



CARING FOR CARCINOID FOUNDATION

Dedicated to discovering a cure for carcinoid cancer

Ask the Doctor

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1) I have just been diagnosed with carcinoid/NET. How should this affect my diet? Will I need to make drastic changes to my eating habits or only small ones?

Whether or not you need to make any major diet changes will depend on a number of things. Not all carcinoid/NE tumors are the same and this means that how they are treated and managed is different from person to person as well. Some carcinoid tumors are located in such a way that they can block part of the digestive tract. The tumor can press on and crowd internal organs, including the esophagus, stomach, or intestines. If this is the case, then you may need to follow a diet to reduce the risk of blockages in your GI tract.

In these cases, your doctor or dietitian may prescribe something called a low residue diet. This reduces the “bulk” in the diet so that it is less likely to get stuck in the GI tract. To follow a low residue diet, you avoid bulky, fibrous, and hard to digest foods, such as beans and peas, nuts, seeds, raw vegetables, fruit with the skin on (the fruit flesh is fine), popcorn, salads, and high-fiber cereals, such as those with wheat bran in them. Instead you focus on eating easy to digest foods such as plain baked chicken, white rice, potatoes without the skin, white toast, and other similar items.

You don't necessarily need this type of diet. It is only for people who are at risk of having a blockage in their intestinal diet due to the location of their tumor.

Another possible issue with carcinoid/NE tumors is that they can cause malabsorption of some nutrients. Again, not everyone with carcinoid tumors has this problem. It depends on the location and type of tumor. But if a person is having malabsorption, he or she may need to take enzymes with meals and snacks to help them absorb their food better. They may have problems absorbing fat soluble vitamins, for example, such as vitamins A, D, E, and K. In these cases, a dietary supplement to help make up for the reduced absorption may be prescribed. If you don't have malabsorption, however, then you won't need to supplement your diet with enzymes, vitamins, and minerals.

If you are feeling generally good and are not having any symptoms that affect your ability to eat well and absorb nutrients, then a well-rounded, healthy diet is a good idea. This means

focusing on getting lean protein from fish, low-fat dairy, egg whites, beans, chicken, and soy foods. Also focus on getting healthy, complex carbohydrates including vegetables, fruit, whole grains, beans, nuts, and seeds. In general, most health experts suggest that two-thirds to three-quarters of your plate should be covered by complex carbohydrates. The remaining one-fourth to one-third is for lean protein. And keep simple carbohydrates from processed foods such as regular soda, cookies, cakes, pastries, donuts, and table sugar to a minimum.

Again, keep in mind that this type of diet is excellent ONLY if you are not having any symptoms or side effects that affect your ability to eat well and absorb food properly. If you are having symptoms and side effects, the best thing you can do is ask your doctor for a referral to a dietitian so you can receive a personalized nutrition plan to meet your particular needs.

2) Is sugar—corn syrup, white sugar, etc—harmful to cancer patients? That is, does it cause tumors to grow? A lot of people say this. I love desserts, so I'd like to know if I need to reduce my daily sugar consumption or if sugar is fine in moderation.

This is a great question and I get asked this often. Unfortunately, the facts about sugar and cancer can be confusing and often are presented in a way that is misleading and anxiety-producing for people with cancer.

The concept that sugar feeds cancer is not particularly useful because sugar feeds every cell in our bodies. Our bodies need glucose, or simple sugar, for energy. Even if you cut every bit of sugar out of your diet, your body will make sugar from other sources, such as protein and fat.

So it is true that cancer cells need sugar to grow, just like healthy cells, but keep in mind that there is nothing particular about sugar that "feeds" cancer cells any more than sugar feeds all cells in our body. Glucose is glucose and our bodies will make glucose for energy regardless of what we eat.

There is a catch though. While sugar itself isn't an issue, how your body responds when you eat large amounts of simple sugar is a concern. This is because when you eat a lot of sugar, your body produces a lot of insulin.

Insulin is a natural substance, a hormone, made by the body. Insulin is what allows your cells to absorb glucose (a simple sugar) from the bloodstream. Your cells then use this glucose for energy. In this way, insulin can spur cell growth, because it allows cells access to energy.

For healthy cells, this is a good thing. However, cancer cells can be encouraged to grow more, too, when we over-produce insulin. Some insulin in the body is normal, but excess insulin may encourage cancer cells to grow more, which is not a good thing.

You don't have to avoid every bit of sugar in your diet. Nor should you avoid all carbohydrates. The best sources for healthy, complex carbohydrates are vegetables, fruit, whole grains, and legumes (beans) and these very foods that appear to fight cancer best.

There are three other things in the diet that can help reduce the amount of insulin produced by the body when you do eat sugar and carbohydrates. These are protein, fat, and fiber. When eaten along with even the simplest sugars, these three items help the body to make less insulin in response to simple sugar. Basically, protein, fat, and fiber help your body process sugar in a more healthful way.

