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# After Gastrointestinal Carcinoid Tumor Treatment

## Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- [Living as a Gastrointestinal Carcinoid Tumor Survivor](#)

## Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about cancer coming back or treatment no longer working.

- [Second Cancers After Gastrointestinal Carcinoid Tumor](#)
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# Living as a Gastrointestinal Carcinoid Tumor Survivor

For some people with gastrointestinal (GI) carcinoid tumor, [treatment](#)<sup>1</sup> 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](#)<sup>2</sup>. 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 years, then every 1 to 2 years for then next 7 years) and doctor visits every 1 to 2 years for 10 years
- Blood and or urine tests (5-HIAA, Chromogranin A) may be helpful for some patients but are not always recommended for routine follow-up.

For some rectal tumors, sigmoidoscopy is recommended 12 months after treatment and possibly annually thereafter. Your doctor may follow one of these schedules, but might have reasons to recommend a different schedule as well.

Follow-up visits and imaging tests may be slightly more frequent for those patients whose cancers could not be completely removed with surgery, who have cancer that has spread to other organs like the liver, or have cancers that are growing very quickly.

## Ask your doctor for a survivorship care plan

Talk with your doctor about developing a [survivorship care plan](#)<sup>3</sup> for you. This plan might include:

- A suggested schedule for follow-up exams and tests
- A list of potential late or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- A schedule for other tests you might need, such as [early detection \(screening\) tests](#)<sup>4</sup> for other types of cancer, or tests to look for long-term health effects from your cancer or its treatment
- Suggestions for things you can do that might improve your health, including possibly lowering your chances of the cancer coming back

## Keeping health insurance and copies of your medical records

Even after treatment, it's very important to keep [health insurance](#)<sup>5</sup>. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

At some point after your cancer treatment, you might find yourself seeing a new doctor who doesn't know about your medical history. It's important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment. Learn more in [Keeping Copies of Important Medical Records](#)<sup>6</sup>.

## 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](#)<sup>7</sup>, [eating well](#)<sup>8</sup>, [getting regular physical activity](#)<sup>9</sup>, and [staying at a healthy weight](#)<sup>10</sup> 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](#)<sup>11</sup> 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](#)<sup>12</sup>.

For more general information on recurrence, you may also want to see [Understanding Recurrence](#)<sup>13</sup>.

### **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](#)<sup>14</sup>.

### **Getting emotional support**

Some amount of feeling [depressed, anxious, or worried](#)<sup>15</sup> 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](#)<sup>16</sup>.

## Hyperlinks

1. [www.cancer.org/cancer/gastrointestinal-carcinoid-tumor/treating.html](http://www.cancer.org/cancer/gastrointestinal-carcinoid-tumor/treating.html)
2. [www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html)
3. [www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html)
4. [www.cancer.org/healthy/find-cancer-early.html](http://www.cancer.org/healthy/find-cancer-early.html)
5. [www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html)
6. [www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html)
7. [www.cancer.org/healthy/stay-away-from-tobacco.html](http://www.cancer.org/healthy/stay-away-from-tobacco.html)
8. [www.cancer.org/healthy/eat-healthy-get-active/eat-healthy.html](http://www.cancer.org/healthy/eat-healthy-get-active/eat-healthy.html)
9. [www.cancer.org/healthy/eat-healthy-get-active/get-active.html](http://www.cancer.org/healthy/eat-healthy-get-active/get-active.html)
10. [www.cancer.org/healthy/eat-healthy-get-active/eat-healthy.html](http://www.cancer.org/healthy/eat-healthy-get-active/eat-healthy.html)
11. [www.cancer.org/healthy/stay-away-from-tobacco/benefits-of-quitting-smoking-over-time.html](http://www.cancer.org/healthy/stay-away-from-tobacco/benefits-of-quitting-smoking-over-time.html)
12. [www.cancer.org/cancer/gastrointestinal-carcinoid-tumor/treating/by-stage.html](http://www.cancer.org/cancer/gastrointestinal-carcinoid-tumor/treating/by-stage.html)
13. [www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html)
14. [author-prod.cancer.org/editor.html/content/launches/2018/09/24/2018\\_copy\\_edit\\_review\\_gicarcinoid/content/launches/2018/07/24/2018\\_review\\_-\\_gicarcinoid/content/cancer/en/cancer/gastrointestinal-carcinoid-tumor/after-treatment/no-longer-working.html](http://author-prod.cancer.org/editor.html/content/launches/2018/09/24/2018_copy_edit_review_gicarcinoid/content/launches/2018/07/24/2018_review_-_gicarcinoid/content/cancer/en/cancer/gastrointestinal-carcinoid-tumor/after-treatment/no-longer-working.html)
15. [www.cancer.org/treatment/survivorship-during-and-after-treatment/coping.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/coping.html)
16. [www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/life-after-cancer.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/life-after-cancer.html)

