

FALL 2010 DYSAUTONOMIA news

Holiday Edition!

HOME FOR THE HOLIDAYS

By Kristina M. Gundersen

Everyday can seem like an exercise in battling boredom when you're housebound with a chronic illness, but it can be especially emotionally distressing during the holidays. Here are a few fun ways to celebrate if your symptoms make it hard to leave home.

Get creative!

- Compile a scrapbook of seasons past to share with family and friends. The on-line, virtual scrapbooking services like Snapfish or Shutterfly can be a wonderful way to "publish" those special memories
- Create gifts from scratch! Everyone appreciates a practical or homemade gift like a knitted blanket or beaded earrings.
- Photograph your holiday decor, frame the finished product, and voila! Instant custom artwork.

Get musical!

- Learn to play or practice your favorite instrument and tackle some holiday tunes
- Be your own DJ! Make and share a holiday playlist online to keep the season bright.
- Invite a few friends over, sing karaoke or carol to holiday music, record it and upload the session to YouTube to share with family and friends worldwide.

Get smart!

- Crossword puzzles, word finds or Sodoku are all great ways to keep your mind going strong when the weather outside is frightful.
- Play a game of solitaire on your own or Rummy with a small group.
- Break out some nostalgic classics from the garage or attic like Candyland and Chutes and Ladders to play with a friend.

Get happy!

- Bake some cookies or your favorite seasonal dessert. Sit down while cooking like my wise great grandmother.
- Watch holiday movies or read your favorite book from childhood to bring back good memories.
- Treat yourself to a Netflix subscription and get new release movies delivered to your door.
- View old family movies and photo albums with your family. Be prepared to relive a few embarrassing moments along the way!
- Spread joy by sending greeting cards and e-cards to your loved ones.

Happy Holidays! May your season be bright and symptom-free!

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Dysautonomia News is a quarterly publication of the Dysautonomia Information Network. Subscribe to Dysautonomia News at www.dinet.org/join.php

DINET wishes everyone a happy holiday season!

Dysautonomia News exists to inform and educate. The content should not be used as a substitute for professional medical advice, diagnosis or treatment. Readers are encouraged to confirm all information with other sources and a physician. Please keep in mind that research is evolving and future discoveries may change or disprove some currently held beliefs.

meet the member...

Janie is 37-years-old and has had POTS for 4 years, but her road to diagnosis was a long one. Before she became sick, she worked full-time as a Registered Nurse and specialized in post-anesthesia nursing. She worked hard, loved her job, and rarely got sick, so it was a surprise when she came down with mono in June of 2006. She needed an entire month to recover from mono and finally began to feel normal by the end of the summer.

In September of that year, she and her fiancé Shawn were driving home from church when another driver drove through a stop sign into the side of their convertible. Shawn suffered a minor head injury as well as several herniated and bulging discs in his neck and lower back. Janie had back pain as a result of the accident, but also injured her left hip. At first, the hip pain was only mild but became so severe by the end of the year, that Janie limped all of the time. Her doctor ordered many scans of her hip but they never showed any injury. Finally, she had to leave work in May of 2007 because she was no longer able to walk without crutches due to pain. She had her first exploratory hip surgery in June of 2007 and the doctor found that her femur was dented as a result of the accident. He repaired her femur as well as some torn cartilage. However, pain kept her from walking normally and she had a second exploratory surgery in January of 2008. The doctor then found a ruptured ligament that had been missed during the first surgery. It took 10 more months of aggressive physical therapy, but finally she was able to walk normally!

In October of 2006, Janie was working in the recovery room and began to feel fluish. She was giving one of her patients pain medicine when she suddenly became dizzy and almost passed out. She was able to put herself on a heart monitor and noticed that her blood pressure was very high and her heart rate was over 160 beats per minute. That day marked the onset of her POTS. She visited over a dozen doctors over the next 3 years. Most of the doctors agreed that there was something wrong, but they didn't know how to diagnose or treat her.

