

Healthy Living for Cancer Survivors: Bone Strength, Nutrition, and Exercise

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Presented by:



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Contents

I. Introduction	3
II. Healthy Living for Cancer Survivors.....	4
III. Personal Story	14
IV: Question and Answer	18
V. Conclusion.....	21
VI: Speaker Biography.....	22
VII: About Sharsheret.....	23
VIII: Disclaimer	24

Leo: Good evening, everyone, and welcome to today's program, "Healthy Living for Cancer Survivors, Bone Strength, Nutrition and Exercise."

At this time, all participants are on a listen-only mode. Later, you will have the opportunity to ask questions during the question-and-answer session. You may register to ask a question at any time by pressing the "star" and "1" on your touch-tone phone. You may withdraw yourself from the queue by pressing the "pound" key. Please note this call may be recorded. I'll be standing by if you should need any assistance.

It is now my pleasure to turn the program over to your host, Shera Dubitsky.

I. Introduction

Shera Dubitsky: Thank you, Leo, and thank you for joining us this evening as Sharsheret presents "Healthy Living for Cancer Survivors, Bone Strength, Nutrition and Exercise."

I feel like we are the opening act for the biggest TV rated debate in US history, so we will definitely keep an eye on the time, but we want to make sure you get this information. Again, my name is Shera Dubitsky, and I am the Director of Navigation and Support Services at Sharsheret. I would like to begin by thanking Amgen and the Cooperative Agreement DP14-1408 from the Centers for Disease Control and Prevention for their generous support in making this evening's program possible.

We are delighted to welcome so many of you on tonight's call. Sharsheret is a national not-for-profit organization supporting young Jewish women and their families facing breast cancer. Our mission is to offer a community of support to women of all Jewish backgrounds diagnosed with breast cancer or at increased genetic risk by fostering culturally-relevant individualized connections with networks of peers, health professionals and related resources.

Although our expertise is in young women and in Jewish women, we do offer support to anybody who reaches out to us. As we head into Rosh Hashanah, Yom Kippur, we have an opportunity to speak with family members and to really learn more about our histories, including our health histories. As many of you know, one in 345 individuals in the general population carry the BRCA mutation. For those of Ashkenazi Jewish descent, meaning, those families from Eastern European Jewish background, that number is one in 40, so this is astounding and it really bears repeating. Ashkenazi Jews are 10 times more likely to carry the BRCA mutation resulting in as high as an 80% lifetime risk of being diagnosed with breast cancer and as high as a 44% lifetime risk of being diagnosed with ovarian cancer.

Sharsheret is receiving questions daily having to do with hereditary concerns, so feel free to speak with our genetic counselor for either a one-on-one consultation

or to set up a family conference call. In addition to genetic concerns, we field questions from married women and single women, from community members and we connect all who reach out to us with resources and support. Particularly around this time of year, we are addressing many concerns about spirituality and holiday preparations.

The high holidays are a time when we reflect on our life, ourselves, our priorities and our practices. This is a good time to attend to our spiritual and physical health. Tonight, we are offering information and tips about healthy living with a focus on bone health, nutrition and exercise.

We are very fortunate to have a speaker who can address all these topics. Dr. Kathryn Schmitz is a professor at Penn State University's College of Medicine. She is an exercise interventionist who has led multiple trials and research, amongst which has led to a particular program called Strength After Breast Cancer, which has now been delivered to over a thousand breast cancer survivors. An online educational training program to prepare exercise professional and physical therapist to deliver the program has been delivered to over 200 outpatient rehabilitation specialists.

Dr. Schmitz has published over 180 peer-reviewed scientific papers. She has received research support from the Robert Wood Johnson Foundation, the Susan G. Komen for the Cure, and the Agency for Healthcare Research & Quality. She has served on many expert panels and wrote the cancer survivorship section of the recently published U.S. DHHS report of the Physical Activity Guidelines Advisory Committee.

