After Gastrointestinal Carcinoid Tumor Treatment

Living as a Cancer Survivor

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

- What Happens After Treatment for Gastrointestinal Carcinoid Tumors?
- Lifestyle Changes After Treatment of Gastrointestinal Carcinoid Tumors
- How Might Treatment for a Gastrointestinal Carcinoid Tumor Affect Your Emotional Health?

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.

- If Treatment of Gastrointestinal Carcinoid Tumor Stops Working

What Happens After Treatment for Gastrointestinal Carcinoid Tumors?

For some people with gastrointestinal (GI) carcinoid tumor, treatment 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. (When cancer comes back after treatment, it is called a recurrence.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer
survivors have learned to accept this uncertainty and are living full lives. Living With Uncertainty: The Fear of Cancer Recurrence gives more detailed information on this.

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. It has its own type of uncertainty. Read When Cancer Doesn't Go Away for more about this.

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 probably ask questions about any problems you may have and examine you and 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. Some may last for a few weeks to months, but others can last the rest of your life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

Doctors often advise most people who have had their GI carcinoid tumors completely removed to return after several months for a complete physical exam and imaging tests to look for any signs of recurrence. Blood and or urine tests may be helpful for some patients. Further visits may be recommended every several months after that. For small rectal tumors, proctoscopy is often recommended 6 and 12 months after treatment. Small tumors of the appendix, when adequately treated, usually don't require close follow-up, as they are very unlikely to recur. Repeat upper endoscopy once or twice a year is usually recommended for patients with stomach carcinoids who have high gastrin levels. Your doctor may follow one of these schedules, but he or she might have reasons to recommend a different schedule as well.

It is very important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think about their cancer coming back, this could happen.

Should your cancer come back, When Your Cancer Comes Back: Cancer Recurrence can give you information on how to manage and cope with this phase of your treatment.

Seeing a new doctor

At some point after your treatment, you might see a new doctor who doesn't know
anything about your medical history. It’s important to be able to give your new doctor the
details of your diagnosis and treatment. Gathering these details during and soon after
treatment may be easier than trying to get them at some point in the future. Make sure
you have the following information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- If you had surgery, a copy of your operative report(s)
- If you stayed in the hospital, a copy of the discharge summary that the doctor wrote
  when you were sent home
- If you were treated with radiation (including radiopharmaceuticals), a copy of your
  treatment summary
- Since some drugs can have long-term side effects, a list of your drugs, drug doses,
  and when you took them
- Copies of your imaging tests (which can often be stored digitally on a DVD, etc.)
- Contact information of the doctors who have treated your cancer

The doctor may want copies of this information for his records, but always keep copies
for yourself.

- References

  See all references for Gastrointestinal Carcinoid Tumor

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Lifestyle Changes After Treatment of Gastrointestinal Carcinoid Tumors

You can’t change the fact that you have had cancer. What you can change is how you
live the rest of your life – making choices to help you stay healthy and feel as well as
you can. This can be a time to look at your life in new ways. Maybe you are thinking
about how to improve your health over the long term. Some people even start during
cancer treatment.

Making healthier choices
For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on alcohol, or give up tobacco. Even things like keeping your stress level under control might help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society at 1-800-227-2345.

**Eating better**

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small meals every 2 to 3 hours until you feel better. You might also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is to start healthy eating habits. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

You can get more information in *Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions*.

**Rest, fatigue, and exercise**

Extreme tiredness, called fatigue, is very common in people treated for cancer. This is not a normal tiredness, but a bone-weary exhaustion that often doesn’t get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to
their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it’s normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. If you haven’t exercised in a few years, you will have to start slowly, maybe just by taking short walks.

Talk with your cancer care team before starting anything. Then, try to find an exercise buddy so you’re not doing it alone. Having family or friends involved when starting a new physical activity program can give you that extra boost of support to keep you going when the push just isn’t there.

If you are very tired, you will need to balance activity with rest. Sometimes it’s really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. (For more information on dealing with fatigue and other treatment side effects, see the “Physical Side Effects” section of our website.)

Keep in mind exercise can improve your physical and emotional health.

- It improves your heart fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

Getting regular physical activity also plays a role in helping to lower the risk of some cancers, as well as having other health benefits. For more on this, see American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention.

- References
See all references for Gastrointestinal Carcinoid Tumor

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How Might Treatment for a Gastrointestinal Carcinoid Tumor Affect Your Emotional Health?

When treatment ends, you may find yourself overcome with many different emotions. This happens to a lot of people.

You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationships with those around you. Unexpected issues may also cause concern. For instance, you might be stressed by financial concerns resulting from your treatment. You might also see your cancer care team less often after treatment and have more time on your hands. These changes can make some people anxious.

Almost everyone who is going through or has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, religious or spiritual groups, online support communities, or one-on-one counselors. What’s best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It’s not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you. You can also read Distress in People With Cancer or see the “Emotional Side Effects” section of our website for more information.

- References

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If Treatment of Gastrointestinal Carcinoid Tumor Stops Working

If cancer keeps growing or comes back after one kind of treatment, it’s possible that another treatment plan might still cure the cancer, or at least shrink it enough to help you live longer and feel better. Clinical trials also might offer chances to try newer treatments that could be helpful. But when a person has tried many different treatments and the cancer is still growing, even newer treatments might no longer be helpful. If this happens, it’s important to weigh the possible limited benefits of a new treatment against the possible downsides, including treatment side effects. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer, when you have been through many treatments and nothing’s working anymore. Your doctor may offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. Your doctor can estimate how likely it is the cancer will respond to treatment you are considering. For instance, the doctor may say that more treatment might have about a 1 in 100 chance of working. Some people are still tempted to try this. But it is important to have realistic expectations if you do choose this plan.

Palliative care

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called palliative care.

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is that the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance,
radiation or chemotherapy might be used to help relieve pain caused by a large tumor. But this is not the same as treatment to try to cure the cancer.

**Hospice care**

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more by reading [Hospice Care](#).

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times filled with happiness and meaning with family and friends. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you’ve always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

You can learn more about the changes that occur when treatment stops working, and about planning ahead for yourself and your family, in [Nearing the End of Life](#) and [Advance Directives](#).

- [References](#)

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