

# DYSAUTONOMIA NEWS

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Dysautonomia Information Network - June Newsletter 2016



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# Mindfulness

By, A. Shrapnell



**M**indfulness is very in vogue both with those wishing to improve their wellbeing through healthy lifestyle change and healthcare professionals. Because of this and emerging evidence it is becoming more widely accepted by healthcare professionals (in the United Kingdom and the US) as a way to help patients manage their own medical conditions better.

When I first heard about mindfulness I was skeptical as to how effective it would be at minimizing and controlling physical symptoms caused by an underlying disease process. This article aims to help to explain how current research believes mindfulness can improve both physical and mental health.

The basic intention of mindfulness is to bring a deeper awareness of the moment to moment experiences. This was first introduced into the medical setting in the 1970s in

the form of providing meditation sessions to sufferers of chronic pain in Massachusetts, USA. Following on from this, there has been a multitude of papers written to consider the effectiveness of mindfulness and healing. Siegel et al (2016), describes a three stage progression as mindfulness is integrated into a patient's care.

The first stage consists of an increase in activity in the left frontal lobe. The significance of this from a neurological standpoint is that it reflects a change to a more reflective, neutral state. This is followed by an increase in immune function, even in individuals that had initially presented with immunosuppressive conditions. This second phase is considered responsible for the drastic improvement in patients with psoriasis, (Flook 1996).

Stage three consists of the more subjective improvement in physiological and cognitive well

being. In the case of dysautonomias, such as postural orthostatic tachycardia, this may yield a reduction in brain fog.

A systematic review was carried out at the University of British Columbia in 2015. It considered the findings of 20 previous studies that assessed the areas of the brain that activate during and after mindfulness. Whilst these studies identified eight different areas of the brain that are affected by mindfulness, there are two that are particularly important when considering the effect of mindfulness on dysautonomias and chronic disease.

As discussed earlier, mindfulness has an effect on the front left side of the brain. This area is associated with self-control, direct attention and behavior. Any impulsivity or reduction in mental flexibility may be attributed to poor performance here. During mindfulness the patient actively resists distraction, self-regulates and returns to focus on multiple occasions. This honing in of focus is thought to assist with focus through uncertainty (by decreasing anxiety).

The Hippocampus is located in the middle temporal lobe, and is part of the limbic system. Most

importantly, it is the centre for emotional control, memory and the autonomic nervous system. The effect of mindfulness on this region may have the greatest effect on the symptoms of dysautonomias. Patients that have heightened levels of cortisol have been shown to have smaller hippocampus'. Whereas those who have undertaken a mindfulness program experienced an increase in grey matter, decreasing symptoms such as anxiety and depression, and more importantly, increasing the stability of the Autonomic nervous system.

## Summary of Benefits:

- ◆ Eight weeks of mindfulness showed an improvement in the immune profile of those with breast or prostate cancer, they also experienced a reduction in stress.
- ◆ Reduction in cortisol, causing an increase in grey matter in the hippocampus which may help the symptoms of dysautonomias.

**Whilst the evidence presented to you in this article is brief, it demonstrates that recent research has proven that there is the potential to decrease the symptoms of dysautonomias and potentially improve autonomic function through mindfulness.**

### \*References:

Zachariae, E., Oster, H., Bjerring, P., Kragballe, K., Effects of psychological intervention on psoriasis: a preliminary report, Journal of the American Academy of Dermatology, 34(6), 1008-15, June, 1996.

Siegel, D. (2016). Reflections on the Mindful Brain. [online] Available at: <http://www.openground.com.au/articles/Siegel-article.pdf> [Accessed 25 Apr. 2016].



# Exercise With POTS

By, Gwen Leyden

I wanted to write an inspirational article on how to stay positive and not get discouraged when working out with Dysautonomia. But, after each sentence I wrote, I felt more and more like a hypocrite. These last two weeks have been very difficult. Today it felt almost impossible to get through my workout. I felt like I couldn't breathe. I had to stop between each set and fight to get a full breath. Each time I stood up after bending over from putting down a weight or even tying my shoe, I became really dizzy.

Tears of frustration filled my eyes and to be honest I just wanted to punch something and I wanted to punch it hard. Some days I want to scream out "THIS SUCKS!!!" Then I realized that after everything a POTS sufferer deals with each day, it's okay to get mad and say "this sucks!" It's okay to allow yourself to cry for a moment. So how do I pick myself up and move forward? I'm not saying that my

way is the right way but these are tips I have used over the years to help me continue to exercise with POTS. I hope they may be helpful to you.

As always, check with your physician to see what is appropriate for you and if you can use a certified trainer or PT to give you advice, all the better.

