

Colitis, Crohn's Disease, and Malnutrition Are No Match for This Devoted Couple

When Chad and Anar decided in late July that they needed to shed some of the extra weight gained during the pandemic, they had lots of experience to draw upon.

Chad, who is generally fit, has been watching his diet and keeping his diabetes in check for more than 20 years by carbohydrate counting, measuring food portions, and exercising. For the past five years, he has successfully excluded gluten from his diet, too. Anar is a registered dietitian who assesses and makes parenteral and enteral nutrition recommendations for home patients who cannot eat orally.

After a couple of weeks, Anar had lost four pounds, and Chad had lost 10. Instead of feeling healthier, however, Chad started having unusual gastrointestinal problems, which sent him to the bathroom more and more frequently.

When Chad started losing a pound a day and had blood in his stool, they knew those symptoms were definitely not caused by eating a healthier diet. The couple quickly sought medical advice.

Chad's doctor ordered a colonoscopy and diagnosed severe colitis, a disease that causes inflammation of the colon. He was sent home with a prescription for prednisone and some general information about colitis. That night his symptoms worsened, sending him to the emergency room.

Chad was admitted to the hospital overnight. Tests ruled out a perforation of the bowel, a serious complication of colitis. He was given a dose of steroids to reduce the inflammation, sent home, and instructed to stay on a liquid diet until he could tolerate solid food. Chad's symptoms, however, didn't improve, and he could not advance beyond liquids.

At this point, Chad's weight had dropped 17 pounds, from 203 to 186 pounds. "I felt so terrible; eating was the last thing on my mind," recalled Chad.

His condition only worsened. After weeks of continuous pain, severe diarrhea, and weight loss, Chad went to a new gastroenterologist who suspected he was suffering from



Chad and his wife, Anar, a registered dietitian.

Crohn's disease, a widespread inflammation throughout the large and small bowel.

Chad was admitted to the hospital for what he hoped would be three to five days of IV steroids to calm down the inflammation, followed by medication taken at home. That optimistic possibility turned into an 11-day stay.

At first, Chad improved. He slowly started to eat solid food again. And then, suddenly the bleeding, cramping, and pain increased. A second colonoscopy showed that the inflammation remained severe despite the high-dose steroid treatment.

In an effort to further ease the inflammation and give his bowel a rest, for five days Chad was restricted from eating any food and could only have ice chips.

As a dietitian, Anar knows how vital nutrition is in healing process. She had talked with Chad's doctors multiple times about starting parenteral nutrition (PN) through a PICC line inserted in a large vein in the arm.

Chad's doctors were concerned as a PICC line carries with it a risk of infection. They felt that his nutrition status would improve once the inflammation was under control.

"These were our lowest days—when all hope felt like it was slipping away," says Anar.

What concerned Anar was that Chad's care team wasn't as worried about his extreme weight loss. And they seemed to be unfamiliar with the use of nutrition therapy and the potential healing benefits it can provide patients. "I brought it up every day once he was admitted to the hospitalist and GI team during daily rounds. As a home infusion dietitian, it was very discouraging that nobody seemed to be worried about his nutrition."

After eight days in the hospital, Chad's weight had fallen to 169 pounds. He had lost 34 pounds in less than a month.

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Colitis, Crohn's Disease, and Malnutrition, continued

It was then that Chad's doctor began a more aggressive drug therapy and—much to Anar's relief—also ordered parenteral nutrition.

Chad quickly felt the benefits of PN. "Within the first day or two, I felt more alert and less sluggish. I felt more alive," recalled Chad. A few days later, he was well enough to continue his medication and recovery at home as long as parenteral nutrition continued until he could eat solid food again.

A nurse visited their home, provided all the needed supplies, and taught them how to set up and disconnect the PN. She came back weekly to check Chad's progress and take blood samples. A dietitian worked with his physician to adjust the PN formula to meet his needs.

"I must admit that despite my 17 years as a home infusion dietitian, that first visit from the nurse was overwhelming. There are so many supplies and such care to follow sterile technique. It gave me a real perspective of how it must feel for our patients and caregivers," said Anar.

At first, Chad received PN for 18 hours a day. As he improved, it was reduced to 12 hours a day and then from once a day to four times a week.

"I still didn't feel great, but being home was fantastic. Being hooked to the PN pump for 18 and 12 hours at a time was challenging," admitted Chad.

"I'd tell myself, 'Yes, this is inconvenient, but I know it will help me.' I had a backpack for my pump, and sometimes I was happy to put it on and walk to the mailbox to get the mail." Chad's spirits were buoyed by his two daughters, who always provided laughs when he needed them.

Chad gained weight as his condition improved. In October, his dietitian stopped the PN for a week and checked his blood work. His lab results were good, and he was able to have the PICC line removed.

By late October, Chad weighed a healthy 180 pounds but was still on the road to recovery. "I lost all of my muscles when I was hospitalized for 11 days. I think you could say I'm still 'de-conditioned.' But I'm going out and exercising. I'm even more conscious about what I eat because of my Crohn's diagnosis. And I've cut out dairy because it can be inflammatory in my case."

Chad knows how extremely fortunate he is to have had his own in-home dietitian who could explain and answer his questions about PN therapy. His advice to those who aren't so lucky: "Talk with others who have been on it. Find a support outlet to help you keep a positive outlook."

New Perspectives from a Practiced Professional

Anar also has some observations and advice for clinicians now that she's experienced PN from a caregiver's perspective.

She sees a clear need to expand clinical nutrition education for physicians—both specialists and hospitalists—to broaden their focus beyond treating a specific disease symptom.

"Malnutrition happens so quickly and can have such a cascading impact. Physicians need to keep nutrition as part of their care plan," she suggested.

Even with her experience, Anar found the initial introduction to home PN a little overwhelming. She thought all of the nurses visiting their home "were wonderful" yet believes they can do more to ease the stress of caregivers.

"Even though we were able to figure it out after a few days, it would have been helpful if the nurse had explained each supply item in the initial delivery—which consisted of three large boxes. For example, 'This is the heparin syringe'... 'This is the saline syringe'... 'This is the hydro seal for showering.'"

Anar also said watching an online video helped cement her understanding of the proper procedures. She encourages nurses to let home caregivers know about all of the available training resources. "Getting instructions before being discharged from the hospital would have been good for Chad, so he would have known what to expect," she added.

Her advice to other caregivers: "Be patient with yourself. You will get it. Managing it will become very routine."

Anar also has some suggestions for her colleagues. "As dietitians, we want to ensure that our patients get top nutrition care and receive their formula safely while meeting all of their nutrition needs. However, it's just as important to make things easy for the patient. Consider offering them some other options so they feel that they are an active participant in their care plan.

"While it's common to infuse PN overnight, at one point, Chad was thinking about infusing during the day as the fluids and frequent trips to the bathroom kept him up all night. While he never made the transition to daytime, he definitely considered it," she said.

She believes giving patients on long-term PN a day off from treatment every now and then can also be beneficial. "If they want to skip a night of PN to attend a concert or a wedding or celebrate Christmas, help your patient find a way to make it happen."