

# My Action Plan For Stopping the Symptoms of

## MITRAL VALVE PROLAPSE SYNDROME DYSAUTONOMIA

Including the Overlapping Symptoms of  
POTS, Fibromyalgia and  
Chronic Fatigue Syndrome/ME

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***Without*** Cardiac or Psychiatric Drugs

***Without*** Multiple Trips to the ER

***Without*** Fear and Anxiety

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Healthcare System Administrator  
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My Action Plan  
For Stopping the Symptoms Of  
Mitral Valve Prolapse Syndrome-Dysautonomia

By

Joan Anderson

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The author and publisher are not providing or recommending medical, psychological or any other kind of personal, professional services in this book and expressly disclaim all responsibility for any injury, damage, negative consequences or loss that the reader may incur as a consequence of following the information detailed in this book.

Instead, this book explains how, with the help of many healthcare professionals and extensive research, the author developed her action plan. The content is solely the opinion of the author as it pertains to her own personal medical and health needs.

This book is designed to explain the processes and methods used to research and learn about the author's personal health issues. The information contained in this or any other documents should not be construed as a claim or representation that any procedure or product mentioned, including supplements and homeopathic remedies, constitutes a specific treatment or cure, palliative, or ameliorative for any condition.

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Before making any decisions based on the information found in this book, a person should first check with his or her physician. To protect the identities of the people whose actions or stories appear in this book, no names have been used, and in some cases, the author created composites.

Some of the information in the book is based on, to the best of the author's recall, discussions with doctors and other people with MVPS or writings of other people with MVPS as well as on her research notes and experiences. Conclusions regarding all this information, which may be noted in this book, are based on the author's personal opinion as it relates to her situation specifically and her health and medical issues.

The author is not a doctor. She is a person who was diagnosed with Mitral Valve Prolapse. The information in this book is intended to share her treatment experiences, her opinions and research methods and how MVPS has affected her. In a medical emergency, call 911 immediately.



Mother and Me

This book is dedicated to my mother  
who suffered all her life with the many symptoms of  
Mitral Valve Prolapse Syndrome but was never diagnosed.  
I did not know. I did not understand. Now I do.

## **Author's Note**

The author has no underlying structural or functional problems with her heart. She was diagnosed with Mitral Valve Prolapse when a physician listened to her heart and noted a benign click as the mitral valve closed. The author has what is called Mitral Valve Prolapse Syndrome—Dysautonomia, a problem with the autonomic nervous system and not the heart.

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Author of *Panic Free*,

*The 10-Day Program to End Panic, Anxiety, and Claustrophobia*

And Founder of The Soar Program for Nervous Flyers

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## **Breaking the MVPS Symptom Code**

My MVPS symptoms mimic serious health problems leaving me confused because I do not know what they mean. It feels like they are sending me messages about my health in a foreign language. This breakdown in communications complicated everything.

I was running from doctor to doctor and often to the emergency room looking to experts to interpret these confusing and scary symptoms. I wanted them to tell me I was okay or provide necessary medical attention if needed. That useless pursuit was only helpful for that specific event leaving to me to deal with the next ambiguous symptom on my own.

I knew I had to learn how to better understand my body's signals. I searched for information, interventions and tools I could use at home to help me assess my symptoms, make sound decisions and stop worrying.

Getting a better understanding of my body's language helped me target the actual problem and to determine when and where to seek a medical consultation. Understanding my body was paramount to finding answers and taking positive action.

## **The Author's MVPS Medical History**

### **I Have Walked in Your Shoes**

*Duh-duh-dum!* My experience with MVPS began with a rapid, but mild flutter in my chest and has since taken me to the gates of hell. A few minutes after that first faint sensation, the flutter happened again. I sat up in bed and the feeling stopped. The next night when I laid down, the same thing occurred.

I wasn't particularly worried about these gentle flutters but I had never felt them before. I mentioned the sensation to my doctor on my next visit. I was 31 years old and in good health. The flutters had become an almost nightly occurrence. I would lie down, and then the fluttering would start. I would sit up and the feeling stopped.

The doctor listened to my heart and found nothing wrong. He surmised that the accumulation of caffeine in my system from four daily cups of coffee was responsible for the flutters. The quiet of night made the sensations more noticeable. That made sense. I eliminated coffee from my diet, but the flutters continued.

Every time I saw a doctor, whether for my well-woman examination or for a cold or flu, I mentioned the fluttering. Each time the doctor listened to my heart and heard nothing. My heartbeat was strong and normal. But I had nagging questions. If the flutters were nothing, why wouldn't they go away? If the sensation was normal, why hadn't I felt it throughout my life?

