



Taking a Negative and Making a Positive

by Sarah of OI Resource

There is a lesson in life that I have been trying to learn for a long time. It shows itself very clearly to me in my experiences with Chronic Fatigue Syndrome (CFS)/Orthostatic Intolerance (OI). It is that no matter how bad the circumstances look now and how many doubts I have about the future, God is always working behind the scenes to bring the next answer into my life. It will come suddenly and without warning and often in unexpected packaging. I never know where the next answer is going to come from, but I do know that no matter where I am, He can get the answer to me. There are so many days that it sure would help if I would remember that and look forward to and hope for future improvements in all areas of my life without getting caught up in how badly things seem to be going!

My life has been affected by CFS/OI since I was nine when my mom got sick in 1988. Then I also became sick with CFS/OI when I was fifteen in 1994. We had the similar experience of having a healthy, successful life with lots of plans for the future, but we both woke up with the "flu" one day (over 6 years apart) from which we did not recover.

In 2000, after about five years of having been diagnosed with CFS and being mostly bedbound, some information came across my bed that would change the direction of my life. I was reading Dr. David S. Bell's CFS newsletter (The Lyndonville News) and he started explaining OI and its relationship to CFS. He had been working for several years with a specialist, Dr. David H. Streeten, who had been investigating OI for a long time. This information was revolutionary to me. Over the years I had looked at other illnesses, but I did not fit their patterns. OI was the one problem that could tie everything I'd experienced together and could explain most, if not all, of my remaining symptoms. It explained why lying down had become my best treatment option. It explained why being up was so hard and other variations of awful. It was also exciting because there is such a simple test for it. I failed! Finally, things started making sense and I could see how previous experiences fit together into a whole picture.

Early the next year, I read Dr. Bell's book, Faces of CFS, as I searched for treatments. I had been learning about OI, but I was still surprised by one of Dr. Bell's and Dr. Streeten's experiments. First, I was surprised by how easily just standing replicated CFS symptoms, and then I was surprised by how simply putting pressure on the legs and abdomen relieved symptoms during standing. There was a problem of mobility with the pressure pants being used (in their experiment, MAST trousers). That was when God gave me the idea of a g-suit.

I did not know exactly what a g-suit was, but I found out that g-suits are pants that fighter pilots wear to push blood back up to their heart and brain. (NASA also uses g-suits for the problem of OI with their astronauts. They are also pursuing other treatments to keep blood from pooling in astronauts' legs.) Pressure pants were originally invented in 1903 for use during surgery by Dr. George Crile. A g-suit sounded like it might help me, but how was I going to convert a g-suit from military use to medical use?

In August 2001, I started wearing a g-suit daily and have had much success with it. I have put together a website (www.OIResource.com), which includes all of the research I collected from many sources about OI and g-suits. It also contains information about an exciting possible treatment for those with orthostatic intolerance called an Impedance Threshold Device (ITD). It is a small, simple breathing device that was invented for CPR in the 1990's. I use an ITD and it has helped me improve. With the help of a g-suit and ITD, I have been able to pursue more in-depth testing and treatments, and I've participated in several research studies.

I hope in the future to always remember that no matter how long it has been

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since I have made progress, God is always working in my life. In particular, He has many doctors and researchers in place who are dedicated to understanding and treating OI successfully. Through my website, I would like to help people find out if OI is causing problems for them and encourage them to find the best possible treatment. I know from experience that OI treatment should add tangible quantity and quality to everyday life. With current treatments and future developments, I know that my time is coming and I will get to show my full potential again and live my life full of learning, creativity, and energy!

Sarah

contact@oiresource.com

www.OIResource.com

Continually Searching

We are still searching for DINET's next leader. This is a volunteer position that can be performed out of your own home. Please take in mind that this is a wonderful opportunity to make an incredible difference in numerous lives. For more information, please refer to our [last newsletter](#). If you are interested in the position, please email Michelle Sawicki at staff@dinet.org.

We are also searching for people to help with our newsletter. Please email staff@dinet.org if you can help.

Thank you.

Does your place of business or family give to charity? If so, please let them know about the Dysautonomia Information Network, www.dinet.org. DINET is completely funded by member's donations and can't exist without them. Thank you!

