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"I Want To Survive and Thrive": Diet and Physical Activity Recommendations for Breast Cancer Survivors
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Dear Dr. Dwyer

We appreciated the comments from you and the reviewers and made all of the changes as you indicated in your email of July 8, 2018. The line numbers are slightly different in the final version.

We look forward to seeing this column in print.

Cordially, Kathy

ABSTRACT

In this paper we review current diet and physical activity recommendations for long time survivors of breast cancer. We also hear the voice of SURVIVOR and her response to the diagnosis of a post menopausal breast cancer, the type of care she received and her readiness to respond to diet and physical activity recommendations. Suggestions for interprofessional nutrition and physical activity counseling across the continuum of cancer care are given.

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4 "I Want To Survive and Thrive": Diet and Physical Activity Recommendations for Breast Cancer Survivors

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Kathryn M Kolasa PhD, RDN, LDN and Anne R. Bouchenoire BFA

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- Kathryn M Kolasa PhD, RDN, LDN is professor Emeritus, Brody School of Medicine at East Carolina University, Greenville, NC and contributing editor to Nutrition Today.

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- Anne R. Bouchenoire BFA survives and thrives as a grandmother, painter, avid reader, and adventurer, as well as retired global brand management executive.

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ABSTRACT

In this paper we review current diet and physical activity recommendations for long time survivors of breast cancer. We also hear the voice of SURVIVOR and her response to the diagnosis of a post-menopausal breast cancer, the type of care she received and her readiness to respond to diet and physical activity recommendations. Suggestions for interprofessional nutrition and physical activity counseling across the continuum of cancer care are given.

INTRODUCTION

There are more than 15.5 million cancer survivors in the United States, most over the age of 65 years and the numbers are growing. Of those, 3.6 million are females with breast cancer. In 2016, 67% of survivors had survived 5 years or more after diagnosis; 44% have survived 10 years or more; and 17% have survived 20 years or more (1). For those with advanced cancer, regaining health after difficult treatment can be challenging. Nutrition and physical activity cancer recommendations for lifestyle modification have been disseminated by the U.S. Department of Health and Human Services and leading cancer organizations (2-5) for more than two decades yet many women report never having a serious discussion about their diet during or after cancer treatment (6-7).

Call out insert about here: Nutrition and physical activity cancer recommendations for lifestyle modification have been disseminated by the U.S. Department of Health and Human Services and leading cancer organizations (2-5) for more than two decades yet many women report never having a serious discussion about their diet during or after cancer treatment

The nutritional needs of the woman changes over the course of survivorship and in recent years the evidence for healthful diet, weight management and physical activity (PA) for survivorship has been translated into guidance (8-17). Although nutrition and PA advice may be given to survivors while in active treatment through workbooks and pamphlets, Registered Dietitian Nutritionists (RDNs) are not usually on the cancer team and oncologists have rarely provided such guidance (7,18). Surveys document that many women are not meeting the diet and PA recommendations (6-7). As recently as 2017, Klassen and coworkers noted that a common barrier to nutrition counseling in cancer care settings is a lack of role identification for providing nutrition and PA counseling among the health professionals treating the woman throughout the cancer continuum (6). The cancer continuum includes 1) active treatment, 2) recovery immediately after treatment, 3) long term disease free or stable disease and 4) advanced cancer and end of life (9). In this article we review the nutrition and PA recommendations for women in all but stage 4. We also present the voice of a SURVIVOR describing her response to her diagnosis and treatment, access to nutrition advice and readiness to change over her survivorship. She tells her story to an interprofessional group that includes medical, nursing, dietetics, physical therapy, pharmacy, clinical psychology, social work, and exercise science learners.

SURVIVOR: I wanted to survive and thrive. Wouldn't it be great if when a woman wakes up from surgery her surgeon said, 'Congratulations, you are now a cancer survivor! Don't be surprised that we consider you a key part of our care continuum team. We'll work together with you to maximize your quality of life. We'll move step-by-step through the medical treatments and your corresponding nutrition and physical activity goals at each step. We'll help you help us – so when possible, you can reduce the side effects with diet and physical activity and set yourself up to thrive... as a survivor.'

CASE

Our SURVIVOR is 69 years old and now an 12-year survivor of post-menopausal Stage 3 invasive ductal carcinoma given a 5-year survival rate of 64%. The chart note from this visit is in Table 1. She presented in the nutrition clinic after a group of old friends, all survivors, learned that one had helpful consultations with a registered dietitian nutritionist (RDN) starting during her treatment and continuing through her survivorship. Our SURVIVOR, whose BMI is in the healthy range, told the RDN she came more out of curiosity than to seek a plan to reduce risk of recurrence or other chronic disease, but she did keep a 7-day diet record and provided a list of dietary supplements as requested (Table 1). Looking back, our SURVIVOR who was a corporate executive in a health care products and services company, reported that she approached her cancer diagnosis first with a complete handover of health to her doctor and medical team, then came to realize she had a role in getting back her quality of life.