## 1 Modify, Modify, Modify.

So what if you can't do a burpee (squat thrust) and who really wants to anyway? Change it so you can do your own version of one. I have learned to modify everything so that I still consider myself "able" to do it.

## 2 Me vs. The Gym.

Each time I step foot in the gym (or workout at home) I see it as myself vs. POTS. If I'm only able to do 5 minutes that day, I consider that a win for me. Am I frustrated? ABSOLUTELY! However, it's still a victory.



### **3 No Full Body Workouts or Exercises.**

I do not do full body workouts or exercises (ex: burpees). Full body workouts leave me completely exhausted so I stick with working 1-3 body parts at a time (ex: back and shoulders). It gives me a shorter workout and you only fatigue a couple muscle groups rather than all of them.

### **4 Stick with Machines.**

If I'm feeling a little more "off" or dizzy I stick with machine workouts so that I can sit between sets. Machine workouts allow you to rest all other muscle groups while you work the intended muscle. For example, on a machine shoulder press, you sit at the machine and only work your shoulders. If you were to do a standing shoulder press you would be using your legs, your core and your shoulders.

### **5 Keep Something Nearby to Stay Stable.**

No matter what type of day I'm having I always make sure there is something nearby to hold onto when I stand up from a seated position, after squatting down, or being bent over. I've been doing this for over 6 years and still to this day, before doing any exercise, I look around to see what I can use for balance.

### **6 It's Okay to Stop.**

If I feel it's just too bad of a day

or I am not safe, then I go home and rest instead. Period.

### **7 Bad Day? Any Workout Helps.**

The worse I feel, the more important it is to get up and move. Moving around helps get blood flow to those muscles and joints that ache so badly. For me, this is by far the most difficult advice and on some days I just cannot get myself to do it. Still, if you know it might help, you may try and feel better as a result.

### **8 Yoga is Your Friend for Pain.**

The days when I have the most pain, I will do a yoga workout that focuses on slow movements to stretch every muscle. There is a great one by Jillian Michaels and a couple by Autumn Calabrese.

### **9 Practice Balance.**

I know many of us have 'off balance' days (I'm pretty sure mine are every day, ha!), I like yoga workouts that focus on balance and tightening your core (which is key in a good balance) and I like to practice those as often as I can. Jillian Michaels and Autumn Calabrese are my favorites for these as well. A physical therapist once told me that of her elderly patients who had not fallen, the one thing they had in common was that they started practicing yoga at a younger age. The

workout by Jillian Michaels works balance and stretching.

### **10 Nutrition is key.**

I have such a slow digestion process that I have to be insanely careful about what I eat and how often I eat. Eating too big of a meal or two meals too close together can leave me extremely bloated and in a lot of pain. Finding out which foods can cause that can be tricky, so a journal can be a great asset.