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Meet the Member

by Melanie Bassett

Angela (Angelika_23)



Angela is thirty-five years old and has been a member of DINET since April 2007. Her forum name, Angelika_23, is comprised of two parts. Angelika was her name in German class during high school and her favorite number is 23. Most people just call her Angela, but close friends call her Ang.

Angela has been ill since 2001. She was hospitalized and diagnosed with POTS in April 2007. She also has been diagnosed with inappropriate sinus tachycardia, chiari I malformation, fibromyalgia and scoliosis.

Angela's family includes her husband, Jeff, and their three children:

Christopher, Joshua and William, who are all musically talented. The family is complete with a wide variety of

pets, including a Blue Fronted Amazon Parrot named Muffin (who is 25 years old). Muffin was Angela's first "baby." Dozer, a Halloween Muffin Crab, two cats named Kitten and Stormy and two dogs named Beau (a boxer) and Jasmine (a Pekinese) complete her pet family. I would guess that they must have a very big house in Ohio!

When away from her pets, Angela works as a Human Resources Coordinator. She has shared some of what she has learned in this occupation on DINET's forum. I know I made a copy of the advice on the Family Medical Leave Act that she once posted.

Angela's current hobbies include A LOT of reading and paper and pencil role playing games (i.e. Dungeons & Dragons) with a group of people who understand her illness and are very sensitive to her health situation.

In the past, Angela and Jeff used to competitively swing dance. They would dance at least 3-4 nights a week for hours without a break. We all agree and believe that someday we will see them on the reality TV show, "So You Think You Can Dance."

When asked to share her favorite childhood memory, Angela replied, "going boating with my dad." She loves being on the water, listening to the waves, laughing in the sun and just enjoying the smells of summer. She always patiently waited her turn to ride in the tube.

Angela is inspired by her husband and children. She also has a network of true friends. I believe when illness strikes it is one of the best times to find out who your true friends are. True friends are the ones that stick with you through the good times and the bad. I think we all weed our friend garden when we become ill, and sometimes the weeds just wither away on their own it seems. One of Angela's special friends spends time sharing a one on one Bible study with her. Time spent with her friend and actively participating in Bible study has helped Angela put her illness in perspective. Angela is no longer angry about her illness and no longer feels desperation like she did in the beginning.

Angela feels that God is using her illness to teach her many things. She is currently looking forward to the future and wondering if her destiny is to be

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healed. When and if she becomes healed, she will use this experience to help others who are struggling through illness. Angela leaves the following quote to remind others that anything is possible with God.

"Philippians 4:13 --- I can do all things through Christ who strengthens me."

From the feedback that we have received in the past, the Meet the Member column seems to be enjoyed by our members. We would love to eventually feature all of our readers. Please contact both Michelle Sawicki (staff@dinet.org) and Heather Thompson (Tigger852@msn.com) and share your story. You will be sent a short questionnaire to complete. Our goal is to publish four member profiles per newsletter, so I'm begging pretty, please with sugar on top! Thank you so very much, and please let me know if you have any questions.

Heather Thompson

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The Patient's Voice

Views expressed in The Patient's Voice are not necessarily those of the Dysautonomia Information Network or its members.

"Glass"

Why do they look at me like they do?
 Am I so different than they?
 On the outside I look 'fine'
 But on the inside it is a different world
 Doctors tell me 'you are imagining it'
 Family tells me 'stop doing that'
 'You could hurt yourself'
 'You should rest'
 'Take care of yourself'
 What about what I want?
 Doesn't that matter anymore?
 Why won't they listen to me?
 Don't they understand I'm sitting right there?
 When they talk about me
 When will they finally realize
 I am not made of glass!
 I am not a doll that should be put on a shelf
 Just because I am sick, doesn't mean I can't still be a mom, wife, friend
 It doesn't mean that I can't help them anymore
 Please see me for what I am!
 I am a STRONG woman with dreams, wishes, and hopes too
 I am a person who wants to help clean, cook, garden
 Please let me help while I still can
 For there may come a day where I truly can't and I want to enjoy it while it lasts-
 Why can't you understand that?

Lizzy 3-4-08

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.

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Q&A with the doctors

Ask a question!

Do you have a question for DINET's medical advisors?

Visit <http://www.dinet.org/q&a.htm> to ask your question today!

