

## **Pillars of Treatment for CVS: What Patients Have Taught Me.**

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What is the proper treatment of CVS? It would be a mistake at this point in time to think of treatment only in terms of finding *the* curative drug. Effective medications are as important as any other aspect of management, but CVS is much more complex than, for example, appendicitis. Appendicitis has a brief course and a rapid cure; patients don't feel anxious or out-of-control of that illness for very long. One doctor's visit usually suffices to solve the problem. But CVS isn't like that. I've yet to meet the CVS patient who received the correct diagnosis, let alone the solution to their problem, during their first visit to a doctor. The physical pain and suffering of CVS may be as bad or worse than that of appendicitis. Nevertheless, CVS patients experience months, years or decades of no answers and no "fix."

Another difference between CVS and appendicitis has to do with the effects caused by the stress of each illness. Stress doesn't have much to do with the cause of appendicitis and relief of the emotional stress doesn't help much. Surgical removal is what it takes. By contrast, CVS causes many patients persistent, often overwhelming stress. The first visit to a doctor may not yield a correct diagnosis. There are no blood tests, x-rays or findings on physical examination that are markers for CVS. CVS, like migraine headache, is a "functional disorder", i.e. one in which normal organs *function* in a way that cause symptoms - symptoms that may be as bad or worse than those of organic disease. Therefore, the capability of a doctor to diagnose a functional disorder depends upon his/her clinical experience with patients having that disorder. Doctors who are good at diagnosing CVS have taken histories from many CVS patients and have learned its characteristic clinical patterns – what patients experience and how they try to cope. A key goal of CVSA has been to get the word out to clinicians and to the public that CVS exists and has identifiable features, that it is not "rare," that it affects individuals of all ages (infants to elderly), and that it can be managed successfully.

Unlike patients with acute appendicitis, CVS patients develop worry and anxiety about their illness, its unpredictability, its misery, its power to disrupt lives and deplete families. We know from the work of Yvette Tache, Ph.D. UCLA, and other scientists working in the area of mind-brain-gut physiology, as well as natural scientists dating back to the early 19<sup>th</sup> century and before – that emotional stress isn't just spiritual or metaphysical. Anxiety, such as the feeling of having a devastating illness that no one understands or can help, causes the release of stress hormones that stop the stomach from working normally and cause nausea. Thus, feeling out-of-control of CVS makes CVS worse.

What are the signs that an individual's CVS is becoming worse? And what process causes deterioration? The worsening of CVS is signalled by the emergence of a coalescent pattern of attacks. For example, a patient who might have had 3-day episodes a few times a year begins having them every month or two, then every few weeks. At worst, complete coalescence occurs and patients may have nausea, vomiting and other

awful symptoms for a week or weeks at a time and be sick more than they are well. Fiona McDonald, Ph.D. Genetics, medical author and CVS patient, observed that the onset of nausea can become a conditioned reflex. The more one suffers during attacks, the more one becomes anxious and depressed at the prospect of another attack. This emotional burden is accompanied by changes in normal brain chemistry that lower the threshold for nausea. Such unavoidable dread becomes self-fulfilling as the next episode sets in. The more scary the prospect of another episode, the more out-of-control one feels and the more likely its onset becomes.

Another way that anxiousness contributes to coalescence of episodes is how it affects stomach function *between* episodes. Most of us have experienced “butterflies in the stomach” when we’re nervous. This is an everyday example of how stress alters how the stomach functions. About 20% of healthy people experience functional gastrointestinal symptoms. One of the commonest functional GI symptoms is called “dyspepsia.” It’s felt in the upper abdomen as an uncomfortable fullness, tight feeling, ache and/or burning. Many dyspeptic individuals wake up in the morning with upper abdominal discomfort and nausea. They may or may not vomit, but if they do, it has nowhere near the intensity of the nausea and vomiting of a CVS attack. They usually skip breakfast, manage to go to work or school and feel better later in the day. Dyspepsia is induced by stress. As CVS patients become increasingly stressed, many develop dyspeptic nausea between episodes. This stresses them even more, to the extent that the distinction between inter-episodic wellness and vomiting attacks becomes blurred. They feel more or less sick all the time.

So, does management of CVS merely amount to “finding the right pill” or combination of pills? I think not. The patient with CVS is not merely “a vessel of disease.” What’s important isn’t just the malfunction of his or her brain and GI tract. The human being who is doing the suffering needs to be taken into account. Just as getting worse is driven by hopelessness and dread, so getting better can be driven by hopefulness and realistic optimism.

At our current state of knowledge, it’s unlikely that any two doctors have the same approach to the management of CVS. It has as yet no “standard treatment.” Treatment must be individualized to the patient and “fine-tuned” over time. Nevertheless, my experience with more than 320 CVS patients of all ages has taught me that management must be sensitive to the patient as a thinking, feeling human being with a life history.

I believe that optimal management must include five elements:

- 1) A knowledgeable **physician** who is caring, patient, accessible and responsive. Encounters with doctors who are unfamiliar with CVS or who don’t believe it exists, or who make implausible diagnoses (“the flu” for the 6<sup>th</sup> time this year!), or who subject the patient to repetitive diagnostic tests that lead nowhere, or who administer IV fluids then send the patient home still sick, or who don’t offer continuity of care, or who are too easily defeated by failure – add to all this the experience of having to wait for hours to receive at least some relief. You have a situation that creates more anxiety and despair and the development of coalescent patterns of episodes.

2) **Medications** that work; there are many.

3) A **rational plan** for deployment of effective medications based on the triggering and predisposing factors in each patient's case; along with consideration of which of the 4 phases of CVS the patient is in at the time care is sought. (My *Empiric Guidelines for the management of CVS* is accessible on my website, [www.ch.missouri.edu/fleisher](http://www.ch.missouri.edu/fleisher) . Also, official treatment guidelines developed by Dr. B Li and colleagues will soon be published by the North American Society of Pediatric Gastroenterology & Nutrition.)

4) **Promptness.** Some illnesses, such as eczema, colds or colitis, usually don't present as emergencies. The patient can be seen the next day or the next week. Other illnesses can have disastrous outcomes if attention to the patient's pain and fear is put off. Make a heart patient, whose chest pain is causing him to panic, wait 4 hours to be seen, and the likelihood of a fatal arrhythmia increases. Treatment of a CVS episode must be prompt and patient-centred (what the patient needs, when the patient needs it). A cyclic vomiting attack may be a different kind of emergency to that of a heart attack, but Emergency Department personnel need to know that the need for prompt care is the same in both cases. I know of cases in which patients became so fed-up by their experiences in Emergency Departments that they refused to go back when they really needed to, causing serious and, in at least one case, catastrophic results.

5) An "**escape mechanism**": Management must include a fall-back method for relieving a patient during an episodes that couldn't be prevented, aborted or terminated. A patient in this condition needs a way to escape from misery until the episode blows over. Inescapable agony conditions fear of the next episode which, in turn, predisposes to nausea and results in coalescence rather than less frequent, shorter, easier-to-manage attacks. Deep sleep makes cyclic vomiting cease. It also makes the patient insensitive to nausea and the other miseries of the emetic phase. After prompt correction of the patient's dehydration, I try to terminate nausea, pain and anxiousness with IV medications. If I don't succeed, I continue maintenance IV fluids and keep the patient deeply asleep and undisturbed until the episode runs its course. When patients feel they can rely on getting prompt relief, coalescent trends abate and they gain a sense of being in-control of their illness instead of its helpless victim. That's when recovery begins.