Dr. Schmitz is the lead author of the ACSM Roundtable on Exercise for Cancer Survivors, which published guidance for exercise testing and prescription for cancer survivors in July 2010. She is very accomplished, to say the least. Dr. Schmitz, the proverbial floor is yours.

II. Healthy Living for Cancer Survivors

Dr. Schmitz: What's really cool is that I'm only 21!

Okay, so, yeah, I got a lot of letters after my name. This is what happens when you get older.

This is just a brief overview. Really, we're going to talk about the evidence-base for exercise after breast cancer and what exercise prescription might look like specifically for cancer survivors, and then we'll finish off with a section on nutrition for the cancer survivor.

So one of the issues, and those who are listening who have had their treatments done, they're done with it know this, is that breast cancer is a gift that keeps on giving. It is unfortunately one of those situations where you finish your treatment and you think you're done, but you're not. Other things happen.

The other thing that is a little bit frustrating I think from the perspective of the patient and the survivorship community is that all of the adverse effects of cancer treatment that are on this wheel here on the slide are generally studied by researchers like me in isolation, and so there are actually very few studies out there that look at how many women get away without having any of these issues. We actually have done one such study, and it turns out that it's actually a minority of women. Usually, I mean, if you feel like, "Gosh, am I the only unlucky one that continues to have fatigue for a while or that has changes in bone pain, arthralgias, joint pain?" No, you're not the only one.

CIPN, by the way, is chemotherapy-induced peripheral neuropathy. Thankfully, something that goes away for most women after they're done with their treatment, unless you were treated with a platinum-based chemotherapy, in which case it lasts generally for a very long time.

The other thing that happens as a result of having gone through a breast cancer treatment is that survivors find themselves paying a lot of money out of pocket for issues like the ones that were on the previous slide. In fact, the average from a study that I was a part of that we published in 2015 was about \$10,000 US per year. That's an average. There may be women who pay nothing and there may be women that pay a whole heck of a lot more.

What we also found from that same study, it was a longitudinal follow-up study of over 600 survivors, was that having upper body symptoms that lingered long after treatment, persistent cancer-related fatigue and poor upper body function was associated with an increase in out-of-pocket costs. So, if you had 4 or more common adverse treatment effects that, your out-of-pocket costs were generally twice as high as for other people.

That led us to conclude from this paper that interventions that would cost less than \$4,000 per patient might actually be worth having your insurance company pay for them, and we're working in that direction, trying to see if we can get third-party payers to understand this. The point is that why would you need to exercise even if somebody is kind of pushing you to listen to this webinar, and this is not your favorite thing and you haven't drunk the exercise Kool-Aid as it were? This could be a motivator. It's possible that if we can help some of the symptoms with exercise, then it may actually drop your out-of-pocket healthcare cost.

Let's go through some of the things that improve as a result of doing exercise. Exercise does help with physical function. One of the things that I hear repeatedly in the 15-plus years that I've been working with breast cancer survivors is, "I aged a decade in that one year of treatment." That's a very common finding not just for breast cancer survivors, but we do have evidence

from a very large trial published in JAMA in 2009, over 600 patients, and, more recently, a trial that I led called the PAL Trial, we published in the Journal of Clinical Oncology that twice weekly strength training prevented a very meaningful decline in physical function when compared to the controlled group.

We also know that increased strength is associated with improved functional capacity in general in older adults. The average breast cancer survivor is over age 55, and so that's going to be a time when strength training is going to be useful anyway. We also know in addition to the strength training that aerobic exercise is associated with improved physical abilities. Aerobic fitness, in general, if you are more aerobically fit, then you have better physical function. You can get things done more easily in your life.

I occasionally feel like this woman who's sleeping on her laptop keyboard. This data is actually from the same study that I quoted earlier with the out-of-pocket expenses. This was a follow-up of 600 breast cancer survivors, actually, in Australia. We were looking at whether women reported that they had cancer-related fatigue. This is different than just, "I'm tired at the end of the day." It's something very distinct from that. This is cancer-related fatigue, which feels more like you're kind of flu-y and tired.