SURVIVOR: I became very conscious that “what you eat could kill you” or help cure you. My everyday goal became to eat healthy. I felt pretty much on my own to plan the what and how to eat healthy. My diet became about eating real food, being mindful of portion sizes, including low fat milk or plain yogurt daily, noting foods with antioxidants, avoiding processed meat, and limiting alcohol to one 5 oz glass of wine a day. The information about soy foods and estrogen was confusing so I just avoided tofu and soymilk. My husband had often been the primary food preparer and we enjoy many cooking styles, but we started to use less butter and cream and eat more fish and meatless meals, always with a wide variety of fruits and vegetables.

Call out insert about here: I became very conscious that “what you eat could kill you” or help cure you. My everyday goal became to eat healthy. I felt pretty much on my own to plan the what and how to eat healthy.

BACKGROUND

Dietary Guidelines for survivors of breast cancer

During treatment the overall goal of nutritional care is to maximize the quality of life by preventing or resolving nutrient deficiencies; achieving or maintaining a healthy weight; preserving lean body mass; and minimizing nutrition related side effects. As survivors often experience accelerated aging and frailty and have significantly elevated risks for premature mortality and serious morbidity, the goals after treatment would also include reducing risks for diet related chronic conditions. Sixteen years ago, Rock and Demark-Wahnefried summarized the evidence on the relationship between nutritional factors and survival after the diagnosis of breast cancer concluding that while much was still to be learned, healthy weight control with an emphasis on exercise to preserve or increase lean muscle mass and a diet that includes nutrient rich vegetables could be recommended (8). Other reports touting improved survivorship by achieving and maintaining a healthy weight; engaging in regular moderate PA and achieving a dietary pattern high in vegetables, fruits, dietary fiber and whole grains and reduced fat and eating foods that contain soy followed (9-18). O'Neil and coworkers found that most survivors were aware that fruit and vegetable consumption, engaging in PA and having a healthy body weight could potentially reduce their cancer recurrence risk yet over one-half of survivors said they were not maintaining a healthy body weight, about one-third were not engaging in diet and exercise behaviors to reduce their cancer risk and perhaps needed assistance in translating awareness into action (19). Some oncology health professionals might argue that the two dietary intervention studies in survivors do not provide compelling evidence of the effectiveness and therefore do not give a priority to nutrition counseling (20). Interestingly, while there is a robust literature on the knowledge and attitudes toward nutrition of health care professionals treating heart disease, diabetes, and obesity, there is almost nothing about oncology professionals. Even so, the diet and PA guidelines have been accepted based more on the effects of comorbidities than on cancer specific survival (7). Survivors, for example, were

found to have an increased risk of cardiovascular disease with dietary patterns that were high in empty calories, fat, saturated fat, sugars, alcohol, and sodium, and lower in dietary fiber, vitamins D and E, potassium, and calcium (21). They found the dietary patterns did not change in quality with years from diagnosis.

The 2018 World Cancer Research Fund's Third Expert Report shifts emphasis from individual foods and nutrients to focus on avoiding different patterns of diet and PA that combine to create a metabolic state that is generally conducive to the acquisition of the genetic and epigenetic alterations that lead to the phenotypical, structural, and functional alterations in cells described by the hallmarks of cancer. Thus, the most benefit is to be gained by treating the diet and PA recommendations as an overarching preventive package. The 2018 AICR diet for survivorship recommendations are in Table 2 and noting that survivors should follow the prevention guidelines if they can.

Call out insert about here: The 2018 AICR diet for survivorship recommendations are in Table 2, noting that survivors should follow the prevention guidelines if they can.

The Third Expert Report provides the details of factors that modify the risk for menopausal breast cancer: convincing evidence or increasing risk (alcoholic drinks, body fatness, adult weight gain, adult attained height); probable evidence of decreasing risk (total PA, body fatness in young adulthood, lactation; and the limited or suggestive evidence of decreasing risk (non-starchy vegetables, food containing carotenoids and diets high in calcium) (10). The report also lists many factors where the evidence is too limited to make a conclusion. It should be noted that the risks for premenopausal breast cancer are different and can be found at <http://www.aicr.org/continuous-update-project/breast-cancer.html> (22,23).

Physical Activity; Side Effect and Weight Management. Evidence linking increased PA to improved cancer outcomes has been found by an expert panel to be preliminary but promising (17). However, the solid evidence that diet, PA, and reduced adiposity play critical roles in preventing cardiovascular disease and diabetes and exert a positive influence on quality of life led the American Society of Clinical Oncology (ASCO) to recommend health care professional in oncology promote PA across the cancer care continuum (14). An inverse relationship between PA after a cancer diagnosis and mortality; benefits such as cardiorespiratory fitness, decreased fatigue and depression, beneficial changes in insulin, inflammation, and immunity; and improvements in quality of life; have been observed in studies of breast and colon cancer survivors (24,17). The most effective interventions include self-monitoring, individualized guidance, or coaching, and setting clear goals and expectations (17).

