It’s finally here. Spring. I so look forward to its arrival. Thawing out, seeing more sun and planting my garden literally and figuratively.

I’ve heard from other folks that spring brings mixed emotions when dealing with their dysautonomia. For those suffering with mast cell activation and seasonal allergies, I hear its perplexing -- balancing treatment, outings and daily life.

I had an isolated allergic reaction of unknown origin last year for the first time. As my ears and throat started to itch, I started coughing. Two out of five of my kids have allergies, so my purse contained an arsenal of over the counter medications. “What to take”? I asked myself. I didn’t want to throw my system into a tailspin with over the counter meds I had never used before.

I called my cardiologist. My cardiologist referred me to my primary care physician. The verdict? Yes, I was having an allergic reaction. “So, again, what should I take?” The doc recommended one of the three different meds already in my purse. He asked me to stay put and monitored me while I took it. No bad reaction, just a small rise in my heart rate. It did take the addition of another medication to eventually clear all my symptoms. A process that, prior to Dysautonomia, would have merely have been a blip on my system.

We can’t talk about spring and only speak about...
allergies. For healthy people and patients dealing with chronic illness, spring ushers in wonders as well as challenges that may require a bit of preparation.

My unofficial tips for spring:

1. Spring cleaning starts in your medicine cabinet, purse and/or drawer. Check for leaks, expiration dates and if you are like me, check inventory on certain items you don’t want to be without—ever.

2. Take time to enjoy the weather. Curl up in the sunny spot on the sofa, sit outside or take a ride with the windows down.

3. Spring is a great time to refresh your mind, body and spirit. Think fragrances, growth and renewal.

4. Try your hand at gardening. Whether it’s outside in your garden, a pot on your porch or deck or on your window sill. I share my daily water with my low maintenance bamboo on my nightstand and the kids/ hubby help with veggies and herbs.

5. Don’t forget to share your experiences this season with your DINET friends. We are really growing as a community.

Blessings,
Jac

“Hope lies in dreams, in imagination, and in the courage of those who dare to make dreams into reality.”
**DINET is looking for a new President!**

Are you compassionate, organized, and interested in serving the dysautonomia community? If so, please consider helping DINET as our next President. Skills that will be helpful in this role include:

- The ability to work as a team member, be flexible, empathetic and help to develop and direct projects that perpetuate DINET’s purpose.
- A good understanding of POTS and at least a very basic understanding of the other dysautonomias featured on DINET.org.
- A basic understanding of medical terminology
- Research skills (in order to stay abreast of the latest medical advances and to possibly help update DINET’s website and newsletter whenever extra help is needed)
- Leadership skills, including the ability to provide direction in a clear manner
- Computer skills (email, web searches, and social media skills. Website editing skills would be a bonus but are not required.)
- Fundraising experience, including grant-writing (this isn’t essential, but certainly useful)
- Willingness to adhere to DINET’s mission of raising dysautonomia awareness and promoting dysautonomia education, support, networking and promoting only evidence-based medical information.

*If you are interested in the position of DINET President, please email Michelle at staff@dinet.org for an application*
POTS began for me - as it does for many - suddenly and with little warning. I’ve told the story hundreds of times in doctors offices, to teachers who wondered why I missed so much school, to a few close friends, and to those who care to ask. And here I am telling it one more time - here.

I want to share my experience with members of DINET and dysautonomia patients or their loved ones because I want to document that POTS can go away. It did for me, and my life was restored. Hi, I’m Zanny Merullo. I’m 17 years old, in 11th grade and currently attending boarding school. I beat POTS.

Eighth grade was one of the high-points in my life. I had grown past my physically awkward stage, had become one of the youngest varsity athletes at my school, had fun with friends and family, maintained excellent grades, and, in general, was succeeding in life. Until that winter. Multiple sinus infections grouped with intense friendship drama, pressure from my basketball coach, and an incredibly busy schedule left me stressed and sick for weeks. Having been diagnosed at age 3 with the genetic disease, Cystic Fibrosis, I was accustomed to frequent doctors visits, varieties of tests, and medications. However, I never had so many sinus problems. My glorious year came to an end.

