

QUESTIONS YOU *MUST* ASK YOUR CARE TEAM TODAY

GUIDE TO UNDERSTANDING

Healthmonitor®

Carcinoid Syndrome



- Skin flushing?
 - Diarrhea?
 - Heart racing?
- It could be
carcinoid syndrome!

**KNOW THE SIGNS—
AND LEARN
YOUR TREATMENT
OPTIONS!**

***“I’m living life
to the fullest!”***

How adventurer,
avid runner, writer
and mother of three
Catherine Gravatt is
forging ahead despite
carcinoid syndrome

COMPLIMENTS OF YOUR HEALTHCARE PROVIDER

GUIDE TO UNDERSTANDING Carcinoid Syndrome



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Special thanks to our medical reviewer:

Richard R.P. Warner, MD, founder and medical director of the Carcinoid Cancer Foundation and director of the Center for Carcinoid and Neuroendocrine Tumors at Mt. Sinai Hospital, NY



And special thanks to our partner, **The Carcinoid Cancer Foundation**

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For more information: Health Monitor Network, 135 Chestnut Ridge Road, Montvale, NJ 07645; 201-391-1911; healthmonitor.com ©2017 Data Centrum Communications, Inc. Questions? Contact us at customerservice@healthmonitor.com

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Get back to feeling your best!

Allan W. was sitting in his gastroenterologist’s office, waiting to hear that a food allergy or possibly even Crohn’s had been causing his strange symptoms lately. He’d been suffering from regular diarrhea—despite sticking to a bland diet—and he’d been having strange hot flashes and even waking up with night sweats.

“My wife actually joked with me, ‘Maybe you have menopause!’ ” laughs the 55-year-old systems director.

Allan’s doctor, however,

suspected something much different. A few years earlier, a routine colonoscopy found a carcinoid tumor in Allan’s colon. He’d had surgery to remove the cancer and some follow-up chemotherapy, and thought he was in the clear. Further scans had shown his colon was cancer-free.

However, when Allan’s strange symptoms started showing up, his doctor ordered another colonoscopy and an MRI. As it turned out, not only had his cancer returned, but now it had spread to his liver. A urine test

confirmed that Allan had high levels of 5-HIAA, a substance produced when the body has too much serotonin—a side effect of the carcinoid tumors.

Allan was relieved to have a diagnosis—the high serotonin levels had been the culprit behind his GI distress, hot flashes and night sweats. In fact, his condition even had a name: carcinoid syndrome. ▶



What is carcinoid syndrome?

Carcinoid syndrome affects about 1 in every 10 patients who have a carcinoid tumor, or about 14,000 Americans. Usually found in the GI tract, the lungs or the pancreas, carcinoid tumors are made up of hormone-producing (neuroendocrine) cells. Often, they begin to produce their own hormones, resulting in an overload of serotonin, bradykinin, histamine and/or prostaglandins.

In most cases, the liver is able to filter out the excess hormones, but if the tumor spreads to the liver, the organ can have difficulty doing its job, throwing hormone levels out of balance. What's more, carcinoid tumors that form in the lungs or pancreas can leak excess hormones directly into the bloodstream, bypassing the liver altogether, also causing an

imbalance. It is precisely that hormone imbalance that is likely to trigger carcinoid syndrome.

How is it diagnosed?

Because carcinoid syndrome is rare, it can be tough to diagnose. If you suspect you have it, you can ask your doctor about the following tests:

- **5-HIAA URINE OR PLASMA TEST.** People with carcinoid syndrome often have high levels of 5-HIAA, a substance produced when your body processes serotonin.

• **SEROTONIN TEST.** Doctors can also look for high levels of serotonin in your blood.

There are also several tests that can test or look for the neuroendocrine tumor itself:

- **CHROMAGRANIN A (CgA) TEST.** A blood test can show if you have high levels of CgA, a protein often found in carcinoid tumors.

- **POSITRON EMISSION TOMOGRAPHY (PET) SCAN/68-GALLIUM SCAN.** In this test, a patient is injected with a radioactive dye, then undergoes a 3D scan to look for tumor cells.

