

# Coping with Carcinoid Diarrhea

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We are going to talk about carcinoid disease and diarrhea. We really need to focus closely on this subject. First part of this is about digestion and diarrhea. You know what happens when you put the food in your mouth as it makes its way to your GI tract so we are going to talk about how our intestinal tract works. We process about nine liters of fluid daily and in this picture you can see the little appendage hanging down that is the appendix, but that is where the small intestine and the large intestine join together and that is part of the two feet area that Dr. Kvols discussed where the majority of our gut carcinoids originate.

The small intestine's job is to absorb nutrients. That is all that does. We eat the food, it goes into our stomach, it is digested and then the small intestine pulls out all the things that our body needs for metabolic and cellular activity.

Large intestine or your bowel all it does is absorb water. That is its whole job. So this is how diarrhea happens. Looking at an intestine, you have the inside wall that you have the blue arrow coming out. You have the yellow arrow going in that illustrates the increased secretions of fluid and electrolytes. This is what happens when we ingest the food and when we have decreased absorption of fluid and electrolytes. It can be because of problems with serotonin. It can be problems with some of the hormones that are released from these carcinoid tumors. These are osmotically active and that is what propels them through and then hence, you see the diarrhea.

It is definitely a balancing act. We have to evaluate everyone for dehydration and evaluate for electrolyte imbalance. Why do we do that? Well, electrolyte imbalances can become life-threatening. If you have buckets and buckets of diarrhea like Dr. Kvols talked about with the VIPoma patients they can die because the sodium gets very low, the potassium gets very low and these are critical for normal heart function and normal blood pressure. For you to be you we have to have normal electrolytes.

I want to discuss absorption and elimination as well. The small intestine absorbs about seven and a half liters of fluid and that is with all the food and all the drink that you take in every day. Only 200 ml's is excreted through your stool. That is a very small amount. The rest is absorbed in your bowel. So now we have to determine what is the cause of the diarrhea. Is it syndrome or surgery? When we talk with our patients when they first come in - I have diarrhea therefore, I have carcinoid syndrome, but that is not always the case and let me show you why.

With syndrome you'll have watery stools. You may have five or more stools per day. It may be associated with food intake. Some patients find that when they eat fatty foods, boy, it goes right through them. They have wine or high fiber foods, boy, they get the diarrhea. A patient said at lunch today that any time she eats citrus it goes right through her, and she has weight loss. That is probably one of the most important factors too in determining what is going on with your diarrhea.

With surgery patients, when you have that terminal ileum removed they too will have loose stools. They can have two or more loose stools per day. It too is associated with food. Many of these patients have problems right after they eat and it too can be associated with weight loss. So this a conundrum. Okay, which is it? Do I have carcinoid syndrome or is it because I have had my terminal ileum removed? We need to evaluate. This is the guy that will draw your blood and take it to the lab and figure it out. Do you have a high Chromogranin A? Are your electrolytes normal? Are they abnormal? You will turn in your 24 hour urine for 5-HIAA. Many of the patients that have elevated 5-HIAA will also have associated diarrhea.

Serotonin is a very good marker to use. If it is initially evaluated and it is abnormally elevated that may be a good marker for you and as Dr. Kvols and Dr. O'Dorisio pointed out serotonins fluctuate. They can be higher in the morning and lower in the afternoon. It is also associated with stress. It can be higher during periods of high stress. Foods also influence your serotonin level.

High Gastrin levels are also associated with diarrhea. Excess gastrin causes increased motility in the gut and motility means things just rapidly go through it. This is released when you eat and that is why some patients with elevated gastrin levels have diarrhea.

Small bowel resection is the most common surgery that is performed on carcinoid patients. Of course, the terminal ileum is the most common site. The ileocecal valve is located here and that is typically removed at the time of surgery. This is the area that bile salts are released to break down the fats we eat. The bile salts are very irritating to this area and so this release of bile salts leads to diarrhea - rapid motility of the intestine to excrete this substance. This explains why many patients who eat a fatty meal are having bowel movements so quickly after eating.