That summer, being an athlete, I went for mile-long runs five days a week in rural New England. My sinus problems had not subsided, but they were
in the background and allowed me to live a fairly normal life. Suddenly though, one day I woke up and could not get out of bed. I wondered if it was the high humidity, or if I’d gone running too much. I took the day off. But the next day, I faced the same problem, and the day after that it was even worse. The couch became my permanent residence. I slipped into a lazy schedule of sitting and watching TV, coercing my sister into setting the table and doing my other chores, and even sleeping on the couch after I’d eaten. My parents, of course, were worried and took me to my CF doctor, who blamed my fatigue on a chronic sinus infection and scheduled a sinus surgery for later that summer. Glad for an answer to why I was feeling so poorly, I underwent the procedure. Immediately afterwards, however, it all went very wrong.

Excruciating head pain kept me dependent on pain killers, brought me to the emergency room, and caused me to take morphine six times a day for a month and half. In the meantime, I found a new sinus doctor who claimed the first one had botched the surgery. I scheduled a second sinus surgery for October of that same year. By this point, I had missed the first few weeks of ninth grade, and was slowly withdrawing from morphine, which caused pain so severe I was unable to think.

It wasn’t until February of the next year, that I was diagnosed with Postural Orthostatic Tachycardia syndrome. After five different doctors, ten different medications, and diagnoses of lupus, fibromyalgia, and mono, I finally saw a diagnostician who figured out I had POTS - solely by the change in my hand temperature from when he first shook it to when he touched it during the examination! I was told that I needed a cardiologist, and to be sent to a rehabilitation center in Boston where I would take classes and be placed on a rigorous exercise and diet regimen to keep my POTS under control. Determined to make it back to school for the rest of my 9th grade year, I refused the offer and began to exercise on my own. On day one, I started by walking ten steps outside of my house, but my atrophied muscles tired quickly. Within several months, however, I regained enough strength to go to two classes a day, and play on the golf team.

The next year, although markedly better than the first year with POTS, was one of the most challenging of my life. For me, the most difficult part of chronic illness wasn’t the physical symptoms, the endless number of doctors appointments, or even missing school, but rather the emotional toll chronic illness took on my life. Not only did I feel frustrated with my body, but I also faced the constant realization that I was incapable of doing normal tasks that I had taken for granted. I couldn’t walk up the stairs, stand for minutes at a time, or stay focused. Some days I was unbearably sad and wondered if my life would ever reach a state of normalcy again. Would illness plague me for the rest of my life? I struggled with being behind in school, and not able to keep up with varsity sports. My whole life had completely changed.

My parents worried for my health and happiness, instructed me to try different therapies. I had acupuncture treatments, but my heightened pain
sensitivity made the sessions unbearable. Then I tried cranio-saccral therapy. However, I never had so many sinus problems. An intuitive healer helped me very much with the emotional baggage from POTS, but my physical symptoms remained the same. I wore compression stockings, took medicine to regulate my blood pressure, and saw a cardiologist every few weeks. For months I maintained a simple lifestyle - filled with treatments and doctors and exercise. But I didn't realize that I was slipping into a deep depression.

In the summer before my tenth grade year, I decided I could not go back to my former school - everything had changed so drastically. I needed a change of scenery and lifestyle. Having visited Italy and felt it to be the “home of my heart”, I decided I wanted to study abroad for my tenth grade year, regardless of my health issues. Amazingly enough, that decision ended up making all the difference.

To be continued…. Look for part two in DINET’s summer newsletter.
Isn’t there always something unsettling happening? Somewhere in the world, an event will be reaching into our lives with its icy fist and will grip our parent-hearts.

Sometimes it is big enough or scary enough to warrant going to the news services. Then we watch our shiny big screens and turn away horrified. Sound bytes of a few seconds are aimed at providing the juiciest details, so that even children can understand. We watch highlight reels of the worst of the world’s news. Today, it was a family drowned in a lake by their mother. As I watched, I carried on breathing, my air still scented with fragments of Easter Eggs in crumpled foil nests. I guiltily moved my thumb to the ‘off’ button. Spring is in the air; I move into another room. Getting on with my parenting to-do lists -- pushing the sad headlines away.