- **SOMATOSTATIN RECEPTOR SCINTIGRAPHY (SRS).** For this scan, a patient is injected with somatostatin and a radioactive material to help detect tumors.

What treatments are available?

Treatment for carcinoid syndrome often starts by treating the carcinoid tumors themselves. How your healthcare team decides to treat your cancer depends on the stage, aggression and location of your cancer, as well as your overall health.

Cancer therapies

Typically, if a carcinoid tumor can be removed by surgery, that will be the first option; if the tumor is able to be completely removed, the patient may be considered cured and syndrome symptoms will end.

If surgery to remove the tumor isn't an option—either due to its location or because the cancer has spread—your care team may also recommend the following, or a combination thereof: chemotherapy, radiation, immunotherapy, biologics (such as interferon) or targeted therapy.

Liver therapies

If carcinoid tumors spread to the liver, certain liver therapies, such as hepatic artery embolization (where blood flow is cut off to the tumors), radiofrequency ablation (where tumors are killed with heat)

NEWER THERAPIES

There are several therapies currently in clinical trial stage that have recently, or may very soon, become FDA-approved for treating carcinoid cancer and carcinoid syndrome, including mTOR inhibitors, peptide receptor radionuclide therapy and telotristat.

and cryotherapy (where tumors are frozen), may also be recommended.

Somatostatin analogs

Many people diagnosed with advanced carcinoid cancer may also be given monthly injections of somatostatin analogs. These injectable medications, including octreotide (sandostatin) and lanreotide (somatuline depot), are made of proteins that help break down excess hormones in your system, helping reduce the symptoms of carcinoid syndrome, and sometimes helping slow the growth of carcinoid tumors.

Left untreated, carcinoid syndrome is more than just uncomfortable, it can cause life-threatening complications (learn more on page 15). If you're experiencing any of the symptoms, it's important to discuss them with your healthcare team as soon as possible. Allan is glad that he did!

"I take medication now to control my symptoms and it has really helped," says Allan. "Carcinoid felt very overwhelming at first, for both me *and* my wife. But now I feel back in control." 🗣️



YOUR HEALTHCARE TEAM

You may see only one or several of these medical professionals to help you manage your carcinoid syndrome.

General practitioner/family care doctor—an MD who provides primary healthcare to patients; your GP may be the first to diagnose carcinoid syndrome and may coordinate your care with specialists

Oncologist—an MD who specializes in cancer and can coordinate your care with other members of your healthcare team

Medical oncologist—an MD who treats cancer with medicine, including chemotherapy

Radiation oncologist—an MD who treats cancer using radiation

Surgical oncologist—an MD who treats cancer with surgery

Palliative care doctor—an MD with expertise in pain-relief methods

Endocrinologist—an MD who specializes in the endocrine system and can help treat the hormonal imbalances caused by carcinoid cancer

Gastroenterologist—an MD who specializes in diseases of the GI tract; he or she may treat you if you have carcinoid tumors in your stomach, intestines, colon or liver

Pulmonologist—an MD who specializes in diseases of the lungs; he or she may treat you if you have carcinoid tumors in your lungs

Cardiologist—an MD who specializes in the cardiovascular system and can help treat carcinoid heart disease

Hepatologist—an MD who specializes in diseases of the liver; he or she may treat you if you have carcinoid tumors in your liver

Physician assistant—a healthcare professional who is licensed to practice medicine and write prescriptions

Nurse practitioner—an advanced-practice nurse who is licensed to practice medicine and write prescriptions

KNOW THE SYMPTOMS!

It's important to learn the signs of carcinoid syndrome, since it can sometimes be tricky to diagnose, and may be confused with more common medical issues, such as IBS or menopause. Symptoms can also vary from person to person, but the most common include:

- **Skin flushing.** The skin—typically the face and upper torso, but sometimes the legs—develops a purplish or red hue and feels warm. It can last anywhere from a couple minutes to a few hours, and may be triggered without cause or due to stress, eating or alcohol.
- **Diarrhea.** Frequent (sometimes up to 20 times a day) watery stools, which may be accompanied by cramps.
- **Rapid heartbeat/damaged heart valves.** Your heart feels like it's racing, even if you're inactive.