Question:

I am a 26 yr. old dentist that has been diagnosed with Dysautonomia and MVPS in the states two years ago. My biggest concern is hand tremors, which cause problems in my field due to the overactive sympathetic nervous system to stresses. I am currently on 40mg of Inderal per day but still have a very overactive sympathetic system. I have problems seeking doctors that understand my condition in Egypt, so I would like to have your help in alleviating such bothering symptoms.

Answer:

Tremors can be caused by several different disease processes. First and foremost, you should determine if you actually have Dysautonomia and mitral valve prolapse. The definition of mitral valve prolapse has changed over time. If you actually have sympathetic overload, sometimes Clonidine given at a very low dose (0.1mg at night or 0.1mg bid) can help. This change should be reviewed and followed up by your treating physician.



- Dr. Suleman, The Heartbeat Clinic, Texas

Question:

Can you tell me if there is any information regarding how the weather affects people with POTS? It seems my symptoms become a lot worse in the winter whereas I can only detect a small change in the fall and spring. It is very difficult for me to function in the winter.

Answer:



I know of no systematically collected data about seasons and symptoms in POTS. Anecdotally, I expect that symptoms are often worse in the summer than winter-presumably related to the increased heat. I do not have a cogent explanation for the worsening in the winter.

- Dr. Satish Raj, Vanderbilt University Medical Center

Question:

I have POTS and have managed to self treat myself with herbal compositions, diet, exercise and magnesium + Vitamin B6. I work full time as a physiotherapist and do not need to lie down during the day. My question is how free of symptoms are patients who take medications? I have noticed an exacerbation of symptoms in the spring and fall -is this my imagination or a general observation?

Answer:

Response to medications is quite variable among patients. However, my impression is that in most patients the medications may help to improve symptoms and functioning, but they do not totally "cure" the symptoms. It sounds like with the current cocktail of vitamins and supplements that you are doing fairly well. Again, I have not noticed a spring/fall worsening of symptoms. This is not to say that it is not true, but I cannot currently explain this phenomenon.

- Dr. Satish Raj, Vanderbilt University Medical Center

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My seventeen year old daughter has been diagnosed with POTS. She has severe issues with "brain fog." Is brain fog due to fatigue or the lack of oxygen from decreased blood circulation?

Answer:

"Brain fog" is a term that people typically use to describe lack of concentration, attention and a general lack of "mental" energy. It can certainly be due to "physical" fatigue that accompanies any chronic illness. Brain fog is described by patients with POTS, NCS, chronic fatigue syndrome and fibromyalgia, but it is also common in a variety of other neurologic, cardiovascular and autoimmune conditions. Unfortunately, the cause of mental fatigue is not clearly understood at this time, but addressing factors that are treatable, such as improving sleep, managing potential depression or anxiety and improving nutrition and "physical" endurance can help alleviate and improve mental and cognitive status. For POTS, maintaining adequate fluid and salt intake is essential for both physical and mental energy. Using stimulants in small doses such as certain medications or caffeine can be another therapeutic option that can increase alertness in patients with POTS. I often recommend continuing to perform cognitively challenging tasks as much as possible, such as reading, writing, doing cross-word puzzles, etc., despite the "brain fog," in order to maintain cognition, memory, concentration and attention.



- Svetlana Blitshteyn, Kinkel Neurologic Center, LLP, Buffalo, NY

Question:

Can a person who has dysautonomia be incontinent of urine during an episode? I have seen the "seizure like" symptom listed but nothing about urine incontinence.?

Answer:

Urinary incontinence can sometimes accompany a fainting spell. However, any episode that involves a sudden loss of consciousness without any warning signs and is accompanied by urinary incontinence should be thoroughly investigated for a possibility of a seizure disorder. Only after a seizure has been ruled out by appropriate testing is it safe to conclude that the episode of urinary incontinence with loss of consciousness was NOT a seizure and was likely due to syncope (fainting.)