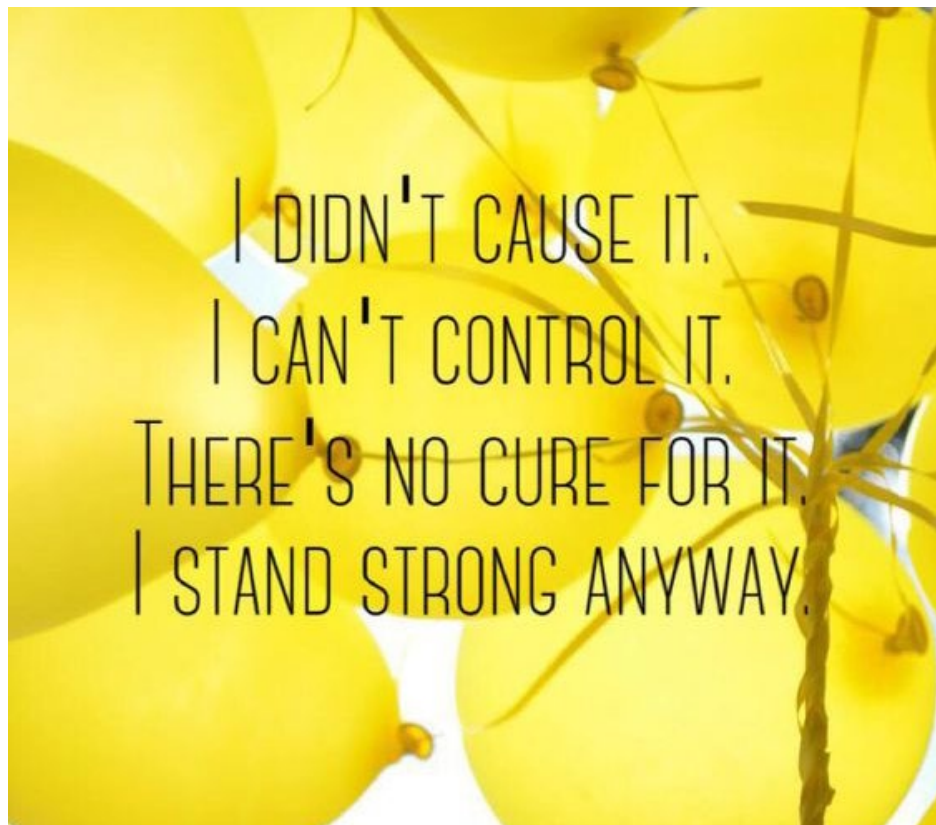
### **11 Listen to your body.**

I have found this to be most important. Every person is different and everyone's symptoms and triggers are different. Pay attention to your body when working out, or when eating (how your stomach feels after a certain food), or simply doing things around the house, etc. Keep a journal for a while. It will help you find triggers and see patterns that you might not consider.

When many of us see photos of ourselves from the past, we think about who we used to be and what we were able to do. It can bring about such sadness at times. The truth is that the same person still exists, but what we are able to do has changed. I see POTS/Dysautonomia sufferers as the strongest people I have ever met - my heroes. Yes, before Dysautonomia you could maybe run for miles or hike trails but look at how much you

overcome each day with a condition that affects pretty much every bodily function. You deal with it, you face it and you overcome it. To me that strength is far greater than running for miles or hiking the most treacherous trail.

Is it fair to have to deal with this condition? Absolutely not. I see life as a series of choices. Dysautonomia is a condition that many of us can't change or control at times. The only thing you can change is how you see yourself with Dysautonomia and how you handle and manage life with it. You either see yourself as less than who you were or as a strong fighter. I see you all as Superwoman and Supermen - to me you all wear capes.



## Workout titles mentioned in article:

The workouts by **Autumn Calabrese** are part of her **21 Day Fix program**. My favorite DVDs are the Pilates and Yoga Fix ones. They provide a great stretch.

**Yoga Meltdown Level 1** is a 35 minute workout by Jillian Michaels and it's probably my favorite and has been great for my balance. It can be found on Youtube.

# Talking to Your Kids

**Editor's Note:** Great thanks to our guest writer, Michelle Roger. Michelle is an Australian writer who graciously gave DINET permission to republish this wonderful article addressing a very difficult topic. This article is from Michelle's blog called "Living with Bob (Dysautonomia)"

**By, Michelle Roger**

To talk to your kids about your illness, or to not talk to your kids about your illness? That is the question facing every parent living with chronic illness. Do you tell them? If you do, what do you tell them? Is it better to shield them? Is it better to ply them with chocolate and give them a new Xbox game and pretend this question never came up? Or alternately, ply yourself with chocolate and hide in your bedroom watching repeats of The Walking Dead on your laptop, and pretend that the question never came up?

For most of your kids, there is likely

another reality. No matter how old, they already know something isn't right. And in all likelihood, they will be creating other more scary scenarios in their head. Kids will fill in the blanks when you don't. And often the filler is negative. It's one of those times a kid's imagination and creativity can be quite unhelpful. Just because you aren't discussing your illness, doesn't mean they aren't still thinking about it and worrying.

My kids were young when I first became ill. My youngest was 8 and my

eldest 11. It was a hard and scary time. Initially, I had no idea what was wrong. Dealing with the stress of the unknown and my own over-active imagination was consuming most of my waking moments. I thought I was doing a good job of protecting them from my worries and failing health. What I didn't realize is that kids are always watching and are more in tune to what is happening around them than we think. Saying "mum's just a bit unwell", and generally minimizing things, wasn't working. But in my own distress, I was oblivious.

<http://bobisdysautonomia.blogspot.co.nz/>



Problem was, that whilst I was doing this, my kids were convinced I was dying. Worst of all, they didn't want to share their fears with me for fear of stressing me out. Instead, they were quietly worrying themselves sick.

When they finally told me, it ripped my heart out. Here was I, thinking I had protected them from what was going on. But instead they had born a huge burden alone. In that instant I felt like the world's worst mum. From that moment on, I decided to talk openly with my kids about my health. Well, okay, that moment may have been preceded by tears and gut-wrenching guilt, but once that passed, I decided I wouldn't hide things from my kids again.

Now admittedly, there are aspect of this illness that you can't hide. Passing out, for example, is pretty hard to cover up. But there is a huge difference between your children being witness to the event and actually discussing what happens and why. Uncertainty feeds fear. For us, it really is true that knowledge is power.

So what are my main tips?