Post-menopausal breast cancer survivors are known to have a 2-8% bone loss due to chemotherapy and aromatase inhibitor (AI) therapy and reduced use of upper body following surgery (25). PA along with optimizing calcium and vitamin D intake can reduce risks for fracture and loss of function (26).

There is mounting evidence that weight management improves overall health and well-being and reduces the risk of morbidity and mortality (17). Weight management will be addressed later in this paper.

CASE REVISITED

The RDN congratulated our SURVIVOR on her weight management, eating and PA plan. Her intake of fruits and vegetables and dietary fiber is particularly good. With her permission, we discussed her interest in improving her intake of calcium, vitamin D, omega 3 fatty acids, potassium, and magnesium from food rather than supplements in order to reduce the long term and late effects of the cancer and its treatment, as well as the risk for chronic disease. The RDN clarified that the belief that soy isoflavones mimic the level of estrogen and potentially spur the growth of cancer cells is

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4 unsubstantiated, and that eating soy foods would offer her more meatless options and may help reduce
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6 risk of all-cause mortality (27-28). She was pleased that when comparing her healthy habits with
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8 adherence by study subjects she was doing well (6). She will continue to follow a whole food plant-
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10 based diet and be physically active.
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18 PRESENTATION TO HEALTH PROFESSIONS LEARNERS 19

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21 RDN: We have a breast cancer survivor willing to share the story of her cancer diagnosis, treatment, and
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23 survivorship with you—with a focus on the role nutrition and PA might play. She like most breast cancer
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25 patients received little formal nutrition and PA counseling from her oncology or primary care teams
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27 (6,20). That's not surprising as treatment decisions become increasingly complex there is little time for
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29 discussion with the physician about diet and even in comprehensive cancer centers there rarely is a RDN
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31 on the team. There is scientific evidence to support the effectiveness of nutrition therapy to increase
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33 effectiveness of oncology therapy and to reduce nutrition impact symptoms among individuals who
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35 have cancer (13). There is evidence too that an RDN has a role as a member of the interdisciplinary team
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37 caring for adult oncology patients by determining the optimal nutrition prescription and developing the
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39 nutrition care plan for all phases of illness (13). Unfortunately, there is an estimated one RDN for 2,600
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41 cancer patients (7). Other health care providers, throughout the cancer continuum of care can play an in
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43 important role in providing not only information about diet and PA but importantly the "how to" (28).
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45 Our SURVIVOR reflects on when she might have been ready and benefited from advice about diet and
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47 PA from the Cancer Care Team.
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VOICE of SURVIVOR: The cancer diagnosis was an unexpected jolt of surprise, dismay, fear, stop.

Call out insert about here: The cancer diagnosis is an unexpected jolt of surprise, dismay, fear, stop.

Going from rarely sick to this life-threatening condition and not knowing how to navigate my own health care was daunting.

Going from rarely sick to this life-threatening condition and not knowing how to navigate the health care system was daunting. Indeed, leading up to the week of my discovery (inverted nipple, lump behind it), I would have described myself as in very good health. With the results of my biopsy, my ob/gyn (family doctor) immediately set up an appointment with a breast cancer surgeon. My mindset was be brave. I tried to hear everything while numb with anxiety. I needed to know he could fix it. He wanted to know my biggest concerns. To get it out. The how and the when. Ok, first tests, then surgery; chemo, radiation, and hormone therapy were all possibilities. It was serious and needed some urgency. The advice was all medical. I was clearly overwhelmed. Glad my husband had come with me, so much to remember. Was there something I should do? I was given a pamphlet to read, and a treatment handbook (30). Then I needed to match this personal life upheaval with a work life already scheduled.

I wrote in my diary and letters to family/friends: "Just like that all my priorities have changed. Work becomes a kind of background noise as I make plans for a 6-8 week leave of absence. It seems my rollercoaster of feelings can be as quick into a dive of sadness as rushing with forward determination. One moment frightened, the next moment calm. Just too much to take in when you're on this rollercoaster of emotions. I am brave, and then not so brave. But I am determined! It may be sizeable, but it is curable."

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4 *The surgeon's office set up appointments for labs, gave me recommendations for plastic surgeon,*
5 *oncologist and radiologist and set surgery for the following week. My body image options were*
6 *limited. I would probably need radiation after chemo. The C-Section scar tissue on my abdomen ruled*
7 *out using my own skin to reconstruct and I was not inspired to put foreign substances into my body*
8 *that might need replacement in five years.*

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11 *I was admitted to hospital for a 24-hr stay. I received another folder of informational materials. I woke*
12 *up with a sense of loss and pain. My left breast and 14 lymph nodes were gone. The assisting*
13 *physician came by briefly to see how I was and answer any questions. I hardly knew what to ask. I was*
14 *given a detailed set of pages dealing with post-op care, including instructions for the drain, and an*
15 *appointment to have stitches removed. That afternoon at home I received a call from the nurse who*
16 *would support me via phone through my cancer treatments. We would step through questions and*
17 *details about managing pain, dealing with the drain, then a follow-up series of exercises for my left*
18 *arm. There was the treatment handbook for me to consult for all the rest I needed to know. I skimmed*
19 *it, made some notes. The doctor had gotten the cancer out, now I faced the "new me" and wanted to*
20 *believe I could be healthy again.*

