

Poor Appetite, Nausea, Vomiting, and Weight Loss

Many people with cystic fibrosis (CF) have gastrointestinal (GI) disturbances that can affect their quality of life. These may include poor appetite, nausea, vomiting, and weight loss.

Although poor appetite usually means loss of interest in food, for people with CF it can also refer to poor oral intake even if the desire to eat is still experienced. This can occur because eating is associated with abdominal discomfort or pain, or a rapid feeling of fullness.

In those with CF, poor appetite may be accompanied by nausea, and sometimes nausea is accompanied by vomiting. Nausea can come and go, or can become persistent. Sometimes it occurs only after eating a large meal. As a result of poor oral nutrition related to appetite loss or nausea, some people with CF struggle to maintain their weight.

These symptoms can prevent a person with CF from enjoying usual activities and social interactions.

What Can Cause Poor Appetite, Nausea, Vomiting, and Weight Loss in CF?

People with CF may have one or more GI symptoms, and one symptom can appear to lead to another. Sometimes these symptoms appear when a person with CF becomes ill with an acute illness, like a pulmonary exacerbation. For example, severe cough may result in nausea or vomiting. Poor appetite and nausea may improve with treatment of the exacerbation.

There are also many other possible causes of these GI symptoms:

- CF directly affects the GI tract. Most people with CF have poor functioning of the pancreas (known as “pancreatic insufficiency”) and need to take enzymes to properly digest and absorb food, which helps

prevent weight loss. However, even if your body makes enough pancreatic enzymes (also known as “pancreatic sufficient”), you can also have these symptoms.

- CF-related diabetes can cause abnormal function of the nerves to the GI organs, which then can cause slow emptying of the stomach and intestines (gastroparesis).
- People with CF often get other GI problems which can cause such symptoms as acid reflux or heartburn, inflammation of the intestine or pancreas (pancreatitis), gallstones, or a blockage in the stomach or intestines.
- Some medications used to treat CF can cause GI side effects.
- Weight loss that worsens with pulmonary symptoms may signal the development of a chronic lung infection, such as non-tuberculous mycobacteria.

High stress, anxiety, or depression can also cause or worsen these GI symptoms. Some people with CF develop an eating disorder, like anorexia or a syndrome called avoidant/restrictive food intake disorder (fear of eating leads to eating only a few foods, despite knowing it is not healthy). Sometimes, weight loss is due to the development of a different disease, like a thyroid problem.

What Can I Do to Help?

Describe your symptoms to your CF care team, including how they started, whether they come and go, whether they are worsening, any triggers, and what makes them better. It is also important to communicate the severity of your symptoms, if possible using a scale, like “mild,”

“moderate”, and “severe”. Also note the quality of the symptoms—how you describe the sensation in words (like “pain” or “discomfort”). Finally, your CF care team will want to know about related problems, like your mood, eating patterns, and any difficulty with doing activities that are important to you.

There may be self-management strategies that can help you cope with these symptoms:

- If you are feeling nauseated or vomiting, stay as well-hydrated as you can. If you cannot do so, you may need IV fluids and IV medications to help. Smaller and blander meals may help, as well as avoiding strong smells.
- Consider keeping a symptom diary like the one below and making sure to eat even if you are not hungry. Have a healthy snack handy if you are too busy; using a nutritional supplement, which can be recommended by your CF care team, may be a good way to obtain extra calories.
- If you have acid reflux, try controlling it using over-the-counter antacids or acid-suppressing medications, like famotidine or omeprazole.
- If symptoms like poor appetite appear related to constipation, laxatives that you can buy over-the-counter may be a helpful first step.
- If stress is high, consider using a self-management approach to help you; your CF care team may be able to offer you training in approaches like relaxation, guided imagery, or progressive muscle relaxation.
- Staying physically active can help ease stress and anxiety and keep your gastrointestinal tract working well.

What Can My CF Care Team Do to Help?

Your CF care team may want to order tests to evaluate possible causes of your symptoms and help provide guidance on the most appropriate treatment addressing the underlying disorder. They may prescribe medicines or other treatments, or may recommend that you see a physician who specializes in the GI problems that people with CF experience.

What Are Some Medical Treatments?

- If you are taking pancreatic enzymes, your CF team may try to find the best dose of this medication for you, adjust nutrition, or use a proton pump inhibitor medication (especially for children) to help enzymes work.
- For poor appetite and weight loss, your CF team may offer a medication, such as cyproheptadine or dronabinol. Some health care providers will talk with you about a trial of medical cannabis for persistent poor appetite. Be aware that its use is subject to state regulations and federal limitations.
- To ease nausea and vomiting, many medications may help. Some medications, like ondansetron, directly suppress nausea. Some reduce acid reflux, which may be the cause. If nausea or vomiting appears to be related to gastroparesis, a drug like metoclopramide may be prescribed to improve emptying of the stomach and intestines.
- If you have CF-related diabetes, improving glucose control can help with unintended weight loss or other GI symptoms. If you haven't been diagnosed with CF-related diabetes, your team may encourage you to get your annual oral glucose tolerance test to screen for pre-diabetes and diabetes.
- If no reason can be found to explain your weight loss, sometimes a feeding tube (G-tube) is needed, especially in children or before lung transplants are performed.

When Should I See My CF Care Team?

Consult your provider immediately if you experience abrupt changes in your symptoms, such as severe abdominal symptoms with or without fever, or vomiting bile or blood.

What Can I Expect if I Use Highly Effective CFTR Modulators?

Your pancreatic enzyme dose may need an adjustment, and changes in your eating habits may contribute to the beneficial effects of CFTR modulators.

- You may experience weight gain. For people with CF, nutrition has an important impact on lung health. If you are concerned about the physical or emotional effects of gaining weight, talk to your CF team.
- Some individuals may notice changes in the movement of food and contents through the stomach and intestines.
- People have reported changes in the way that normal contractions and functions of the stomach and intestines are sensed, which can cause discomfort. If you experience this, nerve moderating agents may be helpful (such as nortriptyline, duloxetine, or gabapentin; consult your provider to see which option works best for you).

Gut Health Symptom Diary

Use this diary to record your symptoms, activity level, food and beverage intake, mood and other triggers. You can review it with your CF provider.

	MORNING (5 am – 11 am)	AFTERNOON (12 pm – 5 pm)	EVENING (6 pm – 8 pm)	NIGHT (9 pm – 4 am)
Food/beverages consumed				
Bowel habits				
Symptoms				
Medicines				
Exercise				
Mental Wellbeing				

Source: Adapted from <https://sibosurvivor.com/low-fodmap-diet/>