Janie's symptoms included high blood pressure and high heart rate while standing, chilblains (a type of Raynaud's) when she got too cold, red and burning feet when she got too warm, burning pain in her hands, feet, face, and mouth as well as chest pain and profound fatigue. Year after year went by and her symptoms grew worse. Thankfully, her primary care doctor witnessed the decline in her health and became her advocate. She referring Janie to specialist after specialist with the hope that someone might be able to help her. Also, she was the first doctor who suspected an autonomic disorder to be the cause of her symptoms. Finally, Janie saw a neurologist late in 2008



Janie and her husband.

who told her that he didn't know of any local doctor who could treat dysautonomia, but he would try to help her get into the Mayo Clinic in Rochester, Minnesota. He faxed Janie's referral that same day.

The next morning Janie received a call from Mayo and they gave her an appointment with Dr. Fealey, an autonomic neurologist, in the end of January, 2009. Shawn, now her husband of two years took time off from his job as a Special Education Teacher so that he could help her fly from Oregon to Rochester. She used a wheelchair most of the time because of her severe fatigue and orthostatic symptoms. Shawn helped push her to all of her appointments and tests. It was worth all of the work! During her two-week stay, Dr. Fealey was able to rule out serious possible underlying illnesses and determined that she had hyperadrenergic POTS (Postural Orthostatic Tachycardia Syndrome) and small fiber neuropathy. He felt that mono probably was the cause of her illness.

Getting a diagnosis was very helpful for Janie. She found a cardiologist who remembered her from her time working as a nurse. He told her he was committed to helping her to become as functional as possible. He prescribed carvedilol which helped her chest pain immensely. The neurologist who referred her to Mayo was a small fiber neuropathy specialist. He was able to prescribe medications that made her pain more tolerable. Janie also uses compression hose and sometimes abdominal compression, lots of salt and fluids, and goes for daily walks with her husband.

Her symptoms still prevent her from working, but she is able to cook and do some housework. Shawn and Janie tried to have children and even went to fertility specialists. All of their

(continued on page 3)

Under the Weather

(meet the member continued)

fertility tests were normal and the doctor couldn't explain their infertility. So Shawn and Janie looked into private adoption but were told that they would have to disclose Janie's disability which would make it unlikely for a pregnant mother to choose them as adoptive parents.

They still wanted to be parents so they took classes to become foster parents. A few months later, they received a phone call that a little girl needed a foster family. Future adoption might also be possible. They took the little girl into their home and thoroughly enjoy caring for her. Taking care of an active child is sometimes a challenge for Janie, but her mom lives close by and loves helping to care for her foster granddaughter.

Janie's DINET name is "Thankful." She chose this name to help her to remember the blessings in her life.

It's no surprise to any dysautonomia patient that extreme hot weather or extreme cold weather can exacerbate symptoms. But what about the weather we can't see? Atmospheric changes in barometric pressure can wreak havoc on our bodies, particularly on our sensitive autonomic nervous systems. If you're anything like me, for 'no reason' you may wake up on a rainy morning with intense symptoms and they may last throughout the day. Perhaps changing barometric pressure causes these surprising symptoms.

Barometric pressure is defined simply as the pressure caused by the weight of the air above a given point. Rapid variation in barometric pressure from high to low or low to high is a likely culprit for triggering an onslaught of symptoms in sensitive individuals. Sudden or drastic changes in barometric pressure have been linked to headaches, joint pain, muscle cramps, inflammation and trouble breathing. The human body is thought to be the best barometer around. Changes in your symptoms may easily predict changes in the weather. If the barometric pressure drops dramatically, it means a storm is brewing. If it rises, it means good weather will follow. Start tracking unusual or intense symptoms in relation to the weather to test how accurate your body's barometer is.