It’s overwhelming to think of what is going on in our world. When I contemplate human beings tortured, imprisoned, separated forever from their loved ones, or killed--I can’t stay with those thoughts. I don’t want to consider the reality of all that bad news. My mother-heart feels it acutely and knows that for the people inside those news stories, it won’t be over by the next headline. Their stories will go on to affect them and their families for generations. It’s a horrific reality. Small wonder we choose not to watch. How fortunate we are that we can choose not to watch – we can postpone
considering these harsh realities. We can postpone to a time when we don’t have the small ones beside us, asking questions and turning up those beautiful, wide-eyed faces. Not yet. I don’t want to explain it all to them yet.

How do you face those terrible headlines, as a parent? In my own little world, I find myself clinging to the presence of hope. It tugs me upward. Hope is a buoyant human trait. It is an odd thing, when we are all mortal, that we have developed this protective mechanism from the brutal truth. We are all subject to tragedy, suffering, and loss. At some point in our lives, our exemption cards run out and we will be visited by personal heartache. It’s a guarantee. It might not be considered newsworthy. It might not be a single point in time, but a long drawn-out journey. An onlooker might see the worth of our entire human experience in that suffering, When suffering comes the worthiness of our own story will be carried by us, or by our loved ones – it is fragile—our mortality.

I am staggered by how hope renews itself, in the face of terrible odds. I remember, that movie with Harry Connick Jr. and Sandra Bullock …you know the one? It is the title not the story line that captured me….. ‘Hope Floats.’ It has always stayed with me--that title. How true it is. We can be sinking in the quagmire, or drowning in despair. We can be pulled under by terrible headlines. Or by the realities of life with a chronic illness. Or by the sadnesses and tragedies experienced by close friends, and by the wider circles in our community, our country, or our world. We think about those difficult things, and when we feel ourselves going under, we can grab hold of our flotation device – HOPE-- and rise up. Our lungs fill with fresh air, and our faces turn to the sunlight. We, again, can believe.

Spring is the season for hope, new beginnings, and joy. And hope is not always easy to find. Your flotation device might be something small, like a creative pursuit. It might seem inconsequential, like that little saying always repeated to your children at bedtime. It might be your faith, or your family, a favorite TV show or author. It might be looking up at the sky when what surrounds you is disheartening. It’s not perfect. But sometimes I reckon hope might just be the best mechanism our human race has, as we hurtle through time on this little blue planet. And you can be sure that your children are watching as you cast about for hope. You can show them how to find it. It’s a priceless gift, and it is born of your own experience. Hope is bigger than love, because it comes when what we love is lost to us. Hope is bigger than understanding, because we can’t always understand why people hurt people but we can hope for reconciliation. Hope keeps us afloat when our humanity pulls us into the depths. Peace, love and understanding are the tenets for a brighter future and being buoyed by hope just might allow us to achieve them.

Hang on to hope. Give it a chance. Let it pull you up and support you.
A GUIDE TO DORM LIFE
(with dysautonomia)

by Meredith Wells

It is tough enough to survive dorm life when you are “normal.” But it can be particularly challenging when you have dysautonomia. Now it is getting to that time of year to make dorm decisions for the fall. Choosing roommates? Choosing dorms? All can be daunting questions. Here are what I see as the ins and outs of those choices - whether it be dorm or apartment life.

While attending my summer orientation for college back in 2013, I was lucky enough to get to live in one of the nicest and newly renovated freshmen dorms and be surrounded by other students in my major. Following my housing registration, I took a survey that matched me to a compatible roommate. The next thing you know, we were buying color coordinating comforters and making plans about arranging the furniture. Move in day came and went and our first semester of college was in full swing; we worked well together because we were very different (which kept things interesting) but we lived very similarly. Then I became sick.

I’ll spare you my story because the details would be very familiar. I will tell you however, that despite getting sick my roommate and I continued to work well as roommates through our freshmen year and even decided to live with each other again for our sophomore year. But with this year came significant changes -- challenging changes. I now had a diagnosis, a wheelchair, a changed lifestyle, and it all had to fit into a tiny dorm room. And my roommate still had to fit in there, too.

