



Dysautonomia News

Summer 2014

A Guide to Living With Dysautonomia

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My So-Called “Bucket List” After Dysautonomia

By, Melanie

One of my favorite songs of all times, long before I became ill, was Tim McGraw’s “Live Like You Are Dying”. In fact, I even knew all the words and would sing along (horribly out of tune) each time I would hear it blast on the radio. I would like to believe I lived life to the absolute fullest even when I was healthy. Of course, there were some missed opportunities, and a few days I would have liked to replay. But for the most part, I can look back and say “I had and made a wonderful life.” I guess that is probably one of the reasons I enjoyed that song so much. I often relished its reminder to try to live each week and each month as though I am not promised

tomorrow. As it turns out, we are not promised a tomorrow!

In my young life, many of the things on my ‘to do list’ had meticulously been checked off one by one. My biggest dreams, goals, and aspirations had been mostly accomplished at a young age. There were still a few odds and ends that I had hoped to one day tackle. I guess you could call it a bucket list. My list was short and was mostly filled with things that were small dreams. The majority of all I had hoped and dreamed for had already come to fruition. Those who knew me well, knew that being a wife, mother, and missionary had topped my list for many years and were my heart’s true desires. I guess I can say I was LIVING my bucket list!

However, after I became very sick, I was going through the few things in my mind that I had yet to accomplish, tackle, or achieve. As I began

to jot them down, disbelief set in. Not ONE thing on that list could be finished! My "So-Called Bucket List" had turned into my "You-Can-Never-Do-Any-of-This List." All I could say in sobs was: "I'm not done yet!" There was so much more I wanted to do, be, and see. I remember that moment vividly. It was a sobering one, to say the least. As a matter of fact, a year later, I haven't quit crying out that phrase every few months. My dysautonomia was going to try to define me after all.

I was encouraged by our family counselor to make a new list. Come up with things that I CAN do and make a new bucket list. Ok, let's see... hmmm... Yep, same problem. Everything I tried to come up with was impossible! I have a severe type of dysautonomia which has left me in a 24/7 reclined position. I can walk around 3-5 minutes at a time, and I can never have

my legs down while seated, even in a car. No matter what form or kind of dysautonomia you may have, I'm positive it has changed your life, your abilities, your hobbies, and your bucket list in some way. If you jotted down a few things you had planned on doing one day, they will most likely be altered because of illness. But that isn't the end of your story, unless you let it be the end.

So, after a few weeks of throwing an internal temper tantrum, I got a chance to regroup. I realized that my bucket list will not look like anyone else's list. I guess it's not suppose to. Mine had to be more meaningful than before, had to be much more deliberate in non-tangible treasures, and it belonged JUST TO ME! I won't share my NEW bucket list, but I can tell you that I'm slowly checking off a few things every few months. Some things I may not get the chance to finish, or even start for that matter, but the list is

one I believe I was destined to find. It's one that no man could steal, no storm could destroy, and its value cannot be measured. My 'so-called bucket list' is very different than I had ever imagined it would be in my later years. But then again, so is my life! I won't say I don't long and yearn for the old list..... because I do! I always will. However, this new list is one only I can fulfill-yet it's rewards are going to be seen and reaped by those who surround me. I may pout and whine a little bit from time to time about the things I will not get to accomplish, or see, or visit and all those endless limitations that come with living life from the bed. However, I will also choose to be conscious of the things that I may have missed if I hadn't been the one who lives life from the bed. I do know that my treasure and bucket list is priceless and one that will last forever!

The Parenting Corner: Through Your Child's Eyes

By, Gwen

If there is one thing parents with dysautonomia know, it is guilt. The guilt that comes from having to tell your child "No", because you are having a "POTS-ie" day. Some days, for me, that guilt is far worse than any dysautonomia-related symptom. With summer and warmer weather quickly

approaching, I am already getting nervous about it. If I'm in the heat for more than five to ten minutes we have to race back inside to the air conditioning. My son runs and grabs my fan, directs it towards me, holds my daughter back away from it and says "Watch out Izzabelle, it's a dizzy one!"

