



cancer.org | 1.800.227.2345

After Gastrointestinal Carcinoid Tumor

**Living as a Gastrointestinal Carcinoid
Tumor Survivor**

- [Ask your doctor for a survivorship care plan](#)
- [Keeping health insurance and copies of your medical records](#)
- [Can I lower the risk of my cancer progressing or coming back?](#)
- [If the cancer comes back](#)
- [Second cancers after treatment](#)
- [Getting emotional support](#)

For some people with gastrointestinal (GI) carcinoid tumor, [treatment](#)¹ may remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer coming back. This is a very common if you have had cancer.

For other people, the cancer may never go away completely. These people may stay on drug therapy or get regular treatments with chemotherapy, radiation therapy, or other therapies to try to help keep the cancer in check. Learning to live with cancer that does not go away can be difficult and very stressful.

Follow-up care

When treatment ends, your doctors will still want to watch you closely. It is very important to go to all of your follow-up appointments. During these visits, your doctors will ask if you are having any problems and will examine you and may order lab tests or x-rays and scans to look for signs of cancer or treatment side effects. Almost any cancer treatment can have [side effects](#)². Some may last for a few weeks to months, but others might last a long time. Some side effects might not even show up until years after you have finished treatment. It's important for all GI carcinoid tumor survivors, to let their health care team know about any new symptoms or problems, because they could be caused by the cancer coming back or by a new disease or a [second cancer](#).

Doctor visits and follow-up tests

Standard recommendations for doctor visits and follow-up tests have not yet been defined for GI carcinoid tumors. Initial guidelines suggest that for most people who have had their GI carcinoid tumors completely removed:

- Very small (less than 1cm) and low-grade (grade 1) GI carcinoids may require minimal or no follow-up due to a low risk of the cancer coming back
- GI carcinoids that are bigger (larger than 1 cm), grade 2 or grade 3, or have lymph nodes with cancer may require more frequent imaging tests (a CT scan yearly for 3

Can I lower the risk of my cancer progressing or coming back?

If you have (or have had) a GI carcinoid tumor, you probably want to know if there are things you can do that might lower your risk of the cancer growing or coming back, such as exercising, eating a certain type of diet, or taking nutritional supplements.

Adopting healthy behaviors such as [not smoking](#)⁷, [eating well](#)⁸, [getting regular physical activity](#)⁹, and [staying at a healthy weight](#)¹⁰ is important. We know that these types of changes can have positive effects on your health that can extend beyond your risk of GI carcinoid tumors or other cancers.

Quitting smoking

If you smoke, quitting is important. Although most GI carcinoid tumors do not appear to be linked with smoking, more studies are needed. Of course, [quitting smoking](#)¹¹ can have other health benefits such as improved healing, lowering your risk of some other cancers, as well as improving your outcome (prognosis) from the cancer. If you need help quitting, talk to your doctor or call the American Cancer Society at 1-800-227-2345.

About dietary supplements

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of GI carcinoid tumors progressing or coming back. This doesn't mean that no supplements will help, but it's important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits on what they're allowed to claim they can do. If you're thinking about taking any type of nutritional supplement, talk to your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

If the cancer comes back

If cancer does come back at some point, your treatment options will depend on where the cancer is, what treatments you've had before, and your health.

For more information on how recurrent cancer is treated, see [Treatment of Gastrointestinal Carcinoid Tumor, by Extent of Disease](#)¹².

For more general information on recurrence, you may also want to see [Understanding](#)

[Recurrence](#)¹³.

Second cancers after treatment

People who've had a GI carcinoid tumor can still get other cancers. Learn more in [Second Cancers After Gastrointestinal Carcinoid Tumor](#).

Getting emotional support

Some amount of feeling [depressed, anxious, or worried](#)¹⁴ is normal when GI carcinoid is a part of your life. Some people are affected more than others. But everyone can benefit from help and support from other people, whether friends and family, religious groups, support groups, professional counselors, or others. Learn more in [Life After Cancer](#)¹⁵.