“Living with a chronic illness and a roommate takes a lot of patience (on both sides), compromising and coordinating.”
Our first challenge occurred the instant I wheeled through the door. It didn’t work. My dad and I spent hours configuring the room into countless arrangements as we tried to get the bed away from the entryway. I also needed my bed low to the ground because I have seizure-like syncope episodes that could cause me to end up on the floor. The only way to make it work was to loft my roommate’s bed. Between lofting her bed and taking the bigger closet to store my wheelchair and my shower chair, my roommate was not the happiest of campers. And this was only the beginning of the challenges we would face as roommates. Living with a chronic illness and a roommate takes a lot of patience (on both sides), compromising and coordinating. Here are some ways way to acknowledging that there are two of you in the room—both with needs.

1.) Take Care of Yourself
I cannot stress enough that the first step to creating a dysautonomia-friendly dorm situation is to take care of yourself. You cannot expect your roommate to understand that your needs are important, if you don’t act as if they are. In other words “walk the talk.”

• Get lots of sleep (earplugs and eyeshades can make life more pleasant for your roommate who may still need to study)

• Drink plenty of water

• If you are the most symptomatic in the morning take showers at night

• Exercise (it can help prevent blood pooling)

• Take your medications

• Get a Medical Alert Bracelet

2.) Make your room dysautonomia-Friendly
Here are some items I consider essential to creating a comfortable space for a dysautonomia patient.

• Refillable water bottle

• Blood pressure monitor

• Heating Pad – use for pain or gastrointestinal issues

• First Aid Kit

• Salty Snacks

• Reading Pillow – for the days you can’t leave your bed

Optional but Recommended
• Shower chair

• Ankle weights – for leg strengthening exercises (you can even do these from your bed)

• A set of stationary pedals – place these in front of your desk chair and you instantly have a recumbent workout in the comfort of your room.

• Extra Throw Pillows – for folks who have convulsive syncope episodes; you can prop these
around your bed to protect yourself from hitting your head against the wall.

• Area rug – most dorms have tile floors so if you faint, a run will cushion your fall.

3.) Communicate With Your Roommate

Just as you cannot expect your roommate to understand your needs if you do not take good care yourself, you cannot expect your roommate to know what you need if you do not convey them. This step is the key to creating a dysautonomia-friendly space. Your roommate is not a mind reader. And neither are you. Communication is a two-way street and a chronic illness does not give one permission to not listen/pay attention to the other person in the room.

• Communicate all your needs

• Explain everything you need to do in order to take care of yourself

• If your stuff takes up space, explain to your roommate why you need things ex. a wheelchair, shower chair, etc. and then work very hard to store them in a considerate manner

• Be Specific

• Be direct, not passive and ask your roommate to be the same with you.

• Ask them how you can help them help you - and on the flip side, ask them what you can do to make things easier for them

• Make compromises when you can

While you might not experience the typical college life, you will find with creative problem solving, honest communication and being aware of your roommate’s needs that college and living in a dorm will be worth all the extra work.

I hope this helps!

Join us on Facebook. www.facebook.com/DysautonomiaInformationNetwork

DINET Spring Newsletter 2015
Candice, a 38-year-old mother of two, embodies “Mommy-on-the-go.” She maintains a full-time job, gets the kids to school, cleans house and chauffeurs her children to a host of afterschool activities. On the side, she has found time to get her black belt in Taekwondo. But, she has a secret. She also has that invisible illness -- dysautonomia.

Candice began experiencing dysautonomia symptoms after the birth of her second child. Her packed life did not allow her time or energy to take care of herself. Her days ended in extreme fatigue. She would often make it to work, but lacked the energy to properly clean the house or spend quality time with her family. Then, upon standing, she began to feel dizzy and lose her vision. Though her symptoms were highly physiological, she rationalized them with statements like, “I’m just a busy mom.”

As her physical activity level declined, tensions in some relationships increased. It was difficult for others to understand how she was, sometimes, too bone-achingly tired to complete the housework or keep up with the kids. After all, she looked fine. Candice was clinically diagnosed with POTS after two years of doctoring. Her diagnosis, in some sense, was a relief.
Her fatigue was not laziness, and her symptoms were not “all in her head.”

Today, Candice admits that life with POTS can be frustrating. She often yearns for an energy level that is considered normal for her age. She can be beset with bouts of fear regarding her future with POTS. However, dysautonomia has forced Candice, a natural go-getter, to slow down and take care of herself. She has worked with professionals to improve her diet and supplement intake. She lets herself rest when her body asks her to slow down, and she has a partner who supports her, understands her body and helps out in the home.