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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](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. *JAMA Oncol*. 2018 Jul 26. doi: 10.1001/jamaoncol.2018.2428. [Epub ahead of print].

See all references for Gastrointestinal Carcinoid Tumor ([www.cancer.org/cancer/gastrointestinal-carcinoid-tumor/references.html](http://www.cancer.org/cancer/gastrointestinal-carcinoid-tumor/references.html))

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## Second Cancers After Gastrointestinal Carcinoid Tumor

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

## 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](#).<sup>7</sup> Tobacco is linked to an increased risk of many cancers and might further increase the risk of some of the second cancers seen in patients with GI carcinoid tumors.

To help maintain good health, survivors should also:

- Get to and stay at a [healthy weight](#)<sup>8</sup>
- Keep [physically active](#)<sup>9</sup> and limit the time you spend sitting or lying down
- Follow a healthy eating pattern that includes plenty of fruits, vegetables, and whole grains, and limits or avoids red and processed meats, sugary drinks, and highly processed foods
- Not drink [alcohol](#)<sup>10</sup>. If you do drink, have no more than 1 drink per day for women or 2 per day for men

These steps may also lower the risk of some cancers.

See [Second Cancers in Adults](#)<sup>11</sup> for more information about causes of second cancers.

## Hyperlinks

1. [www.cancer.org/cancer/prostate-cancer.html](http://www.cancer.org/cancer/prostate-cancer.html)
2. [www.cancer.org/cancer/melanoma-skin-cancer.html](http://www.cancer.org/cancer/melanoma-skin-cancer.html)
3. [www.cancer.org/cancer/breast-cancer.html](http://www.cancer.org/cancer/breast-cancer.html)
4. [www.cancer.org/cancer/colon-rectal-cancer.html](http://www.cancer.org/cancer/colon-rectal-cancer.html)
5. [www.cancer.org/cancer/lung-cancer.html](http://www.cancer.org/cancer/lung-cancer.html)
6. [www.cancer.org/cancer/bladder-cancer.html](http://www.cancer.org/cancer/bladder-cancer.html)
7. [www.cancer.org/cancer/cancer-causes/tobacco-and-cancer.html](http://www.cancer.org/cancer/cancer-causes/tobacco-and-cancer.html)
8. [www.cancer.org/cancer/cancer-causes/diet-physical-activity/body-weight-and-cancer-risk.html](http://www.cancer.org/cancer/cancer-causes/diet-physical-activity/body-weight-and-cancer-risk.html)
9. [www.cancer.org/cancer/cancer-causes/diet-physical-activity.html](http://www.cancer.org/cancer/cancer-causes/diet-physical-activity.html)
10. [www.cancer.org/cancer/cancer-causes/diet-physical-activity/alcohol-use-and-cancer.html](http://www.cancer.org/cancer/cancer-causes/diet-physical-activity/alcohol-use-and-cancer.html)
11. [www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/second-cancers-in-adults.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/second-cancers-in-adults.html)

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