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23 *Cancer happened. My attitude — beyond that sense of loss — deal with it! Long way to go yet. Chemo*
24 *came with a punch. No, my body would not tolerate these drugs easily. A night of total nausea to*
25 *solve before adding a separate drug before each chemo session, every other week. Now there would*
26 *be steroids in my system. I was more in-tune with my body and pain signals, with the phrase 'listen to*
27 *your body' gaining new meaning. I followed the treatment stages without question. I felt acutely the*
28 *loss of control/choice. That all my decisions were necessarily being made for me; that my ordered*
29 *world has been turned upside down. My sense of self was fluid, not confident. Just doing what had to*
30 *be done. There was a kind of lethargy that took over when I was so drained by treatments. I needed to*
31 *know how to help myself, to get as far from self-pity as possible. It's a terrible blow to have such an*
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4 *intimate part carved out, even to survive. Eating for comfort or eating for cure? Would it make a*
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6 *difference? Exercise to regain arm mobility and exercise to get fresh air and feel better. I consulted my*
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8 *'cancer bible,' the book by Dr. Carolyn Kaelin (31) who lived through breast cancer herself; and*
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10 *subscribed to the Harvard Women's Health Newsletter (32). I was determined to go back to work by*
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12 *the end of the second chemo session, just after I lost all my hair. With mouth sores, anemia, 'chemo*
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14 *brain', radiation (skin issues) and aromatase inhibitors (joint pain) still ahead. But the desire to regain*
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16 *some control in my life was restless. I bought a wig and new bras to fit a prosthesis and learned make-*
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18 *up tricks to disguise the lack of eyebrows and eyelashes. I collected more diet and exercise*
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20 *information. I kept working because it was my source of health insurance but began a plan to retire.*
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22 *Top of mind, was that two good friends, recovered from stage 3 cancer who'd gone back to their high-*
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24 *powered jobs had died in the last year, just two years 'cancer-free.' I was determined to consider an*
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26 *alternate lifestyle. I knew the stress of my corporate management life would probably kill me, too. My*
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28 *new normal was so not my old normal. Quite a mix of physical, emotional, and psychological hurt. I*
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30 *needed to know who I could be, what I could do; how to not just survive, but thrive.*
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38 *I can look back at the first years after all the treatments and aromatase inhibitors (AIs), and see those*
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40 *years were overshadowed by a numbness and introspection that could be described as depression,*
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42 *though I wanted to think I was just learning to take it easy. I'm not sure now that it was that simple.*
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44 *The easy start-to-finish focus on projects was gone. Annual mammograms were a source of anxiety.*
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46 *Taking the AIs, you are not drug-free; you try to figure out if what you are feeling is natural aging or*
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48 *effects of the pills. I wrote, 'I'm wondering if we can admit that an unwritten side effect of the 5 years*
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50 *of AIs is the insidious thought that one is still 'sick.' Oh, how hard it is to break free of this drag of*
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52 *drug-dependence to get to full confidence in a body that just might keep up with all the energetic*
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54 *plans of mind and spirit.' The point is that part of this cancer battle we have to win is the fight to*
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overcome the side effects (physical and emotional) and be the person, the very best person, we can be (or aspire to be), no matter what.

RDN: Cancer can cause profound metabolic and physiological alterations that can affect nutritional needs. Treatment side effects like pain, fatigue, mucositis, nausea and vomiting, anemia, diarrhea, constipation, mouth sores, changes in taste and smell can limit food and fluid intake leading to malnutrition and a weakened immune system (2). You didn't have an RDN on your team to give you guidance on dealing with, for example, your mouth sores. An RDN would have told you in addition to the special mouth wash that the texture and temperature of food is very important. Since individuals react differently to textures, the RDN would have tailored a diet plan that ensured you took in adequate nutrition without lots of chewing and "mouth time". How did you deal with side effects of your treatments?

SURVIVOR: My reaction to the first chemo session was unremitting nausea. All the usual remedies that evening/night just made it worse. I don't recall getting nutrition advice but rather added medicines to treat or prevent the symptoms. By the 4th session of chemo I had mouth sores. And it was the extent of it that surprised me. It forced a diet change because anything spicy, crispy, or hard would hurt, and easily cause bleeding gums. More soups, applesauce, and ice cream. I managed but agree that nutrition guidance would have helped. My appetite diminished, and it just added to the cumulative exhaustion at the end of chemo.

RDN: Let me mention to our learners that an RDN can help people experiencing nausea and fatigue by helping design a schedule of timing of meds, rest, eating small meals, hydration, and physical activity.

The RDN can help create an eating pattern that is convenient yet healthy.

