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My Action Plan for Stopping the Symptoms of Mitral Valve Prolapse
*Including the Overlapping Symptoms of
POTS, Fibromyalgia and
Chronic Fatigue Syndrome/ME*

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Chapter 4

Five Conflicting Characteristics of the MVPS Diagnosis and How Knowing Them Has Helped My Treatment

from the book, “My Action Plan for Stopping The Symptoms of Mitral Valve Prolapse/Dysautonomia”

by
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Over the years I have adjusted to the ever-changing names for my condition. I have been told I have mitral valve prolapse (MVP), mitral valve prolapse syndrome (MVPS), MVPS-Dysautonomia (MVPS-D), and MVP dysautonomia (MVPD). The medical tests have also changed during that time for both diagnosing and refuting the condition.

Mitral Valve Prolapse Diagnosis

On initial diagnosis of mitral valve prolapse (MVP), the doctor described this “click-murmur syndrome” as an instance in which overly large valve leaflets fail to close smoothly, making a clicking sound. Other names for the harmless condition included Barlow’s syndrome and floppy valve syndrome.

Some people with MVP require treatment when the valve does not close completely and causes regurgitation. The blood leaks back through the valve instead of moving forward. This real, visible pathological and physical problem can be serious enough to require surgery.

Fortunately, I do not have regurgitation, mitral valve issues, or any cardiac problems. My collection of symptoms has been referred to as mitral valve prolapse syndrome - dysautonomia.

The MVP and the MVPS Disconnect

At diagnosis I was assured I had a functioning, healthy heart with a valve that closed completely. With that good news, I went back to my life. Nothing had changed except the presence of a click as the mitral valve closed, noted by some doctors during physical exams, and occasional mild flutters. MVP symptoms like palpitations, shortness of breath, cough, fatigue, dizziness, anxiety, migraine headaches and chest discomfort can come and go or disappear for years.

For more information, you can read the unsigned article “Mitral Valve Prolapse” on the National Heart, Lung, and Blood Institute’s webpage.

Looking back, I experienced mild and intermittent instances of some of those symptoms long before I was diagnosed. At first, I never found those issues problematic, and I failed to connect any of them to MVP.

Many years later, everything changed, beginning with stroke-like weakness down one side of my body. Chest pain became a recurring symptom, followed by daily arrhythmias, irritable bowel episodes and a litany of other classic MVPS symptoms.

The MVPS Diagnosis:

Characteristic 1: A Floppy Valve with Unrelated Symptoms

When my mitral valve prolapse problems began, I didn't know what was happening. As the symptoms mounted, I feared I would die, and I felt that no one was helping me. That was when I turned to the internet.

I can still remember sitting in my chair in the dead of night wrapped in a blanket with a cup of hot tea, glued to the monitor. My fears escalated as I searched my symptoms and read the serious conditions that were associated with them.

Then an MVPS website popped up that gave me pause. I was told I had MVP. What was the “syndrome”?

After visiting multiple websites, I leaned back with tears of relief filling my eyes. I had MVPS. Several more doctors would come and go before a medical professional confirmed my diagnosis, but I knew I was right. Finding a benign reason for my symptoms gave me my life back—I was okay.

Or Was I?

With time, I began to doubt that my problems could be explained by a benign syndrome. It became harder to attribute the constellation of worsening and multiplying issues to MVPS.

When symptoms flared, I experienced a cascading event. One issue led to another until I found myself in a full-blown episode of an MVPS flare-up. I felt no relief knowing that I only had MVPS.

Is Everything MVPS?

The frightening arrhythmias and chest pains could easily have been caused by a separate issue. As I grew older, I could not ignore the fact that women in high-stress jobs often suffered heart attacks in their forties.

Who was to say that a person with MVPS could not have a heart attack or throw a clot when all my symptoms could be interpreted as warnings of just such an event? Additionally, I had a ton of frightening noncardiac symptoms that were, at times, debilitating. A stomach bleed, for instance, put me in the hospital for two days.

The MVPS Symptoms

My list of symptoms kept growing, but from what I have read, each individual experiences a unique combination of what can seem to be an unlimited list of MVPS-related problems.

A minor symptom for me could cause someone else greater issues. The following list represents the typical MVPS symptoms. I have experienced those marked with an asterisk and will not be surprised if I face more in the future.

