**Gastro-Esophageal Reflux Disease ("GERD")**

**Lifestyle Therapies**
1. Avoid eating or drinking 2 hours before bed.
2. Eat small frequent meals throughout the day – with the biggest meal at lunch.
3. Sleep with upper body in a raised position so that the esophagus is higher than stomach – by using a wedged pillow or by placing blocks under mattress head to raise it 6-8 inches.
4. Avoid wearing clothes that fit tightly around the waist – as it may increase pressure over the stomach when bending at the waist causing reflux symptoms.
5. Stop smoking (if currently smoking)
6. Avoid or minimize acid producing foods (e.g. fat, chocolate and coffee)

**Medications**
Proton pump inhibitors (PPI) are used to suppress acid production – and in persons with scleroderma, higher than recommended doses may be required to stop the symptoms. Missing even a couple of PPI doses may cause an increase in acid production and rebound of severe symptoms. PPIs should ideally be taken 30 minutes before breakfast and dinner (if needed).

**How Does the Digestive System Work in Persons with Scleroderma?**
Muscles in the gut push food and liquid down from the mouth to the intestine (colon), where nutrients are absorbed and waste is excreted in the form of stool. In persons with scleroderma, as blood vessels become damaged, nerves that stimulate the bowel receive decreased amounts of blood. Over time, this lack of blood supply affects the strength and tone of the gut muscles. The gut muscles become weakened, moving slower and with less coordination. This weakening process starts in the esophagus (food pipe) and stomach, and may work its way down to the small and large intestine.

**Orpharyngeal (Mouth)**

**Symptoms:** Dry mouth causing opening, swallowing and chewing difficulty, gum disease

**Cause:** A condition called Sjogren’s Syndrome (occurs in 20% of persons with scleroderma)

**Treatment:** Drinking small frequent sips of water to maintain mouth moisture is the preferred treatment for most. Sugar-free lozenges, gum, over-the-counter dry mouth products and prescription medications are sometimes helpful. Dental exams are recommended every 3 to 6 months – so patients may develop personalized care plans that include preventative treatments and facial exercises to help slow the progression of scleroderma symptoms of the mouth and face.

**Liver**
About 10% of scleroderma patients may have liver involvement, known as primary biliary cirrhosis. If this complication occurs, it usually occurs 10–15 years after the onset of scleroderma.

**Symptoms:** Itchy skin and fatigue.

**Diagnosis & Treatment:** Doctor prescribed medication (such as ursodeoxycholic acid) after diagnosis is made through physical exam and blood tests for anti-mitochondrial and anti-smooth muscle antibodies.

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Esophagus (Food Pipe)

**Symptoms:** Heartburn (sensation of burning behind the breast bone) from the stomach creating irritation on the esophagus. Other symptoms may include dry cough at night, recurrent chest pain behind the breast bone, persistent hoarse voice, asthma (wheezing and shortness of breath), regurgitation of food (expulsion of undigested food from the mouth), difficulty swallowing, mouth ulcers and the taste of acid in the mouth.

**Cause:** Weakening of the gut muscle valve between the stomach and esophagus allows acid to “splash” back up into the esophagus causing reflux (Gastro-Esophageal Reflux Disease - GERD). The acid, while tracking back into the esophagus and Persons with scleroderma may experience belly pain, distension, vomiting, and the taste of acid in the mouth.

**Treatment:** The treatment of acid reflux requires both lifestyle changes and medications that can decrease acid production and increase the motility of the gut muscle.

Stomach

**Symptoms:** Sensation of nausea, vomiting, fullness, or bloating sensation and distention. In some persons with scleroderma, the stomach can also have telangiectasia (dilated blood vessels) lining the walls of the stomach – this is also known as “watermelon stomach” due to its appearance on endoscopy. Slow and intermittent or rapid bleeding from these dilated blood vessels can cause anemia (low red blood cell count). In this case, the person may or may not have stomach symptoms and may only feel very tired and fatigued.

**Cause:** Slow emptying of the food (also known as gastroparesis) into the small intestine.

**Treatment:** Treatment for gastroparesis will involve the use of lifestyle changes (same as those used to treat GERD), and depending on symptoms, doctor prescribed medications such as anti-reflux agents, anti-secretory agents, pro-motility agents, bacteria suppressing antibiotics and laxatives. For “watermelon stomach,” use of endoscopic laser treatment – performed by gastroenterologists or surgeons experienced in scleroderma, may lead to improvement in the anemia and symptoms. Multiple laser treatments (every 2 - 4 weeks) may be required before the bleeding stops completely.

Small Intestine (Small Bowel)

**Symptoms:** Similar to gastroparesis (bloating sensation and distention, nausea and vomiting), however abdominal pain may also occur. In addition, weight loss, inability to gain weight, diarrhea with foul smelling stools, which may be oily or hard to flush. Symptoms may also include pseudo (false)-obstruction – a condition in which the bowel is not physically blocked as in true bowel obstruction but instead stops working because of weakened gut muscles – in these circumstances, persons may experience belly pain, distension, vomiting, and the inability to “pass gas.”

**Cause:** Three common causes of weight loss or inability to gain weight in persons with scleroderma: gastroparesis, small bowel bacterial overgrowth, and untreated depression.

**Treatment:** Antibiotics are used for 10-14 days at a time to reduce the overgrowth of bacteria in the small bowel. Often, treatment has to be repeated to keep the bacteria level low. Pro- motility agents are often used in combination. Pseudo-obstruction requires hospitalization and complete rest of the small bowel. During treatment, the person is given IV (intra-venous) nutrients along with pro-motility agents. Venting (placing a small surgical tube into part of the small intestine called the jejunum) may be performed as needed, to aspirate air out and to help prevent the patient from becoming distended.

Large Intestine (Colon)

**Symptoms:** Pain, feeling of incomplete emptying of the bowel, constipation or diarrhea.

**Cause:** Weakening of the gut muscles and impaired motility.

**Treatment:** Liberal use of water and laxatives that stimulate the nerve endings in the gut wall, which make the muscles in the intestine contract with more force. A high fiber diet without a laxative is not helpful as it just adds to the amount of waste the bowel is struggling with. There is debate whether the chronic use of laxatives such as Senna* can somewhat worsen constipation over time; however, there are no definitive studies proving this currently. The person may take a laxative every other day to maintain a healthy bowel regimen.

Rectum

**Symptoms:** Rectal incontinence (accidentally soiling the underwear before being able to get to a bathroom) occurs in up to a third of people with scleroderma.

**Cause:** Weakening of the rectal muscle and poor control of the rectal sphincter.

**Treatment:** Biofeedback therapy may be helpful by improving voluntary squeezing of the rectal muscle. Major scleroderma centers offer classes to teach people this technique. Surgery by an experienced surgeon might also be helpful. Preliminary studies have shown promise of sacral nerve stimulation (nerves that control rectal tone) in decreasing episodes of rectal incontinence.

Recognizing Symptoms & Understanding Treatments