### **Finding a Specialist**

An internist, who had been my doctor several years earlier, closed his general practice to specialize in cardiology. I made an appointment with him. As I drove to his office, I began to have doubts. I felt great and hadn't felt any fluttering in days.

I checked in with the receptionist and looked around the waiting room. I was a 31-year-old, healthy woman in a room filled with extremely sick older people. My doubts grew. Did I really need to see a cardiologist? I did not know that this was only the beginning of a lifetime of doubts and confusion revolving around my Mitral Valve Prolapse Symptoms.

### **The First Diagnosis**

Surprisingly, the doctor took me seriously at a time when heart disease was considered a problem for men, not women. After asking me a round of typical cardiac questions, he pulled out his stethoscope and listened to my chest. He took his time. No one else had listened to my heart that carefully. He asked me to stand up and slowly squat down and stand back up again while he listened. I did this several times while his stethoscope moved across my chest and then my back.

"I heard a click," he said. "You have Mitral Valve Prolapse." I had never heard of the condition before. I was relieved when he told me that the relatively benign disorder did not require medical treatment except a course of antibiotics before dental and surgical procedures as a precaution against the low risk of an infection in the heart called endocarditis.

He told me that he was seeing more people with MVP but that most had no symptoms. Then he scheduled an echocardiogram that confirmed his opinion. My valve was billowing but closing completely and there was no regurgitation or blood backing up.

## **Fifteen Years Later**

That mild and innocuous fluttering that my doctor said was no cause for concern, would 15 years later, usher in an array of frightening symptoms. They terrorized my body, attacked my spirit, dictated my life choices and sent me to the doctor more times than I could count—and to the hospital on more than one occasion.

No one told me about the “*syndrome*.” I didn’t even know I had it until, without warning, a sledgehammer hit me that, at times, literally took my breath away.

## **The Symptoms Begin With a Vengeance**

During one of the happiest and healthiest periods of my life, MVPS insidiously reared its head. I was working as an administrator for a hospital health system. I loved my job and was enjoying a high level of professional success. Then one day, while reading the newspaper, I noticed my right arm, which I was using to hold one side of the paper open, was tingling and feeling weak.

I put down the paper and rested my arm but the weird feeling remained. I decided to go to the clinic to see my doctor who ordered a head CAT (CT) scan to determine if there was any brain damage indicating a stroke. I was fine and was told that I was having a migraine aura headache.

Then one night, out of the blue, intense chest pain awakened me. A few seconds passed before I could even comprehend what I felt. It was an incredibly stressful time for me. There were extra pressures at work and home, but I knew I shouldn’t ignore chest pain.

I went to the emergency room at the hospital where I worked. They took good care of me and ran tests to rule out a cardiac event. The diagnosis pointed to upper stomach issues as the cause of the pain. I went home relieved.

After that I started having nagging low back pain that intensified until I couldn’t even lift my purse. Muscle relaxants and pain pills didn’t help. The problem evolved into sciatic nerve pain. I couldn’t walk more than a few steps without excruciating pain.

I had never been so incapacitated. Diagnosed with a bulging disk, I spent more than a month in bed. Just as surgery was looking inevitable, acupuncture put me back on my feet.

Not long afterward, I had minor surgery that, because of a small complication, sent me back into the operating room only hours later. The double anesthetic and surgery took a tremendous toll that delayed my recovery. Later I realized this incident along with my back problem had aggravated my MVPS symptoms.

## **The Stress Test Debacle**

Before my surgery, I took a stress test because I was having mild, occasional chest pain. The test results showed a false positive. The electrical readings from the EKG indicated a significant arterial blockage. When the doctor stopped the treadmill and told me, fear shot through me.

I was quickly laid on the exam table for an echocardiogram. The doctor watched the monitor to see if my blood flow was indeed impaired. I waited, still hooked up to the EKG leads. I was breathless, panting from the fear and from my workout on the treadmill.

Moments later the cardiologist casually said, “No, you’re fine. The echocardiogram shows a normal flow. It was a false positive. You’re perfectly fine to undergo surgery.”

I also had a false positive on two other occasions that left me doubting the validity of the stress test. How could I trust the results either way? My doctor told me that a false positive still leaves a 15-20% error rate. That means that there is still a 15-20% chance that the stress test is correct and a problem does exist.

So, which is right? Since I consistently had false-positive stress tests and I was having mild chest pains, a dark cloud of doubt hovered over me. I decided I would never do a stress test without an accompanying echocardiogram to confirm the results.

### **More Chest Pains**

I was glad to know my heart was stable and strong during both my surgeries, but that bit of comfort didn’t last long. Only six weeks later, the chest pain returned with greater force. I rushed to the hospital where I worked. After running all the typical cardiac tests, the doctors diagnosed acid indigestion again and sent me home.