What, if anything can do to avoid the negative effects of changing barometric pressure? Unfortunately, there is no surefire way to avoid them aside from relocating. The tropical paradise, Honolulu, Hawaii is reported to have the most stable barometric pressure in the United States. Sunny San Diego California, is a close second. Rainy Seattle, Washington, my home area, is not the best place for a person with dysautonomia. Just when my body finally adjusts to one pressure, it can rise or fall dramatically without warning in a very short time. This leaves my body confused and struggling to stay normal. If only we could all move to Hawaii...

DINET would like to say

Thank You
to *Alexia Anastasia*
for mailing hundreds of DVDs to
our members. We appreciate all
you've done, Alexia!

**CALLING
ALL WRITERS**

Dear Dinet Readers,

We are always looking for new writers for our newsletter. You do not have to be a professional writer, just have something special to say. We are looking for writers who can convey their thoughts in a conversational tone. Could you tell us a story, write us a poem, or send us helpful hints—ideas that will help or inspire other DINET readers? Do you have a child with dysautonomia and you could give other parents tips for coping? Do you have unique ways to handle dysautonomia and continue in your work or profession? Have you found help corresponding with another about dysautonomia... how has that helped? If you wonder if a topic is appropriate please write our volunteer coordinator Janie at j_farrens@hotmail.com and she will be able to provide you with guidelines.

Best wishes always,

The DINET newsletter staff

Occupational Therapy and POTS: Where More Things are Possible

While we all know what 'POTS' means, many of us may not know what Occupational Therapy is and how can it help. POTS may drastically change our lives, leaving us wanting to get back to those activities that make us who we are, as well as regain our independence. As an Occupational Therapy student who also has POTS, I am here to share with you that Occupational Therapy can help. It is concerned with activities of daily living and making the most of your abilities no matter what your limits are. OTs are allied health professionals who can make a difference.

OTs are trained to look at the individual from many different aspects and put the pieces together to provide a holistic view. They identify the individual's supports and barriers to living a life to its fullest. I would like to share with you some basic principles that may help you better to participate in the meaningful "occupations" in your life.

Disclaimer: The contents of this article are for informational use only. It is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

ENERGY CONSERVATION: The first basic principle is energy conservation. Each activity has an energy cost. For example, resting in bed requires the least amount of energy; whereas, dressing requires about twice the energy. Standing requires even more energy, especially in POTS patients whose increased heart rate may expend 3 times the amount of energy than a normal person. By learning ways to conserve energy an individual can increase their ability to be fully functional and time management can make a huge difference.

TIME MANAGEMENT: Time management is an invaluable tool for life and for energy conservation. This involves learning the skills to plan one's activities so that tasks requiring high energy levels are interspersed with tasks requiring low energy levels. For example, housekeeping tasks are high energy while doing paper work is low energy.

Plan activities for when you feel the best. If fatigue is present more in the morning then plan accordingly. Perform those higher energy tasks later in the day when fatigue is less prevalent. If pain is present and one manages it with medication, plan activities to coincide with the maximal benefit.

Learn to get in touch with your body. It will help you develop an internal sense of limits and understand when your body is telling you to stop and rest. Learn to build rest into your day to prevent over-fatigue and flare-ups. Make a plan for a day, a week, a month where you incorporate a balanced lifestyle that include both activities and time for rest.

IDENTIFYING PRIORITIES: Become skillful at identifying priorities. Identify the most important things for you to do and delegate or eliminate other activities. Look at your standards and the way you do things. Do you need to wash your car every week or send out 50 Christmas cards every year? By delegating or eliminating unnecessary activities you are saving energy for all those other important activities such as those that give you a greater sense of fulfillment. Ask yourself should I do this or that? Should I save my energy for taking care of my kids...or studying for that exam?

FATIGUE: Fatigue is a hidden disability. Communicate with your loved ones. It is essential. Often they may not know what you need. They might struggle with the idea that they are taking away your independence. Learn how to ask for help and talk about how changing roles are affecting you and what you would like from or expect of them. This is so important I am repeating...talk to your loved ones!!!