### **1. Be prepared:**

Working out how to explain your illness and what it means before the discussion occurs, will help greatly. For a complex disorder like Dysautonomia it can be hard to explain. If stumped, ask fellow patients (on the forum?) how they explain their disorder. There

is bound to be an explanation you can use.

### **2. Tailor the information to the age and maturity of your child:**

The information a child needs, and can process, at 8 is very different than at 15. But whatever their ages, or level of maturity, there are ways to talk to them. Early on, we told my kids that I had a heart problem, and the doctors were trying to make me better. Over the years, our process has evolved as they have matured. Now at 15 and 18, they want more detail. They know about the autonomic system and the problems I face. They know about my meds and the types of doctors I see and why. We are now open about the whole



situation. But it is a journey. It is easier to discuss these things now, as we have been discussing them in some form or another for 7 years. Each conversation builds on the previous one.

### **3. Answer the questions they ask:**

Don't overwhelm them with details (technical or otherwise) unless they ask. Take it step by step. Some kids want simple answers. Others are suckers for detail. It can be a weird mindset for a parent, but you have to step back and let them lead the conversation.

### **4. Be honest:**

My two asked me to promise to tell them if something serious was happening. My first reaction as a mum was to protect them. But in agreeing, I gave them a sense of reassurance. They no longer lay awake at night worrying if I was hiding bad news from them. If we weren't discussing it - it wasn't an issue.

### **5. Conversations can happen anywhere:**

If there are big issues to discuss, a specific family meeting can be great. But I've have found that most conversations begin when you least expect them. Questions are asked whilst you're making tea, whilst driving, at the checkout, waiting for a movie to start, late at night (mine

are big on this, and many discussions have happened at 11pm or later). The important thing is to take the opportunity you are given whenever it happens, and go with it. The timing may be inconvenient, but it is the time your child is finally comfortable and ready to discuss difficult issues. You simply have to go with the flow.

### **6. Empower them with solutions:**

Teach your kids what to do if something happens - for example, what to do if you pass out. This can be a scary time, but if kids know what to do it can alleviate much of the stress. Teach them how to dial 000, 911, 999 or whatever the emergency number is in your country. Give them a contact person they can trust to call in an emergency or if they are scared. Simply knowing to bring you water, or a salty snack when you are starting to fade gives them a sense of control.

### **7. Include them in the process:**

Sit down and work out a plan with them. For example, if mum is on the floor and she won't wake up ring the emergency code. If mum wakes up, bring her water, salty snacks, a blanket, keep the dogs off her (a necessity in our house).

### **8. Empower them with knowledge:**

When an illness is chronic there are symptoms which are simply part of your day-to-day. My kids are pretty attuned to what is normal for me. They know the cues for when I need to sit or lie down and it is all handled with minimal fuss. If I'm cooking tea and getting pale or starting to sway, they grab me a chair and a drink straight away. It's normal. It also means that they can detect when something more serious is going on (when I collapsed last week). When every day is punctuated with symptoms that can be scary (something I really notice when we have visitors who aren't used to my health issues), knowing what is white noise and when it is time for action, relieves a lot of tension.

### **9. Lead by example:**

Learning how to deal with your own stress and choosing how to live your life with an illness is vital. Kids learn by example, and as parents we are the main influence on their lives. If we are consumed by illness and not managing our stress they will also be consumed by our illness and stressed as well. When we take care of ourselves, we are taking care of them. We cannot put ourselves last. If our kids see us managing in healthy ways they will learn these skills as well.

### **10. Utilize support services for kids:**

If you are worried that your child isn't

telling you what they are feeling or you don't feel confident to discuss these issues there are services available. In Australia, Kids Helpline 1800 55 1800, is a fantastic free telephone and web counseling service for children. Similar services exist in most Western countries. You can provide your children with information about these services and let them ring at need. Professional family counseling can also be valuable. Let your child's school know about the situation. For example, they can provide counseling if needed, or simply alert you to changes in your child's behavior. We met with our children's teachers and let them know what was going on. Whilst no major issues arose, the teachers appreciated being told and it definitely gave me peace of mind.

### **11. Kids are resilient:**

This is the final, and in many ways,

the most important point. We often underestimate how resilient our kids are. But the one thing I have learnt over the last 7 years is that kids can show an incredible amount of strength and empathy. They surprise me every day. If they feel loved and supported it is possible to make it through. We can't always protect them from the stressors of life, but we can provide them with the tools to manage them.

We have had many ups and downs over the last few years. At times it has been stressful and tough. They still worry. I still make mistakes. And things go pear-shaped at times. But overall, we are maintaining a reasonable balance under difficult circumstances. Being open with our children has been confrontational and hard at times. But that's not unlike many of the issues we have to discuss with our kids as parents. We can do it. And our children

will be the better for it.



