

The Vegetarian Low Iodine Diet and Strategies for Surviving Radioactive Iodine Treatment With The Aid of Consumer Electronics

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(latest draft, March 2010; comments and suggestions for improvement are welcome)

In preparation for my radioactive iodine treatment, I spent two weeks on a low-iodine diet. The idea is that my remaining thyroid cells (cancerous and noncancerous) would then be more receptive to the radioactive iodine, suck it up, and kills themselves, thus killing the cancer.

The thing is, iodine is in everything. Because iodine is in most commercially available salt, and everything you buy that's premade is salted. Iodine is also present in most dairy products (not egg whites), soy, and anything from the sea (not an issue for me). The low iodine diet is not necessarily low fat or low salt, though it sort of works out that way because you basically can't buy much in the way of processed foods and even salty homemade food has less salt than non-salty-tasting processed or prepackaged food. The hypervigilant even avoid canned foods (though Canadian canneries apparently don't use iodine washes--yes, the Thyroid Cancer Canada people have checked, so I didn't worry about this). Low iodine diets also place limits on grains and certain kinds of rice, but it appears those limits aren't really necessary and if you're not eating any meat, you certainly don't have to worry about cooking your own grains, pasta and rice so long as you're not starting with a salted product. Of course I'm neither a doctor nor a dietician, just a fat vegetarian, so there's a healthy "your mileage may vary" with my advice, though I did drop a few pounds in my two weeks on the diet, and everything I write here is backed up with research. But if I'm wrong, it's your problem, not mine (well, mine too as I'd rather not have blown my RAI treatment!).

The best low-iodine diet guide I've found can be downloaded here --

http://www.thryvors.org/pdf/LID_pamphlet_print_ready.pdf -- though it assumes you eat meat and fish.

Now, it would seem that a low iodine vegetarian diet would simply be vegan, but there's a hitch: you can't use soy products. Pick up any vegan cookbook from the US, Canada or the UK and soy is all over it, from soy sauces as a ubiquitous flavoring to soy protein

products as meat replacements. So while both Carrie and regularly enjoy vegan cuisine, much of it was not available to us this time around. And frankly, by the end of it, I was craving dairy or soy *badly* and even looked longingly at the chili-mac recipe in the *Thyroid Cancer Low Iodine Cookbook* -- <http://www.thyca.org/Cookbook.pdf> -- (which has excellent muffin recipes, by the way). But I don't actually know how to properly cook meat so I didn't even try.

Carrie was a trooper and ate the same dinners I did, though she often added things like bottled hot sauce and yogurt that I couldn't. For my part, I got protein from nuts and peanut butter, but somehow that didn't satisfy at the end. Between all the mashed potatoes on my soft food diet when I had the trache in and the peanut butter over the last two weeks, I know a couple foods I'll be avoiding for at least awhile.

The real drag of the diet for busy people is that you more or less can't have any convenience foods. So everything must be made from scratch if you want to be sure about things and sometimes it just happened. For instance, we couldn't find no-salt canned tomatoes at our corner fruiterie (they're readily available at supermarkets) and so sometimes used fresh tomatoes in their place, which were fine but added a step to the cooking.

So, some of our successes:

Pasta and vegetable sauces. In a regular-iodine situation, I'd put some parmesan on top, which I had to skip. I made up for it sometimes with a little truffle oil, which adds a little of its own bang. Tuesday night we made a huge pot of pasta e fagioli (we do it more as a stew than a soup), which we ate for dinner. I think boxed up leftovers in two plastic containers (\$1.25 for both at the dollar store) and had the nurses at the hospital store them in their fridge and microwave for my dinner. I also made a porcini pesto that was pretty good although a bit on the mild side. The recipe actually calls for it to go with ricotta and I think that would be ideal. But that was good for several meals served with noodles. One could also put it on bread.

Salads were more or less the same. Carrie's the salad chef and we always make our own dressings, so we just used the Windsor Kosher salt. Sometimes we like cheese in our

salads, which of course I couldn't have, but avocado was a nice treat instead. Our salads are usually somewhat elaborate--lettuce, endive, red onion, red bell pepper, sometimes fruits or nuts, carrots, sometimes other vegetables.

We didn't do a lot of vegetable sides (which we often do as an alternative to salads), but I did make herbed, steamed carrots one night and another night Carrie shredded some brussels sprouts and fried them up with cumin seeds.