Each person I interview for this column teaches me something about living with chronic illness. Candice helped me see that so many moms believe they should be able to do it all. They often think, “I should be able to work full-time, take care of my kids, take care of my home, maintain a perfect marriage and regularly visit with friends and family.” These impossible expectations are particularly difficult for those of us with dysautonomia, whose bodies, quite literally, force us to slow down. Candice is an example of someone who was once filled with nearly impossible self-expectations, but has now found the more fulfilling path of self-acceptance. She knows to fight for herself and her health. She lives by the mantra that other’s standards are futile if, at the end of the day, she did the best she could.

So, Dear Reader, at the end of today I want you to tell yourself, “I did the best I could with what I had, and that was good enough.” Give yourself a big hug and settle into bed for a restful night and a great tomorrow.
MEDICAL Q & A

Answers to your questions By DINET’s Medical Advisors

Q

Can cerebral hypoperfusion occur in patients with the hyperadrenergic form of POTS?

-Annie

A

1. In syncope cerebral hypoperfusion is the “final common pathway”
2. We do transcranial Doppler with our tilts and I have not seen any difference in hyperadrenergic POTS and neuropathic POTS. We do see cerebral hypoperfusion in hyperadrenergic POTS. We have not published our data. I will try to do statistical analysis on our data.

Amer Suleman MD, FSCAI FHRS
Adjunct Professor, UT Dallas
RESEARCH IN REVIEW
by Laura Sabadini

DYSAUTONOMIA - GENERAL

Autonomic Involvement in subacute and chronic immune-mediated neuropathies
Autonomic function can be impaired in many disorders in which sympathetic, parasympathetic, and enteric arms of the autonomic nervous system are affected. Signs and symptoms of autonomic involvement are related to impairment of cardiovascular, gastrointestinal, urogenital, thermoregulatory, sudomotor, and pupillomotor autonomic functions. Availability of noninvasive, sensitive, and reproducible tests can help to recognize these disorders and to better understand specific mechanisms of some, potentially treatable, immune-mediated autonomic neuropathies. This paper describes autonomic involvement in immune-mediated neuropathies with a subacute or chronic course.

Mazzeo A, Stancanelli C. DiLeo R, Vita G.
PubMed PMID: 23853716
PubMed Central PMCID: PMC3703364
Full Text: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3703364

NCS/PAF/MSA/OH

Droxidopa for neurogenic orthostatic hypotension: a randomized, placebo-controlled, phase 3 trial
OBJECTIVE: To determine whether droxidopa, an oral norepinephrine precursor, improves symptomatic neurogenic orthostatic hypotension (nOH).
METHODS: Patients with symptomatic nOH due to Parkinson disease, multiple system atrophy, pure autonomic failure, or nondiabetic autonomic neuropathy underwent open-label droxidopa dose optimization (100-600 mg 3 times daily), followed, in responders, by 7-day washout and then a 7-day double-blind trial of droxidopa vs placebo. Outcome measures included patient self-ratings on the
Orthostatic Hypotension Questionnaire (OHQ), a validated, nOH-specific tool that assesses symptom severity and symptom impact on daily activities.

**RESULTS:** From randomization to endpoint (n = 162), improvement in mean OHQ composite score favored droxidopa over placebo by 0.90 units (p = 0.003). Improvement in OHQ symptom subscore favored droxidopa by 0.73 units (p = 0.010), with maximum change in “dizziness/lightheadedness.” Improvement in symptom-impact subscore favored droxidopa by 1.06 units (p = 0.003), with maximum change for “standing a long time.” Mean standing systolic blood pressure (BP) increased by 11.2 vs 3.9 mm Hg (p < 0.001), and mean supine systolic BP by 7.6 vs 0.8 mm Hg (p < 0.001). At endpoint, supine systolic BP >180 mm Hg was observed in 4.9% of droxidopa and 2.5% of placebo recipients. Adverse events reported in ≥ 3% of double-blind droxidopa recipients were headache (7.4%) and dizziness (3.7%). No patients discontinued double-blind treatment because of adverse events.

**CONCLUSIONS:** In patients with symptomatic nOH, droxidopa improved symptoms and symptom impact on daily activities, with an associated increase in standing systolic BP, and was generally well tolerated.