Hyperlinks

1. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/treating.html
2. www.cancer.org/cancer/survivorship/long-term-health-concerns/cancer-as-a-chronic-illness.html
3. www.cancer.org/cancer/managing-cancer/side-effects.html
4. www.cancer.org/cancer/survivorship/long-term-health-concerns/survivorship-care-plans.html
5. www.cancer.org/cancer/screening.html
6. www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html
7. www.cancer.org/cancer/survivorship/long-term-health-concerns/keeping-copies-of-important-medical-records.html
8. www.cancer.org/cancer/risk-prevention/tobacco.html
9. www.cancer.org/cancer/risk-prevention/diet-physical-activity/eat-healthy.html
10. www.cancer.org/cancer/risk-prevention/diet-physical-activity/get-active.html
11. www.cancer.org/cancer/risk-prevention/diet-physical-activity/eat-healthy.html
12. www.cancer.org/cancer/risk-prevention/tobacco/benefits-of-quitting-smoking-over-time.html
13. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/treating/by-stage.html

14. www.cancer.org/cancer/survivorship/long-term-health-concerns/recurrence.html
15. www.cancer.org/cancer/survivorship/coping.html
16. www.cancer.org/cancer/survivorship/be-healthy-after-treatment/life-after-cancer.html
17. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/references.html

References

Harms of Cigarette Smoking and Health Benefits of Quitting was originally published by the National Cancer Institute. NCI website. <https://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco/cessation-fact-sheet#q9>. Reviewed December 19, 2017. Accessed July 11, 2018.

Kushi LH, Doyle C, McCullough M, Rock CL, Demark-Wahnefried W, Bandera EV, Gapstur S, Patel AV, Andrews K, Gansler T; American Cancer Society 2010 Nutrition and Physical Activity Guidelines Advisory Committee. American Cancer Society Guidelines on nutrition and physical activity for cancer prevention: reducing the risk of cancer with healthy food choices and physical activity. *CA Cancer J Clin*. 2012 Jan-Feb;62(1):30-67.

National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Neuroendocrine and Adrenal Tumors. V.2.2018. Accessed at https://www.nccn.org/professionals/physician_gls/pdf/neuroendocrine.pdf on August 5, 2018.

Singh S, Moody L, Chan DL, et al. Follow-up Recommendations for Completely Resected Gastroenteropancreatic Neuroendocrine Tumors. *JAVrP ncoloo Tm 0 0 0 rg /GS168 g al. 7*

Second Cancers After Gastrointestinal Carcinoid Tumor

- [Types of cancer](#)
- [What can you do?](#)

Cancer survivors can be affected by a number of health problems, but often their greatest concern is facing another cancer. Sometimes people with a gastrointestinal (GI) carcinoid tumor develop a new, unrelated cancer later. This is called a **second cancer**. No matter what type of cancer you have or had, it's still possible to get another (new) cancer.

Types of cancer

Unfortunately, being treated for one cancer doesn't mean you can't get another. People who have had cancer can still get the same types of cancers that other people get. In fact, certain types of cancer and cancer treatments can be linked to a higher risk of certain second cancers.

People who have or had a GI carcinoid tumor can get any type of second cancer, but they have a higher risk than the general population of developing:

- [Prostate cancer](#)¹
- [Melanoma](#)²
- [Female breast cancer](#)³
- [Colon and rectal cancer](#)⁴
- [Lung cancer](#)⁵
- [Bladder cancer](#)⁶

What can you do?

Many people with a GI carcinoid tumor are treated with medicines that keep the disease in check without curing the disease, so they need to see their doctors regularly. Let your doctor know if you have any new symptoms or problems. They could be from the carcinoid tumor getting worse or from a new disease or cancer.

All people with a GI carcinoid tumor should not use any type of tobacco and should

[avoid tobacco smoke.](#)⁷ Tobacco is linked to an increased risk of many cancers and

malignancies in patients with neuroendocrine tumors of the digestive tract and pancreas. *Endocr Relat Cancer*. 2012 Feb 13;19(1):95-9. doi: 10.1530/ERC-11-0315.

Kauffmann RM, Wang L, Phillips S, et al. Incidence of additional primary malignancies in patients with pancreatic and gastrointestinal neuroendocrine tumors. *Ann Surg Oncol*. 2014 Oct;21(11):3422-8. doi: 10.1245/s10434-014-3774-7.

Rock CL, Thomson C, Gansler T, et al. American Cancer Society guideline for diet and physical activity for cancer prevention. *CA: A Cancer Journal for Clinicians*. 2020;70(4). doi:10.3322/caac.21591. Accessed at <https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21591> on June 9, 2020.