For an example of how this works, think about fruit and fruit juice. The amount of insulin your body makes after you eat a piece of fruit is much lower than the amount of insulin produced when you drink fruit juice. Whole fruit contains fiber and that fiber helps balance out the sugar in fruit.

For another example, think about eating specific foods together to get a healthier snack or meal. Instead of having two pieces of fruit as a snack, try having one piece of fruit and a small handful of nuts. The nuts contain protein, fat, and fiber. These three things help your body keep insulin in balance.

The most important point is that sugar itself is not bad. However, too much sugar, especially when eaten without protein, fat, and fiber to balance it out, can cause our bodies to make too much insulin. It is not the sugar, but rather the insulin that may be a problem for spurring cancer cell growth. To prevent this, you should limit the simple sugar in your diet, but there is no need to follow a stringent diet and swear off every single dessert. The key is moderation. Here are a few tips for enjoying sugar, in moderation:

- For the most part, stick with naturally occurring sugar, such as the sugar that is found in fruit. This is a much healthier option than processed sugar that is found in candy, cake, desserts, pie, and baked goods.
- Avoid concentrated sources of sugar, such as soda and fruit drinks. It is OK to have 100 percent fruit juice in moderation. Stick to a 6-ounce serving. But avoid fruit drinks that don't contain any real fruit juice.
- Limit your "treats," such as dessert, to just a couple of times each week. Have a modest serving size.
- Focus on whole, healthy, unprocessed food, including vegetables, fruit, whole grains, legumes (beans, lentils, and peas), nuts, and seeds.

3) Large meals affect my health-I feel sluggish and my intestines feel fragile. Should I switch to a daily meal plan of 5 small meals? Should each meal include protein, veggies and a carb?

If large meals make you feel sluggish, you are absolutely correct that you should focus on eating smaller, more frequent meals and snacks. There is no reason that you have to eat 3 large meals per day.

Five small meals and snacks is a good place to start. Include good sources of lean protein, such as baked chicken, fish, egg whites, low-fat dairy, and soy foods. You mentioned that your intestines feel "fragile". This could mean many things, but it sounds like you need easy-to-digest carbohydrates such as plain oatmeal, toast, fruit without the skin (if you are having loose stools avoiding the tougher skin can help), baked potatoes, baked sweet potatoes (without the skin), white rice, and yogurt.

If you're having loose stools or diarrhea, you'll want to steer clear of tough fibrous foods, such as raw vegetables, high-fiber or bran cereals, nuts, and seeds. You can include well-cooked vegetables, because the cooking makes them easier to digest. If you are not experiencing diarrhea or losing weight, you can include more vegetables.

As a final note, be sure you discuss your new nutrition needs with your family and friends. For many people, mealtimes are the only time they have to connect with loved ones. If you aren't able to sit down to a regular meal, you may feel disconnected from the very people you need the most. Make sure you find other ways to catch up, such as taking a walk, going to a movie together, or meeting for coffee or tea.

4) I am starting to work with a nutritionist to make sure I have a good diet and nutrition...my regular doctor ordered blood work so that we could identify what I might not be absorbing enough of...what is the most up to date blood work I should be getting that my nutritionist will need?

Without knowing a full diet history and your particular medical situation, it is difficult to know which nutrients you may be missing in your diet or absorbing poorly. Carcinoid can cause a variety of symptoms that may or may not affect a person's ability to digest and absorb food and nutrients.

Even so, there are some nutrients that deserve special attention. Your doctor likely will order a complete blood count or CBC. Among other things, this test will tell you if you have iron-deficiency anemia. However, it only will pick up anemia if you are moderately to severely anemic. To detect minor anemia, before it becomes more established, you need a more sensitive set of tests that includes serum ferritin, transferrin level (total iron-binding capacity), and serum iron.

Other nutrients that can be low in people with cancer include vitamin D and vitamin B12, but this is by no means a rule. Some cancer patients have adequate levels of these nutrients and others come up short. You can request tests to check your D and B12 levels.

One way to determine if you may be low in certain nutrients is to consider other symptoms you are experiencing. For example, if you have "greasy" or very foul-smelling stools that float, this can be a sign that you are not absorbing fat very well. If this is the case, you may be low in fat-soluble nutrients including vitamins A, D, E, and K.

Another symptom that some people with carcinoid experience is diarrhea. If you are experiencing chronic diarrhea, you may be low in minerals including potassium, magnesium, and even sodium. These minerals are easy to test for and will be a part of your basic lab work (blood tests).