What is the treatment for this? I have some answers to share with you. Most common medications that you will have prescribed for your diarrhea are Imodium. I bet almost everyone in here has taken Imodium at one time or another even before diagnosis because you may have been told that you just may have irritable bowel syndrome, take Imodium, it will be okay. Paregoric, old drug, works great. A lot of older folks in the audience may have given it to their children as infants when they had tummy aches and we give that to our patients for diarrhea. It does help slow down the motility and it helps normalize the stools.

Tincture of opium is another good drug to use for diarrhea. This can be used in combination with Imodium. Paregoric can be used in combination with Imodium too and that is by prescription only. Lomotil, another drug that I am sure most of you have had at one time or another. That is also a good drug and the reason the Lomotil works is that it does slow down the intestinal motility like the others do and it helps you to re-absorb some of that water so it will normalize that stools. How many of you guys have we prescribed Questran too? I am sure there are many folks in the audience. The Questran is used because it helps decrease the irritation by breaking down the bile salts in the terminal ileum.

Sandostatin which most of you have heard of and are very familiar with. Sandostatin works by slowing the gut motility as well. Slowing the motility Allows the intestine time to absorb more water and normalize the stools.

Questran is a very good drug. It is FDA approved for lowering cholesterol but we have found that giving it to patients that have had the surgery and their terminal ileum removed it does inhibit the irritation of the bile salts and when that happens and you are going to have normal transit times and when I say transit times I mean that when everything is propelled through your intestine, your intestine has time to absorb the water and give you a normal stool.

Sandostatin - it is FDA approved for carcinoid syndrome and it inhibits release of hormones. Nancy talked a great deal about the hormones and Sandostatin. 5-HIAA is one of those hormones. Gastrin is another one. Motilin is another one. Another hormone that helps modulate is the chromogranin-A and these are all important, but the Sandostatin directly works on the motilin, gastrin and the 5-HIAA in reducing your diarrhea. It slows your transit time as well and decreases your diarrhea and that is what we want to do - stop your diarrhea.

Sandostatin can be given by subcutaneous injections. Most times when patients are prescribed this drug it will give initially as 150 microgram subcutaneous injections three times daily for at least two weeks. We want to determine the effectiveness. It is working for you? Because each patient is individual and response is individual we feel it is important to try the drug for two weeks. We then assess the patient by asking how many watery diarrhea stools are you experiencing daily and are you having any other side effects, such as nausea, bloating, excessive gas, or constipation.

We can give Sandostatin LAR IM depot after the initial two weeks as long as it has been effective and

the patient does not have any side effects and it is very well tolerated. As everyone has said here today, the Sandostatin is a naturally occurring substance in the body and most patients tolerate it very well. There are instances of patients that have gotten the LAR injection and it slowed down their gut so much they ended up in the hospital so we want to avoid that and we won't give an LAR before a trial of daily injectable Sandostatin. The usual starting dose of Sandostatin LAR is 20 mg every 28 days.

## QUESTIONS

Q: How long do you have to take the Questran at first?

A: Well our experience and the experience with the patients that we have prescribed Questran to when they had the terminal ileum surgery, the small bowel resection, it takes about two weeks and two packets a day. One packet in the morning and one in the afternoon before they see effectiveness and you can't stop it and say, hey, it's just not working after a couple of days. You need to give it a good two weeks. Okay. The other drugs can be used in combination with the Questran, but I have a case of a lady that had such horrible diarrhea that it affected her quality of life and that is an big important issue for us all. When you can't go to the grocery store, you can't go out to dinner with your friends and family because you need to check out where the nearest bathroom is that will greatly impact you. We put her on the Questran, told her to take it for a minimum of two weeks, she did, and she said she had her life back. Well, consequently, this lady felt so wonderful she thought " I can stop the Questran". She did and she went to the other direction again. So, it is very important the once you find the Questran works for you stay on it. You may be able to decrease the dose to one packet a day. Many patients go on a half packet in the morning and a half a packet in the afternoon and it works very good, but you can't just stop saying I am all better because it is never going to be better.

Q: Have you ever prescribed Creon for the diarrhea?

A: Creon is typically for patients who have had their pancreas resected. We have never prescribed it for patients with gut carcinoids. That has not been my experience and that's why I did not mention it. Patients that have had pancreatic carcinoids which are rare, like Dr. Kvol's mentioned earlier, will typically take a replacement to help in their digestion like Creon, but we don't normally prescribe that for patients with carcinoid.

