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Autonomic Dysfunction (Dysautonomia)

"Dysautonomia" or "autonomic dysfunction" occurs when there is abnormal functioning in nerves controlling many everyday body activities. Some of the functions regulated by the autonomic nervous system are control of heart rate, blood pressure, digestion, bladder function, bowel function, sweating, and even breathing. These are unconscious vital functions important to the body.

Current research revolves around the TLR Receptors (Toll-Like Receptors), the innate threat response receptors that are activated by threats to the body, whether this be trauma, spinal injury, stress, inflammation, food our body perceives as a threat (such as sulphites in a sulphite-intolerant.) This then provokes an immune response, which causes the symptoms in the various parts of the body. There is evidence that the resultant oxidative stress may be a trigger for some autoimmune disease. It certainly appears to explain how the vastly different causes (eg spinal injury, stress, allergy, food intolerance, chemical exposure) can produce the same set of symptoms, but it also provides the background for successful management of the condition. It also explains why when one trigger is activated it can cause increases in symptoms that had been attributed to other causes. For example, you may have minor food intolerance symptoms, but they become severe when you are stressed, or your neck that had been injured in a whiplash is aggravated.

The symptoms seen in dysautonomia are wide and varied, the causes of the symptoms to flare often multiple, but it is all linked. To control this problem, all potential causes and "drivers" need to be addressed. It also appears likely there are significant genetic components, and defects in the methylation pathway (MTHFR gene mutation) figure prominently. There are families with predisposition to dysautonomia.

People with dysautonomia, when the process is active, are typically hypersensitive- to things affecting their senses eg environmental factors such as smells and sounds, and to things happening in their bodies. They are usually hypersensitive to medication; even simple products such as paracetamol- one may be enough for pain. Doses of medication usually need to be reduced to minimize the risk of drug reactions.

Symptoms of autonomic dysfunction can include:

Lightheadedness, tremulousness and presyncope (feeling of faintness)

Heart-rhythm variability with irregular beats or episodes of inappropriate fast heart rate (Inappropriate Sinus Tachycardia -IST). If you get this, listen to your body, as you may find it occurs on certain circumstances such as vacuuming, or twisting your spine getting out of a car etc, but can be provoked by even simple things such as weather change.

Chest pain and shortness of breath, frequently poor exercise tolerance- many people end up having continued investigations into their coronary arteries when really there may be no problem. Again, think about you may have been doing to trigger this off.

Lack of saliva

Dry eyes

Other eye changes - Blurring then graying of vision, blacking out, tunnel vision, sensitivity to light, difficulty with focusing

Feeling full earlier than expected with a meal

Nausea and vomiting

Problems with swallowing – it is common to have oesophageal dysfunction –the process similar to that in IBS, and usually food triggered, although spine triggers and stress may provoke the symptoms. Reflux oesophagitis may be diagnosed, especially when stress provokes symptoms. Persistent symptoms should be investigated.

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Constipation or diarrhoea- irritable bowel syndrome (IBS)- via food intolerance, but it may be present only when you are stressed, anxious etc. Organic disease must be excluded before this can be safely diagnosed.

Temperature regulation disturbance - Hypothermia (from loss of shivering and inability to vasoconstrict to prevent heat loss) and hyperpyrexia (may be of concern to patients with anhidrosis who are exposed to high temperatures).

Hyperhidrosis (excessive sweating), or lack of sweating

Unexplained anxiety

Altered sensation of taste

Incontinence or dysfunction in bladder and/ or bowel functions

Facial pallor

Numbness and tingling especially in the extremities. Itching may precede the burning.

Altered sensation is often worse at night. Cold feet and dry skin may occur

Erectile dysfunction

How does this happen?

Your brain contains about 100 billion neurones or nerve cells. They are a bit like tiny wires, but while wires in a TV are joined to one another by solder, neurones in the brain are joined at junctions called synapses. When you send a signal from one part of the brain to another, it travels along a nerve cell, or neurone, until it reaches a synapse. There the synapse releases a special chemical a "neurotransmitter" which jumps the gap in the synapse and allows the second neurone to pick up the signal and pass it further along until it gets to its destination. There are thought to be about 400 neurotransmitters in the brain for different purposes. The two best studied are serotonin and noradrenalin. These are involved in 3 important circuits: sleep, mood control and pain control.