- Chest pain*
- Palpitations or irregular heartbeat (arrhythmias)*
- Migraine headaches with pain
- Migraine auras with stroke-like symptoms*
- Difficulty with balance
- Fainting or near-fainting spells
- Shortness of breath*
- Shakiness*
- Cold sweats/weak feeling*
- Dizziness/vertigo*
- Numbness in any part of the body*
- Trouble with eyes or visual disturbances*
- Fatigue*
- Hypersensitivities/easily startled*
- Sleep problems*
- Anxiety*
- Depression
- Panic attacks with pounding heartbeat*
- Irritable bowel syndrome*
- Gastroesophageal reflux disease (GERD)*
- Sensitivity to drugs, caffeine, and medications*
- Allergies*
- Asthma/bronchitis

- Aches or pains*
- Back problems*
- Bladder problems*
- Skin irritations and rashes*
- Muscle fatigue or weakness*
- Muscular tensions/twitching*
- Difficulty concentrating*
- Chemical sensitivities and food allergies*

The realization that my MVP had morphed into MVPS changed my view of the problem and its treatment. I couldn't count on my past knowledge.

Any of the first ten symptoms listed above would, for the general population, signal a serious health problem or even a medical emergency—but not for me. These symptoms can be my daily fare. When a symptom flares, I often have to remind myself that I am not in danger and act according to the plan I've developed. The plan is specific for each issue, which helps me treat the problem more effectively as well as determine its risk.

The MVPS Diagnosis:

Characteristic 2: MVPS Looks Like Other Syndromes

The deeper I searched the MVPS diagnosis, the more I discovered symptoms that overlapped with other disorders. My symptoms also appeared among those for fibromyalgia and chronic fatigue syndrome.

I refer to both conditions as MVPS “sister syndromes.” My research indicated that people who did not carry my diagnosis also suffered from many of my symptoms. Why was that the case? Could researching those disorders lead me to answers for my issues? There was only one way to find out.

A Look at Fibromyalgia

Fibromyalgia and chronic fatigue syndrome summaries emphasize symptoms that best represent the particular diagnosis. For example, fibromyalgia information predominately addresses widespread muscle and tissue pain.

I experience flare-ups of both. My skin can become exquisitely painful to the barest touch. That discomfort, however, does not figure heavily among MVPS symptoms nor even as an aspect of my personal list of symptoms.

My MVPS list usually starts with cardiac symptoms such as racing or irregular heartbeat (arrhythmia), chest pain and shortness of breath. All are associated with fibromyalgia and chronic fatigue syndrome, but not prominently.

Reports note that many people with fibromyalgia describe intense, sharp, or stabbing pain in the chest and ribs, which tends to be attributed to costochondritis, an inflammation of the rib cage.

Again, I have been diagnosed with costochondritis and cannot touch some areas of my ribs when they are inflamed. This particular symptom of pain has confused my diagnosis with gallbladder dysfunction, which presents at the tip of the right, lower rib. More often than not, however, the type of chest pains that send me to the ER are esophageal spasms that eerily mimic a heart attack.

I found familiar symptoms among those listed for fibromyalgia, including migraine headaches and irritable bowel syndrome—and, interestingly, mitral valve prolapse.

That’s right. Some people with fibromyalgia could also have MVP as a symptom.

I came away feeling as if someone dumped all the word tiles from one board game and reorganized them to fit the rules of another. People with fibromyalgia appeared to have all the same symptoms that plagued me but presented in a different order of emphasis.

Research supports the inclusion of MVP as a symptom of fibromyalgia. In “Prevalence of Mitral Valve Prolapse in Primary Fibromyalgia: A Pilot Investigation,” published in the July 1989 edition of *Archives of Physical Medicine and Rehabilitation*, authors M.J. Pellegrino, D. Van Fossen, C. Gordon, J.M. Ryan and G.W. Waylonis, theorized that MVP may be part of a more generalized connective tissue abnormality.

Really? My research on MVPS did not include that reasoning. The information I encountered most often purported that the prolapse is hereditary and a marker for dysautonomia.

I had no reason to doubt that characterization. My mother suffered from almost all the symptoms listed as MVPS back in the 1960s although she was never diagnosed.

