

2018

Hi _____,

Consider yourself being in a bear hug, I hope you are feeling a bit better and that this writing helps in some ways. This past year several women in my circle are diagnosed with breast cancer.... Do remember that I have zero medical training as you read the below.

For early stage breast cancer, most patients are monitored only with tumor markers, either Ca27.29 or Ca15-3. Though based on the same glycoprotein Mucin-1, they targeted different epitopes. From research papers that I have read and my wife experience, Ca27.29 seems to be more accurate than Ca15-3. Also, both of these markers are a bit more accurate in the metastatic setting. But more importantly, regardless of stage, these markers do not work for all patients (about 80%). They need correlation (at least initially) with "physical" (imaging, before/after surgery) data before they can be partially relied on. Why "partially"? There are non-cancerous conditions that affect the value of these markers. Also, due to the heterogenous nature of cancer cells, some tumor cells might not over express this Muc gene. Tumor's pathology also changes overtime due to treatment regimens. In using these markers, always look for trend and slope based on multiple values.

I believe in conjunction with tumor marker, a patient regardless of stage should be monitored at least annually with FDG-PET (I believe it detects recurrence earlier than CT scan or marker when accuracy is taking into account) scan. Some oncologists will not do this routinely especially for early stage breast cancer. My wife and I are constantly struggle with requesting scan. The reasons are: fear of knowing, don't want to ask the oncologist for one more thing, and the fear of adding more toxicity to the body. In some cases, even with annual scan (CT or otherwise), only the last known cancerous site is scanned, as opposed to full body. Initially this doesn't seem matter, especially if a patient is under systemic treatment, where the psychology (of scanning only the last known site) is systemic treatment covers the whole body already. But it does, for example, if the currently known site is the lung, and a patient is treated with only Trastuzumab, and only the lung is scanned. If the cancer has spread to the bone yet the marker appears stable, then the bone site would be missed, and additional medicine to help bone met (denosumab, radiation, etc) would not be added to Trastuzumab, until a patient is symptomatic.

Did you ever have Oncotype DX (or similar) test? I am assuming that you are on Tamoxifen? I believe there are intricacies (for lack of better word) in selecting endocrine treatment and how long to be on each one. In your case, most oncologists would pick tamoxifen over aromatase inhibitor, particularly in a pre-menopausal setting. I believe there is room for discussion about this, particularly in conjunction with ovarian suppression.

In every profession, there are mediocre, average, exceptional, and gifted performers. It is exceptionally difficult to tell which is which particularly in the medical field. The only guard against this is to become knowledgeable. There are three major conferences a year in the world, San Antonio Breast Cancer Conference (SABCS), American Society of Clinical Oncology (ASCO), and European Society of Medical Oncology (ESMO), regularly reading their abstracts is helpful. To be sure of one knowledge, there are online CME (continue medical education) tests, that one can takes. In the end, a patient needs a champion (sometime a patient's love one wants to help, but doesn't know what to do), since reading

medical abstracts regularly can be extremely stressful, but at time can be a source of hope. A side benefit is, during office visit, an inform patient or her champion would motivate an oncologist to be rigorous. But remember that oncologists are human too, and are fighting a tough battle with their patients. Most (if not all) the time, oncologist appreciates new information particularly if the info is presented concisely and from a scientific evident based source(s).

Do not count on hospital and/or clinic to keep accurate medical information, particularly if you plan to switch insurance and/or medical provider. Keep a diary and accurate record of your treatments and any supplements that you take. Have a one-page dynamic summary of it. This summary should have the following sections: Current overall status, tumor and genetic pathology, surgical history, treatment regimen history, a few lines about latest scan, and tumor marker trend, other medical issue, list of non cancer medicine and supplement. Make this document very concise and to one page. The idea is to present your hold clinical history in an easy to absorb the whole picture and take least time to read. This will be extremely useful for 2nd opinion or when/if you switch oncologist, see sample page.

What can you do beside taking drug? I believe the following diet and lifestyle are helpful. By the way, it seems difficult for people to make significant lifestyle changes for themselves, however it is easier to do it for someone else, i.e someone else is counting on them to stay healthy. The first thing is establishing a regular exercise routine. Of all the literature that I have read, this is the only one that consistently have data to show it makes an impact on health (in both physically, and psychologically), particularly for cancer patient. Second, eliminate processed food, reduce consumption of meat (particularly red), reduce sugar and carbohydrate (particularly white carb, i.e white rice, white bread) in take, increase consumption of vegetables and nuts, add variety of fruit (though don't over do it to minimize sugar), and add fermented food to your diet. Have at least a 13 hours time span where you eat nothing. For instance, done with dinner by 7PM and eat nothing until 9AM the next day. One source of the reason for this is as followed:

"...Fasting might even be effective in preventing the recurrence of cancer, as suggested by initial results of an epidemiological study conducted by researchers at the University of California at San Diego, published in 2016 in the journal JAMA Oncology. Among 2,400 women with early-stage breast cancer who provided information on their eating rhythm, roughly 400 suffered from new tumors within seven years. But women who fasted for 13 hours nightly had 26% less risk of recurrence than the control group. One possible reason was suggested in data summarized last year from a decade of animal experiments by Valter Longo and a team at the University of Southern California: Cancer cells are less able than normal cells to survive a lack of sugar..."