So how do we handle that guilt? How do we handle telling our kids they can't go to the pool today because Mommy or Daddy isn't feeling well? If you know the answer to that then I am all ears! However, what I do know is that our children wouldn't trade us in for any other parent in the world! When they look at us they don't see a "sick" parent. They see a hero, a supporter, the person who loves them most in the world. The guilt won't go away. We're parents. It just comes with the territory. Sick or not, our children love us unconditionally. Each time my son takes my hand and places it on his head for me to help when my legs are weak and shaky, I know that there is not a single person in the world that could take my place in my child's eyes.

You Don't Beat Chronic Illness, You Live With It!

By, Melanie

Does anyone really ever learn to live with chronic illness? How can a person resolve to live with constant pain and chronic illness for the rest of their lives? Each battle is so unique and each person has their own journey. However, there is a common thread. Living with chronic illness is not only a difficult challenge day in and day out, but also something that will shape the rest of your life. While someone cannot control their illness, they do have some power over how the illness will control them.

Let's clarify something here for those who are not familiar with chronic illness.

Chronic illness is NOT cancer. You don't 'fight' it. You don't 'beat' it. You cannot 'will' it away, or believe it doesn't exist. We do not

use the words 'cure' to mean 'treat', or 'fight' to mean 'deal' with.

Chronic Illness is:

Dealing with,
Coping,
Managing,
Containing,
Living with,
Controlling,
Putting up with,
Handling, and
Living with.

Managing and dealing with chronic illness require that you develop coping mechanisms to move forward with the goal to minimize suffering and maximize daily living as much

as possible. For some diseases there are therapies, treatments, and medications to help ease the pain and the progression of the disease and its effects. For others, it's learning daily to set good parameters and limitations to reduce pain and stress on the body.

Nearly 1 out of every 2 Americans suffer from some sort of chronic illness (approx 133 million). Over 26 million Americans have some sort of severe disability/illness. While some diseases are due to poor health habits, many are genetic, contracted, or through no fault of the patient. Chronic illness can be anything from fibromyalgia, diabetes, and arthritis, to such things as Crohn's, lupus, cardiovascular conditions/diseases, dysautonomia, multiple sclerosis, Parkinson's, rheumatoid arthritis, and so many more! 7 out of 10 deaths in the U.S. are from chronic illness alone. The severity and the longevity of the illness can be as different as night and day. But learning to live with any chronic illness can take its toll on the individual and their family, and can be a daunting daily task just to thrive.

In addition to dealing with their individual disease or illness and all that it entails, many chronically ill patients can and do often suffer from other side-effects from being chronically ill. I've tried to research (and, of course, use some from personal experience) a few of the most prominent things a chronic illness sufferer may have to deal with in addition to their already difficult constellation of disease symptoms:

- * Depression
- * Poor nutrition due to lack of appetite or overeating
- * Sleeplessness
- * Isolation
- * Aches and pains from lack of ability

to exercise

- * Feeling of doom or fear
- * Medicinal side-effects
- * Lack of intimacy
- * Loneliness
- * Stress
- * Lack of emotional or physical support
- * Anger
- * Headaches
- * Financial difficulties due to expensive medical treatments and/or loss of work
- * Loss of relationships
- * Inability to participate in normal activities of life due to physical limitations or lack of mobility access in public places
- * Physical sensitivities: such as foods, lights, chemicals, noises
- * Lack of activities and social outings
- * Guilt
- * Lack of control over life and circumstances
- * Burden to caregivers and family
- * Inability to lead a 'normal' life, career, or education
- * Fatigue
- * Feeling overwhelmed
- * Constant focus on the illness and not the individual
- * And I'm sure there are many, many more!

So, if nearly 1 out of every 2 Americans deal with some sort of chronic illness, where do we go from here?

WHAT ARE SOME WAYS TO DEAL WITH AND COPE WITH CHRONIC ILLNESS?

- * If you can change your lifestyle to fix your illness....DO IT! (e.g. some types of diabetes, hypertension, some forms of heart

disease, and a few others)

- * Get informed! Learn about your disease so that you can help yourself. Knowledge is power.