Both she and her mother often complained of cardiac symptoms with no underlying pathology. I might add that both were considered hypochondriacs. In my experience, doctors tend to fall back on that stereotype when they don’t understand or have not studied the problems that are presented to them.

I have also found that some MVPS symptoms can be listed as symptoms of another MVPS symptom. For example, IBS can be noted as a primary medical problem with a list of associated problems.

One study I read showed that people with IBS are more likely to have other disorders, including migraines, fibromyalgia, and depression. (J. Alexander Cole, Kenneth J. Rothma, et al,

“Migraine, Fibromyalgia, and Depression Among People with IBS: A Prevalence Study,” *BMC Gastroenterology*, June 2006.)

This information offers an excellent example of the intertwined nature of symptoms. I am personally irritated that anxiety and depression seem to be gratuitously added to such symptom lists. In my experience, adding those psychiatric disorders often prevents doctors from focusing on the main problems at hand.

A Closer Look at the Anxiety and Depression Diagnosis

In my opinion, psychiatry has become too intricately involved in the diagnostic process whether needed or not. I believe that fluctuating human emotions are mostly natural, not psychiatric.

Anxiety

Anxiety can consist of numerous symptoms: an impending sense of doom or danger, accelerated heart rate, rapid breathing, sweating, shaking, a feeling of weakness, nervousness, and panic.

Physiologically, the hormone adrenaline causes anxiety and fear. Gratuitous adrenaline release underlies dysautonomia, which causes the majority of MVPS symptoms.

To my thinking, physiological reactions to adrenaline release comprise a common feature of MVPS, not a psychiatric problem of anxiety. Though commonly excreted during times of stress and fear, adrenaline release is not necessarily caused by emotional factors or tied to a psychiatric disorder.

In many instances, adrenaline prepares the body to react to danger and trauma in a lifesaving way. The hormone can temporarily block the pain from serious injury and restrict blood vessels to lessen life-threatening bleeding until medical attention can be sought.

People suffering from heart attacks experience anxiety. The same adrenaline that causes that feeling can, under different circumstances, help a heart to continue to beat.

For more information on these characteristics of adrenaline, see: “What is Adrenaline?” *Hormone Health Network*

“Heart Attack Symptoms: Know What’s a Medical Emergency,” Mayo Clinic.

“Adrenaline Can Restart the Heart but is No Good for the Brain,” 4 September 2018, National Institute for Health Research.

Not Always a Good Thing

I can calmly watch a happy movie on television when an unexpected adrenaline surge triggers anxiety and fear followed by one or more MVPS symptoms. This happens in the absence of upset, fear, nervousness, or worry.

The incident cannot be traced to childhood memories or PTSD. No amount of therapy will stop such episodes, and an anxiety diagnosis followed by drug treatment will not find or address the unprovoked physiological event.

In a stressful situation, the extra adrenaline in my body can turn nervousness into anxiety which then can trigger a panic attack. Now that I understand that sequence, I no longer overreact, which helps calm everything down. More on this in Chapter 16: Breakthrough Treatments That Changed My Life.

Depression

Even though I have had IBS, migraines, and fibromyalgia symptoms, I resent depression being casually dropped into the mix. That inclusion discounts everything else I’ve experienced.

Depression can be caused by underlying health and physiological issues. (See: Mary Ann Block, *Just Because You’re Depressed Doesn’t Mean You Have Depression*, 28 April 2008.)

From my point of view and experience, when high levels of adrenaline run through my body causing anxiety and a host of MVPS symptoms, I don’t feel happy. During those times, if I feel down, blue or depressed, it is with good reason.

A diagnosis of depression paired with a prescription for an antidepressant won’t fix the cause of that feeling. Anyone living with the list of symptoms for fibromyalgia and MVPS has ample and normal reasons to feel down or depressed, especially during flare-ups.

Are the majority of people attending a funeral suffering from the symptoms of depression, or are they just naturally sad? Should everyone who experiences deep sadness take an antidepressant? I would prefer to experience this normal reaction to loss by relying on the natural process to grieve and then heal.

To me, adding an inaccurate psychiatric diagnosis of depression to my list of symptoms can allow a doctor to simply suggest I take an antidepressant—a class of drugs that carry significant risks and side effects. I prefer my doctors to help with the chronic MVPS symptoms that can sometimes cause me to feel depressed rather than simply prescribing a drug to mask the symptom of depression.