- - Svetlana Blitshteyn, Kinkel Neurologic Center, LLP, Buffalo, NY

Question:

By way of a tilt table test, I was diagnosed with dysautonomia three years ago. This was after several years of generally just not feeling well, which included fatigue to the point of barely functioning, facial muscle spasms, chest pain, shortness of breath, tingling in my arms, joint pain, and more. My GP sent me for the tilt table test as a last resort. I am currently taking Midorine twice a day and am on high volume water and salt intake. I tend to go through cycles of having facial muscle spasms, hives/rash, anxiety and fatigue. Recently I have noticed that my vision seems to have changed, and in my left eye I will often feel a sharp pain. I have always had tiny pupils that don't dilate. Also, sometimes I will feel as if I have been pricked by a pin on my left hand and fingers. Could these be related to my Dysautonomia? I am scheduled to visit the Vanderbilt clinic in October and am looking forward to that appointment. I want to understand this condition more fully and make sure I am taking the best care of myself as possible.

Answer:

Because the Autonomic Nervous System controls all areas of the body and because most of OI/POTS is ultimately 2 degrees abnormal pooling of the blood in the abdomen and the legs, this leads to a slight decrease in blood flow to the brain and can lead to just about any symptom. One of the more frequent complaints we hear is of changes in vision-usually this is around the time of other symptoms that are related to the pooling of the blood. Often, when the blood flow to the brain is reduced, the very tiny muscles of the eye will fatigue and cause visual changes or even pain from spasms. BUT don't just assume this is what it is. If you haven't

seen an ophthalmologist, at least have your eyes checked. Hives and rash can also accompany spells of autonomic dysfunction, usually caused by the release of histamine from a special cell called a mast cell. Tests can be done to determine if this is happening with you. Dr. Julian Stewart has done extensive research in this area.

You don't mention the specific subtype of dysautonomia you have but, especially in POTS, when there is a large release of adrenaline in the body, sometimes the body doesn't know how to interpret it and will tell the brain this is anxiety when in fact the sympathetic nervous system (the adrenaline system) is trying to compensate for pooling of blood that can result in falls in blood pressure and the release of excess adrenaline. This is the fight-or-flight mechanism and usually when there is no obvious reason for you to have the release of adrenaline the brain tells you that you are feeling anxious. The symptoms are usually the same: sweating, palpitations, fast heart rate and a general feeling of unease. This can possibly trigger the facial spasms. Until about four or five years ago, about 85% of patients would be diagnosed with an anxiety disorder before they were diagnosed with dysautonomia. The pinpoint pupils are usually an effect of the activation of the other half of the Autonomic Nervous System, the parasympathetic, and it is not unusual to see effects of both the sympathetic and parasympathetic symptoms. Unfortunately, fatigue is probably the most common and often the most debilitating symptom of the syndrome. To make a long story short, you're symptoms could, and probably are, related to the dysautonomia, but we don't want to assume anything. There could be other factors. You are going to one of the best medical centers in the world, especially in the autonomic field, so they will be able to answer your questions better after this evaluation, so continue to follow-up with your physician to make sure other things are not going on. Also, I would suggest that you make a list of your symptoms to take with you when you go to Vanderbilt.

- Dr. Thompson

Question:

I was diagnosed with dysautonomia in 2004. I have many symptoms that are bothersome, but my digestive tract is the worst. I have had chronic constipation for the last five years. I will go two weeks at a time without having a bowel movement. I have seen several gastroenterologists and usually leave the office with a pat on the head and the recommendation for more fiber. I have tried Contulose, Miralax, etc. -you name it. I am very concerned about the toxicity of all of this waste lingering in my system for such long periods of time. I also have severely delayed gastric emptying and dysphasia. I have no problems eating, so I am just wondering if there are any suggestions or treatments out there that I am missing. I am very disheartened right now because whenever I go to the doctor I feel like I am not being taken seriously. I would appreciate any help/input that you could provide me.

Answer:

I have found both in patients and in myself, the gastrointestinal symptoms are frequently overlooked or are tried to be explained in another way from dysautonomia. But more and more we are finding that symptoms such as yours are related to dysautonomia. I am seeing more and more people who have GI problems as one of their main symptoms. I don't know of any definitive studies to point you to, but more and more GI doctors are beginning to feel that patients with dysautonomia have severe problems with the motility of the GI tract. When you mention delayed gastric emptying and dysplasia, you don't mention if you have had a gastric emptying study, an EGD (upper scope) to look for reflux or stimulation, a colonoscopy or a colonic motility study. When you say "you name it" as far as meds, I wonder if the above studies have been done and if you are on a proton pump inhibitor (Prilosec, etc.) because reflux is common in dysautonomia. Also, there are several drugs that can be tried if you have documented gastric emptying problems, but these medications can carry side effects so most doctors want documentation prior to using them. Also, for the chronic constipation, certainly the drug of choice these days is Miralax, but if it is truly a motility problem, Amitiza is indicated. I have read recently that Zelnorm is going to be put back on the market, but it can only be prescribed by a gastroenterologist. The most important thing is to find a gastroenterologist who will listen and work with you. If the above tests have not been done, they need to be considered. If you

have not done so, you may want to look into getting a referral to a major university center for further evaluation.