- * Find a good doctor. This is imperative to your care. You need to know you are trying the best medications and therapies to ease the pain and discomfort. Know that your doctor is on your team.

- * Seek support from others who are suffering from some sort of illness similar to yours.

- * Watch your mental health. Seek professional counselors who understand severe chronic illness or life-altering diseases. You can't do this on your own. Dealing with the guilt, fear, depression, and dramatic changes can be overwhelming.

- * Keep active! Easier said than done. But as someone who has had as little as 90 seconds of stand time, there is always something physical that you can do, even from the bed. It helps your muscles, aches and pains, and mental health. It can be as simple as bed leg raises. Just do it every day!

- * Think positively! Again, easier said than done. I choose joy! It's a choice even in the face of severe physical limitations and pain. People who see the good in life tend to deal with chronic illness easier than others. Just choose joy!

- * Be deliberate about your circle of support. You may have to do some pruning along the way. Not everyone in your family or circle of friends will be your support system. You need people who will encourage,

be present, and be proactive with you!

- * Remember you are more than your disease. Spend the time needed to research and seek medical treatment, but don't let it define you. Continue your hobbies, relationships, and activities as you can.

- * You will have good days and bad days. Learning to live within those parameters is one of the hardest things for me. Accept what you cannot change.

- * If your physical limitations have required you to withdraw, try to keep connected with friends and family. Use the internet, phones, and texting if that's all you can do. Don't withdraw completely.

- * Join a support group. (But be aware of the 'woe is me' and the one-credit-short-of-a-PhD members) :)

- * Open up! People don't know how to help most of the time unless you tell them. Explain what helps and what doesn't.

- * Pray! Studies show that those with faith based views tend to have less depression and deal with the long term effects of illness with more ease as a whole.

- * Eat healthy. No matter what illness you have, eating poorly can add to the side effects of your illness.

- * Get rid of the unnecessary stress. You have enough to deal with already without adding to the stress. Weed out and prune often.

- * Allow time for relationships, intimacy, and friendship. If you are married, it doesn't mean the romance had to die with your old

life. Be creative, make new memories, and celebrate the little things.

* Create a new measuring system. A person who is chronically ill can no longer measure success by the same standard, rewrite your algorithm. Today might be considered amazing because you were able to spend time reading a book to your child. If you continue to measure happiness by the old standard, you will continue to be disappointed.

* Remember you get to be happy, too! Just because you are sick doesn't mean you cannot enjoy life. Allow yourself to be happy.

Buy something just for you. Make the room where you stay most often a happy and cheerful place.

* Acceptance. Learning to accept the cards you have been dealt is half the battle. If you cannot fix it, make the best of it. It's all about turning those lemons to lemonade!

* DON'T STOP DREAMING! Your dreams may have changed or need to be revised, but you can and should still dream. Give yourself a new thing to strive for that has nothing to do with your health. It doesn't even have to be a physical dream. Just don't stop dreaming!

Jordan's Story Meet the Member

Jordan is young woman faced with achieving a balance among the normal dilemmas that most "20-somethings" experience—developing a forward-looking career, maintaining a just-active-enough social life and searching for her true self. We have all been, or will be, in this period of uncertainty and excitement, in which we are figuring out what it means to be a "real" adult. Jordan's time of self-exploration became even more complicated and consuming when she began to experience strange, sporadic symptoms of dizziness and fatigue. Her isolated physical episodes of dizziness that, she thought, happened to everyone grew closer and closer together. When they culminated into a tsunami of debilitating discomfort, she knew she was dealing with something real.

A ten-month diagnostic process led her into offices of cardiologists, neurologists and ENTs. Her diagnosis was discovered through a tilt table test that confirmed Jordan's suffering was due to our familiar friend, POTS. Jordan found the "unknown" period, prior to her diagnosis, to be the most draining part of her journey with Dysautonomia. She knew that her body wasn't keeping up with her ambitions and her work ethic. She regularly dragged herself to a demanding, full-time job despite her body's outcries. However, physically she was struggling to keep up with daily life

activities, and she felt her doctors were occasionally unhelpful and often dismissive. Jordan's body was, seemingly, shutting down beneath her very eyes and the fear of an unknown cause was draining her emotional health. Yet, she had to continually remind herself to search for an answer despite many dismissals from experts. The combination of these factors results in the most difficult time for many of us with dysautonomia.