An easy to do and minimal time to prepare for a couple of meals for the whole week is as follow: Into a blender, put two handful (or so) of spinach/broccoli/kale (or all 3's), half an avocado, an orange, an apple, and a banana (eliminate banana if you want to reduce sugar), and water. Apple, orange, or banana can be replaced with pear, peach, nectarine, etc, the brighter the color fruit the better. Drink a cup or two of this per day. This one pitcher is enough for one person for 3-4 days. Get a big bowl and prepare all the fruit/veggie over the weekend, which takes half an hour and last the whole week. Drink green tea, coffee, or water in addition. Incidentally, if you are a wine drinker try to have only one glass of wine per week.

Get a rice cooker with built-in timer. In the evening (or morning before going to work) after dinner, put some brown rice or quinoa, some green peas/beans (frozen is fine), some carrots, water, and a (or two)

spoon full of fermented miso (or soybean) based. Set the timer for the cooker to be done when you eat it next. Though more time consuming in preparation, potato or pasta can be used for carb, fresh salad of some type, microwave frozen green pea/beans can be used for veggie.

Buy some salmon and/or whatever fish you like, cut them into small serving size, put them into a bowl. Add liquid teriyaki sauce into the bowl. Prepare enough for the whole week. Mix thoroughly, then divide into daily portions, put each portion in Ziplock bags and into the freezer. Teriyaki sauce can be replaced by mixing miso paste with water, or soy sauce, or just plain salt and pepper. For variety, a number of combinations are created by combining different type of fish and sauce. In the morning, take whatever amount needed and put in the refrigeration section. For cooking, one can either bake or pan seared the fish with a little bit of olive oil. If you have time, after taking the fish out, use the same pan to caramelize some onion (prepared during the weekend to save time) or mushroom. In fact, try to incorporate mushroom, particularly turkey tails regularly into the food. Add some Indian (or middle eastern) spice or curry for variety. During eating, try to have some kimchee or fermented ginger with the food. Eat only half full, leaving room for a bit of mixed nuts and/or yogurt as dessert. Incidentally, all of these ingredients are available at Uwajimaya (Japanese grocery store) and Costco (roasted seaweed), remember to read the label to know where they are from.

Serve food using a small plate, eat and chew very slowly, this helps the digestive system, absorb nutrients better, better appreciation food flavor, make you fill fuller faster enabling less calorie intake, and time for meaningful conversation with your love ones. Try to be a vegetarian one day a week. Grill (scrape the burned part of) or bake zucchini (squash, pepper, broccoli, cauliflower, etc) is very tasty when bonito fish flakes are sprinkled on them, or dressed with pepper/sesame/olive oil, or fermented soybean sauce, or ginger soy sauce.

Another veggie option is just mixed salad and chopped dry seaweed and olive oil. For veggie day, do not eat too much soybean-based product (such as tofu), since soybean has plant-based estrogen. If possible once a month, eat nothing for one day. Conversely, when you go out for special occasion, disregard (assuming one doesn't eat out often) all above, and enjoy whatever you order at the restaurant although do try to minimize sweet dessert and alcohol.

All of the above preparation for the whole week should take an hour or a bit more total. Only 10-15 minutes per cooking session and doing the dishes. All of the above is written assuming you have an extremely busy life style. If time permits, take it slow to enjoy the detail of each step of the process, make each dish a bit more elaborate (try miso black cod dish). It can actually be a stress release, and build great relationship when someone else is doing the preparation and cooking with you.

Try to buy everything organic, particularly non-farmed for fish and wild raise for meat. Although farmed Atlantic salmon from Norway is o.k. If fruit is not organic, peel the skin. If fruit/veggie are organic, make sure to wash them thoroughly. Most importantly, do NOT buy ANY food or supplement from China or India. Unfortunately, many of our medicine (particularly generic) are from there. From time to time, as you do these preparation, take a moment and look at the pile of fruit in front of you, the pieces of fish on the cutting board, the variety of medicine in the cabinet, and contrast that to the homeless in fetal position on the side walk, the refugee family waiting in line for water in near desert, the children in cage at the border, or refugees tattering on the high sea, yes cancer is a terrible disease, but we are still much more fortunate than so many others. Everyone has a cross or burden to bear. Give thanks to what we have, by being kind and caring. This attitude does wonder to one's mental state (hence one's immune

system which has a key part in fighting cancer), and of course people around us. I didn't mean to get on the high horse, I just feel for all humanities.

"No person is an island", perhaps more important than physical needs addressed above, I think a big part of mental/psychological supplement is spending time with friends. As with baby and children who needs comforting routine, a ritual of spending time with friends has the same stabilizing/calming effect for adult. I hope that at least once a week, you will make time to do that. We find that regularly spending a couple of hours hangout at local coffee shop (particularly those that have live music) with at least 2+ friends, and just bantering about nothing reduces lots of stress for you and them. Try to have the get together at the same place and at the same time. I am sure your friends will really appreciate that too. Occasionally, taking turn hosting simple coffee and dessert will build deep friendship. Initially, it would take some effort and reminder to get the routine going, but it will be well worth it.

Well, pardon this long writing full of grammar and spelling errors. I hope it's not too confusing and is helpful in some way to you. It is unfortunate that you had breast cancer, but fortunately it was discovered very early and of a non-aggressive type. Even with today medicine, off the top of my head, I can think of five+ endocrine regimens before any sort of "tougher" regimen is needed. In a few more years there will be so much more options. But chances are so good that you never need any for a very long time if at all.

A warm hug and best wishes,

Nguyen