ANALYZING YOUR DAILY LIFE: Analyze and pay attention to the energy expenditures in your daily activities. Find ways to cut corners and minimize energy waste by looking at how you do things. If it takes you 10 minutes in the morning to select an outfit, would it be easier to preselect it at night? If you are tired after you return home from work, could you precook meals so you only have to warm it up?

Examine the minute details of your life and finds ways to maximize your time and energy. Analyze your work station (desk, kitchen) and rearrange it to maximize function. Organize a task before you start it to make it easier to perform and avoid making wasteful steps. Sit when you can. Get a stool or higher chair so you can cook or clean in your kitchen more comfortably (without compromising balance or safety). Chop veggies or meats at the table. Use an electric cart at the grocery store. Shop at smaller stores, or take smaller more frequent trips to the grocery store.

Occupational Therapy can make a difference in the life of a person with POTS—making your life "more possible". I can only suggest generalizations (tips and tricks on how to preserve energy and increase performance). However if you visit an OT, he or she can provide a full assessment and tailor it to you needs. If you would like friendly advice or have a specific topic you would like me to discuss in another article, you can e-mail me at silverflower26@yahoo.com.

A special thanks to our volunteers for making this newsletter possible:

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Dysautonomia Information Network

RESEARCH IN REVIEW

YOUR SOURCE FOR CURRENT
DYSAUTONOMIA RESEARCH!

SEX, HORMONES AND NEUROEFFECTOR MECHANISMS.

Hart EC, Charkoudian N, Miller VM.

Acta Physiol (Oxf). 2010 Sep 27. doi: 10.1111/j.1748-1716.2010.02192.x. [Epub ahead of print]

Incidence and rate of cardiovascular disease differ between men and women across the life span. Although hypertension is more prominent in men than women, there is a group of vasomotor disorders [i.e. Raynaud's disease, postural orthostatic tachycardia syndrome (POTS) and vasomotor symptoms (hot flashes) of menopause and migraine] with a female predominance. Both sex and hormones interact to modulate neuroeffector mechanisms including integrated regulation of the Sry gene and direct effect of sex steroid hormones on synthesis, release and disposition of monoamine neurotransmitters, and distribution and sensitivity of their receptors in brain areas associated with autonomic control. The interaction of the sex chromosomes and steroids also modulates these effector tissues, that is, the heart, vascular smooth muscle and endothelium. While involvement of central serotonergic centers has been studied in regard to mood disorders such as depression, their contribution to cardiovascular risk is gaining attention. Studies are needed to further evaluate how hormonal treatments and drugs used to modulate adrenergic and serotonergic activity affect progression and risk for cardiovascular disease in men and women.

PMID: 20874808

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AUTONOMIC DYSFUNCTION PRESENTING AS POSTURAL TACHYCARDIA SYNDROME FOLLOWING TRAUMATIC BRAIN INJURY.

Kanjwal K, Karabin B, Kanjwal Y, Grubb BP.
Cardiol J. 2010;17(5):482-7.

Background: Autonomic dysregulation (also called diencephalic epilepsy) has been reported following traumatic brain injuries (TBI). However, until now, postural tachycardia syndrome (POTS) has not been reported as a long-term complication in patients who have suffered a TBI. We report on a series of patients who developed POTS after suffering TBI. Methods: Eight patients who were referred to our center had suffered TBI and developed features of orthostatic intolerance following head trauma. The patients' neurological, neurosurgical and autonomic data (charts and/or physician letters) were then carefully reviewed for demographic characteristics, comorbid conditions, symptoms of orthostatic intolerance, medications and response to medication. These patients were diagnosed as having POTS, primarily based on their clinical features and findings from the head-up tilt test (HUTT). The data presented is observational and descriptive (percentages or means). Results: Eight patients (seven of them women) aged 21-41 years had suffered from TBI and had developed features of POTS. All had been normal with no symptoms prior to their TBI. All patients experienced orthostatic dizziness, fatigue, palpitations and near syncope. Six patients suffered from frank syncope. Six patients developed significant cognitive dysfunction, and three developed a chronic pain syndrome following trauma. All of the patients reported severe limitations to their daily activities and had been unable to keep their jobs, and two were housebound. Six patients demonstrated a good response to therapy with various combinations of medication. The symptoms of orthostatic intolerance and syncope improved with the initiation of medical therapy, as well as their reported quality of life. Two patients failed to show any improvement with various combinations of medications and tilt training, and continued to experience orthostatic difficulties. Conclusions: Postural tachycardia syndrome may, in some cases, be a late complication of traumatic brain injury. (Cardiol J 2010; 17, 5: 482-487).