Everyone has a different experience with Dysautonomia. Together, we deal with many similar symptoms, but we also face our own unique challenges. Some of us are able to work and others need to rest. Some people can live independently and some of us need some help. We are all in different stages of figuring out what works for us, and the beauty of groups like DINET is that we can share our discoveries and challenges. Jordan's insight and determination helped her find her personal coping mechanisms, and I am honored to share that she has maintained an active, independent life despite her POTS.

Although she switched jobs since her struggle with Dysautonomia began, she has maintained full-time employment throughout her diagnosis. At first, she had just enough energy for a full day of work and sleep. Socializing, and everything else, had to be put on hold. Her long-term goals were set aside as she focused her energy on her health, and on simply being present at her job. Eventually, she was able to diversify her life. She slowly began to integrate socializing back into her routine. She was able to think about her career goals and made a job change. She figured out when to allow her body to rest, and how to push herself without exceeding her limits. Though medicine was helpful, she found lifestyle changes to be the most beneficial treatment for her POTS. For the first time in her life, sleep, diet and exercise became regular priorities. She knows she will not function without eight hours of sleep. She has grown incredibly knowledgeable and conscious about the food she consumes. Most impressively, she has built up her exercise tolerance to run three miles, daily! In Jordan's words, "POTS is still something that is in my life, however, it is not my life anymore."

Now, about a year after her POTS diagnosis, she isn't the person she was before her life with chronic illness. She definitely is not the person she was when she was being diagnosed with POTS. She is someone who has held onto her dreams, despite her illness. And, as a bonus, she has grown both physically and emotionally through these experiences. Before POTS, she would have troubling anxiety over school, work, and general life things. Now, she thinks of those things as "small stuff," and, instead, focuses on the big picture of life. Her relationship with her parents has strengthened, as they have truly banded together to help Jordan have the most fulfilling life possible. Before dysautonomia, Jordan never put much emphasis on treating her body with the right quality of food, sleep and exercise. Now, to live well, she must care about her body. She has learned not to give up though POTS has instigated her to quit many, many times. She knows how far she has come in life, and she has developed the determination to keep going.

It seems cruel and strangely poetic that dysautonomia hits many of us in our most busy, life-defining moments. It did its best to defeat Jordan when she was working on becoming the adult that she had always aspired to be. But, just maybe, the ominous, foreboding creature of dysautonomia

brings more than sorrow into our lives. As someone who suffers from dysautonomia myself, I have cursed the evil thing countless times. I have asked “Why?” more than I can count. I have cried on the days that I feel useless and burdensome. But, on days that I feel good—like Jordan—I wear dysautonomia-colored glasses. Glasses that help us have a deeper, more complete understanding of the important things in life. As Jordan reminded me—there can be good things that come from dysautonomia. Maybe, it will guide us on a different path than the one we deemed appropriate. Perhaps, it will help us learn the true importance of life. It will definitely be frustrating and defeating at times. But, doesn’t greatness—in any sense of the term—come from growing through life’s obstacles? Thanks, Jordan, for putting the dysautonomia-colored glasses back on my face to help me see all the good that has come to those of us who have suffered, and persevered.

The Ins and Outs of Tilt Table Testing

By, Debbie Zagray, PT, DScPT, CMPT

Tilt table testing is often utilized to determine the cause of fainting. If your doctor suspects that you are experiencing fluctuations in your heart rate or blood pressure when you stand up, a tilt table may be ordered. The tilt table test results will help your doctor determine the cause of these fluctuations as well as treatment options.

The doctor will inform you whether or not you should take your usual medications before the test. They may also request that you fast prior to testing. Because the test is designed to stress the body and potentially cause you to faint, you may also be required to have a family member or friend present to drive you home afterwards.

