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GI TRACT COMPLICATIONS

WHEN THE **GASTROINTESTINAL SYSTEM** IS INVOLVED IN LUPUS,
DIET AND MEDICATION MANAGEMENT ARE KEY

BY NANCY MANN JACKSON

Since her 2004 lupus diagnosis, Susie Flenniken of Redmond, Oregon, has developed chronic gastrointestinal (GI) complications. Her esophagus and stomach are “like one huge ulcer,” she says. Flenniken often loses weight during lupus flares, but because of her GI difficulties and her inability to absorb certain nutrients, she’s unable to eat the fatty foods needed to gain the weight back. In March 2014, she became bedridden after dropping to 85 pounds. Since then, she has gained back almost 20 pounds “with a lot of work, experimentation, meds, and support,” she says.

Bull's Eye/Getty Images

Complications related to the gastrointestinal system occur in approximately 25–40 percent of those with lupus, according to Peter Schur, M.D., co-director of the Lupus Center at Boston’s Brigham & Women’s Hospital and a professor at Harvard Medical School.

Many of the symptoms experienced by people with lupus are nonspecific and often reflect either lupus of the GI tract or the effects of medications taken for lupus.

Sometimes it’s impossible to determine whether the GI problems are caused by lupus or by lupus

medications—and because people with lupus have relatively few medication choices, stopping the medication is often not an option. Instead, Flenniken and others like her work closely with their health care providers to find options for relief.

HOW LUPUS AFFECTS THE GI TRACT

Although complications of lupus “can start at the mouth and go all the way down through the digestive system,” Schur says, the most common GI complaint among people with lupus is heartburn. Heartburn caused by lupus is unlikely to be affected by dietary changes, “unless you’re eating a lot of things that cause heartburn,” he adds. Instead, Schur recommends people with heartburn as a complication of lupus use preventive medications such as Prilosec® or similar generic drugs.

However, GI involvement with lupus can be more severe than heartburn or painless mouth ulcers. Like Flenniken, some people’s lupus-related GI problems are life-altering. For instance, for the past few years, Flenniken has found it difficult to find nourishment because most foods worsen her ulcers or lead to backup in her bile duct, which causes painful pancreatitis. She has endured three recent hospitalizations for pancreatitis, during which she could eat only ice chips for several days—she had to avoid even mild foods like chicken noodle soup, because the chicken fat could cause a relapse.

Today she spends much of her time planning what she can eat and experimenting to see which foods—and how much of each—will cause pain. Many of her favorites don’t make the list. “I love raw tomatoes,” Flenniken says. “But I can’t eat anything acidic like tomatoes. I can’t eat red meat or many vegetables.”

Most frustrating is the fact that Flenniken’s doctors haven’t been able to give her a list of foods to eat or not to eat. There’s no reliable way to know which foods will cause her pain except for trial and error, so she’s spending her time figuring it out on her own.

Aileen Rodriguez, a graduate student in Orlando, Florida, also deals with GI complications related to lupus. After being medicated for a major lupus flare in October 2013, Rodriguez began to experience frequent



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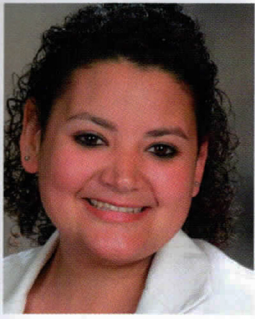
—SUSIE
FLENNIKEN

vomiting and severe digestive issues. To avoid the pain and discomfort, she almost stopped eating altogether and lost nearly 70 pounds. “That started to affect my emotional and mental health,” she says. “I felt like a completely different individual. I was barely eating, and I had no energy.”

From November 2013 to June 2014, Rodriguez hardly left her home because she felt so anxious about the potential for developing digestive issues while in class or in a meeting. While her health is better now, she has had to completely change her diet. “Digestive issues are always on my mind. When somebody says, ‘Let’s go out to eat,’ I have to really think about whether I should go. At work, where my department often provides meals for employees, they don’t know how to accommodate for so many limitations. It’s a constant challenge.”