The autonomic nervous system is the unconscious or automatic nervous system that controls and regulates virtually all of our body functions and systems, such as blood pressure, pulse, temperature and sleep patterns. It is made up of 2 parts, the "sympathetic nervous system" and "parasympathetic nervous system".

The sympathetic system can best be thought of as controlling the "fight or flight" reactions of the body, producing the rapid heart rates, increased breathing, and increased blood flow to the muscles that are necessary when an individual is in danger or under stress.

The parasympathetic system controls the "quiet" body functions, for instance, the digestive system. Simplistically, the sympathetic system gets the body ready for action, while the parasympathetic system gets the body ready for rest. And in normal individuals, the parasympathetic and sympathetic components of the autonomic nervous systems are in perfect balance, depending on the body's immediate needs.

When autonomic dysfunction, or dysautonomia occurs, this nervous system is "out of balance", and at various times the parasympathetic or sympathetic systems inappropriately predominate. These body functions speed up or slow down, often at inappropriate times, sometimes causing inexplicable or distressing effects.

Sufferers of dysautonomia can experience all these symptoms or just a few of them. They can experience one cluster of symptoms at one time, and another set of symptoms at other times. The symptoms are often fleeting and unpredictable, but on the other hand they can be triggered by specific situations or actions. (Some people have symptoms with exertion, for instance, or when standing up, or after ingesting certain foods.)

Commonly symptoms can be triggered by activity involving the spine. It can be so specific that symptoms may start when looking to one side or looking up, hyperextending the neck, or using a

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mobile phone. Spine- associated symptoms are commonly found in people with certain occupations where there is frequent twisting of the spine, eg nurses, dentists, hairdressers, and very commonly in people with scoliosis and following accidents where the spine is involved. It is common to have rotational injuries to the upper thoracic spine in car accidents as the body is hurled forward in a seatbelt, or the neck injured in a whiplash injury. Problems may not become apparent for some time, even years, after the event. As symptoms progress, even if the injury was to the thoracic spine, it is common to have different parts of the neck trigger symptoms off.

Injuries to shoulders can provoke extreme symptoms through "Thoracic Outlet Syndrome," a problem so important and discussed separately.

Dysautonomias caused by viral infections, toxic exposures, or trauma, especially to the shoulder, neck, mid-thoracic spine and sacro-iliac regions, often have a rather sudden onset, so symptoms can often be tracked to definite "activators." There may be more than one. The initial "activator" may differ from the "drivers." Where food intolerance is the primary cause of symptoms, the onset can be very subtle, although commonly it too requires a trigger, which could be an injury again, moulds, chemical exposure, viruses or commonly an infection such as Blastocystis or Dientamoeba, or a period of sustained or severe stress.

Autonomic dysfunction can affect many or only one part of the autonomic system. Many people have this but it is so minor that it is considered normal for them. In others, it can be so severe as to ruin their quality of life. Anxiety often becomes a problem, and as the symptoms of anxiety are very similar, so there is often a blurring of boundaries in exactly what is causing what symptom.

Managing anxiety is very important in managing autonomic dysfunction. Doctors easily recognize the symptoms of anxiety, and people are usually diagnosed as having an anxiety disorder. Fortunately the common medications used to control the anxiety also damper down the dysautonomia, reinforcing the doctor's diagnosis, and for many people, sufficient improvement in symptoms that they can cope with their problems. There is commonly a mechanical component, which if identified can improve or stop the waves of anxiety, irrespective of medication.

Working out what are the triggers to the dysfunction is very important, as sorting this out may enable the process to be controlled. Frequently people have had years of unexplained symptoms and have been told they have to live with them, or that it is all psychological, which is usually not the case.

Many people with dysautonomia also have evidence of autoimmune disease, and here Hashimoto's disease of the thyroid figures prominently. Other autoimmune disease eg Sjogrens syndrome and SLE need also to be considered while sorting it out. Once the causes and drivers are sorted, there is usually an improvement in these diseases. Research is showing the blurring of boundaries between inflammation, dysautonomia with auto-immune diseases, cardiovascular disease and even cancer.