# *I Need Backup - Send Endorphins!*

By, Amy Keys

An endorphin is a neuro- transmitter - essentially, it is a chemical messenger that passes along a signal from one neuron to another. Endorphins are a part of the nervous system and are released from mainly the pituitary gland, as well as the spinal cord. They primarily interact with receptors in cells within the brain which handle emotion and restrict pain; however, they are also responsible for delivering feelings of bliss, joy, and contentment.

Allow me to explain endorphin release into the body in a language that I understand well from my background as a police dispatcher: the language of law enforcement. If an officer were to arrive on the scene of a call and realize that the situation was starting to escalate, that officer would quickly radio and ask for backup - code 3! Essentially that is what the body does. If the hypothalamus (the officer in charge) senses pain it will request endorphins be released - a 'Code 3' (lights and sirens). Another situation when endorphins may be released is during times of high stress (also known as a critical incident- this one usually will require a sergeant for paperwork or a 'debrief' of some sort afterwards). We are all well-aware of the stress response. Too aware.

The most widely known way to release endorphins other than pain or stress is exercise. If you have ever seen the movie "Legally Blonde," you might remember that during a cross examination, it is emphasized that 'exercise gives you endorphins, endorphins make you happy. Happy people just don't shoot their husbands.' It is true that exercise releases endorphins, but if you live in a world of dysautonomia and exercise intolerance, rest assured there are other ways to release endorphins:

♦ **Laughter** - No matter the reason, laughing increases the release of endorphins. Watch a funny movie, stand-up comedian, or even just Youtube videos. And you can choose the topic.

♦ **Music** - Incorporate music into your day- whether it's playing an instrument or just turning on music that makes you happy. Do it!

♦ **Vitamin D** - Get a dose of vitamin D- being outdoors in the sunlight, even just for a few minutes can do wonders for your body. One benefit is that endorphins are increased quickly after being in the sun. Of course use caution to avoid overexposure and sunburn and stay hydrated if you'll be out for longer periods.

♦ **Fun** - Have good old-fashioned fun- play a game with a friend, child or pet. Work on a craft or project. (A word of caution: DIY home improvement and décor projects can be very satisfying if they turn out well, but can also be very frustrating if they do not... just my words of advice from a wife who has done both successful and unsuccessful projects with her husband.)

♦ **Help someone** - this can be referred to as a 'helper's high'. Taking the focus off of yourself and your situation can help drive you towards a goal of helping a friend or even a stranger in need. (Don't show up unannounced though, you never know which neighbors wear pants regularly and which don't.)

♦ **Fall in love** - if you are currently not in love, I doubt my ordering you to fall in love will make it happen. However, Phenyl ethylamine is produced in the brain when you fall in love there is a major release of endorphins. I have good news though. Phenyl ethylamine is also found in dark chocolate, because really dark chocolate is love. If you can't fall in love, fall in dark chocolate.

♦ **Spicy foods** - hot peppers include a component known as capsaicin which provides the heat feeling. The brain can interpret this as pain which automatically causes a release of endorphins.

♦ **Alcohol** - in moderation it can also increase endorphins; however, with dysautonomia it can be a double-edged sword. Yes, it may release endorphins, and it may also caused increased or drastic symptoms.

♦ **Serotonin** - another mood boosting chemical released from the brain is serotonin. Interestingly enough, if you crave certain foods that may be an

**What is an endorphin and why do you need to have them? How do you increase the frequency with which they are released?**

An endorphin is a neurotransmitter, or a messenger that carries a signal from one neuron to another. These are released to reduce pain and deliver feelings of bliss and euphoria.

**How are Endorphins Released?**

**Step 1:** police officer arrives on scene and realizes backup is needed.

**Step 2:** Officer radios asking for backup right away.

**Step 3:** Help arrives on scene running lights and sirens!

A high stress situation or a critical incident will also cause a release of endorphins.

**In Endorphin terms:**

- Step 1: The hypothalamus senses pain.
- Step 2: The hypothalamus requests endorphins immediately be released.
- Step 3: Endorphins are released which decreases pain and boosts happy feelings.

**Other Triggers for Releasing Endorphins**

Exercise is one of the most well-known ways to boost endorphins in the body. Don't fret if you have decreased tolerance to exercise. There are plenty of other ways!

- Get some sunlight
- Laugh
- Do something kind for someone else
- Enjoy music
- Play a game
- Do a craft
- Eat something spicy
- Fall in love- if that doesn't work- see below

**The Almighty Chocolate**

Dark chocolate contains the chemical Phenylethylamine, which is produced in the brain when you fall in love and it majorly increases endorphins.