Other symptoms can include facial lesions or rashes, difficulty breathing, joint pain, stomach pain, low blood pressure, night sweats, persistent fatigue and unexplained weight loss.

“I’m still living life to the fullest!”

Carcinoid cancer couldn’t slow down Catherine Gravatt—and neither has carcinoid syndrome. Here’s how this adventurer, runner, writer, wife and mother of three is forging ahead. —BY LINDSAY BOSSLETT



Catherine Gravatt’s symptoms began innocently enough when she experienced stomach cramping partway through a half marathon back in 2014.

“It felt like a burning sensation,” she recalls. “I pushed through and ran the race and ironically was really happy with my time (1:59!). I went to a GI specialist when the pain persisted after the race, and was treated for a mild ulcer.”

Like many patients with carcinoid syndrome, Catherine’s symptoms didn’t ring any alarms for her doctors. Especially since, at 40 years old, she also appeared to be in prime health.

“The pain did subside with the ulcer treatment, but it would return intermittently,” the Chapel Hill, NC, resident says. “Then I began having lower back pain, too. I was also experiencing fatigue and losing weight from lack of appetite. I thought my symptoms were likely due to raising three young girls, enduring two big moves in two years, working and running. But my instincts and intuition told me something was wrong and I needed to find it.”

“I was diagnosed with a cancer I’d never heard of!”

Despite her doctor’s protestations that she was fine, Catherine insisted on an endoscopy and a colonoscopy to discover the source of her pain. That’s when doctors found a mass in her intestines.

“Three days later, once the mass was biopsied, I received a call from my doctor,” she says. “In the midst of chaos of kids at my house playing, she delivered the news that I had a type of cancer I had never heard of. Little did I know it would become part of my everyday life.”

Catherine had a section of her intestines taken out, as well as 65 lymph nodes, and was sent home with the hope that her carcinoid tumor had been completely removed. But her strange symptoms persisted—and then new symptoms started appearing.

“Why was I flushing?”

“After my surgery I began experiencing flushing,” she says. “I could feel the heat and would rush to the mirror to try and ‘catch’ it in

action. It was so confusing because I could feel it and I could see it, but it would go away fairly quickly.”

Despite knowing she’d had a carcinoid tumor, Catherine’s doctors didn’t see any connection between her symptoms and her cancer. It wasn’t until she sought the opinion of a GI oncologist at Duke who specializes in neuroendocrine cancers that she got some answers.

“He listened, initiated the appropriate tests and found the lesions on my liver,” she says. That meant her cancer had spread, and finally gave her an explanation for the cramping, stomach upset, flushing and fatigue: Catherine had carcinoid syndrome. Her tumors were not all treatable, but she started on a medication to help control her syndrome symptoms. She also hopes to avoid the heart damage that carcinoid syndrome can sometimes cause.

“My symptoms are under control”

“The medication has stopped my flushing symptoms almost entirely. That has really eased my anxiety.

I find that if I’m not having symptoms, I can kind of forget I have cancer sometimes. And I know that if it ever stops working I have other options.”

While managing her carcinoid cancer and the syndrome it causes hasn’t been easy, Catherine refuses to let it slow her down.

“I am super active, look healthy and am living life as fully as I can,” she says. “I wake up each day and listen to my body. I look into the faces of my incredible girls and know that anything less than positive is not an option. I have an inner desire to keep pushing forward. There are so many people relying on me to be here. I take it one day at a time and find something good in each day. I also laugh. Life is full of humor if you see the funny in each day!” 📌