Tired but relieved, I went to work the next day only to be called by the head of the emergency medicine department that afternoon. All EKGs administered in the ER are routinely reviewed by other doctors. The physician who went over my EKG saw some irregularities and recommended that I follow up with my cardiologist. Panicked, I called the office and was told I could come right in.

The cardiologist’s office was across the street from mine so I was there in minutes. He ran another EKG that was also irregular. Although he did not think the results indicated a serious problem, he told me that the only way to be sure was to do a cardiac catheterization.

During the procedure, a thin tube is inserted in an artery or vein and threaded through the blood vessels to the heart. This allows the doctor to find and sometimes treat any problems. The cardiologist sent me home to consider that option.

### **The Cardiac Catheterization**

The choice wasn’t an easy one. I didn’t want to do a cardiac catheterization, but since the chest pains continued, not knowing wasn’t a risk I wanted to take either. The luxury of choice became irrelevant, however, when, several days later, I awakened in the middle of the night with another round of intense pain.

I went to the emergency room again and was admitted. After much discussion, I agreed to undergo the cardiac catheterization which was performed that day. Although heavily sedated, I was awake throughout the entire procedure.

After what seemed like only minutes, the doctor told me that I was okay. There were no blockages. I left the hospital relieved but feeling battered from all the procedures. I felt emotionally and physically drained. It was an omen of what was to come.

## **MVPS Gets Nasty**

Over the next few months, MVPS took over my life and my health. One symptom after another pounded my body leaving me terrified and bewildered. On any given day, I had one or more symptoms: migraines, dizziness, IBS flare-ups, reactions to food sensitivities, anxiety, hot flashes, arrhythmias and sensitivities to chemicals and fragrances. I was a mess and scared all the time.

I knew I had to do something to pull myself together or I would continue in a downward spiral. The cardiologist offered to give me a prescription for a beta-blocker and an anti-anxiety drug. I declined and instead began a journey to find better answers on my own. Even when I felt too sick to work, I still forged forward, determined to regain control.

## **Diagnosing Myself**

Researching a health issue was a natural path for me. I have worked in various areas of the healthcare field for most of my professional life. I was sure I could find effective treatments for my condition. But first, I had to find out what was wrong with me.

I left the hospital without a helpful diagnosis but with a basic clean bill of health. I also had a feeling of being somewhat patronized. This would later turn into outright disdain from one of the doctors I saw in the clinic.

Fortunately, the Internet was coming into its own with lots of information available so I didn't have to spend hours at the medical library. I began my search at home.

My inquiries regarding my symptoms led me to several MVPS sites. I was surprised. I didn't know that MVP could cause so many problems. But it was still a relief to know it was nothing more serious, even if it was an alarming departure from my past experiences with this disorder.

## **Finding a Treatment/Finding a Doctor—The Journey Begins**

I spent hours on the Internet reading everything I could find, including bulletin board postings from symptomatic patients whose experiences equaled or exceeded mine. They were not dying, but they were not living well either. Almost all the postings I read were from people taking prescription drugs daily to try to control their symptoms.

These drugs included beta-blockers, antidepressants, anti-anxiety medications, or a combination of them all. It did not appear that the people taking drugs who posted online were finding relief. When I studied the drugs and potential side effects, I learned that the medications were not necessarily a panacea for MVPS but instead could cause some of the same symptoms as MVPS or new symptoms.

In light of my past problems tolerating drugs, the risk wasn't worth it. Delaying or refusing cardiac or psychiatric drugs would not cause irreparable damage to me. MVPS is not considered life-threatening. These facts affirmed my decision to seek a non-drug route for symptom relief.

Today, I am significantly better. My health has noticeably improved and for the most part, my symptoms are under control or gone. If a problem should occur, I have the tools to deal with it quickly and



effectively. As a result, I am not at the mercy of MVPS symptoms. I am not living in fear or running to the ER. I am learning new information all the time that is helping me continue to improve.

This book began as treatment research notes. I wanted to be able to refer to the pertinent information I had found during a flare-up. Now that I have compiled my notes into a book with my memories, experiences and professional input, this volume serves as my action plan to remind me of the treatments I have found that have been helpful to me.

My Action Plan  
Stopping the Symptoms Of  
Mitral Valve Prolapse Syndrome-Dysautonomia

Without Cardiac or Psychiatric Drugs  
Without Multiple Trips to the ER  
Without Fear and Anxiety

By  
Joan Anderson

An Award-Winning Medical Reporter  
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Mitral Valve Prolapse Syndrome Patient

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