PMID: 20865679

(Research continues on page 6)

ORTHOSTATIC AND NON-ORTHOSTATIC HEADACHE IN POSTURAL TACHYCARDIA SYNDROME.

Khurana RK, Eisenberg L.
Cephalalgia. 2010 Sep 6. [Epub ahead of print]

OBJECTIVE: Orthostatic and non-orthostatic headache spectrum was prospectively studied in 24 consecutive patients with postural orthostatic tachycardia syndrome (POTS).

METHODS: Patients were interviewed about clinical aspects of headache and its precipitation during head-up tilt (HUT). Autonomic functions were assessed using a standard battery of tests. The relationship of orthostatic headache to cardiovascular variables was examined using unpaired two-tailed t-test. **Results:** Orthostatic headache occurred during daily activity in 14 patients (58.3%) and during HUT in 15 patients (62.5%). Age under 30 years and increasing duration of tilt were predictive for orthostatic headache. Of the 24 patients, 23 (95.8%) had non-orthostatic headache fitting the criteria of migraine or probable migraine.

CONCLUSIONS: Orthostatic headache affected two-thirds of POTS patients, especially those under age 30. Patients with orthostatic headache should be clinically assessed for POTS and informed of this association to reduce short-term morbidity. Migraine afflicted almost all POTS patients. This co-morbidity should be considered in management of POTS.

PMID: 20819844

EXERCISE PERFORMANCE IN ADOLESCENTS WITH AUTONOMIC DYSFUNCTION.

Burkhardt BE, Fischer PR, Brands CK, Porter CB, Weaver AL, Yim PJ, Pianosi PT. J Pediatr. 2010 Aug 31. [Epub ahead of print]

OBJECTIVE: To test the hypothesis that excessive postural tachycardia is associated with deconditioning rather than merely being an independent sign of autonomic dysfunction in patients with postural orthostatic tachycardia syndrome (POTS).

STUDY DESIGN: We retrospectively analyzed records from 202 adolescents who underwent both head up-tilt and maximal exercise testing. Patients were classified as POTS if they had ≥ 30 min⁻¹ rise in heart rate (HR) after tilt-table test; and deconditioned if peak $\dot{V}O_2$ uptake was $< 80\%$ predicted. Changes in HR during exercise and

recovery were compared between groups.

RESULTS: Two-thirds of patients were deconditioned, irrespective of whether they fulfilled diagnostic criteria for POTS, but peak $\dot{V}O_2$ uptake among patients with POTS was similar to patients without POTS. HR was higher at rest and during exercise; whereas stroke volume was lower during exercise, and HR recovery was slower in patients with POTS compared with patients without POTS.

CONCLUSIONS: Most patients who presented with chronic symptoms of dizziness, fatigue, or pre-syncope, were deconditioned, but, because the proportion of deconditioned patients was similar in POTS vs non-POTS groups, we conclude that HR changes in POTS are not solely because of inactivity resulting in deconditioning. PMID: 20813382

VASOVAGAL SYNCOPE:

Cerebral blood flow abnormalities in patients with neurally mediated syncope.