Catherine’s top thriving tips

- **DON’T STOP FIGHTING.** “I just try to push through and keep going. When I had my surgery, I was so determined to get back up. After the first day, I would take my IV pole—which I affectionately called ‘slim’—and walk a mile around the halls every single day until I was released. It was so hard and I was so slow, but I just needed to feel like I was moving forward—figuratively and literally.”
- **KEEP MOVING, HOWEVER YOU CAN.** “I still race occasionally; however, I am only competitive with myself. Running is where I conjure strength, think through life and just breathe. I also recently applied for a spot with Athletes for Cancer, an organization that provides young adult cancer survivors an opportunity to attend an adventure camp. I am hopefully attending a surf camp in Hawaii in the spring or fall!”
- **GET HELP WITH WHAT TO SAY.** “My husband and I decided to not initially share the news with my young daughters, as we felt the surgery was enough for them to endure. After the discovery of the spots on my liver and beginning medication to control the syndrome, we consulted with a child/life specialist at Duke who guided us through the steps of sharing the news with the girls. They have handled it beautifully. My older daughter asked, ‘Mom, did you have cancer when you were snowboarding in February?’ I was so happy to just say ‘Yes, I did! See? Cancer isn’t holding this mama down!’”
- **SEEK SUPPORT.** “My husband and my parents have been by my side through every grueling step. The love and care I have received are life-sustaining. I also have amazing friends who make me laugh even in the darkest of moments. They refuse to let me get bogged down, but they let me shed a tear when I need to, too.”
- **EDUCATE YOURSELF.** “Carcinoid syndrome is such an ‘unknown’ and the learning curve on how to live with it is steep. Education and streamlining the information for those newly diagnosed, as well as those who have been living with the disease, is essential.”



Are your symptoms under control?

Managing carcinoid syndrome can be challenging, but finding the right treatment can make all the difference. Fill out this tool and share it with your healthcare team to make sure you're doing all you can to thrive.

List the current medications you are taking, including anything over-the-counter or any supplements you are taking:

List any conditions (e.g. diabetes, heart disease, etc.) you've been diagnosed with since your last visit:

List any major life events (e.g. job change, divorce, moving) that have occurred since your last visit:

Check the boxes to indicate any symptoms or side effects you're experiencing and how often they are affecting your life:

SYMPTOM	DOESN'T AFFECT ME	RARELY	A FEW TIMES PER WEEK	DAILY	MULTIPLE TIMES PER DAY
Diarrhea					
Stomach cramping					
Nausea/vomiting					
Constipation					
Skin flushing					
Difficulty breathing					
Rapid heartbeat					
Dizziness					
Headache					
Joint pain					
Fatigue					
Feeling down or depressed					
Other (please specify):					

NOW APPROVED



FIRST AND ONLY



ORAL TREATMENT FOR CARCINOID SYNDROME DIARRHEA

Indication

XERMELO™ is a prescription pill, used along with somatostatin analog (SSA) therapy, for carcinoid syndrome diarrhea in adults who are not adequately controlled by SSA therapy.

Important Safety Information


- ♦ XERMELO™ may cause constipation which can be serious. You should stop taking XERMELO™ if severe constipation or severe, persistent, or worsening abdominal pain develops
- ♦ The most common side effects of XERMELO™ include nausea, headache, increase in hepatic enzymes, depression, flatulence, decreased appetite, swelling of your hands and feet, and fever

For more information about XERMELO™, talk to your doctor or see the next page for the Brief Summary of Full Prescribing Information.

You may report an adverse event related to Lexicon products by calling 1-844-539-7427 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report serious problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Talk to your doctor to see if XERMELO™ can help you. Visit XERMELO.com to learn more.