- Dr. Thompson

Question:

My blood pressure is always normal; I never have pooling in my feet or legs and when I am standing my pulse stays at about 115bpm. The problem is that I do have all of the other horrible symptoms of POTS. While I have been diagnosed with POTS, is there a possibility that this could be something else?

Answer:



Yes, this can be many things including POTS or an associated problem called inappropriate sinus tachycardia. You need to rule out other conventional problems such as thyroid disease, forms of anemia, pheochromocytoma and more. This will require a medical visit to determine if something else could be going on.

- Dr. Julian Stewart, New York Medical College

Question:

My fifteen year old daughter was diagnosed with dysautonomia two years ago. She has now been diagnosed (at a sleep disorders clinic) with narcolepsy. Is there any association between these two disorders?

Answer:

There could be an association in the sense that the central nervous system is involved in both. The problem is that "dysautonomia" is really a non-diagnosis and just means that something is wrong with the nervous system. I certainly would not like to place that handle on kids with simple faint.

- Dr. Julian Stewart, New York Medical College

Dr. Stewart recently contacted us regarding two different studies that his clinic will be conducting. They recently received funding from NIH to study Vascular Dysfunction in Chronic Fatigue Syndrome. The study is for 15-29 year olds.

The below articles from Dr. Stewart contain more information on his studies.

Vascular Dysfunction in CFS – CFS with and without POTS

We are investigating "Vascular Dysfunction in CFS" in the young (aged 15-29 years). This means problems with blood vessels and circulation. In many young CFS patients we have already demonstrated a circulatory problem called postural tachycardia syndrome or POTS. Our understanding of the mechanisms of POTS is incomplete and not all young CFS patients have POTS. We have proposed that even though some CFS patients do not have POTS, they may still have problems with small blood vessels that can be detected in skin.

When you come for your testing, we will perform a type of tilt testing and other simple noninvasive tests to determine whether you have POTS or not. We will also determine the type of POTS. If you do not have POTS, we will complete testing over a total of two days using a technique called intradermal microdialysis (explained in the consent and in the website). There is a total subject fee of \$300.

If you do have POTS, we invite to stay two additional days to undergo tests specific to POTS (4 days in total). On the first of the two days we will study tests of breathing and the function of the nervous system. This is listed on our website as "Hyperpnea in Postural Tachycardia" and carries a subject fee of \$300. On the second of the two days we will test specific treatments for POTS which carries a subject fee of \$150.

Further details of the research and representative consent forms can be found on my web-site, www.syncope.org.

Please reply to:

Courtney Terilli, Research Coordinator

Courtney_Terilli@NYMC.edu

Telephone 914-593-8888

Or

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Hyperpnea in POTS, Local Vasoconstriction in POTS, Sympathoexcitation in POTS

We are currently continuing our studies of postural tachycardia syndrome in the young (aged 15-29 years). However, our understanding of the mechanisms of POTS is still incomplete.

Our current investigations can be separated into 3 days of study. On the first of the two days we will study tests of breathing and the function of the nervous system. This is listed on our website as "Hyperpnea in Postural Tachycardia" and carries a subject fee of \$300. On the second day we will study changes in the skin response to drugs regulating angiotensin, nitric oxide, and oxidative stress using the minimally invasive methods of microdialysis similar to prior experiments. On the third day we will test specific intravenous treatments for POTS. Days 2 and 3 each carry a subject fee of \$150.

Further details of the research and representative consent forms can be found on my web-site, syncope.org.

Please reply to:

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Research in Review

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Orthostatic hypotension: evaluation and treatment.

Maule S, Papotti G, Naso D, Magnino C, Testa E, Veglio F.