Before treatment, 30% of women reported that they were having those symptoms, so, perhaps, because the cancer was more active at that time. During treatment, the vast majority of women who report cancer-related fatigue, but then post-treatment, you can see at 12 months after treatment, 25%, so a quarter of women, are still experiencing persistent cancer-related fatigue.

We know this. We can predict that fatigue is going to happen during chemotherapy and during radiation treatment. There is some inconsistent evidence about what happens after that, but the best evidence we have tells us that about one in five, 20% of women, still have some kind of decrease in their energy level. They are fatigued up to 5 years post-breast cancer treatment, so it can be a persistent problem.

What else improves fatigue? Exercise. The data on this are so profound that we have not just individual studies, but meta analyses that have come together to bring together the results of many studies and, as a result, there is an organization in our country called the National Comprehensive Cancer Network. It is a network of about 40 cancer hospitals, some of the major cancer hospitals across the United States. They come together and they put together treatment guides. They're very powerful. They're powerful to the extent that, if your doctor were to prescribe a chemotherapy regimen that was other than what the National Comprehensive Cancer Network recommended, your insurance company might not cover it. With that kind of power behind this organization, it is notable that they say that aerobic exercise is the number 1 recommended non-pharmacologic treatment for cancer-related fatigue during and after treatment. The thing that's challenging, of course, is if you tell someone, "Hey, you know, you're fatigued. You should be exercising. That will help you," and the answer

might be, "What part of 'I'm fatigued did you not understand?' I'm fatigued." The point is it's counter-intuitive. It's difficult to kind of convince people that it will be helpful, but we have extraordinary compelling evidence that it is actually helpful. What's really neat is that it's not a lot of exercise that has to be done. It actually is just 20 to 30 minutes 3 times a week of walking, so moderate-intensity exercise.

Then there's the aches and pains, and I've put it as aches and pains rather than saying arthralgias, but this is basically what happens with aromatase inhibitors. It's very common now that women with hormonal-sensitive breast cancers will be prescribed an aromatase inhibitor that they're asked to take for even 10 years of their life. It's very difficult because those aromatase inhibitors are pretty invariably, at some point while you're taking them, associated with aches and pains what's called arthralgias. The things that can help with that are medications. There are some medications that can be used. Certainly, switching aromatase inhibitors have been tried, and some women find that that does help. If you discontinued the aromatase inhibitors, that certainly helps, but that's not recommended because we know that taking the aromatase inhibitors for a longer time is associated with reduced risk of recurrence.

Then acupuncture, interestingly, has been shown to be quite helpful with reducing the aches and pains associated with taking aromatase inhibitors. I used this first bullet point in order to gain your trust. I have put up slides thus far that simply say, "Exercise. Exercise. Exercise." For these aches and pains, exercise is not the only thing, but it is on the list. We have a recent study that's gotten a lot of press called Project HOPE. It was published from my friend, Melinda Irwin, at Yale. She found that twice weekly resistance exercise plus aerobic exercise combined, over the course of a year, reduced pain levels in women taking aromatase inhibitors more than any other intervention that anybody who's tried at this point.

Again, it's a little counter-intuitive. Again, I have aches and pains. They tell you to exercise and you say, "But I have aches and pains," so you kind of have to push through it a bit.

Now, we'll talk about bone health.

Bone health is a major issue in breast cancer survivors for a broad variety of reasons. Certainly, there are treatment-related causes of bone health problems. There are women who are diagnosed especially if they have the BRCA mutation and they were diagnosed younger or they're just diagnosed younger regardless of any BRCA mutation. Any woman who's diagnosed pre-menopausal who goes through chemotherapy-induced premature ovarian failure is going to have a higher risk of osteoporosis over the long term.