**Endorphins are released mainly from the pituitary gland.**

**But Wait, There's More**

Endorphins are also believed to:

- Enhance the immune system
- Postpone aging
- Lower blood pressure
- Modulate appetite

It only takes a smile to make every hour happy hour

Disclaimer: Do not call 911 when you feel like you need an



indicator that you are low on endorphins and serotonin. People who desire carbohydrates and fats, may be in need of an endorphin release. While fats and sugars can deliver endorphins, it may be in your best effort to try some other items from the endorphin list rather than to reach for the cupcakes.

No, I can't work out like I used to, but I can put together a care package for a friend. I can make time to play with my dogs or get out a board game for a Friday night in. I can spend time in the sun and have a dark chocolate iced mocha to keep my endorphins and Phenyl ethylamine levels up. Surely, I am responsible enough about my health to find activities that will increase those needed endorphins.

It seems to me that it would be better for us to stop focusing on what we can't do for our health and start focusing on what we can do!

\*Information cited in this article was obtained from the following sites:

<http://science.howstuffworks.com/life/endorphins.htm>  
<http://bebrainfit.com/increase-endorphins/>

Endorphin graphic by Amy Keys

# Meet the Member:

## *Claire's Story*



**By, Chelsea  
Goldstein**

Living with Dysautonomia often means we have to adjust our definitions of normal. How do we measure a normal life? A normal body? Claire, a thirty-one year old renaissance woman living in Melbourne, Australia, defies the ordinary in almost every aspect of her life. She is a teal-haired beauty with a quirky way of speaking, a milliner (that's hat-maker for us laymen), a writer and a tinkerer of projects. She believes that her deviance from general normalcy is a result of accommodating her Dysautonomia.

In her early twenties, Claire was diagnosed with post-infectious Chronic Fatigue

Syndrome. Although not feeling well, she managed to work as a full time nurse. When she was 26, however, she began catching every illness that cycled through the hospital where she worked. She began to miss shifts at work, and found difficulty in balancing her health and career. Claire comes from a family of medical professionals, so, between their knowledge and her own medical expertise, she was quickly referred to a cardiologist who diagnosed her with Orthostatic Intolerance, Orthostatic Hypotension and tachycardia.

Claire pinpointed the differences between the Australian and American medical

systems, as related to Dysautonomia. She believes that the U.S. is pursuing more Dysautonomia research, and provides patients with better access to intravenous

Santiago in Spain. This book gave Claire her “a-ha” moment—the moment that encouraged her to make change, and take control of her life. She walked the last 110

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***"She learned not to blame her body for her new limitations, but to thank it for what it could do each day."***

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saline. However, Australians receive universal healthcare. This provides them more coverage for healthcare, as well as support services, like in-home assistance, for those on pensions (i.e. Disability).

Claire underwent the same cycle of illness that many of us do. She once worked in her demanding job as a nurse, participated in a roller derby league and exercised regularly. But eventually, her body grew exhausted so she quit her job. For a few years she volunteered for St. John's Ambulance but that proved too much for her body. After so much loss, she felt the anger and depression that far too many of us with chronic illness experience. In addition to losing her sense of purpose, she lost old friends who couldn't, or wouldn't, understand her new circumstances.

During this time of loss and introspection, Claire's stepfather gifted her a book - "The Year We Seized the Day." It chronicles the journey of two people, with their own challenges, who walked the Camino de

Kilometers of the Camino de Santiago. It was tough. Really, really tough. She walked slower than most others, she took frequent breaks and she stayed in hotels every other night to get proper rest. But she walked it, and that is what matters.

After this walk, Claire began to accept herself, and her body, in their present states. She began to understand that her depression was very normal for people with chronic illness. She learned not to blame her body for her new limitations, but to thank it for what it could do each day. She began to see the positive aspects of living with a chronic illness; it connected her with a new network of friends, and it encouraged her to pursue her more creative passions. She has found her own way to cope with the days that are not filled with beautiful hats and Spanish walks. She has learned to accept help, use assistive devices, and keep herself looking nice because it always makes her feel just a little bit better. So, is Claire normal? Definitely not, but we think that she is pretty awesome.

# Medical Q & A

## Answers to Your Questions by DINET's Medical Advisors

**Q:** Since increasing one's salt intake is recommended for most POTS patients, What's the best way to prevent long-term kidney problems given that, recommendation? Pat, OH

**A:** There is a lack of long-term outcome data about the effects of salt intake. Many, but not all, POTS patients may have a problem with renal sodium handling. It is not clear if sodium will have the same effects in these patients as the general population. Over time, all medications/advice should be periodically reassessed, If symptoms have improved and hypertension is starting to replace the hypotension/normotension seen in most POTS patients, then it would be reasonable to cut back on the augmented sodium intake and see if it is still needed.