In my frame of reference, depression is natural. I may need to grieve for what I have lost in order to accept the loss, start over, and move forward. That philosophy has always worked for me.

Common Symptoms of Fibromyalgia

Those items bearing an asterisk are symptoms I experience with MVPS. The overlap of symptoms between fibromyalgia and MVPS is obvious.

- Pain and tender points*

- Fatigue*
- Sleep problems*
- Concentration and memory problems, known as “fibro fog”*
- Anxiety*
- Depression
- Morning stiffness*
- Numbness and tingling in hands, arms, feet, and legs*
- Headaches*
- Irritable bowel syndrome*
- Urinary problems*
- Sensitivity to cold or heat*
- Dizziness*
- Chest symptoms*
- Breathing problems*

Chronic Fatigue Syndrome, The Other Sister Syndrome

My personal research revealed articles and documentaries exposing the unfairness of the benign name “chronic fatigue syndrome,” and suggested what amounts to a conspiracy by medical professionals to discount the seriousness of the condition.

Only recently has chronic fatigue syndrome (CFS) been recognized as a real and serious problem, which is now also referred to as myalgic encephalomyelitis (ME). Accepted as more accurate to the underlying issue, the new name is not descriptive, however, of the more profound yet often discounted symptom of fatigue.

That doctors do not question the fatigue that often occurs with other health issues amazes me. Unrelenting fatigue can be indicative of some chronic underlying problem. (See: The Mayo Clinic staff article, “Symptoms: Fatigue”)

“Myalgic” means related to the nerves or nerve pain. “Encephalomyelitis” refers to inflammation of the brain and spinal cord, typically due to acute viral infection. Taken singularly or in combination, these words do not refer to little things.

To learn more, see the *New York Times* opinion piece (18 March 2017) by Julie Rehmeyer and David Tuller, “Getting It Wrong on Chronic Fatigue Syndrome.”

Those still living with this syndrome may derive some comfort from being validated after suffering the long-term perception that they are somehow malingering. That validation does not, however, relieve their symptoms or daily pain.

People with CFS/ME experience overwhelming fatigue that sleep or rest does not alleviate. They lack the energy for simple, everyday tasks like preparing a meal, showering, or dressing.

Anyone who has ever been knocked down by the flu can understand the feeling of being unable to function, but unlike the flu, CFS/ME fatigue does not resolve in a few days. Some CFS/ME sufferers become completely disabled.

Some of the more common symptoms in addition to the fatigue of CFS/ME include:

- Muscle and joint pain and aches
- Headaches
- Flu-like symptoms
- Digestive issues, like irritable bowel syndrome
- Chills and night sweats
- Allergies and sensitivities to foods, odors, chemicals, or noise

I have had all of these symptoms, but the occasional fatigue I feel is not as severe as those diagnosed with CFS/ME.

Other Markers for CFS/ME

I also have been tested and shown positive for the Epstein-Barr virus (EBV) and Lyme disease, both associated with CFS but not commonly connected to MVPS.

Epstein-Barr can cause mononucleosis or “mono,” and although it can resolve in a few weeks, EBV can sometimes become chronic. Initial symptoms include fatigue, headaches, fever, sore throat and swollen lymph nodes. In some cases, chronic fatigue and swollen glands and a general feeling of being unwell can persist for months to years.

Lyme disease is caused by a type of bacteria carried by deer ticks. An infected tick can transmit the bacteria through its bite. If treated early, the disease can be cured with antibiotics. Cases that go undetected can cause chronic symptoms involving the joints, heart, and nervous system.

(See: “Symptoms of Post-Treatment Lyme Disease Syndrome,” Healthline.)

Is CFS/ME the manifestation of EBV and Lyme disease, or does CFS/ME represent a complicating factor in an already confusing diagnosis? Either way, in my estimation, they each need to be treated.

The Underlying Condition

Comparing the similarities between MVPS, fibromyalgia, or CFS/ME reveals many overlapping symptoms. The distinction in names does not alter the fact that sufferers experience differing degrees of the same symptoms.

What if an underlying condition exists that causes these similarities in MVPS, fibromyalgia and CFS/ME? Could that common denominator cause the overlapping symptoms?

The MVPS Diagnosis:

Characteristic 3: A Syndrome Is Not a Disease.