We know many women experience chemotherapy-induced peripheral neuropathy, arthralgia and myalgia that might be helped by nutrition although the evidence is very limited. Up to 80% of

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4 individuals receiving a cancer diagnosis report using dietary supplements and botanicals. They report
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6 taking dietary supplements to strengthen their immune system, reduce fatigue, relieve hot flashes, and
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8 other menopausal symptoms, help sleep disorders, anti-inflammatory benefit, antiemetic properties,
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10 and even anti-tumorigenic properties. Some of these supplements have no evidence of benefit, some
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12 can be used safely and have potential benefits and some pose risks (33-35). You have taken the
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14 nutrients recommended by your physician but no other supplements. About half the many women with
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16 breast cancer are prescribed 5 years of treatment with AIs as they provide a clinically meaningful
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18 reduction of recurrence and mortality risk. About half the women taking them, including you,
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20 experience joint pain and bone loss (7) and some have found relief with nutrition (34). Although the
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22 evidence is limited the potential for relief is not noted in the Dietary Supplement Fact Sheets for B6 and
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24 B12 published by the Office of Dietary Supplements (36). Two other sources of evidenced based
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26 information on dietary supplements and cancer include the National Cancer Institute (2) and the
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28 National Center for Complementary and Integrative Health (37).
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35 ***SURVIVOR: Yes, true enough. I was either told or read that I shouldn't take supplements during***
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37 ***chemotherapy and radiation and I followed the rules. Towards the end of my chemo treatments, I was***
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39 ***experiencing frequent hot flashes as well as tingling at the end of my fingers. And some lack of***
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41 ***sensation in my toes and across the balls of my feet. My oncologist suggested a drug that alleviated***
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43 ***this condition and when I asked about anything "natural" instead that I could take/do he suggested***
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45 ***vitamin B6 and B12 and prescribed a dose. I was averse to more drugs with their own list of possible***
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47 ***reactions, so I tried the Vitamin B6/B12. I wasn't aware that there may have been dietary***
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49 ***supplements that would have provided some relief for this or other side effects. I relied on a range of***
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51 ***vitamins to supplement a healthy diet. (I had a stack of articles to consult, and several good***
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53 ***cookbooks.) Here would be another marker moment for a health professional's advice about what's***
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being offered in health food or vitamin stores versus what natural ways could deal with the symptoms.

I wanted to be able to depend on my body again. I wanted to be “actively alive.” Once done with radiation treatments, I focused on as much exercise (which wasn’t much) as I could deal with and as often as possible — walking/hiking or bicycling mostly, and being outdoors on weekends. I really had to start slowly and build on this.

RDN: The estimates of women reporting fatigue, and low PA, is from 15% to 90%. Yet, studies show that PA helps relieve fatigue (37), achieve and maintain a healthy weight, preserve lean body mass, and promote vitality (37-38). Most women experience vasomotor symptoms, including hot flashes that may impact their ability to be physically active. During treatment, the recommendation is to aim for 20-30 minutes of PA three to five days a week but avoid vigorous activity and activities that increase risk of infection (39) and as possible build endurance to meet the recommendation of 150 minutes per week of aerobic activity.

Survivor: Intellectually and practically I understand the recommendation, but an active guide to steer the cancer patient through an exercise program — a physical cheerleader — would really help make this happen in an organized way.

Call out insert about here: Intellectually and practically I understand the recommendation, but an active guide to steer the cancer patient through an exercise program — a physical cheerleader — would really help make this happen in an organized way. Let’s take fatigue as a given.

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4 ***Let's take fatigue as a given. Physical, emotional, and psychological! Strong mix. I was always***
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6 ***exhausted; had suffered a big dip in body image, along with hot flashes, mood swings and the 'chemo***
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8 ***brain' lack of mental sharpness. I had to prioritize my limited energy to reassure worried family,***
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10 ***maintain a minimally acceptable work life and keep track of a stack of hospital, physician(s) and***
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12 ***insurance bills/papers. Still, there were days when I'd take a walk to clear my head. I'd walk more***
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14 ***often to the cafeteria for a glass of water or juice. Take the stairs instead of the elevator to a meeting.***
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16 ***But it was activity I could incorporate into my day, not add to it. It occurs to me that just as we went***
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18 ***over my medical regimen, progress, and reactions, having my oncologist include PA in that analysis***
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20 ***would have been helpful. This man was "curing" me; I needed and wanted his guidance.***
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26 RDN: Traditionally breast cancer survivors have been cautioned against lifting more than 10 pounds and
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28 to limit repetitive upper-extremity activities. Fear of lymphedema also may limit PA (7). However,
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30 progressive resistance training improves muscular strength and functional ability and experts now
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32 recommend interventions (24, 40).
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36 ***SURVIVOR: I was certainly told that despite the pain, basic exercises were necessary so I didn't lose***
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38 ***full motion in my left arm and shoulder. Also warned about lymphedema, so I limited repetitive***
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40 ***activity, such as sweeping, raking, and kayaking.***
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44 RDN: Unfortunately, most women gain weight during treatment and an estimated 65% of survivors are
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46 overweight or obese (7,17). There is strong evidence that being at a healthy weight improves breast
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48 cancer survivorship and there is a positive association between greater body fat and all-cause mortality,
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50 breast cancer mortality and secondary primary breast cancer (17). Weight loss achieved through caloric
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52 restriction, increased PA and behavioral counseling has been shown to be feasible and safe in survivors
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54 (7, 17). The current obesity guidelines (41-42) appear to be applicable, although the safety of medication
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56 and/or surgery have not been established in survivors. ASCO published a provider kit to help counsel
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women about weight management with a focus on healthy lifestyle (14). It appears that you managed, unlike many of the breast cancer patients we see in our clinic, to lose the weight on your own, avoided falling into fad dietary treatments, using unproven dietary supplements and building a health promoting eating pattern.