PATIENT INFORMATION XERMELO™ (zer-mel-o) telotristat ethyl tablets	
Read the Patient Information that comes with XERMELO™ before you start taking the medication and each time you get a refill. There may be new information. This leaflet does not take the place of talking with your doctor about your condition or treatment.	
If you have any questions about XERMELO™, ask your doctor or pharmacist.	
What is XERMELO™? XERMELO™ is a prescription pill, used along with somatostatin analog (SSA) therapy, for carcinoid syndrome diarrhea in adults who are not adequately controlled by SSA therapy. XERMELO™ has not been studied in children under 18 years of age.	
What should I tell my doctor before taking XERMELO™? Before you start XERMELO™, tell your doctor if you: • Have severe constipation or severe, persistent, or worsening abdominal pain Tell your doctor about all the medicines you take , including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of your medicines to show to your healthcare provider and pharmacist when you get a new medicine.	
How should I take XERMELO™? • Take XERMELO™ exactly as prescribed by your doctor. Do not change your dose or stop taking XERMELO™ without talking to your doctor • Take XERMELO™ 3 times a day with meals • Your doctor should start you on another type of medicine known as a somatostatin analog • If you take too much XERMELO™ or overdose, call your doctor or the Poison Control Center right away. Or go to the nearest emergency room	
What are the possible side effects of XERMELO™? XERMELO™ can cause serious side effects. These serious side effects include: • Constipation: XERMELO™ may cause constipation which can be serious. You should stop taking XERMELO™ if severe constipation or severe, persistent, or worsening abdominal pain develops	
The most common side effects of XERMELO™ include: • Nausea • Headache • Increase in hepatic enzymes (gamma-glutamyl-transferase) • Depression	• Swelling of your hands and feet • Flatulence • Decreased appetite • Fever
How should I store XERMELO™? • Store XERMELO™ at room temperature (59-86°F, 15-30°C) • Do not keep medicine that is out of date or that you no longer need • Keep XERMELO™ and all medicines out of the reach of children. Be sure that if you throw medicine away, it is out of the reach of children	
General Information about XERMELO™: Medicines are sometimes prescribed for conditions that are not mentioned in patient information leaflets. Do not use XERMELO™ for a condition for which it was not prescribed. Do not give XERMELO™ to other people, even if they have the same problem you have. It may harm them.	
This leaflet summarizes the most important information about XERMELO™. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about XERMELO™ that is written for health professionals. Or you can go to the XERMELO™ website at www.XERMELO.com .	
What are the ingredients in XERMELO™? Active ingredient: telotristat ethyl Inactive ingredients: colloidal silicon dioxide, croscarmellose sodium, hydroxypropyl cellulose, lactose anhydrous, macrogol/PEG, magnesium stearate, polyvinyl alcohol [part hydrolyzed], talc and titanium dioxide.	
 Revised: 2/2017 Lexicon Pharmaceuticals, Inc.	



Questions for your healthcare provider

1. Do my symptoms indicate I may have carcinoid syndrome? _____
2. What tests will I need to confirm it? What tests will I need to chart my progress? _____
3. What are my treatment options for my tumors? _____
4. What are my treatment options for the syndrome itself? _____
5. How long should I expect to wait until the treatment starts working? _____
6. What are the side effects? Are there any I should call you about immediately? _____
7. Am I a candidate for a clinical trial? Are there any you recommend? _____
8. Are there any lifestyle tips (diet, exercise, etc.) you can recommend to help ease my syndrome symptoms? _____
9. How can I protect my heart against carcinoid heart disease? _____
10. How can I prevent carcinoid crisis? _____
11. Do you recommend I see any medical specialists? _____
12. When should I make my next appointment with you? _____

Making every day better

Living with carcinoid syndrome can often feel frustrating—even overwhelming. But these five patients have learned that it is possible to manage the disease. Read their tips to see if any of their ideas could work for you! —BY LINDSAY BOSSLETT

Keep it real!

Kath Lewis, 54, Trentham, England

Use a calendar.

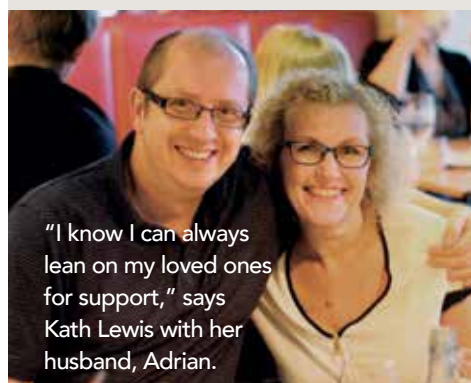
“Everything now revolves around regular clinic visits, treatments and scans. My calendar goes with me everywhere. I also use it to make sure that I’m not late getting the medication for my syndrome symptoms.”

Find activities you enjoy.

“Fatigue can make things difficult now, and I have to be careful how I exercise, so I stick to walking, swimming and some gentle yoga. But I try to keep life as normal as possible and not make it about my illness, and keeping active helps me do that.”

Focus on survivors.

“My diagnosis wasn’t the type of news I wanted to hear, but it is what it is, and there are plenty of people out there with this who are long-term survivors, which gives me plenty of hope.”