I should have made better arrangements for low iodine bread. I'd had a friend offer to bake me some but I didn't get it together to ask him (since I went on the diet right after getting home from the hospital). I really missed bread and with a little planning wouldn't have had to. I bought the rice cakes suggested in some diets but I just don't like rice cakes that much. But we happened to have a box of matzo lying around, which turned out to be a nice bread substitute (which is what it is, after all). Just make sure you don't get matzo that's salted or has eggs in it if you go this route. It is possible to get matzo during the non-passover parts of the year, but you'll have to hit a store with specialty Jewish foods. So it was muffins, matzo, rice and pasta for my carbs. One night Carrie made me popcorn with salt and curry seasoning that was a great snack. We also made haroset, a traditional passover mix of walnuts, honey, apple, wine and cinnamon that goes really well with matzo.

Another staple was beans and rice. We did a sort of provencal vegetables and chickpea dish over rice that was good for a couple meals; and we did a cuban black beans and rice dish (seasons with fresh orange juice, pureed tomatoes, cumin, coriander, paprika, salt and pepper) that was good for another couple meals (Carrie added yogurt and hot sauce to hers). Both were excellent and satisfying.

Breakfasts were mostly muffins and fruit or smoothies. Lunches were either leftovers or some combination of carb, protein and more fruit. Dinners were as above, and snacks included the aforementioned curried popcorn (made in the pan, not the microwave stuff), home-roasted and salted nuts (good but kind of too rich--we would have to learn how to dry roast next time). I really ate almost no dessert for two weeks, which no doubt helped with the weight loss, but when I did, I went for LID-approved chocolate bars and sorbet.

The hospital stay was a little more of an issue. Well, there were two. The first is that you can't really trust your hospital's kitchen any more than you can trust a restaurant. Despite it being a hospital kitchen, it is still a commercial kitchen--you're likely to have underpaid employees working to spec, not medical professionals carefully attending to your particular dietary needs. Montreal Jewish General does not understand vegetarian food to begin with. I have now twice been given fish cakes as "vegetarian" food. (In their defence, that seems to be a Montreal thing. I have known many vegetarians in my life and only two have routinely eaten fish and called themselves veg, but tons of meat eaters here seem to believe that vegetarian means you eat fish and are shocked when I point out that fish are, actually, classified as animals. Though I guess it's arbitrary since so are yeast and I have been known to enjoy bread regularly. Well, we all live our contradictions. I also wear a leather belt. . .ANYWAY) They also don't appear to understand low-iodine even though there's a tick mark. When I arrived at the hospital, my "breakfast" was already waiting in the room, which included white bread (there's no way that's low-iodine) and margarine (unlikely to be unless they've got a deal with Fleischmann's). I took the route suggested in "Despina's Helpful Hints" -- http://www.thryvors.org/pdf/Despina_Helpful_Hints_final.pdf -- and brought in my own food.

But here's where issue number two comes in. What if my taste buds were messed up by the radioactive iodine, or what if I was horribly nauseous? I decided to overpack. Here's what I brought in for food. Sure, it was a bit wasteful but especially since it was only about 10 days since the end of my last hospital ordeal, I valued my comfort over anything more abstract like not wasting food:

Corn muffins from the low-iodine cookbook

Home roasted and salted cashews

dried cranberries and bananas

fresh bananas

matzo

peanut butter

applesauce

rice cakes

an LID chocolate bar

fleischmann's salt-free, lactose-free margarine (stored in the room--margarine can survive for a few days outside the fridge)

a small bag of Windsor kosher salt

two plastic microwaveable dollar store containers, each with a dinner portion of pasta e fagioli. I wrote my name on top with magic marker and had the nurses store them in the fridge. At dinner time, they heated them up for me. After finishing I closed them and threw them out. No smell and I got a nice hot dinner out of it. And like most soups and stews, the pasta e actually tastes better on the 2nd and 3rd day.

I refused the meals they kept bringing, though I did pilfer the plastic "silverware." As Despina pointed out, if you bring it into the room, it will stay as long as you do, so beware of things that will smell or rot. Especially if you get nauseous you will not be a happy camper. Also, remember that even when you're not LID, some hospitals like the Jewish cannot apparently provide real vegetarian food so you need enough to get you through the whole stay. Though I enjoyed some toast Friday morning.

Some people bring their own water. I drink tap water and so didn't bother. I did, however, have Carrie pick up a 20oz cup from Second Cup instead of the small coffee-cup size cups they give you. I tried to drink one of those worth of water each hour, which may have been too much, but my doctor seemed to think it was a good idea. I had the staff deliver ice to me now and then. Curiously, the tap water was really cold during the day, but at night hot water came out both the hot and cold taps.