SURVIVOR: I had gained about 10 lbs. from the time of active work life before cancer to the time I finished the five years of AIs. But it took a few more years to pull together a combination of motivation and good diet/exercise plan on my own to shed those pounds. My mother had managed diabetes with a determined diet change — so I had the mindset that nutrition was important. My treatment handbook (30) had a general chapter about nutrition, but it wasn't reviewed or discussed with me. On my own I gathered articles, referenced my "cancer bible," went online to cancerconnect.org (sponsored by the American Cancer Society); and found resources from the Mayo Clinic (43). Like other survivors I spoke with, we wanted advice more survivor-specific than our oncologist saying, "eat right and exercise."

Call out insert about here: Like other survivors I spoke with, we wanted advice more survivor-specific than our oncologist saying, "eat right and exercise"

RDN: We know for example that "sarcopenic obesity" or a loss of muscle mass with a gain of adipose tissue is common during chemotherapy. Some patients who experience this respond well to weight loss interventions (17-18). When would you have been ready for a session with an RDN to create a diet and physical activity plan?

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4 **SURVIVOR: This is a great question in hindsight! At first, I focused on 'get it out' and just endured the**
5 **chemo regimen without truly understanding there was something I could eat or do to make a**
6 **difference. if you told me about muscle mass and adipose tissue at the same time that I was given the**
7 **news of the diagnosis and surgery — it's too much to handle (or grasp). But if you add a tip about**
8 **nutrition and physical activity before chemo and at each stage of cancer treatments, I've got a**
9 **moment when I am factoring in new information. The treatment handbook (30) did have a section**
10 **that discussed physical and emotional exhaustion from chemotherapy, but ironically, I was probably**
11 **too tired to read it. Talk us through a plan. For example, "Here is what will be happening to you (new**
12 **meds; next chemo drug, radiation etc.) and here is the corresponding plan of diet/nutrition and basic**
13 **physical exercise that will help you offset these reactions." Then it's not about giving up my body for**
14 **the cure, but having a part in the cure, increasing my ability from day one to not just survive, but**
15 **thrive.**

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33 RDN: Is there anything else you would like to share?

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36 **SURVIVOR Twelve years since diagnosis and 6 years since AI treatments, I continue to**
37 **see my oncologist once a year; her support and sage advice about a happiness focus has**
38 **kept my aim on thrive. A very practical nurse at the local clinic has become a good**
39 **friend, encouraging a holistic approach to health and wellness. Her help keeps all my**
40 **disparate aches and pains in perspective: not cancer coming back, simply aging. I'm**
41 **lucky because many long-time survivors feel abandoned after treatments finish. My**
42 **family doctor considers me "cured." Underneath our joy and 'thriving', though, all**
43 **survivors (me too) live with some fear that cancer may return. But now many age-**
44 **related ailments could strike first! I do what I can to be vigilant with diet and physical**
45 **activity. Have I mentioned that every day for the last 27 years, my husband has**
46 **wrapped me in the hug of his love and said the words "I love you." Believing in me even**
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when I've been skeptical. Like an extra dose of courage. So, I smile. Smiling reminds me I am happy to be alive, no matter what.

SUMMARY

Today there is sufficient evidence that the Cancer Care Team should ensure the survivor has access to evidence-based nutrition and physical activity guidance throughout the continuum of cancer care.

However research is still needed on the effect of purposeful weight loss and specific dietary patterns and exercise on various cancer outcomes. Guidance that includes the optimal interventions to promote behavior change. A decade ago our Survivor received nutrition information in handouts and a workbook from her care team. Today she acknowledges that nutrition and physical activity coaching at each stage of care would help mitigate not just the physical, but the emotional and psychological trauma by giving the survivor a more active role in an ongoing recovery. Health care professionals in oncology and primary care settings have a key opportunity to identify responsibility and promote nutrition and physical activity for their patients.

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BIOS

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Table 1. Chart note. Visit with RDN 11 years after breast cancer diagnosis.