“I know I can always lean on my loved ones for support,” says Kath Lewis with her husband, Adrian.



“I don’t have time to feel sick,” says Evelyn Biles [far left], with Ruth, one of her seven adopted children, five of her 22 grandchildren and her husband, Steve.

Use it to reach out to others

Evelyn Biles, 64, Yorktown, VA, and Petaling Jaya, Malaysia

Find your fighting spirit.

“I could let it drag me down, but there’s so much more of life in which I want to participate that I get angry rather than depressed. I’d rather see myself as a Weeble toy that won’t stay down!”

Look for the bright side.

“A friend once asked me if I’d ever wondered, ‘Why me’ and I answered, ‘Why not me?’

Why should I be exempt from any suffering or carcinoid syndrome? I realized that all the things that I had learned bringing up nine children—seven of whom were adopted—had given me the stamina to live through this challenge, as well. It often becomes the bridge, even, to reach out with empathy to those suffering far greater than I am.”

Focus on family—and the good times

Chris Beebe, 33, Imley, MI

Live for yourself.

“Living with carcinoid syndrome has changed me as a person. I used to care what people think, but this has given me freedom from that. I’m just going to do what makes me happy and what is good for my family—they are who come first. I don’t have time for anything else.”

Hold on to the good days.

“You will have bad days and you’ll have good days. In the moment of those bad days you may think they will never end, but they do. It’s important to remember the good times and focus on those.”

Keep perspective.

“I always try to keep in mind it could be worse. Carcinoid can tear families apart. And this was difficult—on me and especially my wife. But we’re managing it; we’re here and we’re okay. And I know if I can handle this, I can handle anything.”



“I want to be there for my family,” says Chris Beebe with his wife, Beth, and daughter, Sarah.



“Riding Abbie helps me forget about carcinoid for a while,” says Sharon Larsen.

Remember what really matters

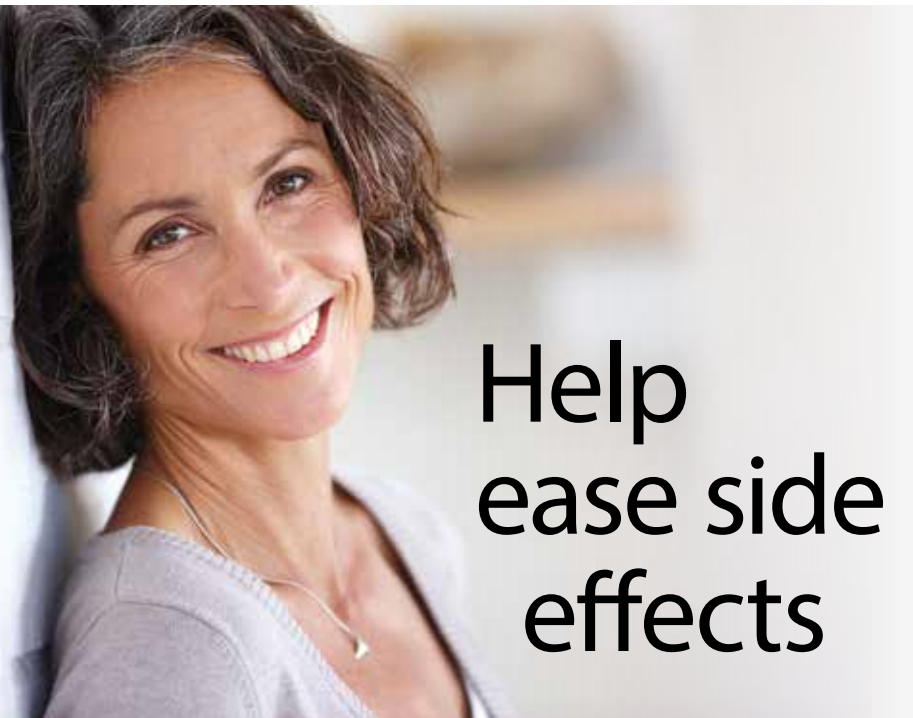
Sharon Larsen, 53, Salt Lake City, UT

Don’t sweat the small stuff.