The test takes place in a quiet room with the lights dimmed. You will be asked to lie on a padded table. The table has a footplate and two sets of straps which fasten around your chest and thighs. You will be hooked up to equipment to monitor your blood pressure and pulse. The doctor may also want to place an IV in your arm to administer medications and/or fluids.

The test will begin with the table in the horizontal position with you lying flat. It will then be slowly raised to a vertical or almost vertical position. Your blood pressure and pulse will be monitored to determine if the readings are going up, going down, or staying relatively the same. Oxygen saturation may also be monitored. You will also be asked to describe any symptoms that you experience during testing.

Some testing protocols also call for the administration of medication, often through the IV or under your tongue. You will be returned to the horizontal position before receiving the medication. This medication will further stress your body. The test ends when the protocol test time is completed (20-45 minutes depending on the protocol), fainting occurs, or significant symptoms develop.

Online Dating and Dysautonomia: Tips and Safety

By, Linda

It's a jungle out there for anyone on the dating scene, and those of us living with a disability definitely have a few extra pitfalls to navigate. Nonetheless, with the increasing popularity of internet & online dating, anyone dealing with dysautonomia can generate a few extra sparks in their love life.

So here are some tips for creating a successful profile and making that online love connection:

1. Be Completely Honest.

Whether it's about weight, age, height, education, marital status ... If you are looking for a serious relationship, the truth will come out eventually. That aspect of yourself that you feel a little insecure about may not even bother your date—however, nobody likes to feel deceived. Besides, most people still consider honesty a desirable quality in a mate.

2. Be Authentic.

Let your wonderful, unique personality shine through the webpage. For example, if you like to do a certain activity (cooking, yoga, underwater basket-weaving...), post pictures of yourself actually performing that activity. Also, express what is important to you, such as your values or beliefs. These things add interest to your profile and shows that you are a real-life, well-rounded person.

3. Be Positive.

A laundry list of complaints about your

past relationships can really turn a reader off. Stating "no liars or cheaters" on your profile will just make it appear as if you are still hung up on some past liar/cheater. Instead, try to focus on describing what you are looking for in a relationship and the quality traits that are desirable to you. Sending the message that you are emotionally available will certainly attract more serious offers and appeal to the more suitable suitors.

4. Be sure to use your most flattering photos.

Probably the most important tip! When online dating, your photos are the first impression of you, so make it a good one! Pictures of you in bright, vibrant colors will naturally attract attention. Red has traditionally been the color of romance, but other bright and vivid colors (either on you or in the background) can yield the same effect. SMILING also makes anyone instantly more attractive!

Applying these few, basic principles to your online profile will certainly leave your inbox maxed out and flooded with offers in no time. But before you hit "send" on that first response, take some time to review these cyber-safety pointers.

5. Be careful not to share too much personal information too soon.

Your full name, phone, residence, workplace, (and definitely credit card number!) shouldn't ever be given out online. Instead, use a

nickname and be very general when talking about your life. For example, you could say that “I’m an accountant” rather than “I’m an accountant for such and such business on this street from 9am-5pm”. Similarly, giving specific details about your favorite hangouts is also risky. You could say “I do yoga on the weekends” rather than “I go to this studio for yoga every Saturday morning.” It’s important to be very selective about sharing your information, because once it’s out, you can never take it back. It only takes one bad experience to realize how easily people can hack into your life with just a little information and an internet connection.

6. Be sure to arrange the first date in a public place.

Also, arrange to get yourself to that public place, rather than have them pick you up. Give a close friend your date’s screen name, phone number, and the details of your meeting. And most importantly, trust your intuition. If something doesn’t add up or feel right (whether online or in-person), proceed with caution and start formulating an exit strategy.

If things go well though, and you wish to pursue the relationship further, consider giving out your phone number at the end of the date. If you still feel uneasy, however, stick to connecting semi-anonymously through the huge variety of texting/ voice/video apps now available that let you converse without ever giving out your phone number.

Unfortunately, not every meeting will end in a love connection. It’s best to avoid turning anyone down in person, however, because you can never predict how people will react

or express their anger. When they ask for another date, you can say “I’m not quite sure of my schedule for the upcoming weeks, but I’ll get back to you.” If they ask again online, you can follow-up with something like “I didn’t quite feel the connection that I am looking for, but I do wish you all the best.”