Orthostatic hypotension (OH) may be dependent upon various neurogenic and non-neurogenic disorders and conditions. Neurogenic causes include the main autonomic failure syndromes, primary (multiple system atrophy, pure autonomic failure, and autonomic failure associated with Parkinson's disease) and secondary (central nervous system diseases, peripheral neuropathies and systemic diseases). Non-neurogenic causes of OH include cardiac impairment, fluid and electrolyte loss, vasodilatation, and old age. A number of drugs may also cause OH, through their vasoactive action or by interfering with the autonomic nervous system. Symptoms of OH are debilitating, often confining patients to bed, and longitudinal studies have shown that OH increases the risk of stroke, myocardial ischemia and mortality. The therapeutic goal is to decrease the incidence and severity of postural symptoms, rather than restore normotension. In non-neurogenic OH, treatment of the underlying cause may be curative. In neurogenic OH a combination of non-pharmacological and pharmacological measures is often needed. Patient education and non-pharmacological measures represent the first step; among these interventions, fluid repletion and physical countermeasures have been proven very effective. Pharmacological treatment comprises a number of agents acting on blood vessels, on blood volume or with other pressor mechanisms. The drugs most currently used are fludrocortisone and midodrine. Fludrocortisone expands the extravascular body fluid volume and improves alpha-adrenergic sensitivity. Midodrine is a peripheral, selective alpha1-adrenergic agonist that causes arterial and venous vasoconstriction. Despite the wide use of these drugs, multicentre, randomised and controlled studies for the treatment of OH are still scarce and limited to few agents and groups of patients. Pharmacological management of OH substantially improves the quality of life of patients, although it may be problematic. The development of supine hypertension and subsequent congestive heart failure should be avoided, especially in those patients with a pre-existing cardiovascular risk, such as in diabetes or ischemic heart disease.

PMID: 17346129

Investigation of postural hypotension due to static prolonged standing in female workers.

[Cardiovasc Hematol Disord Drug Targets.](#) 2007 Mar;7(1):63-70.

Kabe I, Tsuruoka H, Tokujitani Y, Endo Y, Furusawa M, Takebayashi T.

The "Just-in-Time system" improves productivity and efficiency through cost

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reduction while it makes workers work in a standing posture. The aim of this study was to investigate the prevalence of postural hypotension in females during prolonged standing work, and to discuss preventive methods. Twelve female static standing workers (mean age \pm standard deviation; 32 \pm 14 yr old), 6 male static standing workers (30 \pm 4 yr old), 10 female walking workers (27 \pm 7 yr old) and 9 female desk workers (31 \pm 5 yr old) in a certain telecommunications equipment manufacturing factory agreed to participate in this study. All participants received an interview with an occupational physician, and performed the standing up test before working and ambulatory blood pressure monitoring (ABPM) while working. Although the blood pressure of the standing up test did not differ among the groups, mean pulse rates on standing up significantly increased in every group. Hypotension rates in the female standing workers' group by ABPM were 9 persons of 12 participants (75%) for systolic blood pressure (SBP), and were 11 persons of 12 participants (92%) for diastolic blood pressure (DBP). There were significantly higher than those in the female desk workers' group, none of 9 participants (0%) for SBP and 2 of 9 participants (22%) for DBP. The hypotension rates both male standing and female walking worker groups did not differ. Because all 8 workers who were found to have postural hypotension by the standing up test had decreased SBP and/or DBP by ABPM, it is suggested that persons at high risk of postural hypotension during standing work could be screened by the standing up test. The mechanism of postural hypotension may be a decrease of venous return due to leg swelling, and neurocardiogenic or vasovagal response. Preventing the congestion of the lower limbs by walking, managing standing time and wearing elastic hose to keep the amount of the venous return could prevent postural hypotension during prolonged standing work.

PMID: 17721059

The postural orthostatic tachycardia syndrome: a potentially treatable cause of chronic fatigue, exercise intolerance, and cognitive impairment in adolescents.

[Pacing Clin Electrophysiol.](#) 2000 Mar;23(3):344-51

Karas B, Grubb BP, Boehm K, Kip K.

