

LIVING WELL WITH CARCINOID

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The Numbers

- 1.5 cases per 100,000 people (general population) are diagnosed with carcinoid tumors. (Vinick, 2008)

⇒ This translates to approximately 2500 cases per year in the United States.

⇒ Carcinoid tumors occur most commonly in the gastrointestinal or GI tract.

⇒ Carcinoid tumors account for 13% to 34% of all tumors in the small bowel

⇒ Carcinoid tumors account for 17% to 46% of all **malignant** tumors of the small bowel



CHAPTER 1

Think Outside the Box

- How long did it take for a correct diagnosis?
 - How many doctors did you see before you received a correct diagnosis?
 - How many of you travel to cities or states away from your homes to see doctors specializing in carcinoid/NET (neuroendocrine tumor)?
 - How many of you have had it “up to here” with hearing about the “Food Tree” or “Food Guide Pyramid” in response to your nutrition questions?
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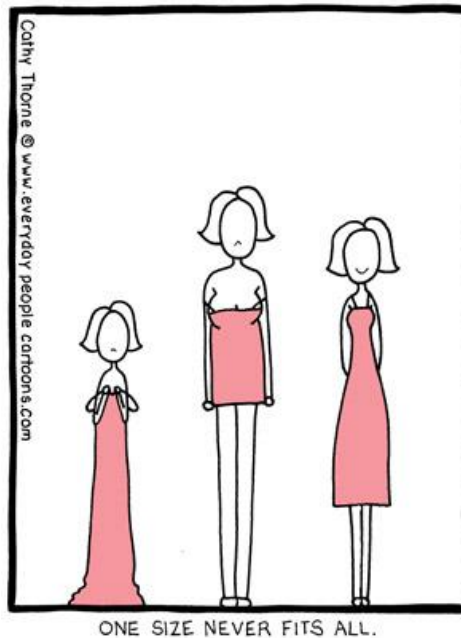
A New Perspective

- You've found doctor who is a specialist!
- There is more information than ever!
 - This is great, but...
 - If my dog could type, he would be able to post information on-line. Sure, he's smart, but he's a dog. His expertise is limited to being a dog. He has no business advising anyone on anything other than being a dog!



You as the Expert

- Everyone does not present with the same symptoms
- What works for one gut does not always work for every gut
- Don't get trapped by "One Size Fits All"



Carcinoid Syndrome

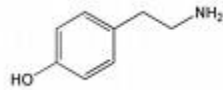
- Flushing, sweating, wheezing, diarrhea, abdominal pain...
- Not everyone experiences the “syndrome”
 - Symptoms may appear individually
 - Flushing may occur without diarrhea and vice versa
- Common triggers
 - Hormone secretions – this is the tumor talking
 - Food – what we eat may not always be the problem, but we can control this, so let’s talk about food...

It's Gotta Be the Food

- Food = Fuel, but what's the right fuel?
- In general, high protein, low fat
 - 1.5 gm protein/kilogram of body weight
 - 20-25% fat
 - 5-10 carbohydrate servings*
- Flushing, diarrhea s/s (signs/symptoms) – common causes?
 - Size of meal
 - Fat content of meal
 - Alcohol, very spicy foods
 - Amine content of foods
- Can food be our medicine?

Amine Content of Foods

- Vasoactive or pressor amines (precursors for adrenaline)
- **Tyramine, Dopamine** – these foods have the **HIGHEST CONTENT**

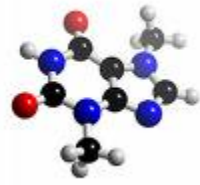


Tyramine molecule

- Aged cheeses
- Alcohol
- Smoked, salted fish and meats
- Yeast extracts, Brewer's yeast
- Fermented foods (tofu, miso, sauerkraut)

Amine Content of Foods

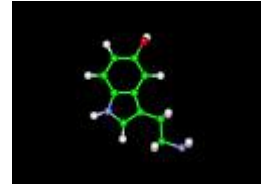
- Vasoactive or pressor amines (precursors for adrenaline)
- **Tyramine, dopamine, xanthenes, theobromine** - these foods are considered **MODERATELY HIGH** in amines, but need not be avoided entirely, just watch intake
- Caffeine (large amounts) coffee, colas
- Chocolate (especially dark)