Joo EY, Hong SB, Lee M, Tae WS, Lee J, Han SW, Ji KH, Suh M. J Neurol. 2010 Oct 1. [Epub ahead of print]

The aim of this study is to investigate regional cerebral blood flow (rCBF) in patients with syncope. We compared brain single photon emission computed tomography (SPECT) images of neurally mediated syncope patients with those of age/sex matched healthy volunteers. (99m)Tc-ethylcysteinate dimer (ECD) brain SPECT was performed in 35 patients (M/F = 17/18, mean 36.6 years) with syncope during the asymptomatic period, and in 35 healthy volunteers. For statistical parametric mapping (SPM) analysis, all SPECT images were spatially normalized to the standard SPECT template and then smoothed using a 14-mm full width at half maximum Gaussian kernel. The mean duration of syncope history was 4.9 years and the mean number of syncope episodes was 6.3. In all patients, syncope or presyncope episodes occurred during head-up tilt tests, and all were the vasodepressive type. SPM analysis of brain SPECT images showed significantly decreased rCBF in the right anterior insular cortex, left parahippocampal gyrus, bilateral fusiform gyri, bilateral middle and inferior temporal gyri, left lingual gyrus, bilateral precuneus and bilateral posterior lobes of the cerebellum in syncope patients at a false discovery rate corrected $p < 0.05$. There were no brain regions that showed increased rCBF in syncope patients. Furthermore, we found a negative correlation

between the total number of syncopal episodes and the rCBF of the right prefrontal cortex, and between the duration of syncope history and the rCBF of the right cingulate gyrus at uncorrected $p < 0.001$. Decreases of rCBF in multiple brain regions may be responsible for autonomic dysregulation and improper processing of emotional stress in neurally mediated syncope patients, and frequent syncope episodes may lead to frontal dysfunction.

PMID: 20886349

MANAGEMENT STRATEGIES FOR RECURRENT VASOVAGAL SYNCOPES.

Vaddadi G, Corcoran SJ, Esler M.
Intern Med J. 2010 Aug;40(8):554-60.

Vasovagal syncope (VVS) is the commonest cause of recurrent syncope and has a high level of morbidity in both young and elderly patients. Diagnosis and treatment are often unsatisfactory despite the fact that syncope has a lifetime cumulative incidence of 35%. A detailed history can often yield an accurate diagnosis in most young patients. Older patients are more likely to present in an atypical manner and although the yield is low, a more comprehensive diagnostic assessment may be needed. It is important to identify patients with low supine systolic blood pressure who are prone to recurrent VVS. These patients represent a distinct subtype of VVS and may respond to a tailored therapeutic approach. Treatment options for VVS are limited because of a paucity of randomized trials. The backbone of therapy is educating the patient, avoiding precipitating factors, maintaining hydration and the application of physical counter-pressure manoeuvres. Drug therapy is rarely warranted; however, fludrocortisone, alpha-agonists, such as midodrine and dihydroergotamine, and selective serotonin reuptake inhibitors may be helpful in some patients. Permanent cardiac pacing is rarely needed and randomized trials do not support its use.

PMID: 20718882

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IS IT POSSIBLE TO ACCURATELY DIFFERENTIATE NEUROCARDIOGENIC SYNCOPES FROM EPILEPSY?

Duplyakov D, Golovina G, Garkina S, Lyukshina N.
Cardiol J. 2010;17(4):420-7.

Global cerebral hypoperfusion resulting in syncope, and asynchronous discharge of cerebral neurons leading to seizure, are two major mechanisms of transient loss of consciousness. They both have a lot in common in clinical and historical settings, although with a high prevalence of incorrect diagnosis, even by well-trained staff. The aim of this review was to try to combine data from both a cardiologist's and a neurologist's perspective (history taking, special questionnaires, serum prolactin, EEG, CT/MRI, tilt-testing, loop recorders).

PMID: 20690104

CARDIORESPIRATORY AND CEREBROVASCULAR RESPONSES TO HEAD-UP TILT I: INFLUENCE OF AGE AND TRAINING STATUS.