*Satish R Raj MD MMSCI FPCPC*

*Associate Professor of Cardiac Sciences*

*Libin Cardiovascular Institute of Alberta*

*University of Calgary*

**Q:** Is it beneficial to build up the immune system of patients with Dysautonomia with vitamin/mineral supplements? If so, can this cause complications with interactions with medications for dysautonomia? Rose IL

**A:** There are no studies to show that supplements are effective in patients with dysautonomia, and as far as I know, there haven't been any studies showing that any supplement or vitamin is efficacious in improving the immune system in healthy population. There is some indication that high doses of vitamin D may have anti-inflammatory properties, but more studies are needed to address any role of vitamin D in dysautonomia. You can ask your doctor if taking vitamin D 5000 IU per day is safe for you.

*Svetlana Blitshteyn, MD*

*Director of Dysautonomia Clinic*

*Clinical Assistant Professor of Neurology*

*University at Buffalo School of Medicine and Biomedical Sciences*



**Q:** My Dysautonomia doctor says that my ANS Dysfunction can skew results for autoimmune disorders. My immune system seems to be in overdrive because I rarely get the usual colds and flu. And in fact my anti-CCP level ( a marker for erosive Rheumatoid Arthritis) is positive. Rheumatoid Factor is negative. I do have swelling in my knees, fingers, lips, tongue – but this could be due to changes in supplements, mast cell issues, or other edema. Have you ever heard of a false positive for this test because of Dysautonomia? I wonder how this gets sorted out. Jane, IL

**A:** A brief answer is that no, dysautonomia does not cause elevated CCP, and given your symptoms and signs of joint pain and swelling, a consultation with an expert in rheumatoid arthritis (RA) is necessary. There are RF-negative forms of RA, so one does not need to have all of the inflammatory markers present to be considered positive for RA. Additionally, we have shown in a study on POTS and autoimmunity that there is a higher prevalence of co-morbid autoimmune disorders (including RA) in patients with POTS than in general population, and in many cases, the autonomic disorder is likely secondary to the underlying autoimmune process (Blitshteyn S. Lupus 2015; 1364-1369\*\*). Anecdotally, once you treat the underlying problem - such as RA if it is confirmed by your rheumatologist - the symptoms of dysautonomia tend to improve as well.

*Svetlana Blitshteyn, MD  
Director of Dysautonomia Clinic  
Clinical Assistant Professor of Neurology  
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**\*Editor's note:** Coincidentally, the abstract for this article is included in this issue's Research in Review article. A full link to the article text is included.

**Q:** Are repeat Tilt Table Tests recommended and if so how often? Julie, OH

**A:** No, routine repeated tilt testing is not recommended. Orthostatic tachycardia can be re-assessed with a 10-min stand test. Some physicians may want to repeat more formal autonomic function testing that might include a brief-tilt. This can be used to assess changes in clinical status.

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# Research in Review

## **Autoimmune markers and autoimmune disorders in patients with postural tachycardia syndrome (POTS)**

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### **ABSTRACT**

**Objective:** In recent years, there have been a number of studies suggesting that POTS may have an autoimmune etiology. This study examined whether the prevalence of antinuclear antibodies (ANA), other markers of autoimmunity and co-morbid autoimmune disorders is higher in patients with POTS than in the general population.

**Methods and Results:** Medical records of 100 consecutive patients with POTS evaluated at our clinic were reviewed. In this cohort (90% females, mean age 32, range 13-54 years), 25% had positive ANA, 7% had at least one positive aPL antibody and 31% had markers of autoimmunity. When compared to the general population, patients with POTS had a higher prevalence of ANA (25% vs. 16%, OR 1.8, CI 1.1-2.8,  $p<0.05$ ), aPL antibody (7% vs. 1%, OR 7.5, CI 3.4-16.1,  $p<0.001$ ) and co-morbid autoimmune disorders (20% vs. highest estimated 9.4%, OR 2.4, CI 1.5-3.9,  $p<0.001$ ). The most prevalent autoimmune disorder was Hashimoto's thyroiditis (11% vs. up to 2%, OR 6.1, CI 3.2-11.3,  $p<0.001$ ), followed by RA (4% vs. up to 1%, OR 4.1, CI 1.5-11.2,  $p<0.01$ ) and SLE (2% vs. up to 0.12%, OR 17, CI 4.1-69.7,  $p<0.001$ ). The prevalence of CVID was very high (2% vs. 0.004% OR 510.2, CI 92.4-2817.8,  $p<0.001$ ), while celiac disease showed a nonsignificant trend toward increased prevalence.