The problems of evaluating dysautonomia

The severity of the symptoms in people with dysautonomia are typically far out of proportion to any objective physical or laboratory findings and this lack of objective findings makes life very difficult to diagnose the problem correctly. Diagnosis will usually end up dependent on the main symptom. This means that those whose main complaint is easy fatigability are likely to be diagnosed with CFS. Those who pass out are labelled as vasovagal or neurocardiogenic syncope. Those whose resting pulses are noticeably high are said to have sinus tachycardia. If dizziness on standing up is the chief problem, POTS is a likely diagnosis. Diarrhoea or abdominal pain gets you irritable bowel syndrome. Upper GIT symptoms are commonly labeled as oesophagitis or oesophageal dysfunction. Chronic pain may lead to a diagnosis of fibromyalgia, a common association with dysautonomia. Whatever the diagnosis, however, a dysfunctional autonomic nervous system almost always plays a major part in causing the symptoms, so linking all the causes and working on each collectively and individually is vital.

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Treatment

Evaluating autonomic dysfunction can be very difficult, and it often takes a great deal of time to identify exactly what is happening, and then to work out the various causes.

As a great number are caused by injuries to the spine, assessment by a physiotherapist experienced in this condition is vital. I find pilates specifically targetted to the injured area to be most helpful. Targetted pilates then progresses to increasing aerobic exercise, with hydrotherapy a valuable therapy. Acupuncture can also be a valuable treatment, and in severe dysautonomia it is often valuable to calm down the hypersensitive autonomic system before attempting any physical therapy. Sometimes short treatments with anti-inflammatory agents are helpful to relieve pain and joint inflammation.

Vascular Compression Syndromes: these are present in all patients tested in the POTS research project, and these are currently being investigated in other dysautonomic and fibromyalgia patients. These are dealt with in detail in "POTS."

Diet: It has been looking closely at the disease patterns and finding the same inflammatory chemicals in almost all of them, whether it be a thyroid, fatty liver, chronic pancreas, or diverticular disease, aortic dilatation to name but a few. Then there is good data that IBS- associated inflammation produces the same inflammatory responses as has been seen to cause the neuropathic pain in fibromyalgia (IL-8), or ascending aorta dilatation (IL-6) and breast and prostate cancer (IL-6) you can see how dietary change alone can modify disease processes.

The impact of the gut biome and IBS becomes so very important as you see migratory arthritis as directly food-driven. When you eat food your body sees as a threat, you get Interleukins 2,6,8 and 10 released. Parasites such as blastocystis become very important when you see it causes IL-8 release.

It is very important that patients with dysautonomia eat a nutritionally complete, well balanced diet. Inadequate diets can worsen low energy levels. Preservatives and food chemicals should be avoided. The closer the diet is to the "natural product" generally the fewer the problems. Food intolerance is a very common associated problem, triggering the TLRs, with resultant increase in dysautonomic symptoms. People with this often have very restricted diets as the immune system struggles to deal with perceived threats from ingested foods.

Totally elimination of caffeine may be required, especially when there are problems with heart rate. Caffeine is a stimulant drug found in many drinks (such as coffee, tea, and colas) and some foods (such as chocolate). Caffeine tends to stimulate the autonomic nervous system and may worsen symptoms.

You should work toward the reduction / removal of sugar in the diet. A surge in blood sugar stimulates the autonomic nervous system and may make symptoms worse. You should have a mid-afternoon high-protein snack, instead of sugary food. When you need to lose weight, fad and crash diets should be avoided. "Diet pills" too should be avoided as these can worsen symptoms. The autonomic nervous system and inflammatory pathways are described in "Irritable Bowel Syndrome."

Fluids: Adequate fluid intake is also very important. Many symptoms (such as dizziness, weakness, light-headedness, etc.) are due to low blood pressure and low blood volume that can be helped through drinking adequate amounts of water.

Physical activity: Maintaining a daily level of physical activity is probably the most important thing people with dysautonomia can do other than removing the triggers that provoke the TLR receptors. Some daily level of moderate activity helps to stabilize the autonomic nervous system, and in the long run makes "relapses" of symptoms rarer and of shorter duration. Physical activity may even hasten

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the day when symptoms disappear. Again, pilates should be considered. Yoga, tai-chi, and massage have been reported to help as well. Walking and hydrotherapy are usually excellent choices of aerobic exercise, once your physiotherapist has established there are no problems associated with this.