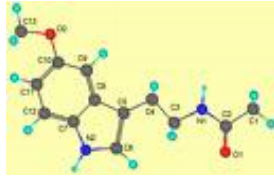
theobromine molecule

- Peanuts, brazil nuts, coconut
- Avocado, banana, raspberries
- Pizza

Serotonin in Foods

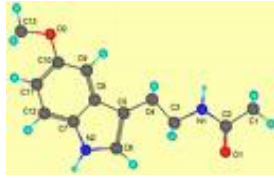


- Serotonin in foods
 - Don't fear the serotonin – in food form, it is not a cause of flushing and/or diarrhea
 - It will influence a 24-hour urine test, so avoid foods high in serotonin prior to the 5HIAA test
 - Foods high in serotonin will not fuel tumor growth
 - Some foods high in serotonin are also high amine foods – the amine content is the cause of signs and symptoms, not the serotonin itself



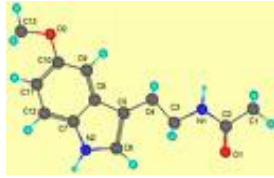
Foods High in Serotonin

- Foods **HIGH IN SEROTONIN**
 - Walnuts (black and English)
 - Pecans
 - Plantains
 - Banana
 - Kiwi
 - Plums
 - *Tomatoes (less so when cooked or processed)



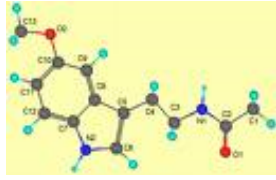
Foods Moderate in Serotonin

- Foods **moderate in serotonin**
 - Avocados
 - Dates
 - Grapefruit
 - Cantaloupe
 - Honeydew
 - Olives
 - Eggplant
 - Nuts: Brazil, filberts, almonds, cashews, coconut, macadamia nuts



Foods Low in Serotonin

- Foods **low in serotonin**
 - Berries: strawberries, blueberries, raspberries, cranberries
 - Apple
 - Cherries
 - Papaya
 - Mango
 - Pear
 - Peach
 - Citrus: orange, lemon, lime
 - Carrots
 - Cucumber
 - Lettuce
 - Nuts: American chestnuts, pistachios, pine nuts, nutmeg, sunflower seeds
-



Foods with Almost No Serotonin

- Foods **with almost serotonin**
 - Beef
 - Ham
 - Chicken
 - Fish
 - Milk
 - Parmesan cheese
 - Corn
 - Potatoes
 - Rice
 - Coffee
 - Tea
 - Wheat germ

Foods Confusion

- So no aged cheeses, but Parmesan is okay?
- Parmesan may have little serotonin, but it does have a high amine (tyramine) content
- Won't cause false positive 5HIAA urine test, but may contribute to carcinoid symptoms if eaten in large amounts



Food Clarification

CHAPTER 3

- Tyramine-rich Meats – **AVOID THESE**
 - Dried, fermented meats, sausages, salami
 - Pickled herring
 - Spoiled or improperly stored meats
 - Spoiled or improperly stored animal livers
- Alternative Meats – **CHOOSE THESE**
 - Fresh meat, poultry, fish
 - Fresh processed meats (oxymoron?)
 - Lunch meats
 - Sliced ham
 - Hot dogs (Kosher)

Tyramine & Alternatives

Tyramine-rich Vegetables - **Avoid these**

- Broad bean pods (fava bean pods)
- Sauerkraut
- Most soybean products
 - Tofu
 - Soy sauce
 - Tempeh

Alternative Vegetables - **Choose these**

- All other vegetables
- Soy milk, fresh boiled edamame
- Pizzas with:
 - Non-tyramine rich cheeses such as mozzarella
 - Canadian bacon instead of pepperoni

Tyramine-rich Dairy – **Avoid these**



Just say no!

- Aged cheeses
 - Cheddar
 - English Stilton
 - Swiss
 - Bleu cheese

Alternative Dairy – **Choose these**

- Processed cheese: Velveeta, American cheese slices
 - Cream cheese
 - Ricotta cheese
 - Mozzarella cheese
 - Cottage cheese
 - Yogurt

What about Niacin?