The MVPS diagnosis helped me to research and learn more about this life-altering health problem and reassured me that I was not alone and dying. But I had to break out of the MVPS diagnosis to find better answers for one simple reason: MVPS is not a disease but a *syndrome*.

By definition, a “syndrome” lumps multiple unidentified symptoms together to form less of a diagnosis and more of a characterization. Inherently, this indicates no single cause or defined cure.

(See: “What Exactly Are Syndromes?” *Health: The University of Utah*.)

Disease vs. Syndrome

A disease, on the other hand, can be defined as a medical condition of the body that usually can be measured. High blood pressure would be a good example, unlike a headache which is a symptom that cannot be objectively quantified.

Symptoms are subjective. They are felt by the patient but can’t be seen. That is the case for all my MVPS symptoms. Even though I can feel them, no test can find the problem. It has been my experience that some doctors who cannot see the problem tend to discount the issue and label it a wastebasket diagnosis.

See: “Sign vs. Symptom,” *Medical News Today*.

A “Wastebasket” Diagnosis

According to The Free Dictionary, when a syndrome is referred to as a “garbage can” or “wastebasket” diagnosis, the inference is that the identification is not based on physiological proof and cannot be specifically described. Therefore, the thinking goes that the description is scientifically useless because it is too broadly inclusive.

I have heard the term used during my tenure working in the healthcare system. In my opinion, a wastebasket diagnosis can sometimes lead a doctor to assume an emotional root cause for a physical illness. I believe this to be evident when a patient receives a psychiatric diagnosis along

with a syndrome, such as depression or anxiety commonly associated with MVPS. Both chronic fatigue syndrome and fibromyalgia have been tagged as “wastebasket disorders.”

A report that focused on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), published in the *Health Care Women International*, “[Dismissing chronic illness: A qualitative analysis of negative healthcare experiences](#),” supports my premise.

The report states: “Our findings of this patient-focused study echo those of prior physician-focused researchers. Many participants reported being told their ME/CFS symptoms were the consequences of a psychological issue, with depression being the most frequent inappropriate attributed cause” supports my premise. In comparison to other chronic problems, little information appears online about MVPS. However, most of my symptoms are listed as a wastebasket diagnosis. [These include irritable bowel syndrome, interstitial cystitis, costochondritis and gastroesophageal reflux.](#)

To make the situation worse, many doctors I have known believe that other healthcare professionals who tried to help me with my “syndrome” were “quacks.” Because those doctors had nothing to offer me, they seemed to believe that no other physicians could have answers and were therefore worthy of criticism for trying.

One doctor I consulted was adamant that I should not go on the Candida diet that one of my more helpful physicians recommended to treat my chronic yeast infections. The diet reduces foods that cause fungus growth, including gluten, sugar, alcohol products, and some dairy products but includes protein, healthful fats, vegetables, and probiotics. The objecting doctor told me he didn’t want me to waste my time on an unproven treatment. How thoughtful. He didn’t change my mind, and as it turns out, the diet helped. Perhaps the actual time I wasted was spent in his office.

Selling a Syndrome

Validation of a syndrome seems to carry greater benefit for drug companies than for patients like me. Once named, a syndrome can become the focus of numerous drugs recommended for symptom control.

But I cannot stress often enough that, to me, a symptom is only a clue, not a disease. Remember that it was only after a drug company validated MVPS that a cardiologist who had previously discounted my condition changed his mind and attempted to give me a drug to ease my symptoms.

No thanks.

Drug companies referred to as “malady” or “disease” mongers are not above making up findings to increase sales, a problem discussed by John LaMattina in his *Forbes* article, “There Go Those Drug Companies Inventing New Diseases Again.”

I have found no reports that any scientist has ever discovered the origin of MVPS along with an effective treatment. This leads me to wonder if some creative people working at a drug company made up a new condition by adding an “S” to the MVP diagnosis and then offered a boatload of drugs to treat the condition.

How did MVP become MVPS? I have not found an answer to that question. For that matter, how did I end up with MVP in the first place? Some doctors hear the click; others don’t. Some echocardiograms have shown the valve flopping, but the two most recent ones did not.

If these negative findings are correct and I don’t have MVP, then how can it be a marker for MVPS? It seems to me that I could as easily be diagnosed with either of the two sister syndromes, fibromyalgia and chronic fatigue syndrome/myalgic encephalomyelitis.