**CLASSIFICATION OF EVIDENCE:** This study provides Class I evidence that in patients with symptomatic nOH who respond to open-label droxidopa, droxidopa improves subjective and objective manifestation of nOH at 7 days.

PubMed PMID: 24944260
Full text: [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4115605](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4115605)

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**The changing face of orthostatic and neurocardiogenic syncope with age**

**AIM:** Reports of the outcomes of syncope assessment across a broad spectrum of ages in a single population are scarce. It is our objective to chart the varying prevalence of orthostatic and neurocardiogenic syncope (NCS) as a patient ages.

**METHODS:** This was a retrospective study. All consecutive patients referred to a tertiary referral syncope unit over a decade were included. Patients were referred with recurrent falls or orthostatic intolerance. Tilt tests and carotid sinus massage (CSM) were performed in accordance with best practice guidelines.

**RESULTS:** A total of 3002 patients were included (1451 short tilt, 127 active stand, 1042 CSM and 382 prolonged tilt). Ages ranged from 11 to 91 years with a median (IQR) of 75 (62-81) years. There were 1914 females; 1088 males. Orthostatic hypotension (OH) was the most commonly observed abnormality
(test positivity of 60.3%). Those with OH had a median (IQR) age of 78 (71-83) years. Symptomatic patients were significantly younger than asymptomatic (P = 0.03). NCS demonstrated a bimodal age distribution. Of 194 patients with carotid sinus hypersensitivity, the median age (IQR) was 77 (68-82) years. Those with vasovagal syncope (n = 80) had a median (IQR) age of 30 (19-44) years. There were 57 patients with isolated postural orthostatic tachycardia syndrome. Of the total patients, 75% were female. They had a median (IQR) age of 23 (17-29) years.

CONCLUSION: We have confirmed, in a single population, a changing pattern in the aetiology of syncope as a person ages. The burden of disease is greatest in the elderly.

http://qjmed.oxfordjournals.org/content/104/8/689.long

The spectrum of clinicopathological features in pure autonomic neuropathy
We assessed the clinicopathological features of nine patients with pure autonomic neuropathy, that is, neuropathy without sensory or motor deficits. The duration from symptom onset to diagnosis ranged from 1 month to 13 years. Of eight patients in whom serum antiganglionic acetylcholine receptor antibody was determined, four were positive. All patients who tested positive for this antibody manifested widespread autonomic dysfunction, with the exception of one patient who only experienced orthostatic hypotension. However, patients who were negative for the antiganglionic acetylcholine receptor antibody presented with partial autonomic failure. One of these patients had diffuse parasympathetic failure and generalized hypohidrosis but no orthostatic hypotension, which is clinically compatible with postganglionic cholinergic dysautonomia. Electron microscopic examination revealed a variable degree of reduction in unmyelinated fibers. Compared with normal controls, the patients had a significantly increased density of collagen pockets (p < 0.05). Additionally, the percentage of Schwann cell subunits with axons (out of the total number of Schwann cell subunits associated with unmyelinated fibers) was significantly decreased (p < 0.01). The density of unmyelinated fibers tended to decrease with increasing time between the onset of autonomic symptoms and biopsy (p < 0.05). In conclusion, the clinical and pathological features of pure autonomic neuropathy vary in terms of progression, autonomic involvement, presence of the antiganglionic acetylcholine receptor antibody, and loss of unmyelinated fibers.

Multiple system atrophy: Using clinical pharmacology to reveal pathophysiology

Despite similarities in their clinical presentation, patients with multiple system atrophy (MSA) have residual sympathetic tone and intact post-ganglionic noradrenergic fibers, whereas patients with pure autonomic failure (PAF) and Parkinson disease have efferent post-ganglionic autonomic denervation. These differences are apparent biochemically, as well as in neurophysiological testing, with near normal plasma norephrine in MSA but very low levels in PAF. These differences are also reflected in the response patients have to drugs that interact with the autonomic nervous system. For example, the ganglionic blocker trimethaphan reduces residual sympathetic tone and lowers blood pressure in MSA, but less so in PAF. Conversely, the α2-antagonist yohimbine produces a greater increase in blood pressure in MSA compared to PAF, although significant overlap exists. In normal subjects, the norepinephrine reuptake (NET) inhibitor atomoxetine has little effect on blood pressure because the peripheral effects of NET inhibition that result in noradrenergic vasoconstriction are counteracted by the increase in brain norepinephrine, which reduces sympathetic outflow (a clonidine-like effect). In patients with autonomic failure and intact peripheral noradrenergic fibers, only the peripheral vasoconstriction is apparent. This translates to a significant pressor effect of atomoxetine in MSA, but not in PAF patients. Thus, pharmacological probes can be used to understand the pathophysiology of the different forms of autonomic failure, assist in the diagnosis, and aid in the management of orthostatic hypotension.

