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International Foundation for Gastrointestinal Disorders (www.iffgd.org)

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What is Cyclic Vomiting Syndrome (CVS)

CVS is a chronic disease marked by severe, recurrent episodes of nausea and vomiting in a person who is otherwise healthy. CVS episodes often flip-flop with states of wellness. Vomiting may occur every 5-10 minutes for several hours during an episode. On average, CVS episodes last 3-7 days but vary with each person.¹ An episode may be accompanied by stomach pain, tiredness, sensitivity to light, and/or headaches. Episodes may begin at any time of the day, but often start in the middle of the night or early morning hours. They may be triggered by positive ‘stress’ (vacations) or negative stress (job loss).²

Many patients have a long history of symptoms and frequent emergency department (ED) visits and hospitalizations.³ A clear diagnosis may have been difficult to obtain which can be frustrating! Therefore, we are providing you with information to help you better understand the disease, best manage your symptoms and improve overall well-being.

Phases of CVS

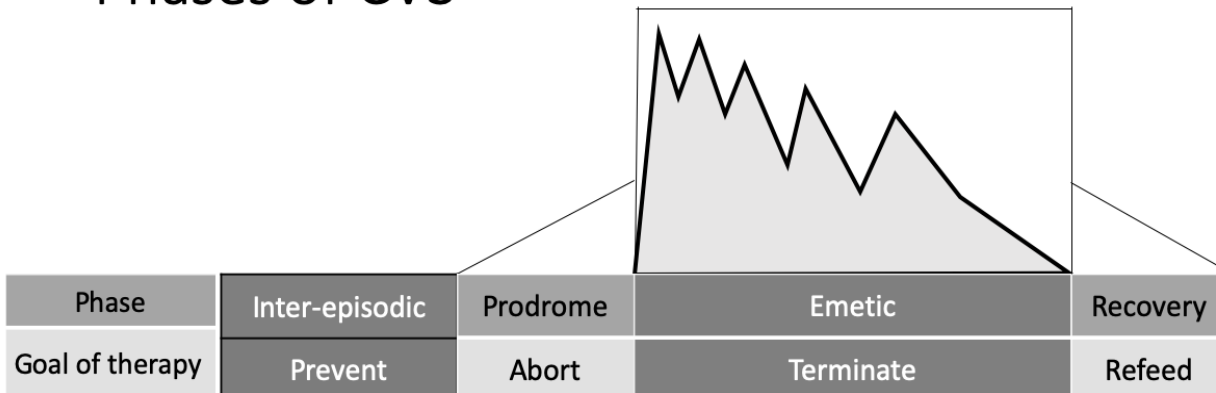
CVS consists of four phases as shown below

What causes CVS?

The specific cause of CVS is unknown but both genetics and environmental factors likely play a role.⁴ While some genetic mutations have been associated with CVS in children, whether or not these actually cause symptoms is unclear. A system called the endocannabinoid system has also been shown to affect CVS. Our bodies produce substances that are similar to those in cannabis which are helpful in combating stress and preventing nausea and vomiting. Problems in this system may be one reason patients develop CVS.⁵ Also, studies of the brain using MRI (a type of scan that uses magnetic radiation) show that patients with CVS respond differently to stress. *In summary, though CVS is a disorder of the gut, the center for vomiting is in the brain and abnormalities in the brain-gut axis likely cause CVS.*

Phases of CVS

Nausea, vomiting & retching, abdominal pain and multiple autonomic symptoms



Adapted from “Cyclic Vomiting Syndrome in 41 adults: the illness, the patients, and problems of management. BMC Med 2005

Characteristics of each phase and what patients and caregivers can do during each phase