- Symptoms of niacin deficiency:
 - Pellagra (scaly skin lesions on sun-exposed areas)
 - Diarrhea
 - Nervousness
 - Depression
- Supplement 25mg –50mg twice daily of:
 - Nicotinamide or No Flush Niacin
 - Many OTC (over the counter) forms of niacin may induce flushing, so look for the above forms

Niacin Content of Foods

- 40% = meat, poultry, fish
 - 38% = grain products
 - 11% = vegetables
 - 4% = legumes, nuts, soy
 - 2% = fruit
-
- Niacin content is one reason why a protein rich diet is necessary
 - 1.5 gm protein/kg of body wt
 - 150# person = 68 kg = 102gm protein/day
 - 4 oz chicken breast = 28 gm protein (7 gm protein/ounce)
 - 1 egg = 7 gm protein

Food for Thought

- Raw vs. cooked
 - Certain raw vegetables may cause gas and are more easily digested when cooked
 - Small portions may be tolerable, so watch quantity
 - Certain foods deliver more vitamins and minerals when cooked (mushrooms, tomato)
- Try Beano
 - It works great with gassy vegetables such as broccoli and raw salads



Chewing the Fat

- Do all fats cause diarrhea?
 - NO!
 - YES!
 - WHAT?!
- Avoid greasy, fried foods high in saturated fat
- Avoid trans-fats
- MCT's = medium chain triglycerides (Muscle Milk is a ready to drink protein shake w/MCT's)
- Choose foods rich in omega-3 fatty acids
 - Salmon (not smoked or cured)
 - Tuna
 - Ground flaxseed (not too much – very rich in fiber)

The Skinny on Fats

- Omega-3 fatty acids in foods are well tolerated
- Supplemental Omega-3 (fish oil) may not be well tolerated
 - Excellent anti-inflammatory benefits
 - May be beneficial for depression or low mood
 - May raise HDL (good cholesterol) and lower LDL (bad cholesterol)
 - May cause diarrhea

Digesting Fats

- MCT's (medium chain triglycerides)
 - Form of fats that are easily absorbed by the body (used as fuel rather than stored)
 - OTC ready to drink = Muscle Milk
 - MCT Oil (add to smoothies, foods for increased calories)
 - Try GNC or other body-builder friendly store
- Pancreatic Enzymes
 - Especially helpful with sandostatin
 - Requires a prescription



Pancreatic Enzymes for Digestion

- Pancreatic Enzymes
- Don't go to Trader Joe's for digestive enzymes (but they have lots of other good stuff!)
- Do get a prescription for some brand of pancrelipase USP, which contains:
 - Lipase – enzyme for breaking down fats
 - Protease – enzyme for breaking down proteins
 - Amylase – enzyme for breaking down carbohydrates
- Brands I have seen good results with:
 - Creon
 - Pancrecarb








So Who Do You Trust?

- #1 – Yourself
 - You know your body best
 - It helps to pay attention to details
 - As we all learned during potty training – EVERYONE poops! It's okay to talk about it!
- But it's even better to look at it



Bristol Stool Chart

Bristol Stool Chart

| | | |
|--------|---|--|
| Type 1 |  | Separate hard lumps, like nuts (hard to pass) |
| Type 2 |  | Sausage-shaped but lumpy |
| Type 3 |  | Like a sausage but with cracks on its surface |
| Type 4 |  | Like a sausage or snake, smooth and soft |
| Type 5 |  | Soft blobs with clear-cut edges (passed easily) |
| Type 6 |  | Fluffy pieces with ragged edges, a mushy stool |
| Type 7 |  | Watery, no solid pieces. Entirely Liquid |

Poop

- Diarrhea
 - May be triggered by certain offending foods
 - May be directly related to serotonin secreted by tumor
- Steatorrhea:
 - Does it float?
 - Does it have a foul odor?
 - This is a classic sign of fat malabsorption
 - Common after bowel surgery
 - Very common with sandostatin
 - Gas common
 - Bloating common
 - Pancreatic enzymes may change your lives
 - You may also be lactose intolerant (Lactaid products)

The Best Advice on the Net

- <http://www.sitorsquat.com/sitorsquat/home>
 - Know your options!!!
 - Practical site linked from www.charmin.com on clean public restrooms anywhere in the world
 - Application can be downloaded onto mobile device
 - Talk about stress relief!!!



Perhaps something in-between?

More Questions?

For further questions, or to arrange for a private consultation, feel free to contact:

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Thank You!