So when is it a good time to bring up your dysautonomia?

I find that the subject usually comes up within the first couple of chats, when we are starting to get to know each other. It’s a lot to explain, so I simply boil it down to: “I have heart issues and I have to take it easy.” Then I give them my diagnosis and let them “google” it. This way, I don’t have to give a lecture on dysautonomia and the conversation can stay more upbeat and casual.

Although my dysautonomia has never been a deal-breaker for men, I definitely know what personality types to avoid. I generally don’t pursue the more spontaneous personality types; since for me, planning a simple outing is as simple as planning a space launch.

Dysautonomia patient or not, it all comes back to knowing who you really are and knowing the type of person that brings out the best in you. Skipping this step and settling for whoever comes along is a short term solution, but may actually result in more heartbreak in the end.

So if you are still single, find the joy in your life that already exists and appreciate the love that is already all around you—from your family, friends, and especially your pets! After all, there is nothing more attractive than a person who is already living a joy-filled life and who has appreciation for the love they receive. Happy Dating!

GI Symptoms, MCAS & Dysautonomia

Part II: Recommendations, Treatments and Research

Written by Kelly Freeman and Matthew J. Hamilton, M.D.

(Part 1 of this article, signs, symptoms and diagnosis, published in DINET's Spring 2014 Newsletter is available at DINET.org)

Mast Cell Activation Syndrome (MCAS), a condition recognized in a growing number of Dysautonomia patients, often involves specific gastrointestinal (GI) symptoms as well as other system-wide complaints due to abnormal mast cell mediator release. Previously, we examined the diagnostic process and common associated gastrointestinal complaints. Diagnosis of both Dysautonomia and MCAS can be difficult for patients especially when GI symptoms are prominent.

"I would think very few gastroenterologists would think about Dysautonomia as a cause for their patients' GI symptoms", and likely many are unfamiliar with MCAS." – Dr. Matthew Hamilton

In this second article we examine what happens after diagnosis, including specific recommendations for patients, treatment options and future research.

Recommendations

Once MCAS has been diagnosed, it is essential to find a local physician who is willing to learn about Mast Cell Activation (MCA) and manage the treatment plan to minimize acute and chronic symptoms. Effective two-way communication is particularly important in the case of MCAS. This is because the medical community is still learning about what causes MCA and associated disorders. Further, the dissemination of clinical research findings to local treating physicians may be slow.

It is therefore particularly helpful for patients to educate themselves about MCAS through physician experts and reputable online sites such as tmsforacure.org to better understand the following general MCA concepts:

- **Mast cells are protective in nature.** They act much like soldiers with ammunition made of chemical mediators (histamines, prostaglandins, leukotrienes, and other cytokines) that, when working properly, help fight invaders of the body such as bacteria, viruses, parasites, toxins, etc. However, MCA leads to the inappropriate release of these chemical mediators that can play havoc in many and/or all organ systems.
- **Mast cells are a key player in the immune system.** In MCAS, the mast cell abnormally activates and releases chemical components, which have a direct effect on symptoms within the body. This may include vasodilation (effects on blood vessels that results in symptoms such as flushing or light-headedness with standing), and inflammation. Since mast cells have been observed to inappropriately activate in close proximity to the nerves, it is not a surprise that patients may also have autonomic dysfunction.

There is not sufficient evidence that MCAS is auto-immune in nature. In autoimmune disease, the immune system usually attacks itself in one or more localized region(s) of the body. In such conditions, mast cells play a more accessory role rather than a direct role in contributing to localized inflammation. In MCAS, it may be helpful to think of the mast cells as being abnormally overactive or hyper-immune.

- **MCAS Can Be Managed.** Although there is no known cure for MCAS, patients are not seen as having a life-threatening condition as long as they have been diagnosed correctly and managed appropriately. Nonetheless, MCAS can cause chronic and acute symptoms that may affect quality of life and the ability to work, which may also lead to hospitalizations and various medical interventions. The ideal treatment regime considers the “whole patient” and not just one organ system.