PHASE	WHAT IT IS	WHAT TO DO
Inter-episodic phase	Patients usually have no symptoms, but some may experience nausea, low-grade vomiting and abdominal discomfort intermittently.	<ul style="list-style-type: none"> • Identify and eliminate triggers, if possible • Stress management • Prevent episodes by taking your daily CVS medications as prescribed by your doctor.
Prodromal phase	This phase begins the early symptoms, which occur before an episode of vomiting starts. Symptoms in this phase include nausea, abdominal pain, diarrhea, decreased appetite, excessive belching and an impending sense of doom and feelings of panic.	This phase is best managed by resting in a quiet, dark room and taking all abortive medications as prescribed by your doctor. Medications such as ondansetron (Zofran®), sumatriptan (Imitrex®), diphenhydramine (Benadryl®), lorazepam (Ativan®) and are often used.
Emetic phase	This is a period of intense nausea and vomiting. Other symptoms include abdominal pain, hot and cold chills, diarrhea, sweating, excessive salivation and sensitivity to light and sound.	<ul style="list-style-type: none"> • Drink fluids, as tolerated • Continue with medications, as prescribed • If the above measures are unsuccessful, a visit to the doctor's office or ED may be necessary
Recovery phase	Resolution of symptoms <ul style="list-style-type: none"> • You begin to feel more like your normal self • Severe nausea and vomiting will stop 	<ul style="list-style-type: none"> • You should begin to slowly drink fluids and eat, as tolerated • Continue taking your daily CVS medications as soon as you can

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How is CVS diagnosed?

Arriving at a diagnosis may be difficult. You may have seen multiple doctors and tried various treatments, without relief of your symptoms. Although there is not a specific test to diagnose CVS, your doctor can usually make a diagnosis by carefully reviewing your health history and performing a few tests to rule out other diseases that cause symptoms similar to CVS. A diagnosis is made based on medical history and symptoms because *we do not have specific blood tests or X-Ray tests that we can use to diagnose CVS.*

What are some tests that may help my doctor diagnose CVS?

- EGD - A test using a flexible scope with a camera at the end to look at the insides of your esophagus, stomach, and the first part of your small intestine.
- Small bowel follow-through - An x-ray test to look at the stomach and small intestine. It can be helpful to diagnose blockages that can cause vomiting.
- CT scan of the abdomen and pelvis - A test that uses x-rays to take 3-D pictures of specific areas of your body, in this case, the structures in your abdomen and pelvis.
- Gastric emptying study - A test that is done by radiology to measure how your stomach empties food.
- MRI - A test that uses a magnet to take pictures of the organs and structures inside your body.
- 24-hour urine collection - A test that measures the make-up of your urine over a 24-hour period.
- Autonomic function testing - A test that looks at how the autonomic nerves that control the different organs in your body including your intestine respond. This is usually done in the neurology department.

How can I manage CVS episodes?

The good news is that you can act to prevent and manage episodes. The management for CVS involves **lifestyle changes**, daily medications (often referred to as **prophylactic or preventative medications**), medications to take when you start getting symptoms (often referred to as **abortive medications**), and supportive treatment during an episode.⁶ Know your lingo! This will help when you meet with your physician.

Lifestyle changes

Lifestyle changes are very important. Staying well hydrated, avoiding excessive alcohol and taking your daily prescription medications are all important. Also, there are several triggers for CVS. Learn how to recognize and manage them.

Triggers and How to Manage Them

Use a diary to keep track of when episodes occur (or do not occur)

- Try to figure out what brings on your episodes and do your best to avoid these things.
- Regular exercise (avoid over-exercising), regular meal schedules (avoid skipping meals) and moderation or avoidance of caffeine may also help.

Intense excitement and emotional stress

- During vacations, birthdays or other exciting events, take time to relax and breathe when you feel tense.
- Try to get at least 8 hours of sleep daily.
- Learn to relax by listening to music, spending quiet time alone, taking a warm bath, meditating, or exercising.

Foods (these are less common in CVS than thought)

- Avoid fasting, and be sure to eat regular, balanced meals.
- Figure out which foods bring on your episodes and avoid them. Some people have found that cheese, chocolate, beans, or wine can bring on an episode.
- Avoid restricting your diet if there are no identifiable triggers.

Emergency Department protocol

In some instances, when abortive medications do not work, you may need to go to the Emergency Department (ED) to receive treatment to manage your symptoms. This often includes IV fluids, anti-emetic agents and sedatives that are given intravenously. Your CVS specialist or gastroenterologist will usually provide you with a *written protocol to manage your CVS symptoms* that you can share with the ED. This is called an “*emergency department protocol*” and is very helpful in navigating the health care system and providing physicians with a care plan. Below is example of such an ED protocol which can be used by your physician to create one designed for you.