**Conclusion:** Patients with POTS have a higher prevalence of autoimmune markers and co-morbid autoimmune disorders than the general population. One in four patients have positive ANA, almost one in three have some type of autoimmune marker, one in five have a co-morbid autoimmune disorder, and one in nine have Hashimoto's thyroiditis.

Full article text: <http://lup.sagepub.com/content/24/13/1364.long>

## **Post-Exercise Hypotension and its Mechanisms Differ after Morning and Evening Exercise: A Randomized Crossover Study.**

De Brito LC, Rezende RA, Da Silva Junior ND, Tinucci T, Casarini DE, Cipolla-Neto J, Forjaz CL

### **ABSTRACT**

Post-exercise hypotension (PEH), calculated by the difference between post and pre-exercise values, it is greater after exercise performed in the evening than the morning. However, the hypotensive effect of morning exercise may be masked by the morning circadian increase in blood pressure. This study investigated PEH and its hemodynamic and autonomic mechanisms after sessions of aerobic exercise performed in the morning and evening, controlling for responses observed after control sessions performed at the same time of day. Sixteen pre-hypertensive men underwent four sessions (random order): two conducted in the morning (7:30 am) and two in the evening (5 pm). At each time of day, subjects underwent an exercise (cycling, 45 min 50%VO<sub>2</sub>peak) and a control (sitting rest) session. Measurements were taken pre- and post-interventions in all the sessions. The net effects of exercise were calculated for each time of day by [(post-exercise)-(post-pre control)] and were compared by paired t-test (P<0.05). Exercise hypotensive net effects (e.g., decreasing systolic, diastolic and mean blood pressure) occurred at both times of day, but systolic blood pressure reductions were greater after morning exercise (-7±3 vs. -3±4 mmHg, P<0.05). Exercise decreased cardiac output only in the morning (-460±771 ml/min, P<0.05), while it decreased stroke volume similarly at both times of day and increased heart rate less in the morning than in the evening (+7±5 vs. +10±5 bpm, P<0.05). Only evening exercise increased sympathovagal balance (+1.5±1.6, P<0.05) and calf blood flow responses to reactive hyperemia (+120±179 vs. -70±188 U, P<0.05). In conclusion, PEH occurs after exercise conducted at both times of day, but the systolic hypotensive effect is greater after morning exercise when circadian variations are considered. This greater effect is accompanied by a reduction of cardiac output due to a smaller increase in heart rate and cardiac sympathovagal balance.

Full article: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4506120/>

## **Postural Tachycardia Syndrome: Beyond Orthostatic Intolerance**

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## ABSTRACT

Postural tachycardia syndrome (POTS) is a form of chronic orthostatic intolerance for which the hallmark physiological trait is an excessive increase in heart rate with assumption of upright posture. The orthostatic tachycardia occurs in the absence of orthostatic hypotension and is associated with a >6-month history of symptoms that are relieved by recumbence. The heart rate abnormality and orthostatic symptoms should not be caused by medications that impair autonomic regulation or by debilitating disorders that can cause tachycardia. POTS is a "final common pathway" for a number of overlapping pathophysiologies, including an autonomic neuropathy in the lower body, hypovolemia, elevated sympathetic tone, mast cell activation, deconditioning, and autoantibodies. Not only may patients be affected by more than one of these pathophysiologies but also the phenotype of POTS has similarities to a number of other disorders, e.g., chronic fatigue syndrome, Ehlers-Danlos syndrome, vasovagal syncope, and inappropriate sinus tachycardia. POTS can be treated with a combination of non-pharmacological approaches, a structured exercise training program, and often some pharmacological support.

Full Article Text: <http://link.springer.com/article/10.1007%2Fs11910-015-0583-8>

## A tale of two syndromes: Lyme disease preceding postural orthostatic tachycardia syndrome

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## ABSTRACT

The pathogenesis of postural orthostatic tachycardia syndrome (POTS) is poorly understood. However, it has been suggested that altered immune activity or denervation of the autonomic system following illness may be an important trigger. Patients infected with Lyme disease have a small incidence of post-Lyme disease syndrome that share similar characteristics to POTS. We report a short series of two women who present with persistent symptoms of orthostatic intolerance consistent with POTS after treated Lyme disease.

Full Article Text: <http://onlinelibrary.wiley.com/doi/10.1111/anec.12158/abstract;jsessionid=5C42A6D619EF3E82EB2BECC336CB2931.f03t03>



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