I could not find the recommended sour lemon candies in Montreal at Jean Coutu, at other pharmacies, or at grocers. Must be a Quebec thing, or an easter-in-Quebec thing, since the easter candy was dominating the candy aisles at the drugstores. Allan's Sour Fruit Slices were ubiquitous, so I picked up a couple bags of those, and called the company to confirm that they indeed use red dye #40 (which is allowable). They're not sugar free but I wasn't concerned about too many calories the way I've been eating. Upon coming home, I switched to pure unsweetened cranberry juice, diluted with a bit of Perrier, water or diet soda, which has helped keep the saliva glands going, is low in calories, and keeps fluids going into my body.

Other stuff for the isolation period:

I brought the usual disposable toiletries with me, plus a few others specific to JGH. It is one of the driest places I've ever been (my friend M who's lived in desert climates agrees with my assessment) so in addition to the dry mouth mouthwash and eye drops (for reactions to the RAI) I brought in saline nasal spray and skin lotion.

I brought in a small commercial pharmacy worth of drugs. All of my prescriptions, as well as lots of contingency drugs like Gravol, tums, immodium (since I didn't know what it was going to do to my stomach—I only took Gravol once and tossed the rest), Tylenol, etc. That way, I was not reliant upon nurses or assistants to get me my drugs when I wanted them.

When I went to bed, I called the desk and told them not to disturb me and I put a sign on the door, promising to call in the morning when I woke up, though it's hard to sleep past 7 with all the activity in the morning shift. The first night I got repeated and insistent knocks on the door at midnight from someone who was sure I needed to wake up to take Tylenol right at that minute (really? You need to wake me up for unrequested Tylenol?) so I called and complained and the next night was left alone.

The staff at JGH, including my doctor, the resident, and the staff of nuclear medicine, seem considerably more lassaiz-faire about contamination than is common on the internet. In fact, I was told it would be wasteful to throw out the clothes I wore while in isolation. Instead, I wrapped them in plastic, put them in storage for 3 weeks, and then will wash them separately. And set them aside in case I need to go back into isolation.

As others have written, the hardest thing about isolation is isolation. I'm an intellectual and an extrovert, and my isolation was complicated by the damage to my voice from the thyroid cancer and surgeries. I can't talk on the phone very much at all. I had short calls with Carrie, and I emailed my mom a long list of questions about her life before I was born and she called every day and talked to me for 45 minutes to an hour. I spoke a little but not very much.

I brought in DVDs, bought the TV (got lucky there--if you don't catch the TV guy before

you're radioactive, then no TV for you), and brought in the weekend's newspapers, a pile of magazines and a couple paperback books. Again, overpacking. I hardly got into the DVDs, though I got through most of the magazines and about half the newspapers. The absolute coup was that I rigged up internet access in the room. Here's how I did it and some suggestions for those of you without smartphones.

I brought in my laptop. Before the radioactive iodine arrived, I plugged it in and turned it on. I connected it to an old keyboard and mouse. From that point I did not touch the laptop until I left the room. It sat on the table they gave me and I used the window sill to set my food and drink. My grubby paws were all over the keyboard and mouse of course, which are also going into isolation for 3 weeks but if I was paranoid I guess I could throw them out (or you could buy a cheap set just to toss). So far so good. Internet access was achieved via tethering. If you don't know how to do this, work it out at home before you go in (you don't want to spend 2 days troubleshooting and it can be a little fussy to get up and running; I found Apple's directions vague and inaccurate, probably written by advertising heads to make it "look simple"), but if you have a smartphone, you can connect to it from your laptop via bluetooth, and if your service provider allows (Fido and Rogers in Canada do), you can access the internet on your laptop via your smartphone. In my case, it was an iPhone which I encased in a latex glove taped shut at the bottom, plugged into the wall, and more or less left alone for the time I was in the room. So I had internet. Which led to much blogging and lots of correspondence with friends. As a result, I didn't feel alone or isolated at all even though I could hardly talk on the phone. If you don't own a smartphone but do own a laptop, I believe Rogers (in Canada, check with your local providers) sells an "internet stick" where you can get 3G internet for your laptop and you don't even need a contract. It's expensive, but I would have happily paid the \$150 or whatever not to be in total social isolation for two days. I found the connection too slow for the YouTube videos friends sent me, but as I run with a verbose and brainy crowd, text was just fine for me.

Remember that radiation is only spread by your bodily secretions, so don't sneeze or cough on the computer or anything.

That's it. Despite a very high dose of RAI (175mcg) I had some of the usual side effects

but none in spades: a little dry mouth and dry eyes, a bit of nausea after eating for the first 36 hours or so, some fatigue (though this was mitigated by prednisone that I was given to prevent swelling since I have only one vocal nerve left). My taste still seems a little diminished but then my mouth is still pretty dry between glasses of sour-as-possibly-tolerable cran juice.