The name of the diagnosis doesn’t appear to change anything for me. MVPS, fibromyalgia, and CFS/MW are all chronic conditions with no cure and similar symptoms.

I am far more interested in the underlying cause of the symptoms than the name of the condition or syndrome.

The Benefits of Letting Go of the MVP Diagnosis

Maybe I don’t have MVP. My cardiologist and updated medical information have both indicated to me that the diagnosis was faulty and based on old, flawed technology that caused many false positives.

The new technology offers greater accuracy, according to my doctor. The most recent echocardiograms did not show mitral valve prolapse at all. My valve closes perfectly, and my heart is strong.

Dr. Judith Reichman from the *Today Show* reported the following in a January 2005 article:

“Improved tests, however, have led cardiologists to the conclusion that the mitral valve has normal variations and that a ‘whoosh’ or a ‘click’ does not necessarily mean a heart condition.” (See: “Too Much Noise About This Heart Murmur?”) So I ask again; if I don’t have MVP, then how can I have MVPS?

I cannot resolve the contradictory explanation that people can have one without the other. My questions don’t stop there. If the first diagnosis of MVP was false, why do physicians keep building on it? How can there ever be an effective treatment for the problem when medical science cannot explain what condition I actually have? Adding more erroneous disorders to the name does not clarify the problem for me. Why can’t the medical professionals whose aid I seek change my diagnosis to reflect the actual problem?

By letting go of the name and all the treatments associated with it, my action plan became more effective—and continues to improve as I dig deeper and deeper to find the primary cause.

This is what I found. All roads lead me to the diagnosis of an instability in the autonomic nervous system. That explanation makes sense to me and addresses everything I have experienced so far and brings me light years away from that first dubious diagnosis of Mitral Valve Prolapse.

The word “dysautonomia” was added to the original MVPS diagnosis for just this reason. Though helpful, that addition did not provide answers to all my questions, but it has been a good point of focus for my action plan.

The MVPS Diagnosis:
Characteristic 4: Dysautonomia

I originally thought the list of MVPS symptoms could be used as a guide to help me find my actual diagnosis. But then a new theory emerged that an instability of the autonomic nervous system (ANS), not a problem with the heart, caused my wide array of MVPS symptoms. Later statistics showed that there was a subset of patients with mitral valve prolapse who also had autonomic dysfunction and that MVP was a marker for that disorder. Patients in this group, like me, were given an updated diagnosis of “MVPS with Dysautonomia.” But what if MVPS is a subset of dysautonomia? Calling my problem “MVPS-Dysautonomia” would seem to dilute the actual problem when it is the dysautonomia that should be the focus. When I mentally dropped the MVPS diagnosis, the dysautonomia did begin to make sense, but not completely.

Dysautonomia

The autonomic nervous system (ANS) regulates involuntary functions such as heartbeat, pulse rate, blood pressure, breathing, digestion and the urinary system. Dysautonomia is a disorder that occurs when the ANS doesn't work properly, causing such symptoms as those listed below. (Note the similarity to MVPS symptoms.)

- Migraine headaches
- Spacey or dizzy feeling
- Vertigo
- Insomnia
- Hyperventilation
- Skipped or irregular heartbeats
- Raised blood pressure
- Panic attacks
- Chest pain
- Shaking or startled feeling

- Cold hands and feet
- Numbness and tingling
- Bowel and bladder problems
- Irritable bowel syndrome (IBS)
- Exercise intolerance
- Excessive sweating or not being able to sweat
- Fatigue
- Vision problems (blurred vision, vision loss, tunnel vision)
- Chronic fatigue syndrome (CFS)
- Syncope (fainting)
- Postural orthostatic tachycardia syndrome (POTS)
- Fibromyalgia

The Fight-or-Flight Response

When a person faces danger or feels fear, the body releases adrenaline to provoke the “fight-or-flight” reaction. This helps protect us and aids in survival. In the absence of any life-threatening event, the release of adrenaline often triggers my MVPS symptoms.

I have been told my anxiety triggers the adrenaline, but what if it’s the reverse? What if the adrenaline is the precipitating agent that causes my anxiety and triggers the fight-or-flight response? This feels accurate. Often nothing I am doing or feeling would cause a surge in the hormone. Symptoms hit me out of the blue like a bolt of lightning. There has to be another cause for my adrenaline release.