FINDING RELIEF

Rodriguez and her doctors ultimately determined that many of her GI problems were caused by CellCept®, the medication she was taking for lupus. She stopped taking the drug and began taking chemotherapy treatments every six months instead. While the change in medication resolved some of her stomach and digestive challenges, Rodriguez continues



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—AILEEN RODRIGUEZ

to watch what she eats. For instance, she doesn't eat dairy, red meat, or anything made with eggs. And she always has the anti-nausea drug Zofran® on hand, she says.

Flenniken's GI problems do not seem to be caused by medication, but she and her doctors have determined some medications that made the symptoms worse. For instance, prednisone usually helps her with lupus flares, but “does

nothing for pancreatitis,” she says. Also, pain medications such as tramadol (Ultram®; Rybix ODT®) made her pancreatitis worse. However, she had no trouble with sucralfate (Carafate®), a coating drug that eased the ulcers in her esophagus and stomach that developed as a result of her bile duct pancreatitis.

Flenniken has learned to eat several light meals throughout the day, such as nonfatty soups and yogurt. She also keeps a diary of everything she eats so that if she begins to feel bad or gets a stomachache, she can look back and determine what foods may have caused the problem.

Learning to partner with her care providers has also been helpful for Flenniken. Throughout her hospitalizations during the past year, she saw a number of doctors. Each time a new one came in the room ready to recommend treatment, she'd mention that she has lupus, and it would completely change the doctor's strategy, she says. “It can be very frustrating, because we look to doctors to have all the answers, but GI doctors aren't often knowledgeable about lupus, so you have to give them a break,” Flenniken says. “Lupus is a game-changer. You have to keep reminding them you have lupus, and you have to be your own advocate.” ■

SYMPTOMS OF GI INVOLVEMENT WITH LUPUS

Because lupus affects each person differently, people with lupus may have no GI involvement or they may have a wide range of different symptoms. According to Peter Schur, M.D., co-director of the Lupus Center at Boston's Brigham & Women's Hospital and a professor at Harvard Medical School, and Elena Massarotti, M.D., associate professor of medicine at Harvard Medical School and co-director of the Center for Clinical Therapeutics at Boston's Brigham & Women's Hospital's Department of Rheumatology, these are the most common GI symptoms for people with lupus:



- **Dysphagia, or difficulty swallowing.** Up to 25 percent of people with lupus have difficulty swallowing from time to time, and it seems to happen more often during periods of high stress. Depending on the cause, dysphagia can be treated with medication or by eating frequent, small meals.
- **Abdominal pain.** Up to 30 percent of people with lupus suffer from abdominal pain, along with nausea and vomiting. This pain is sometimes attributed to disorders that may be associated with lupus such as infection, pancreatitis, and inflammatory bowel disease.
- **Peptic ulcer disease.** People with peptic ulcer disease have sores in the lining of their stomachs, causing pain. These complications are more common in those taking nonsteroidal anti-inflammatory drugs (NSAIDs).

Changing medication and avoiding alcohol and cigarettes are some of the ways doctors advise reversing this complication.

- **Liver disease.** Up to half of people with lupus develop liver disease, although some complications are less serious than others. They include cirrhosis, hepatitis, fatty liver, and drug-induced liver abnormalities. These conditions are often treated by stopping certain drugs and actively treating lupus.

While not common, Schur and Massarotti say these GI-related complications are also seen in lupus:

- **Pancreatitis.** Approximately 2–8 percent of people with lupus may develop pancreatitis, with symptoms including upper abdominal pain, nausea, and vomiting. Pancreatitis can be treated by giving IV fluids, avoiding food intake, and stopping any drugs that may have contributed to the condition.
- **Protein-losing enteropathy.** This condition is quite rare, but typically occurs in young women. Half of those with protein-losing enteropathy suffer from diarrhea; other symptoms include profound swelling and low levels of albumin in the blood. Patients are typically treated with medication, including corticosteroids or immunosuppressive drugs.
- **Mesenteric vasculitis.** Very rare, mesenteric vasculitis can be a life-threatening condition if it leads to bowel perforation. Symptoms include nausea, vomiting, diarrhea, gastrointestinal bleeding, and fever, and the condition is usually preceded by months of lower abdominal pain. It can be treated with corticosteroids.