Murrell CJ, Cotter JD, George K, Shave R, Wilson L, Thomas K, Williams MJ, Ainslie PN.
Exp Gerontol. 2010 Jun 30. [Epub ahead of print]

The purpose of this study was to examine the combined cardiorespiratory and cerebrovascular responses to head-up tilt (HUT) in young (27+/-4years) and older (65+/-5years) trained and untrained humans. Middle cerebral artery blood velocity (MCAv; transcranial Doppler ultrasound), blood pressure (BP; Finometer) and cardiac output (Q) were measured continuously whilst supine and during 60 degrees HUT for 15min or to pre-syncope in 41 participants [nine young trained; eleven young untrained; twelve older trained; nine older untrained]. Thirty seven of forty one participants completed 15min HUT, and orthostatic tolerance did not differ with age or fitness ($P=0.66$). Supine MCAv was 30% lower in the older participants but the HUT-induced drop in MCAv was not altered by age [-18% (young) vs. -17% (older)], or fitness. Mean arterial BP was maintained during HUT and not altered by age or fitness. In the untrained, peripheral resistance was elevated [11% vs. -2% (trained); $P=0.01$], and Q was reduced [-10% vs. -5% (trained); $P=0.04$] with HUT. Despite these age- and fitness-associated differences in some cardiovascular responses to HUT, orthostatic tolerance was similar across groups. Thus, at least in this healthy population, neither age nor fitness impacts on the ability to adapt to postural change.

PMID: 20600779

(Research continues on page 8)

the Patients VOICE

ORTHOSTATIC INTOLERANCE:

Morbidity and Mortality of Orthostatic Hypotension: Implications for Management of Cardiovascular Disease.

Benvenuto LJ, Krakoff LR.

Am J Hypertens. 2010 Sep 2. [Epub ahead of print]

Orthostatic hypotension (OH) is the failure of cardiovascular reflexes to maintain blood pressure on standing from a supine or sitting position. Although OH may cause symptoms of dizziness or syncope, asymptomatic OH (AOH) is far more common and is an independent risk factor for mortality and cardiovascular disease (CVD). The prevalence of AOH increases with age, the presence of hypertension or diabetes and the use of antihypertensive or other medications. The implications of AOH for the treatment of CVD and hypertension are not well defined. This review provides an overview of the current information on this topic and recommends the more frequent assessment of OH in clinical practice and in future clinical trials. American Journal of Hypertension (2010). doi:10.1038/ajh.2010.146.

PMID: 20814408

T'was the night before New Years

*T'was the night before New Years
And all through Dinet
No one was stirring not even a pet
Good wishes were spoken to people with care
In hopes that true healing soon would be there
These dreams were tucked around everyone's hearts
With visions of 'great days' hitting the mark
Then simultaneously a great idea arose
Striking everyone from their heads to their toes
And with that, a warm thought grew like a light
"Take good care of yourself each day & each night"*

By Judith Pettibone

With sincere apologies to Clement Moore

Some Days

*Some days the smiles won't come
Some days your light does not shine
Some days it is all too much
Some days it takes your try*

*Some days you say no more
Some days you pray please go
Some days you scream inside
Some days you wonder why*

*Some days the dance is gone
Some days the rain is sad
Some days the world is far away
Some days are just a sigh*

*Some days no one hears
Some days no one understands
Some days the anger flares
Some days the happy is a lie*

*Some days you go minute to minute
Some days you want much more
Some days that wanting drowns you
Some days you just cry*

*Some days this sucks
It sucks your energy, your hope, your life
Some days you want to give in and give up
Some days that well bar is just too high*

*But all these "some days" will pass
Then you begin again
To cope, to hope and to pray
And some day this will all be gone!*

By Stacey Yount

SHARE YOUR EXPERIENCES IN THE PATIENT'S VOICE!

The Patient's Voice is a newsletter column where patients can express themselves while writing about experiences relating to dysautonomia —both positive and negative. It is a place to share medical experiences, suggestions, short stories and poetry, etc.

Send contributions to: staff@dinet.org.