The other thing that can happen particularly in the younger women who are diagnosed with breast cancer is either being prescribed Lupron, which is a drug that kind of shuts down the ovaries, and that certainly sends you into a sudden menopause or surgical menopause, surgical ovarian ablation. In addition, of

course, the hormonal treatments are going to be challenging to the bones. Not Tamoxifen, but the aromatase inhibitors are going to stop the estrogen from forming in the first place and, as a result, the bones are going to take a hit from taking aromatase inhibitors.

That's not the only issue. Just because you have breast cancer, it doesn't mean that you don't have these other issues so it's important to put them in context of the fact that inactivity is also associated with poor bone health, particularly, as women age, use of corticosteroids, which is a very common thing that will happen when women are undergoing their chemotherapy or their radiation treatment. They'll be given corticosteroids in order to withstand the treatment better, and that leeches the bones, and then, of course, inadequate intake of calcium and vitamin D, so those need to be things that are of equal focus if we're interested in bone health.

The number one thing, interesting though, again, not exercise, number one thing, you can do to promote your own bone health, if you are a smoker, is to quit smoking. The second thing would be to take in adequate calcium and vitamin D. What's really actually fascinating about the exercise trials that have been done to look at the effects of exercise, and you'll see at the bottom of the slide, we do see some evidence there, exercise alone doesn't work, it has to be combined with taking adequate calcium and vitamin D. What's interesting is that taking adequate calcium and vitamin D without being sufficiently physically active is also not as effective, so bear that in mind.

Then there's the issue of bisphosphonates, that's a drug category that is not used unless somebody is really in frank osteoporosis or headed there quickly. It's a class of drug that has some side-effects that are rather unpleasant and not a drug that you want to take for a very long time unless you really, really have to.

Fascinatingly, stress reduction, believe or not, stress leeches calcium from our bones, so you now have an excuse. You can go back to your family and say, "I'm sorry. I can't do the dishes tonight because I need to relax from my bones," or a massage sounds good to me. Bone density testing is recommended for women who have been through breast cancer treatment and particularly those on aromatase inhibitors in order to periodically check in and see what the direction of changes might be.

We do have fabulous exercise evidence in this area as well. This is not new, interestingly. Mim Nelson published her paper in JAMA in 1994, more than 20 years ago, showing that post-menopausal women were able to maintain or even increase their bone health better if they were doing progressive weight training. We also have outstanding evidence from prostate cancer survivors as well [by the way because they also take hormonal treatments that damage their bones, and then Kerri Winters-Stone has much more recently shown us that breast cancer survivors will be able to improve their bone health even in a home-based exercise program.

Next, what I'll talk about just very, very, very briefly, heart health and breast and prostate cancer. The issue here is that, again, like with the bone health, we need to put what happens with treatment factors together with the personal and behavioral factors. Certainly, getting older is associated with heart disease, being overweight, poor diet, low physical activity level, smoking, high cholesterol and high blood lipids. All of these need to be addressed in dealing with heart health. Of course, if you have had breast cancer and you've had an anthracycline-based chemotherapy regimen and/or radiation to the chest wall, then your treatments may also pose some risks for you, and so that should be particularly motivating then for dealing with heart health.

The great news is that these American Heart Association guidelines for heart health are specific to women and, actually have been around for decades, and they apply to breast cancer survivors just as much as they apply to the rest of the population. Again, the number one thing that you can do for your health, for your heart, for your bones, for many things, if you have cancer risks, if you are a current smoker, please quit smoking. Find a good smoking cessation program and join.

Second, good nutrition and weight control, and we'll talk a little bit more about the specifics as to what good nutrition and weight control means later in this talk. Taking in omega-3 fatty acids, or fish oil kind of thing, as a supplement even, treatment for hypertension and dyslipidemia, taking care of that and making sure that that is under control is important. Then, of course, if you believe that you have been exposed to treatments for your breast cancer that might be damaging for the heart, know that screening for cancer-related heart health problems is available.