Also ask about having a fasting glucose test. Certain types of endocrine tumors can lead to impairments in the way your body regulates blood sugar (blood glucose). In some cases, this impairment may be severe enough that a person develops diabetes. If this is the case, your medical team will refer you to an endocrinologist to help determine the best way to manage both your carcinoid tumor and diabetes.

Ask about testing for various levels of amino acids (the building blocks of protein) in your blood. Some neuroendocrine tumors will cause problems with amino acid balance in the body and can lead to low levels of tryptophan, in particular. If you are deficient in tryptophan, your nutritionist or doctor may recommend a tryptophan dietary supplement.

In addition to testing for levels of various nutrients, you may want to ask that your thyroid function be tested. Changes in thyroid function are common with age, even among people without carcinoid. For this reason, it is a good idea to get a baseline test to ensure that your thyroid is functioning normally.

5) Which foods will be best tolerated when I have diarrhea? Is there anything I can take to lessen its effects?

If you are experiencing diarrhea, there are certain foods you can eat to help. There are also foods to avoid that can worsen diarrhea.

When you are experiencing diarrhea, you want to eat more of the “sticky” foods that contain soluble fiber. Try sticky white rice, oatmeal, white bread, mashed potatoes without the skin, plain pasta, applesauce (no skin), bananas, and canned fruit without the skin (peaches and pears).

You need to avoid tough, fibrous foods such as raw vegetables, fruit with the skin on, nuts and seeds, high fiber and “bran” cereals, whole grain breads, beans and peas, salad, and popcorn. Avoid spicy foods as well. These foods will make diarrhea worse.

One quick and easy recipe to try is “rice congee”. Take regular, long-cooking white rice and cook with approximately 6 times the liquid called for on the box. For example, if the recipe says to use 1 cup water for a certain amount of rice, use 6 cups of water. Cook for the amount of time specified on the box, but allow rice to boil a little more vigorously than usual. Stir occasionally to prevent sticking. If mixture is still very liquid at the end of cooking time, continue boiling for an additional 5 to 10 minutes, until liquid is mostly absorbed and you have a very sticky, gooey rice mixture. Eat ½ to 1 cup of this sticky rice 2-3 times per day. This should help lessen diarrhea.

Also, you may want to try a fiber supplement. This might seem counter-intuitive, because fiber supplements are used to relieve constipation. However, the great thing about fiber is that it normalizes bowel function and it works in both directions. If you are constipated, a fiber supplement can help. If you have diarrhea, a fiber supplement can help. Before you try a fiber supplement, be sure you ask your doctor and dietitian if this is OK. There are some people for whom a fiber supplement is NOT a good idea. For example, if you are at risk of intestinal blockage, then you should not take a fiber supplement.

Once your doctor gives you the OK to try a fiber supplement, you may want to try Benefiber or Konsyl. These are brands that work well. Some people prefer these to Metamucil, which can cause excess gas. Start slow and try ¼ of the recommended dose. Increase as tolerated and be sure to get plenty of fluids.

6) What type of multivitamin regimen should I take? Are there other types of

minor nutrients that I may not receive via a multivitamin?

If you want to take a multivitamin, aim for one that provides no more than 100% to 200% of the recommended dietary allowance (RDA) or dietary reference intake (DRI). You can read the label to find these percentages listed. One brand I like because it does not contain added dyes or artificial ingredients is NatureMade.

Be sure to avoid “mega-dose” vitamins that provide many times the RDA/DRI. Some research suggests that these “mega-vitamins” may do more harm than good. Additionally, high doses of certain nutrients can interfere with the way many medications work.

There are some of nutrients that a multivitamin may not supply enough of. You may need some extra vitamin D so that you get a total of 1000 IU per day from the combination of your multivitamin and your D supplement. If you do not get enough calcium in your diet, you may need a calcium supplement as well. For women of child-bearing age, an additional iron supplement sometimes is needed as well. For a complete list of the RDA/DRI for different nutrients for your age and gender, please see the information provided by the Food and Nutrition Information Center (<http://www.iom.edu/Object.File/Master/7/296/0.pdf>).

For more information about dietary supplements, please see the National Institutes of Health Facts About Supplements Website (http://ods.od.nih.gov/Health_Information/Information_About_Individual_Dietary_Supplements.aspx).

However, before you decide to add additional supplements, be sure to talk to your doctor or dietitian to get the OK to do so. Again, some nutrients can interfere with medications or may be contraindicated for people with cancer.

7) Are you aware of any supplements that might be harmful to those with carcinoid tumors? For example, my carcinoid doctor suggested that I NOT take Echinacea as it is thought to stimulate neuroendocrine tumors.

Unfortunately, there is no “hard and fast” list of supplements that need to be avoided by people with neuroendocrine tumors. There isn’t enough research on this topic to know for certain one way or the other whether a particular supplement may be helpful or harmful.