Dietary supplements: Any time a medical condition exists that doctors treat poorly, purveyors of dietary supplements have an open field for pushing their products. Consequently, thousands of unsubstantiated claims have been made about the ability of various vitamins, coenzymes and herbal preparations to relieve the symptoms of dysautonomia. There may be deficiencies that require correction, but as a general rule, you cannot supplement your way out of dysautonomia. This is especially so in people with methylation defects and usually in those with food intolerance. Most of the expensive dietary supplements and other herbal and nutritional products, simply may not be needed. If vitamin supplements are needed, they are usually specifically targeted and neither extensive nor expensive.

Psychological therapy: Dysautonomia is aggravated by anxiety, just as anxiety can be a symptom of the syndrome. While medication may be required, dealing with the anxiety may require assistance from a psychologist, even if it is only to learn how to control psychological symptoms rather than letting symptoms control you. It is, however, my belief that most anxiety has a physical cause, so looking at what has occurred before the onset of the anxiety provides a link to the underlying cause.

Drug therapies

A host of pharmaceutical agents have been tried in patients with dysautonomia. For years, the stand-by medications were the Tricyclic antidepressants (TCA's) - eg amitriptyline, especially in fibromyalgia and IBS. Recent studies do in fact confirm they help turn off the TLR's that are responsible for symptoms, so there sometimes is still a place.

Selective serotonin reuptake inhibitors (SSRIs) - such as Zoloft, Cipramil and Lexapro, over recent years have replaced the TCA's especially when anxiety and depression co-exist. But they do not work in all people.

For many years, fibromyalgia syndrome was considered a psychological problem, and the mainstay of treatment was with TCA's and exercise, with reasonable success. When there is muscle pain and tightness, such as in fibromyalgia and myofascial pain, a newer product called duloxetine (Cymbalta) is often more effective than others. This affects both serotonin and nor-adrenalin levels, but as the generic versions do not appear to work, exactly what controls the pain eg of fibromyalgia, is uncertain. Medication often needs to be started at very low doses, usually much less than the normal, as in people with dysautonomia, there often appears to be a hypersensitivity to drugs as well as external and internal stimuli. Dampening this hypersensitivity by turning off TLR's seems to me to be the way these products work best. But when you start them, it can be difficult, and always start with a quarter or even less of the normal doses.

The older tricyclic products have been proven to be very beneficial in IBS in reducing symptoms. But again here, IBS is better controlled by finding the triggers, usually food intolerances which is then usually aggravated by stress- making the need for medication less when the culprits are identified and removed from the diet (or minimized).

Anti-anxiety drugs - such as alprazolam (Xanax), diazepam (Valium) and lorazepam (Ativan) occasionally can help to control symptoms of anxiety, especially in patients with panic disorder. There is however a significant risk of dependence. They can be helpful in reducing anxiety while waiting for the "drivers" to be worked out and removed, or other products eg Cymbalta to start working.

Anti-low blood pressure drugs are rarely needed except in exceptional circumstances- Fludrocortisone (Florinef) helps prevent the symptoms caused when the blood pressure drops when the patient is

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upright (a condition called orthostatic hypotension.) Orthostatic hypotension is prominent in vasovagal syncope and in POTS.

Non-steroidal anti-inflammatory drugs – eg, Mobic, Celebrex, Ibuprofen, Voltaren and Naproxen can sometimes help control the pains associated with the dysautonomias, especially when the spine is involved. Many people have chest and back pain, which if left uncontrolled, aggravates symptoms, so it may be helpful to control the pain and get one of the problems out of the way. Sometimes these are needed for extended periods, but generally if appropriate spinal treatment is used, the need for the medication becomes much less, and may not be needed at all.

Many women find the symptoms start with menopause- in fact the typical flushes are autonomically - driven, and for many years, the SSRIs and SNRIs have been used successfully to control flushes in women who had chosen not to have HRT. HRT or similar treatments may need to be considered to control symptoms. Younger women may find their symptoms are worse during their menses, so controlling these may give significant improvement in symptoms. In many women with autonomic instability, problems start with the menopause, and it is not surprising to discover that the flushes of menopause are associated with circulating IL-8 and TNF α .

Whatever medication is chosen to trial, the hypersensitivity of the dysautonomic patient often means very small doses, and perseverance with side effects. It is worth mentioning again that there is no tried and true treatment method that always works in treating patients with dysautonomia. A trial and error approach, requiring the patience of patient, doctor, physiotherapist, dietician and other therapists is almost always necessary.