POTS

Disturbances of gastrointestinal transit and autonomic functions in postural orthostatic tachycardia syndrome

BACKGROUND: Gastrointestinal symptoms are common in the postural orthostatic tachycardia syndrome (POTS). However, few studies have evaluated gastrointestinal transit in POTS. Our primary objectives were to evaluate gastrointestinal emptying and the relationship with autonomic dysfunctions in POTS.
METHODS: We reviewed the complete medical records of all patients aged 18 years and older with POTS diagnosed by a standardized autonomic reflex screen who also had a scintigraphic assessment of gastrointestinal transit at Mayo Clinic Rochester between 1998 and 2012. Associations between specific gastric emptying and autonomic (i.e., cardiovagal, adrenergic, and sudomotor) disturbances were evaluated.

KEY RESULTS: Among 163 patients (140 women, mean [± SEM] age 30 [± 1] years), 55 (34%) had normal, 30 (18%) had delayed, and 78 (48%) had rapid gastric emptying. Fifty-eight patients (36%) had clinical features of physical deconditioning, which was associated (p = 0.02) with rapid gastric emptying. Associations with delayed gastric emptying included vomiting, which was more common (p < 0.003), and anxiety or depression, which was less common (p = 0.02). The tilt-associated increase in heart rate and reduction in systolic BP at 1 min was associated (p < 0.05), being greater in patients with delayed gastric emptying.

CONCLUSIONS & INFERENCES: Two-thirds of patients with POTS and GI symptoms had abnormal, most frequently rapid gastric emptying. Except for more severe adrenergic impairment in patients with delayed gastric emptying, the pattern of autonomic dysfunction did not discriminate among gastric emptying groups. Further studies are necessary to ascertain whether extravascular volume depletion and/or deconditioning contribute to POTS in patients with gastrointestinal symptoms.

Loavenbruck A, Iturrino J, Singer W, Sletten DM, Low PA, Zinsmeister AR, Bharucha AE
PubMed Central PMCID: PMC4286289

Cognitive dysfunction in postural tachycardia syndrome
Mental clouding is an almost universal complaint among patients with postural tachycardia syndrome (POTS) but remains poorly understood. Thus, we have determined whether POTS patients exhibit deficits during neuropsychological testing relative to healthy subjects. A comprehensive battery of validated neuropsychological tests was administered to 28 female POTS patients and 24 healthy subjects in a semi-recumbent position. Healthy subjects were matched to POTS patients on age and gender. Selective attention, a primary outcome measure, and cognitive processing speed were reduced in POTS patients compared with healthy subjects (Ruff 2&7 Speed t-score: 40±9 compared with 49±8; P=0.009; Symbol Digit Modalities Test t-score: 45±12 compared with 51±8; P=0.011). Measures of executive function were also lower in POTS patients (Trails B t-score: 46±8 compared with 52±8; P=0.007; Stroop Word Color t-score: 45±10 compared with 56±8; P=0.001), suggesting difficulties in tracking and mental flexibility. Measures of sustained attention, psychomotor speed, memory function or verbal fluency were not significantly different between groups. The present study provides evidence for deficits in selective...
attention and cognitive processing in patients with POTS, in the seated position when orthostatic stress is minimized. In contrast, other measures of cognitive function, including memory assessments, were not impaired in these patients, suggesting selectivity in these deficits. These findings provide new insight into the profile of cognitive dysfunction in POTS and provide the basis for further studies to identify clinical strategies to better manage the mental clouding associated with this condition.

Arnold AC, Haman K, Garland EM, Raj V, Dupont WD, Biaggioini I, Robertson D, Raj SR
PubMed Central PMCID: PMC4161607