Cyclic Vomiting Syndrome (CVS) Emergency Department (ED) Protocol⁶

_____[name]_____ has an established diagnosis of Cyclic Vomiting Syndrome

Operational definition

- A recurring pattern of discrete episodes of severe vomiting, accompanied by profound nausea and/or severe abdominal pain
- Patient returns to usual health status between episodes (may have inter-episodic nausea and or dyspepsia)
- In some patients, CVS episodes resemble a migraine attack
- Patients may be restless, anxious, and distressed
- Patients are not customarily dehydrated until late in the episode

Therapeutic goal

Rapid recognition and intervention may decrease severity of the attack and promote prompt resolution of symptoms

ED management

1. Clinical assessment: Pulse/Temp/BP/Weight, consciousness, and hydration
2. Laboratories
Examples: CBC, urea, creatinine, LFT's, lipase, glucose, and electrolytes; EKG; Urine analysis; Diagnostic imaging at discretion of attending physician

Treatment (ensure to specify exact dosage recommended for patient)

1. Intravenous fluids
Examples: IV saline bolus if clinically dehydrated; IV D5NS at 100%-150% maintenance
2. For vomiting and nausea
Examples: IV ondansetron; diphenhydramine; metoclopramide; IV fosaprepitant
3. For sedation
Examples: IV lorazepam; IV diphenhydramine
4. For migraine-like presentation
Examples: Sumatriptan nasal; Sumatriptan subcutaneous injection
5. For pain
Examples: IV ketorolac; Opioids (must be used sparingly and with caution given the risk of addiction, dependence with frequent or long-term use. Every effort should be made to use non-opioid alternatives including the use of sedatives and prompt care which can alleviate the anxiety that often drives symptoms.)

Reassess

1. Treatment failure—intensify treatment as indicated above or admit patient
2. Positive treatment response—discharge with instructions for any continuing medications
Examples: Ondansetron; lorazepam; NSAIDs

Other things to think about related to CVS

Due to the largely unpredictable nature of CVS and the stress that goes along with this, you may be experiencing anxiety, depression, panic attacks, or emotional distress. We realize that the stress of being sick is a stress in itself, and therefore we want to help keep you emotionally healthy. In addition to managing your physical symptoms, reduction in life stressors (when possible), learning to cope with stress and increased social support can decrease the number and severity of CVS episodes. Therefore, we have included a list of resources that can help optimize your social, psychological, and overall well-being. Some patients may benefit from therapy and/or visits with a psychologist.

People with chronic illness may use over-the-counter or home remedies to improve their symptoms. *CVS patients often report using cannabis as one of these coping strategies.* However, it is important to know that cannabis use *may* increase the frequency and severity of CVS episodes, actually making you feel worse in the long run. Cyclic vomiting in association with long-standing heavy cannabis use (daily or near-daily use) has been referred to as Cannabinoid Hyperemesis Syndrome (CHS).¹¹ While cannabis is known to stop vomiting in some individuals, others may be susceptible to vomiting and it is possible that cannabis can make symptoms worse.¹² Cannabis contains many compounds and has been associated with mental health problems such as psychosis and increased suicide rates in adolescents and young adults.

What are some things you can do as a caregiver or parent to help the patient in an episode?

- Allow the patient to rest in a quiet area
- Provide warm or cool packs to place on head or neck
- Provide ice chips
- Provide popsicles
- Encourage patient to use his or her prescribed medications to help stop episodes
- If patient is unable to keep fluids down, you may need to bring the patient to the Emergency Department. If this occurs, bring a list of all the medications that the patient currently is taking. *Do not forget to bring their emergency department protocol* (see previous section for example)

About IFFGD

The International Foundation for Gastrointestinal Disorders (IFFGD) is a 501(c)(3) nonprofit education and research organization. We work to promote awareness, scientific advancement, and improved care for people affected by chronic digestive conditions. Our mission is to inform, assist, and support people affected by gastrointestinal disorders. Founded in 1991, we rely on donors to carry out our mission. Visit our website at: www.iffgd.org.

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