The educated patient is the best advocate in dealing with various physicians, hospitals and emergency care centers. Since MCAS patients have varied symptoms, it is crucial that the patient is knowledgeable and seeks to gather clinical data regarding their specific case. The following are helpful items to gather:

- Medical records, consultation notes, discharge summaries, and results of diagnostic and laboratory tests.
- A list of known triggers, including foods or environmental factors that affect symptoms.
- Data that identifies symptom

trends. It is particularly helpful to record which symptoms may be attributed to mast cell activation so that any new or different symptoms can be worked up and treated appropriately.

- A list of current maintenance and breakthrough medical treatments that have been effective for symptom control. The list should include which treatments have been tried previously, why they were discontinued, and any pharmacological allergies/intolerances.

Treatments

When treating GI issues associated with MCAS and Dysautonomia, the plan for each patient should be individualized to optimally treat symptoms and any co-existing conditions. The cornerstone of treatment is to avoid known triggers of symptoms. Along these lines, it is essential to select a diet and exercise plan that balances the avoidance of foods and activities that provoke symptoms with proper nutritional and physical health.

When considering diet options, it is helpful to begin by keeping a detailed food diary that includes any symptoms that are thought to be related to recently eaten foods. In addition to avoiding known food sensitivities, it may also be helpful to reduce fermentable sugars and high residue fibers.

Pharmacological treatments are also an important element of the treatment plan. These medications stabilize the mast cells, inhibit the activation of mast cells, or inhibit the effect of the specific chemical mediators mast cells release. Such medications usually include some combination of the following: antihistamines, oral Cromolyn Sodium, Ketotifen, aspirin,

Reduce Fermentable Sugars	Reduce High Residue Fiber
<p>A low FODMAP Diet (Fermentable Oligo-Di-Monosaccharides and Polyols)</p> <ul style="list-style-type: none"> + Fructose (several fruits, honey, high fructose corn syrup) + Lactose (heavy dairy products) + Fructans/Inulins (wheat, onion, garlic) + Galactans (beans, legumes, soy) + Polyols (artificial sweeteners, stone fruit) 	<p>Many fresh fruits and vegetables that we think of as “healthy” contain high residue fibers that are difficult to digest.</p> <ul style="list-style-type: none"> + Fresh fruits or vegetables with skin and seeds + Heavy roughage such as big salads + Raw cruciferous vegetables such as cabbage, carrots and celery
<p>These carbohydrates are known to ferment in the gut by bacteria found in the intestines. Such sugars are not easily absorbed and are also known to pull water into the GI tract. Avoiding these foods is particularly helpful in irritable bowel syndrome symptoms such as cramping, bloating, gas and diarrhea.</p>	<p>High residue fiber foods are not digested and therefore travel through the intestines and contribute to watery diarrhea, and abdominal cramping and bloating.</p>

Prednisone, Montelukast, and Zileuton. Corticosteroids are considered for severe or refractory cases. Drugs under investigation are Omalizumab (anti-IgE drug) and Quercetin (a natural mast cell stabilizer). Any patient with MCAS and who has had an episode of documented anaphylaxis should carry an epinephrine pen and be knowledgeable about how and when to use it.

Medications are often added in a step-wise manner in order to achieve maximal symptom control at the lowest possible doses. Finding the right medical regimen requires patience and persistence to identify which medications are effective and which may have intolerable side effects. Any medical regimen should be discussed first with the treating physician.

Research

Further research will enhance our understanding of the causes of MCAS and dysautonomias with co-existing GI symptoms. Areas for research that have been identified

include improved diagnostics, genetic factors that may predispose people to MCA, different protease expressions within various organ tissues to understand which chemical mediators are abnormally elevated, and how this may correlate with specific symptoms or response to therapies.

Today, there is a great divide between researchers studying dysfunction of the autonomic nervous system and those studying mast cell disorders. Often easy to assess, diagnostic data such as orthostatic vital signs are overlooked by mast cell disorder specialists. Conversely, information gathered in the patient history by dysautonomia specialists (such as a history of anaphylaxis, flushing and/or abdominal pain) that might suggest the need for a MCAS workup is frequently overlooked.