Table 2. American Institute for Cancer Research (AICR) Guidelines for Cancer Survivors

SIDEBARS/CALL-OUTS (shown in text in bold underline of about where to insert)

Nutrition and physical activity cancer recommendations for lifestyle modification have been disseminated by the U.S. Department of Health and Human Services and leading cancer organizations

(2-5) for more than two decades yet many women report never having a serious discussion about their diet during or after cancer treatment

Survivor: I became very conscious that “what you eat could kill you” or help cure you. My everyday goal became to eat healthy. I felt pretty much on my own to plan the what and how to eat healthy.

The 2018 AICR diet for survivorship recommendations are in Table 2, noting that survivors should follow the prevention guidelines if they can.

VOICE of the SURVIVOR: The cancer diagnosis is an unexpected jolt of surprise, dismay, fear, stop. Going from rarely sick to this life-threatening condition and not knowing how to navigate my own health care was daunting.

Intellectually and practically I understand the recommendation, but an active guide to steer the cancer patient through an exercise program — a physical cheerleader — would really help make this happen in an organized way. Let’s take fatigue as a given.

Like other survivors I spoke with, we wanted advice more survivor-specific than our oncologist saying, “eat right and exercise”

Table 1. Chart note. Visit with RDN 12 years after breast cancer diagnosis.

Chief complaint: Curious about any suggestions for diet and physical activity for prevention of cancer recurrence

SUBJECTIVE**Social history**

Retired corporate brand executive for a global health care products and services company. Completed college with a major in fine art (BFA). Married (25 years) with supportive husband. Lives in relatively stress-free environment with clean air and water. Avid reader of health information and world news. Describes herself as happy and optimistic; delighted to return to painting; and enjoying more frequent visits with family (including the grandchildren) and friends. Reaches out to women with new cancer diagnosis, with matter-of-fact letters of encouragement, touched with hope and humor, about what's happening at each step on the way to survival.

Past medical history

Basically healthy woman who was newly post-menopausal at the time of breast cancer diagnosis. Four pregnancies with three live births by Cesarean section. Breastfed first for 7 mos., second for 9 mos; third for 12 mos.

2007. Breast cancer, left breast. Stage 3 invasive ductal carcinoma with 4 of 14 lymph nodes involved. The tumor was ER/PR positive and HER 2neu negative. Considered aggressive with high risk of recurrence. Five year survival rate: 64%. Treated with mastectomy, 4 months chemo therapy with Emends before treatment to control nausea and vomiting, Adriamycin and Cytosan, w/Neulasta follow-up; Taxol and Herceptin; 5 weeks radiation, Aromatase Inhibitor (Arimidex for 2 yrs with considerable knee joint pain; Femera for 3 yrs with fewer side effects.

2009. Bone density test. Results unavailable. Reports physician stated results were "remarkably good"

Family history

Mother with type 2 diabetes at age 42, breast cancer at age 76, death from a diabetic related stroke at age 81 years. Father death from a stroke at age 91 years. Second of 7 siblings. Older brother died at age 54 yrs from uncontrolled blood pressure and obesity;

Current meds and supplements

Telmisartan 40 mg for hypertension

500 mg calcium and 1,000 IU vitamin D3 (prescribed by her primary care physician)

1,000 mg vitamin C (self prescribed for cold prevention)

1,200 mcg Vitamin B12 (first prescribed by oncologist in 2007)

80 mg ASA EC (aspirin) (prescribed by primary care physician in 2010)

Diet, physical activity and weight history

Tried to eat healthy throughout adult life to manage her weight; social drinker, in moderation. During her corporate life, she ate out several meals a week.

During and following cancer treatment read and saved articles about nutrition and physical activity in health newsletters, the hospital handouts, her treatment handbook (20) and her "bible" for survivorship, "*Living Through Breast Cancer*" by Dr Carolyn Kaelin (40); subscribed to the Harvard Women's Health Newsletter(30) for more information about every aspect of cancer treatment and survivorship; loosely followed Mayo Clinic (41) description of "Mediterranean diet" for cancer prevention (e.g. eats food with antioxidants, avoids processed meat; limits alcohol to one 5 oz glass/day). Confused about safety of soy so then avoided tofu and soymilk. Heard of but did/does not take dietary supplements to prevent/treat breast cancer recurrence, side effects or menopausal symptoms. No organized discussion of diet and exercise with a RDN or other health care professional. Nurse navigators provided helpful "tips."

Lowest/Highest adult non pregnant weight: 126 lbs (1971)/163 lbs (2008); Weight gain with pregnancies: 40, 30, 30 lbs

Moderately active throughout adult life. Current physical activity includes during cold weather walking 40-80 min/wk and 45-60 min riding a stationary bike/5 days/wk. During warm weather amount of time in physical activity similar but shifts to outdoors walking and kayaking. She recently added a weekly yoga class. During and after treatment she struggled to build endurance for more exercise; avoids repetitive motion with her left arm and lifting items over 10 lbs (including grandchildren) as instructed by physician and reinforced by nurse.