If your doctor told you to avoid Echinacea, his main concern may be that this supplement can have immune-stimulating effects, which may not be helpful for someone with your tumor type. Other supplements with immune-stimulating effects that you may need to avoid include the herbs astragalus, goldenseal, bupleurum, ashwaganda, cat’s claw, and siberian ginseng. There are others, but these are some of the more commonly used herbs for turning up the immune system.

Other than the issue of immune system function, there may be other supplements to avoid. For example, some neuroendocrine tumors can affect the way your body regulates minerals, including calcium. If you have high levels of calcium, you should avoid calcium and vitamin D supplements.

Without knowing the specifics of your case, it is not possible to list all of the supplements that you may need to avoid. Your best bet is to talk to your doctor and dietitian about any supplements that you are considering. They can help you evaluate, on a case-by-case basis, which ones are appropriate and which you need to avoid.

8) What supplements or foods might help a patient with carcinoid tumors to build-up (increase) their red and white blood cells and platelet counts?

In order to manufacture new cells, the body needs adequate calories and plenty of protein. This makes sense because your body needs energy, in the form of food, in order to make new cells. I often say that you cannot build “something from nothing”. In other words, if you are losing weight and your body is burning its own tissue simply to keep your heart beating and your metabolism running, there’s nothing left over to build new cells. In this sense, maintaining your usual body weight is one of the most important things you can do.

In addition to this, there are several other things you can do to aid your body in rebuilding blood cells. I have written a number of articles on this topic and I’m going to refer you to these for further information:

- Diet and Food for Better Blood Counts
(<http://www.caring4cancer.com/go/cancer/nutrition/questions/diet-for-better-blood-counts.htm>)
- Anemia
(<http://www.caring4cancer.com/go/cancer/nutrition/symptom-support/irondeficiency-anemia.htm>)
- Neutropenic Diet Questions
(<http://www.caring4cancer.com/go/cancer/nutrition/questions/neutropenic-diet-questions.htm>)
- How Much Protein Do I Need?
(<http://www.caring4cancer.com/go/cancer/nutrition/questions/how-much-protein-do-i-need-to-eat.htm>)

9) Is milk thistle supplement harmful to NET patients with mets to the liver? Is it supposed to be helpful for liver ailments?

Milk thistle is an herb that is believed to protect the liver from damage due to toxic substances and to enhance liver function. Based on this, some health care providers have a concern that if a patient is receiving chemotherapy to treat liver metastases, milk thistle may prevent the drug from reaching the cancer cells. However, this is a theoretical concern, meaning that it is not proven to occur. Some people simply have a theory that it could happen.

There are some case studies suggesting that milk thistle may be helpful to people with liver disease, including cancer. But these are NOT controlled studies and cannot prove cause and effect. They are simply reports of a few people with cancer in their liver who used milk thistle and had a good result.

So this leaves one to ask, is milk thistle good or bad for someone with liver metastases? Unfortunately, we don’t know. My professional opinion, based on the research evidence that

is available, is that milk thistle is safe for people with liver metastases. Milk thistle has a long track record of safe use and research to date indicates that it has low risk of interacting with most other medications.

However, other health experts may come to a different conclusion, and only you and your medical team, working together, can decide if trying milk thistle is right for you. One thing I do want to stress is that if you do decide to take milk thistle, please tell your doctor. Even if your doctor advises against taking milk thistle and you decide to take it anyway, it is important that he or she know you are taking it.

You can have an honest conversation where you “agree to disagree”, but it is vital that your medical team know you are using dietary supplements. They can document this in your medical record and be on alert for any unusual symptoms. These symptoms may indicate that your supplements are interacting negatively with your medications or making your disease situation worse. Only if you tell your medical team will they know what to watch out for.

When it comes to dietary supplements, the most important thing to remember is to keep honest, open communication with your medical team.

10) Is there something that I can eat to improve the strength/health of my bones with metastases?

The best thing you can do for the strength of your bones if you have metastases is to maintain your body weight (don't lose weight) and focus on eating a well-balanced diet with plenty of protein. For more information on getting enough protein in the diet, you can view my article on this topic:

- How Much Protein Do I Need?
(<http://www.caring4cancer.com/go/cancer/nutrition/questions/how-much-protein-do-i-need-to-eat.htm>)

You should not take specific “bone building” nutrients such as calcium and vitamin D without talking to your doctor first. Also keep in mind that for some people with bone metastases, calcium levels in the body can be high. Taking more calcium and vitamin D will make this situation worse. It is OK to have calcium and vitamin D in your diet from food sources.

Finally, talk to your doctor about your concerns and ask if there are any medical options that you should consider for improved bone health. There are some medications that are used to strengthen bones in people with bone metastases. Your doctor can guide you on which of these may be right for you.