The ANS controls our sense of well-being and can quickly change our mood from calm to panicked. If this is the case, then I am a victim of my own chemistry or, more specifically, the dysfunction of my ANS.

Two Sides of the ANS Response

The release of adrenaline from the sympathetic nervous system to help the body survive an attack has been described as being like revving a car motor or hitting the gas.

However, the ANS also includes opposing sets of nerves called the parasympathetic nervous system (PNS). Comparable to applying a car’s brakes, the “rest and digest” PNS can, among other things, slow heart rate—something I can certainly appreciate.

(See: Phillip Low, MD, “Overview of the Autonomic Nervous System,” *Merck Manual, Consumer Version.*)

Finding a way to calm the ANS rather than focusing on my heart and MVP seemed to be a better avenue for helpful answers, a topic I will discuss in greater detail later in this book. For now, I will say that I have never been diagnosed with dysautonomia even though I have all the symptoms. Most doctors I have seen have never acknowledged that I had MVPS much less MVPS with dysautonomia.

In his June 15, 2013, article, “Mitral Valve Prolapse – Part 6 – Getting To The Bottom Of It,” (MyHeart.net), Dr. Mustafa Ahmed explains that the overdiagnosis of MVP in the early days led to the consequence of adding multiple symptoms and findings to that diagnosis. Ahmed, the director of Structural Heart Disease at The University of Alabama in Birmingham, goes on to say, “Later many realized they in fact had a condition known as dysautonomia.”

His opinion appears to be supported by H. Boudoulas and C.F. Wooley’s findings in their February 29, 1988, research report, “Mitral Valve Prolapse Syndrome. Evidence of Hyperadrenergic State.” (*National Library of Medicine*)

The report states, “The term ‘MVP syndrome’ (MVPS) is used to refer to symptoms due to neuroendocrine or autonomic dysfunction that occurs in patients with MVP and that cannot be explained on the basis of valvular abnormality alone.”

Additionally, the researchers found that patients with MVPS showed increased levels of epinephrine (adrenaline) in urine and exhibited hyper-reactions to adrenergic stimulation such as fear.

The MVPS Diagnosis

I can understand the need to cling to the MVPS diagnosis. I feel that need, too. Nothing else seems to be generally accepted as the cause of my symptoms even if the condition is neither accepted nor well understood.

Having a diagnosis still gives me a jumping-off point to discuss my problems and look for answers. Also, I’m not sure that letting go of the MVPS diagnosis to investigate dysautonomia would be helpful as there may be a profound problem with that alternate diagnosis.

The Dysautonomia Diagnosis

In researching ANS dysfunction, I understood why no conventional doctor has treated me for dysautonomia. The current conventional thinking runs like this:

- Dysautonomia cannot be cured.
- Secondary dysautonomia will resolve when the cause is treated.

- MVPS is not considered to be one of those causes.

Doctors do not generally believe that primary dysautonomia exists except when inherited or due to a degenerative disease— which MVPS is not. That leaves me with my original diagnosis and no option for dysautonomia-specific treatment.

I have only come close to having my autonomic nervous system evaluated once. I made an appointment with a new conventional cardiologist. He was concerned with my volatile blood pressure and other adrenal complaints.

A kidney tumor, commonly a cause of dysautonomia, would have explained my symptoms. When that test proved negative, however, the doctor completely ignored the dysfunction that alarmed him originally. I was on my own again.

In retrospect, I may have dodged a bullet. Being an outlier on the dysautonomia spectrum and not accepted by conventional medicine has protected me. Had I been diagnosed, I could have been offered potentially dangerous prescriptions used for patients who do meet the standard for treatment.

One of the drugs I researched carried a “Black Box Warning,” the strictest required by the FDA when reasonable evidence exists to associate the medication with a serious hazard. All the drugs used for dysautonomia, however, come with consequential side effects.

Some of the medications used include:

- Antianxiety drugs
- Antidepressants
- Beta blockers
- Drugs that affect motor impulses
- Anti-inflammatories
- Steroids

With no cure for ANS dysfunction, these drugs could be used in combination for a lifetime to cover multiple symptoms to manage the disorder. To me, that approach seems to be similar to the drug protocol used for MVPS patients. That method exposes the patient to long-term side effects from each drug as well as potential interactions.