Head upright tilt table testing has become an accepted method to measure an individual's predisposition to autonomically mediated periods of hypotension and bradycardia severe enough to cause frank syncope. At the same time it has become increasingly apparent that less profound falls in blood pressure, while not sufficient to result in loss of consciousness, may cause symptoms such as near syncope, vertigo, and dizziness. We describe a subgroup of adolescents that have a mild form of autonomic dysfunction that exhibit disabling symptoms such as postural tachycardia and palpitations, extreme fatigue, lightheadedness, exercise intolerance, and cognitive impairment. During baseline tilt table testing at a 70 degrees angle, these patients demonstrated a heart rate increase of $>$ or $=$ 30 beats/min (or a maximum heart rate of $>$ or $=$ 120 beats/min) within the first 10 minutes upright (not associated with profound hypotension), which reproduced their clinical symptom complex. Similar observations have been made in the adult population and has been termed the postural orthostatic tachycardia syndrome (POTS). We report that POTS may also occur in adolescents and represents a mild, potentially treatable form of autonomic dysfunction that can be readily identified during head upright tilt table testing.

PMID: 10750135

Diagnostic management of orthostatic intolerance in the workplace.

[Int Arch Occup Environ Health.](#) 2003 Mar;76(2):143-50. Epub 2002 Oct 30.

Winker R, Barth A, Dorner W, Mayr O, Pilger A, Ivancsits S, Ponocny I, Heider A, Wolf C, Rüdiger HW.

OBJECTIVE: Orthostatic intolerance (OI) is a syndrome that is characterised by headache, concentration difficulties, palpitation of the heart, dizziness associated with postural tachycardia and plasma norepinephrine concentrations that are disproportionately high when the sufferer is in the upright posture. In contrast to other forms of orthostatic dysregulation - orthostatic hypotension (OH) and postural orthostatic tachycardia syndrome (POTS) - OI, hitherto, could be

diagnosed only by a tilt table examination, with high expenditure. In this paper we examine the reliability and validity of a questionnaire as a screening instrument for OI.

METHODS: We studied 138 young men (mean age 21.6 years) who were undergoing military service. After a medical check and filling in the questionnaire, the participants underwent a tilt table test including monitoring of blood pressure, heart rate and plasma catecholamines, in the supine position and during 30 min of standing. The questionnaire consisted of ten items registering presence and frequency of typical OI symptoms.

RESULTS: Probands (104) showed normal tilt table test results. OI was diagnosed in 14 probands, OH in 6 and POTS in 14. The OI participants scored significantly higher in the questionnaire than the healthy subjects did: the mean score of the OI group was 22.6, the healthy participants had a mean score of 3.9. Participants with POTS had a mean score of 13.5 and subjects with OH had a mean score of 17.0. Reliability analysis showed a Cronbach's alpha of 0.888. Validity analysis showed that 93.5% of the probands with any kind of orthostatic dysregulation can be detected.

CONCLUSIONS: We were able to establish a short questionnaire as a reliable and valid screening instrument for OI. Usage of this questionnaire can simplify enormously the diagnostic management of patients with suspected OI.

PMID: 12733087

Syncope due to autonomic insufficiency syndromes associated with orthostatic intolerance.

[Rom J Intern Med.](#) 2000-2001;38-39:3-19.

Grubb B, Dan GA.

Recurrent syncope may be either a sign or a symptom and may occur due to a wide variety of very different causes. Extensive investigations into the nature of this disorder soon uncovered that it represents only one aspect of a broad, heterogenous group of disturbances of the autonomic nervous system (ANS) that can result in hypotension, orthostatic intolerance, and often syncope. Disorders of orthostatic regulation may be subgrouped into both primary and secondary forms. In primary autonomic failure syndromes, as opposed to the intermittent periods of hypotension seen in the reflex syncopes, patients could develop orthostatic intolerance due to a failure of the ANS to function under normal circumstances. Chronic autonomic insufficiency has two entities: Pure Autonomic Failure (PAF) and Multiple System Atrophy (MSA). Over the last several years, it has become apparent that a milder form of autonomic insufficiency occurs that is now referred to as the Postural Orthostatic Tachycardia Syndrome (POTS). The secondary forms of autonomic failure occur in association with a particular disease process. One of the most important things to remember are the vast number of pharmacologic agents that may either cause or worsen orthostatic hypotension. The principal feature that all of these conditions share is that normal cardiovascular regulation is disturbed resulting in postural hypotension. The cornerstone of evaluation is a detailed history and physical examination. One of the physician's most important tasks is to identify whether hypotensive syncope is primary or secondary in nature, and to determine if there are any potentially reversible causes (i.e., drugs, anemia, volume depletion). It is equally important to educate the patient. Nonpharmacologic therapies are useful. Pharmacotherapy should be used cautiously in selected cases.

