuals with the exact same medical diagnosis are in different phases of treatment and will have different responses to treatment. These students all have different abilities and disabilities and are unique among themselves. Avoid comparisons.



**The college student with a hidden disability is virtually unrecognizable from the non-disabled student on campus.**



## Mornings are Bad

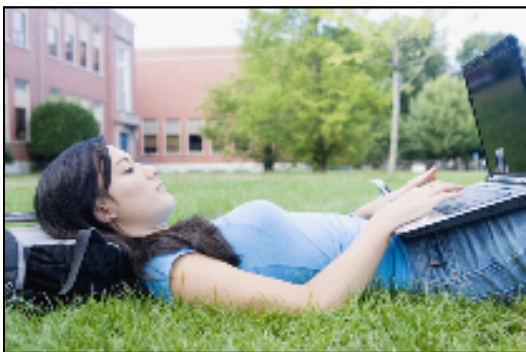
Early morning classes and exams can pose a significant hardship. Blood pressure and blood volume tends to be lowest in the morning. Before running off for the day's activities, dysautonomia patients need time to take their medications, drink plenty of water, eat a healthy breakfast, and allow time for their systems to respond and for the medications to take effect.

## Air Conditioning is Good

Disruption of autonomic function impacts the body's thermoregulatory system (the system that maintains and regulates body temperature). Students afflicted with dysautonomia conditions can not tolerate warm/hot or stuffy environments. Air conditioning is essential.

## Bathrooms Breaks

Dysautonomia patients may experience frequent urination during the day and night. Allow bathroom breaks during classes, tests and exams. If possible they should be placed in a dorm room with it's own bathroom due to frequent urination, immune system concerns, fainting and dizziness.



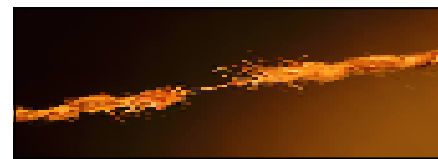
Frequent rest breaks are essential.



## Brain Strain

The aggravating, seemingly minor little things that go wrong each college day and the noisy irritating things which tend to go bump in the night in dorm housing situations — causing stress, disrupting routines and interrupting sleep — can all have a cumulative effect on the brain and its ability to remember and learn.

- Metabolic equilibrium can be easily disrupted in dysautonomia patients and these students will be sensitive to the impact of stress.
- Due to disruption in the regulation of certain brain chemicals dysautonomia patients are prone to insomnia and require a healthy sleep environment.
- Routine is important. Out of medical need dysautonomia students typically go to bed at scheduled times.
- Dysautonomia students do not have the luxury of maintaining an active social nightlife.
- Noise and light reduction at night is usually necessary for sleep.
- A private dorm room is usually the best option for these students. If a private room is not available then the selection of a respectful and cooperative roommate is absolutely essential.



It is unfair to expect a chronically ill dysautonomia patient to "adapt" to a negative and stressful college roommate situation when their systems are not capable of handling such adaptations.



## Physical Limitations

Physically healthy college students are able to rush across campus for classes, meetings, and tutoring sessions. Healthy individuals can stand in lines at the dining hall and book store, sit out in the sun during discussion groups, and attend clubs and activities without health concerns. The dysautonomia student is likely to encounter problems in such settings.

- **Avoid Unnecessary Walking**

Consideration should be made to the distance required to walk to classes, appointments with professors, tutors, study groups, and even to meetings with disability resource staff members.

When possible, schedule such activities near their dorm building or a location that the student can access without over-taxing their systems. Help them conserve their energy for everyday necessary walking and for their medically approved physical therapy sessions.

- **Avoid Long Lines**

These students may need to avoid unnecessary standing (especially in long lines). Even standing to talk to professors after class can be taxing on their systems. They may need to sit when waiting, lean against a wall, squat, etc. They are not being disrespectful to authority – they are respecting their bodies limitations and conserving their energy and trying not to faint.

- **Allow Breaks**

Sitting too long and prolonged concentration can lower blood pressure, inducing or aggravating many symptoms of dysautonomia. Long lectures and exams may be particularly challenging to a dysautonomia student. These students will need to stretch and take frequent breaks.



## Flexibility is a Must

Remember to allow for flexibility as the symptoms of dysautonomia are often inconsistent and the conditions are noted to wax and wane. This unpredictable nature can result in:

- Frequent, unexpected and/or sudden absences. These absences may be brief or they may extend for long periods of time.
- Difficulty meeting deadlines. Even long term assignments may be delayed.

Adaptations for symptomatic days and/or medical relapses will be necessary.

## Testing Accommodations

Testing accommodations are usually necessary.

- Schedule tests in the afternoon.
- Test in a quiet, cool, well ventilated area.
- Allow breaks, extra time, water and salty snacks.
- Unexpected/sudden cancellations may occur.

## Sensory Issues

At various times, the student may not be able to screen out sensory distractions, making it especially hard to focus and function in large group settings. They may not have the necessary “sensory stamina” to tolerate certain types of stimulation.

A student with dysautonomia may find it difficult to tolerate harsh smells, bright lights, loud noises, or other sensory stimuli.