People with chronic, progressive, generalized dysautonomia, a condition that is recognized by conventional medicine, are considered to have a poor long-term prognosis. Death can occur from complications.

I understand that my symptoms are not as severe as people who are diagnosed by conventional medicine with dysautonomia, but why would medicine overlook other people with a milder form of ANS dysfunction? Why is it all or nothing? Many disorders are assessed on a spectrum from mild to severe.

Given the absence of a cure and the potential for serious drug risks, I feel that I am better off not being diagnosed with even a mild form of dysautonomia.

Using the MVPS/Dysautonomia Diagnosis

Even though I feel sure my symptoms result from a dysfunction of the ANS, I use the name MVPS/Dysautonomia for its familiarity. When looking for answers, however, I am not committed to that diagnosis. While serving as a definition and ultimately validation for my problem, the term has not produced a recovery treatment. Today, I focus on the ANS to open doors to better answers.

Lifestyle changes like yoga, exercise, and the elimination of stimulants such as coffee are helpful in calming the ANS. They do not, however, treat the underlying cause of the disorder. My action plan goes deeper than useful lifestyle changes.

When a mold exposure triggered all my MVPS symptoms and caused frightening new ones, conventional medicine offered no help. Instead, I discovered a nonmedical program that taught me to take my body from a state of panic and survival to one of repair and healing. The method gave me back my life. I felt like Dorothy in the *Wizard of Oz*. When I clicked my heels, I discovered the answer had been inside me all along. (More on this in Chapter 16, Breakthrough Treatments That Changed My Life.)

The MVPS Diagnosis:

Characteristic 5: Neuroplasticity and the Autonomic Nervous System

Traditionally seen as static and unchanging, it is now known that the brain adapts to new information and circumstances even after a person reaches maturity. “Brain plasticity,” sometimes referred to as rewiring the brain with new neural pathways and connections, occurs when we learn new skills like using a new software package, or learning how to ski or new dance steps.

Neuroplasticity can also be used to reestablish lost abilities. New pathways can be created to bypass old or damaged ones, for instance relearning how to use an arm or a hand in the aftermath of a stroke.

(See: Dr. Pascale Michelon, “Brain Plasticity: How Learning Changes Your Brain,” *Sharp Brains*, 26 February 2008.)

How Brain Wiring Can Affect MVPS/Dysautonomia Symptoms

The brain continuously learns new things and changes to adapt to new experiences. Habitual experiences reinforce performance like an athlete’s ongoing training to improve his or her abilities.

Like driving a car, any repetitive action becomes ingrained until it can be accomplished without conscious thought. I can drive home every day from work, often arriving with no memory of the familiar route I used. With an understanding of that autopilot function, I asked myself if my fear reaction to chest pains had become ingrained in my brain in a similar way?

(See: Jessica Hamzelou, “Your Autopilot Mode is Real - Now We Know How the Brain Does It,” *New Scientist*, 23 October 2017.)

This Is How the Theory Works

The experience of something new or scary like chest pain is sent to a portion of the brain called the amygdala. This “lizard brain” interprets the information without higher thinking. Only survival instincts are at work.

The amygdala quickly sends a distress signal to the hypothalamus, which sends impulses through the autonomic nerves to the adrenal glands. Consequently, adrenaline, the chemical signaling danger, pumps through the bloodstream.

The next time the situation occurs, the brain automatically signals danger and even more rapidly initiates the same process as a means of protection. When that sequence happens in response to my chest pain, it can immediately put me into a full-blown panic.

Am I reacting to the chest pain, or has it been such a common occurrence that my brain is doing it for me? Could I break the cycle by teaching my brain a new reaction? After some work, I discovered the answer to be a definitive “yes.”

(For more information on the amygdala, see: “The Amygdala,” *The Science of Psychotherapy*, 21 May 2014, and James Sullivan; “Know Your Brain: The Amygdala — Unlocking the Reptilian Brain,” *Brain World Magazine*, 19 April 2019.)

<https://brainworldmagazine.com/know-your-brain-the-amygdala-unlocking-the-reptilian-brain/>

New and dynamic programs based on neuroplasticity have taught me effective methods to rewire or train my brain. I can now stop scary reactions to inaccurate past information. (I will discuss this topic at length in Chapter 16.)