PMID: 15529568

Inappropriate sinus tachycardia, postural orthostatic tachycardia syndrome, and overlapping syndromes.

[Pacing Clin Electrophysiol.](#) 2005 Oct;28(10):1112-21.

Brady PA, Low PA, Shen WK.

BACKGROUND: Inappropriate sinus tachycardia (IAST) and postural orthostatic tachycardia syndrome (POTS) are syndrome complexes with some distinctive features, overlapping clinical manifestations, and potential common mechanisms. Pathogenesis of these overlapping syndromes is poorly understood. Diagnostic and

therapeutic approaches have not been standardized.

PURPOSE: This article provides an overview of the definition, clinical presentation, and proposed mechanisms of IAST and other overlapping syndromes. A stepwise diagnostic approach is suggested. A multidisciplinary management scheme is outlined.

METHODS: A MEDLINE search for English-language articles on IAST, POTS, and chronic orthostatic intolerance published up to 2005 was performed. Published data incorporated with our clinical experience were synthesized and presented in this review.

RESULTS: The population of IAST is heterogeneous and underlying mechanisms are complex and likely multifactorial. Evidence suggests that both cardiac and extracardiac causes are plausible. Regional and limited autonomic neuropathies, at least in part, can provide a mechanism-based explanation of the cardiovascular indices and clinical symptoms in a significant number of patients with IAST. The regional abnormalities can be detected by autonomic testing. Among patients with IAST and evidence of autonomic dysregulation, an integrated autonomic, cardiovascular, and psychiatric management approach appears to be logical and rational when appropriate. Sinus node ablation could be considered in patients with persistent IAST in the absence of autonomic neuropathy and multisystem symptoms. Data from long-term outcomes are lacking.

CONCLUSION: The current understanding of IAST mechanisms is incomplete and management approach is not adequate. Significant effort needed in clinical research to improve therapeutic outcome.

PMID: 16221272

Excessive heart rate response to orthostatic stress in postural tachycardia syndrome is not caused by anxiety.

[J Appl Physiol.](#) 2007 Mar;102(3):896-903. Epub 2006 Nov 16.

Masaki S, Eisenach JH, Johnson CP, Dietz NM, Benrud-Larson LM, Schrage WG, Curry TB, Sandroni P, Low PA, Joyner MJ

Postural tachycardia syndrome (POTS) is characterized by excessive increases in heart rate (HR) without hypotension during orthostasis. The relationship between the tachycardia and anxiety is uncertain. Therefore, we tested whether the HR response to orthostatic stress in POTS is primarily related to psychological factors. POTS patients (n = 14) and healthy controls (n = 10) underwent graded venous pooling with lower body negative pressure (LBNP) to -40 mmHg while wearing deflated antishock trousers. "Sham" venous pooling was performed by 1) trouser inflation to 5 mmHg during LBNP and 2) vacuum pump activation without LBNP. HR responses to mental stress were also measured in both groups, and a questionnaire was used to measure psychological parameters. During LBNP, HR in POTS patients increased 39 +/- 5 beats/min vs. 19 +/- 3 beats/min in control subjects at -40 mmHg (P < 0.01). LBNP with trouser inflation markedly blunted the HR responses in the patients (9 +/- 2 beats/min) and controls (2 +/- 1 beats/min), and there was no HR increase during vacuum application without LBNP in either group. HR responses during mental stress were not different in the patients and controls (18 +/- 2 vs. 19 +/- 1 beats/min; P > 0.6). Anxiety, somatic vigilance, and catastrophic cognitions were significantly higher in the patients (P < 0.05), but they were not related to the HR responses during LBNP or mental stress (P > 0.1). These results suggest that the HR response to orthostatic stress in POTS patients is not caused by anxiety but that it is a physiological response that maintains arterial pressure during venous pooling.

PMID: 17110507

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