“I think knowing that I really am mortal, I’ve become more patient with others. I’m not in a hurry. I want to ‘live in the moment.’ Getting angry over traffic jams just isn’t worth it.”

Find Zen after treatment.

“It can be tough once you get your diagnosis and learn your cancer isn’t treatable by chemo or radiation, and your surgery is done. Suddenly there’s no more daily appointments, no more feeling like you’re really doing something to kill the cancer. When I went from lots of appointments, surgery, tests, etc., to basically a monthly shot, it was like being cut off. But it is normal. A lot of patients feel that way when treatment ends. It doesn’t mean you’ve given up the fight.”



Help ease side effects

These strategies can help you thrive despite carcinoid syndrome, says carcinoid cancer specialist Run Yu, MD, PhD, associate professor of medicine, Division of Endocrinology, UCLA David Geffen School of Medicine.

1 Tame diarrhea

Many patients with carcinoid syndrome are prescribed regular shots of octreotide to help control symptoms, including diarrhea. But for some it's not enough to control symptoms completely. Luckily, there are other options. "A few new therapies, including mTOR inhibitors, PRRT and telotristat, are available now or will likely be available soon to treat the diarrhea caused by carcinoid," Dr. Yu says, adding that over-the-counter loperamide can also help. "A patient with severe carcinoid diarrhea should ask her/his doctors about the new therapies."

There have also been some studies that looked at how diet can affect stomach upset in carcinoid patients. "Generally, patients may benefit from avoiding high-fiber, high-fat and spicy foods," Dr. Yu says, adding

that everyone is different, however, so patients should pay attention to what they're eating to see if certain food items are a trigger.

2 Ease flushing

Flushing can be uncomfortable and even embarrassing. Like diarrhea, it's usually treated with regular octreotide shots, but they don't always provide adequate relief. The good news? The same new treatments that are combatting diarrhea should also take aim at flushing, says Dr. Yu, so talk to your healthcare provider if your symptoms aren't well controlled.

A few lifestyle changes can also help ease symptoms. "Generally, hot food and alcohol should be avoided," Dr. Yu says, adding that chocolate can also be a trigger for some. Other common triggers include stress and being in a hot, humid environment.

3 Overcome breathing difficulty

Wheezing caused by carcinoid syndrome may be a sign of carcinoid crisis (read more on the next page). "Significant wheezing directly caused by carcinoid usually happens during surgical or other procedures and is managed by doctors directly," Dr. Yu explains. If you're having difficulty breathing or wheezing on a regular basis, the more likely cause is asthma. Treatments for asthma include steroids, anti-inflammatories and bronchodilators (inhalers).

4 Relieve achy joints

While there's no direct correlation between carcinoid syndrome and arthritis, many patients do report experiencing joint or muscle pain. "If the pain is severe, the patient should notify his or her doctors," Dr. Yu says. "Exercise, yoga, massage and medications such as NSAIDs all help." Dr. Yu adds that sometimes joint or muscle pain can be caused by a poor diet, or not getting enough nutrition (possibly due to diarrhea). If that's the case, ask your care provider if a supplement or multivitamin might help.

5 Calm a racing heart

Some carcinoid patients may experience a racing heart, either on its own or during episodes of flushing. You can help slow a racing heart by resting, staying hydrated, reducing stress and taking any heart medication you've been prescribed, says Dr. Yu. However, he cautions that "a racing heart in a patient with carcinoid may suggest heart failure, electrolyte disturbances or general physical deconditioning, so it's important to notify your doctors." 📞

Fending off complications

Carcinoid syndrome can not only cause debilitating side effects—it can also increase your risk for life-threatening complications. Find out the best ways to protect yourself.

Carcinoid heart disease

What it is: About half of patients with carcinoid syndrome experience carcinoid heart disease, which occurs when excess hormones released by carcinoid tumors damage the heart. Serotonin, in particular, causes fibrous tissue and plaques to form on heart valves, impairing their ability to open and close. This makes it difficult for the heart to pump blood effectively. Over time, it can lead to heart failure.