There is actually a new sub-specialty called cardio-oncology. There are people at a variety of cancer centers across the country, particularly at the larger ones, that are cardiologists who specialize in the heart health issues of cancer survivors in light of the fact that, not just breast cancer, there are many different types of cancer survivors who are at increased risk for heart issues because of the treatment that they've undergone.

Of course, the other thing, and I hope all of you have known this, I am steeped in this literature, so I assume everyone knows this, that aerobic exercise is long recognized to be protective against cardiovascular disease outcomes and that it is particularly good for those with and at risk for congestive heart failure, which is one of the more common outcomes for breast cancer treatment-related heart issues.

Then lymphedema. Lymphedema is something that women with breast cancer either worry about or have. We know now that exercise helps with lymphedema symptoms. The work that I have done has spoken to this issue. A very large study that we did at the University of Pennsylvania, my prior institution, we showed in a controlled group women who had lymphedema in the study had

twice the number of lymphedema-related flare ups requiring a therapist to deliver treatment to them compared to those who did our weight training program.

The weight lifting women without lymphedema who were at elevated risk for developing lymphedema were 70% less likely to develop lymphedema, increased arm swelling, compared to the controlled group, so a big protective effective of our slowly progressive weight lifting program.

We also have newer evidence that tell us that exercise might actually be helpful during chemotherapy. It's possible that exercise may improve the ability to complete all of the prescribed chemotherapy. In particular, what's interesting is that there was the first study, Courneya, et al, in 2007. It was a study that actually had 3 groups, and one of the groups did no exercise, one of the groups did aerobic exercise, and one of the groups did strength training exercise. What they found was that the what's called the relative dose-intensity, which is to say you were prescribed a 100 units, you've got a 100 units of your chemotherapy, and so relative dose-intensity would be, "Did you get those 100 units," or, "Did you have too many toxicities and too many symptoms?" and they had to cut your dose. What he found was that it was weight training specifically that helped women get through their treatment with the full dose that was prescribed.

We also have some more recent evidence not even published from a colleague of mine in California. It's observational evidence that the reason for this may be that muscle mass, the amount of muscle that you have, may be associated with dose-limiting toxicities during chemotherapy.

I'm going to ask a rhetorical question because you can't answer me right now. Can you lose weight through exercise alone? Answer for yourself, even write down the answer just so that you know you're going to be honest with yourself. Can you? Can you?

No. The answer is no. Exercise alone works well to maintain weight, but not really to lose weight. It's rare for people to be able to lose substantive amount of weight through just exercise. You cannot exercise your way out of a poor diet.

There's a YouTube link here, and I'm hoping that you'll have access to these slides so you can go back later and watch it. It's a pretty cute video that basically has one guy running at 11 miles an hour on a treadmill while the other guy is eating pizza, and they're showing how quickly you take in calories and how hard it is to burn them off. Your poor diet, you cannot exercise your way out of a poor diet. We know that exercise is best actually not for weight loss, but for maintenance. Exercise is useful in the context of weight loss only when combined with caloric restriction.

We also know that exercise can be quite helpful for treatment of type 2 diabetes. If you are diabetic, please know there is such beautiful evidence about the value of exercise for type 2 diabetics, that there is position stand from my home organization, the ACSM, American College of Sports Medicine, that we consider

physical activity a major therapeutic modality. What's fascinating is that it is a short-term effect, which means that exercise has to be done regularly.

We also have evidence that, from the epidemiology, that we can prevent type 2 diabetes as well from a variety of different types of studies, migration studies, cross-sectional studies, longitudinal studies. In addition, there are multiple randomized controlled trials in China as well as in the U.S. that have shown that a program of exercise combined with weight loss can prevent the onset of type 2 diabetes.