Q: Does having 5 or 6 small meals a day help with the diarrhea?

A: It can for many people. They may find if they have a larger meal than usual they may have a little bit of what we call dumping syndrome and it just propels very quickly through the intestines. You may find that if you have five or six smaller meals instead of three very large ones it is better tolerated and less diarrhea. It is real important for everybody to realize that because you have loose stools does not mean you have diarrhea. True diarrhea is watery and if it is loose that is fine. It is better than the alternative which is constipation.

Q: What does the gallbladder do?

A: Okay. The purpose of a gallbladder. The gallbladder stores and concentrates bile. When the gallbladder is gone, the liver puts out the bile each time we eat any fatty foods. Well, the bile salts are irritating to the colon and diarrhea after a fatty meal is common.

Q: You said you have never given Creon for fatty stools and diarrhea.

A: A lady in the front brought that up. She does take Creon and my experience personally is that we never prescribed it and Dr. Kvol's has not prescribed Creon when the patient has been on Sandostatin due to fatty stools and I really don't recall any patients complaining of fat as a particular problem.

Q: Is it better to take the daily shots of Sandostatin or the LAR? Does anyone ever adjust to the

change?

A: They will adjust. Many patients adjust and do beautifully on the LAR. We have had patients that feel like when they are on the once a month injection and they are not actively treating their cancer every day that, they are not doing enough and they want to go back to daily injections. I, however, would be of the other mindset. Hey, I want to be out, busy, active, doing what I want to do. Do I want to be tied to a needle and carrying my meds with me all the time. Not on your life.

Q: cannot hear question

A: I've never heard of that. Maybe Dr. O'Dorisio can answer that for us.

Q: Is it a problem to have 15 to 20 bowel movements a day?

A: That needs to be controlled. When you have that many bowel movements a day it is going to impact your quality of life. The only thing I can tell you from our experience a lot of it is trial and error, what is going to work best for the patient. We need to individualize the medications and the care plan for each patient. There is not any good answer.

Q: Do you ever prescribe rescue shots of Sandostatin?

A: Some patients have done that and I heard a gentleman mentioned in the crowd earlier about the LAR rescue shots or the Sandostatin rescue shots while they are on LAR and, yeah, some people need that. They need something for breakthrough. We find some patients if they are on every 28 day LAR and they are really having a lot of breakthrough diarrhea the seven days before their next shot is due we may increase the frequency of the injections to every 21 days to try and get better control. During that time, we are also measuring 5-HIAA too. We want to know, is there is a correlation there. For some patients increasing the dose of LAR is another alternative. If they are on the 20 mg initially and it is not controlling syndrome and symptoms then it could possibly be increased to 30 mg. We have one patient that is on 40mg every 21 days. That does not happen very often, but again it is individualized. We look at the 5-HIAA. It all goes into what Nancy said when we are evaluating the patient, we want to physically evaluate the patient, we want to look at your lab parameters, we want to look at your CAT scans and put it all together so that we can manage you as best as possible.

Q: Should antibiotics be changed because of the diarrhea?

A: Diarrhea can be a problem with anyone taking antibiotics. Augmentin is one that classically gives a lot of people diarrhea. The best thing you can do if you have to be on an antibiotic, either take it with food and that usually will decrease the diarrhea and sometimes it just a thing that you have to put with for a few days. If it gets severe you might have to take an Imodium or something.

Q: Is yogurt good to take while on antibiotics?

A: Yes, absolutely. Because your gut is full of bacteria that help us breakdown food and when we take these antibiotics to kill the bacteria that is making us sick it is also killing the normal bacteria that helps in our digestion and keep the bowels in balance if you will. Yogurt is a very good thing to help control that. I would recommend to anyone and I do with my children as well if you are on antibiotics eat yogurt everyday because that helps keep your intestinal bacteria normal.

Q: Is Creon good for fatty stools?

A: Yes. As this lady brought up and Dr. O'Dorisio suggested for some patients that is the appropriate thing to do. It is not something like I said that we have done, but it is an excellent idea and excellent approach to helping with those fatty stools so that it will help you breakdown the fats better. The only complaint I hear from patients that are on Creon is gas and bloating. That is true she says.

The end

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