The symptoms: Fatigue, shortness of breath, racing heart
What you can do: If you've been diagnosed with carcinoid syndrome, your care team may recommend regular injections of octreotide or lanreotide, medications that help control your hormone levels and reduce potential damage to your heart. There are also new medications approved or nearing FDA approval that may help.

If you've already experienced heart damage, your treatment plan will depend on the extent of the damage and your overall health—some patients may be prescribed medications such as diuretics and digoxin. Others may be candidates for surgical procedures to fix a damaged valve, including valvoplasty or valve replacement.

In the meantime, leading a

heart-healthy lifestyle—a diet low in saturated fat and sodium and high in fresh produce and lean protein, exercising, quitting smoking and managing stress—can go a long way toward helping you feel your best.

Bowel obstruction

What it is: If carcinoid tumors grow too large in your intestine, or spread to the lymph nodes near the bowels, it can cause your intestines to narrow or become dented. This can make it difficult or even impossible for food or liquid to pass through. Left untreated, obstructions can cause tearing in the intestinal wall, or even cause parts of the intestine to die and become infected.

The symptoms: Severe cramping and stomach pain, loss of appetite, constipation, swelling around the stomach and vomiting

What you can do: An obstruction is a medical emergency. Contact your healthcare team as soon as you experience symptoms. Most obstructions require surgery to be repaired.

Carcinoid crisis

What it is: An extreme form of carcinoid syndrome, carcinoid crisis occurs when a trigger, commonly surgery or receiving anesthesia, causes the tumor to release a flood of hormones.

The symptoms: Severe flushing, difficulty breathing, extremely low blood pressure, confusion, dizziness, rapid heartbeat

What you can do: Certain medications, including octreotide injections, can be administered during a crisis episode to help alleviate symptoms. To prevent carcinoid crisis, let your care team know you have carcinoid syndrome before any medical procedure—even dental surgeries. They may be able to choose an anesthesia less likely to trigger an episode, and should have octreotide on hand just in case. 📞





OUR EXPERT:

Richard R.P. Warner, MD, founder and medical director of the Carcinoid Cancer Foundation and director of the Center for Carcinoid and Neuroendocrine Tumors at Mt. Sinai Hospital, NY

NEW OPTIONS FOR CARCINOID SYNDROME


Q I have advanced carcinoid cancer with multiple tumors on my liver and have been living with carcinoid syndrome for a few years. I get monthly shots of octreotide, but I still experience diarrhea and flushing a few times a day. Do I have any other options? Should I consider a clinical trial?

A Diarrhea and flushing that is unresponsive, or no longer responsive, to octreotide can be treated in many ways. Your options will depend on what, if any, prior treatment was done in addition to octreotide, and may include surgical

removal of tumors in the liver, or other treatments for the tumors, including radiofrequency ablation, hepatic artery catheterization, radiotherapy or chemotherapy. These treatments are effective in a significant percentage of cases. Your healthcare team may also recommend simply increasing the dosage of octreotide—60 mg. every four or even three weeks can be done, or switching to an injection of lanreotide. Finally, there are some new treatments available or that are still in clinical trial phase and will hopefully be approved by the FDA in the next few months.

INTERFERON AND THE BLUES

Q I'm taking interferon to treat my carcinoid tumors and I've been feeling very down lately. Could the interferon be causing this?

A Interferon is well known to have the possible side effects of fatigue and depression. Reducing the dose might help or taking a small dose of an antidepressant can help—but serotonin reuptake inhibitors, monoamine oxidase and ACE inhibitors should be avoided. If symptoms don't improve, the interferon may have to be discontinued and other forms of chemotherapy may have to be tried. 



WE WILL HAVE ACHIEVED OUR MISSION WHEN

EVERYONE

WORLDWIDE IS AWARE OF CARCINOID CANCER & NETS.

UNTIL THEN, OUR WORK IS

NOT DONE.

The Carcinoid Cancer Foundation is the oldest nonprofit carcinoid and neuroendocrine tumor organization in the United States, founded in 1968. The mission of the Foundation is to increase awareness and educate the general public and healthcare professionals regarding carcinoid and related neuroendocrine tumors (NETs), to support NET cancer patients and their families, and to serve as patient advocates.

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www.carcinoid.org