Patients play a key role in advancing research and bridging the gap between these two fields of study. Often patients underestimate the power they have in creating awareness by educating friends, family and even their own physicians who may influence clinical research.

All patients who suffer with MCAS, Dysautonomia and difficult GI issues will benefit with greater understanding within these areas of research. It is this greater understanding that gives us all hope for the future.

Matthew J. Hamilton, M.D. practices in the Division of Gastroenterology and is active in research in the Mastocytosis Center for Excellence at Brigham and Women's Hospital. He is also a faculty member at Harvard Medical School.

Kelly Freeman, M.S.M. is the Founding Director for TheDysautonomiaProject.org She has several years of experience in health care education and research.

Doctor's Question and Answers

Q Is it valuable to determine the type of POTS or search for an underlying cause of severe hypotension along with POTS? Would it potentially change or improve treatment? Of course, this will cost additional money and travel away from home. Would it really be worth spending so much money to have the autonomic testing done?

Thanks,
Cathleen from CT

A I am a very stringent advocate of detailed work up of every case. It does change management choices.

Dr. Amer Suleman

Q If an Autonomic Ganglionic Neuropathy is suggested, which specific antibodies should be tested in the blood?

Thank you very much in advance!

Best wishes,
Erhard from Austria

A All I know is that the Mayo Clinic paraneoplastic panel includes anti-ganglionic antibodies. I believe sample collection and transport requires dry ice and the Mayo labs in Minnesota must be contacted.

That being said, my contacts there have seen very little AAN lately especially in connection with POTS.

Dr. Julian Stewart

Q My question is: could a gastric bypass make POTS worse? I ask because I know that gastric bypass can cause POTS or POTS-like symptoms.

Thanks,
Clara from CA

A Clara, thank you for this interesting question. Gastric bypass operations have really been a revolutionary addition to the treatment arsenal for morbid obesity, and they have helped countless numbers of people.

In addition to weight loss, the procedure seems to be able to reverse insulin-resistance in some patient and reverse hypertension... even before significant weight loss. The improvement in hypertension is thought to be due to a reduction in sympathetic nervous system tone.

In the midst of this, we and others have seen some patients develop new onset syncope and even mild autonomic failure after gastric bypass operations. Blair Grubb's group in Toledo (OH) has published a series of patients with such problems following gastric bypass surgery. One challenge is that we do not know how common this problem is, since this has never been formerly assessed in a group of patients from the onset of gastric bypass surgery. It is not possible to know if the bypass surgery will cause problems in a particular patient, but the short answer to your question is that I suspect that gastric bypass surgery COULD make some POTS patients worse.

Dr. Satish Raj

Q I live in a beautiful part of the country, yet many states away from autonomic clinics and specialists. With a diagnosis of POTS, which specialists would you recommend to make a local team when travel is not feasible? And, why those specialties are relevant to dysautonomia?

Blessings,
Jaclyn from MT

A Jaclyn, I appreciate the challenges that you must face accessing autonomic specialists. While there are not many in any part of the country, there do seem to be a lot fewer such physicians and clinics in the western part of the USA.

I do not have a direct response to your question about the correct mix of specialists to look after a patient with autonomic disorders. The challenge is that autonomic disorders can span across multiple specialties, and does not fit neatly into any one speciality. Personally, I believe that the most important physician to you should be your primary care physician (PCP). Your PCP plays a critically important role, not only as the "first contact" when something happens, but also to help you to integrate the advice of multiple specialists. At the Autonomic Society Meetings, we see physicians that are General Internists, Neurologists, Cardiologists, Endocrinologists and Gastroenterologists. The key may not be the specialty of the specialist, but that he or she have an interest in these problems, and that they are willing to travel along the journey with you.

Dr. Satish Raj

Q Hi, thanks for taking my question. Is it possible for your symptoms to change over the years (even over decades)? For example: tachycardia to bradycardia, chest pain to air hunger and so on...

Kurd from CO

A Yes, but there are also changes in medical and physical status that occur with aging. Any change should prompt a physician visit.

Dr. Julian Stewart