Objective

Weight: 148 lbs; Height 67 in; BMI = 22.9; waist circumference = 31 in. BP = 114/70

Diet analysis: average from 7 day record - 1,626 calories, protein (66 grams), carbohydrates (192 grams), dietary fiber (30 grams), and sodium (1,890 mg), total fat (67 gm), saturated fat (21 gm), omega 3 fatty acids (2.30), vitamins D (62 IU), E (5.4 mg,)vitamin B 6 (1.5 mg without supplement), and B12 (3.1 mcg without supplement), calcium (751 mg w/o supplement), potassium (2,090 mg), and magnesium (263 mg).

<u>Nine Healthy Behaviors (Klassen)</u>	<u>% in study</u>	<u>this patient</u>
Avoided alcohol (< 1 drink/day)	92	yes- 1
Consumed adequate fruits and vegetables (5+serv/day)	72	yes
Limited cholesterol to <300 mg/day.	68	yes-164
Had adequate vitamin D intakes of (>15 ug)	56	62 IU, w/supp 1,062 IU
Had adequate calcium (> 1,000 mg)	52	751 mg w/sup 2,251
Limited saturated fat(<10%)	52	no
Consumed a healthful range of total calories (1,600-2,200 calories)	48	yes
Had adequate fiber (>25 g).	24	yes- 30 gm
Met sodium recommendation of < 1,500 mg	4	no 1,890 mg
Median and range behaviors met	4	4-6

Assessment

11-yr breast cancer survivor determined not only to survive but thrive. Is at a healthy weight. Meeting caloric and most nutrient requirements; nutrients of concern include low intakes of omega 3 fatty acids, the nutrients of concern without supplementation are vitamins D, E and B12, calcium, potassium, and magnesium and, with supplementation, exceeding the Upper Tolerable limit of vitamin C.

Was provided by breast surgeon's office credible nutrition information in "Breast Cancer Treatment Handbook" (29), by oncologist's office pamphlets from the National Cancer Institute, but without discussion of food and exercise priorities.

She experienced a heightened awareness to "listen to her body" and had understood from the moment of diagnosis the need to reduce the stress in her life and strengthen her immune system. The nurse-on-call through the treatment program, recommended exercises for a gradual return to physical activity, beginning with the post-surgery arm exercises. On her own, she worked on developing the breathing rhythms of mindfulness. 8 months after all treatments she resigned from her corporate job, moved to a new home, and attended a series of breast cancer support sessions. Talking about the shared experience was helpful, but the negative outlook of many was depressing. To accept and "actively" thrive as a "new me", the most meaningful advice she got was from her oncologist, as a choice of focus: "to be happy."

Annual visits to her new oncologist and family physician were kept. Minimal discussion of how to eat healthy. Lost weight gained during treatment on her own over several years.

Problem list

1. 2007. Breast cancer, left breast. Stage 3 invasive ductal carcinoma with 4 of 14 lymph nodes involved. The tumor was ER/PR positive and HER 2neu negative. Considered aggressive with high risk of recurrence. Five year survival rate: 64%. Treated with mastectomy, 4 months chemo therapy (Adriamycin and Cytoxan, w/Neulasta follow-up; Taxol and Herceptin); radiation 5 days/wk for 5 w ks; Aromatase Inhibitor Arimidex for 2 yrs with considerable knee joint pain; then Femara for 3 yrs with fewer side effects.
2. 2007. Anemia induced by chemotherapy. Treated and resolved with Aranesp (darrbeoetin alfa).
3. 2007. Fatigue during treatment. Improved but persists.
4. 2007. Joint pain. Relieved with cessation of AIs.
5. 2007. Mood swings. Resolved.
6. 2012. Hypertension. Treated with diet, physical activity, and medication.

Plan.

1. Agreed that in addition to diet for prevention of recurrence, would consider an eating approach to reduce risk of cardiovascular disease and diabetes. Will study information about Mediterranean diet and continue to eat whole food plant based diet. Continue to manage weight with diet and physical activity
2. Maintain physical activity plan to continue to build endurance to address fatigue, reduce risk for both cancer recurrence and chronic disease. Participate in weekly yoga class.
3. Determine feasibility of reducing reliance on vitamin supplements to meet calcium and vitamin D needs.

Table 2. American Institute for Cancer Research (AICR) Guidelines for Cancer Survivors(22)

1. Be a healthy weight
2. Be physically active
3. Eat a diet rich in whole grains, vegetables, fruit and beans
4. Limit consumption of “fast foods” and other processed foods high in fat, starches, or sugars.
5. Limit consumption of red meats and processed meats
6. Limit consumption of sugar sweetened drinks
7. Limit alcohol consumption
8. Do not use supplements for cancer prevention
9. For mothers: breastfeed your baby, if you can
10. After cancer diagnosis: follow our cancer prevention guidelines if you can

<http://www.aicr.org/reduce-your-cancer-risk/recommendations-for-cancer-prevention/>
Accessed June 10, 2018

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