There is really, again, stunning, stunning evidence that tells us that exercise is associated with improved mental health. Depressed individuals are typically less physically active. We know that exercise will not prevent depression, but if, just like with the fatigue and the aches and pains, it's difficult to get a depressed person to be active, but, if you can make it happen, it is going to help. We know from the studies that have been done in Texas that exercise does help to manage mild to moderate depression, anxiety and panic disorders with a magnitude similar to SSRI for a normal of SSRI. It typically helps more with acute anxiety than chronic anxiety.

The other thing that I just ... I love this. I know I'm a geek, but I love this curve because it is so compelling. Really, if you look at it, and what's most important is the word at the very bottom, "persons who exercise 3 or more times a week were more likely to be dementia-free than those who exercise fewer than 3 times a week." This is the kind of data that's the basis for the hypothesis that exercise may be useful for chemo brain, so some of the sort of mental fog that seems to come along with going through chemotherapy.

It was mentioned earlier that the American College of Sports Medicine published a roundtable that provided guidance for cancer survivors in 2010.

What's interesting is that in 2012 the American Cancer Society published very similar guidelines, and they said basically the same thing that we had said in 2010.

The National Comprehensive Cancer Network in 2013 published exactly the same thing. What you'll see is that actually they used as their references the American Cancer Society and the ACSM documents as well.

What do we all say? The overview of the common recommendation across these 3 organizations is that cancer survivors should be doing a 150 minutes a week of aerobic activity, that can be walking, that can be something more intense, 2 to 3 times a week of strength training and flexibility on days when another activities are performed, in other words, daily.

The most important message for all of us that is common across all 3 of the organizations, the American College of Sports Medicine, ACS and the NCCN, is that we should avoid inactivity. In fact, there is a curvilinear association between

the benefits of exercise and how much you do. The person who is on the couch, and we get them up for 10 minutes a day, is going to have a much larger improvement in their health than the person who is already a marathon runner and who's now going to become somebody who does Ironman races. Get it?

Just to put it in a little bit more fine-tuned focus, there are different ways of us dealing with understanding who should go out and go exercise and who needs to have some kind of pre-exercise evaluation and who really needs to go talk to a physical therapist and go through some kind of outpatient rehabilitation. I'm hoping that this information will be helpful to you in figuring out who you are. Those who are low risk, considered to be low risk by these 3 organizations, are those who had early stage cancers, those who have no other comorbidities, meaning, not diabetic, not hypertensive, not morbidly obese, no other major health problems, and you entered into your cancer diagnosis with a high baseline activity level, which means you were meeting that 150 minutes a week before you started your treatment.

Those folks are guided to follow the general recommendations that I quoted a moment ago, and they are okay to go on and do unsupervised exercise in the home, in the community, go on, go find a program and have a good time and benefit from your exercise.

Those who have ongoing peripheral neuropathy, those who have ongoing musculoskeletal issues, those with bony metastases or poor bone health, which is to say someone with osteoporosis, or somebody who has lytic lesions like bony metastases, for those folks, the recommendation is that there be some modifications and, as a result, there might be value to having a prep-exercise medical evaluation in the setting of physical therapy or occupational therapy. You might want to consider starting with a personal trainer or a physical therapist or an occupational therapist.

Those who are considered high risk include anyone who has had lung surgery or abdominal surgery, anyone who has an ostomy, anyone who has preexisting cardiopulmonary disease, so COPD, chronic obstructive pulmonary disease, or heart failure, recent or prior heart attack, those sorts of things, anyone with lymphedema or anyone with extreme fatigue, which is to say you cannot carry out your day-to-day activities because of your fatigue. For those folks, it is highly recommended by these three organizations that that person head to a physician and get clearance to exercise and have a medical evaluation prior to exercise, and then do the exercise in a supervised setting with a personal trainer, with a physical therapist, until you move out of the high-risk category.

There are times when exercise should be avoided, obviously, immediately after surgery; wound healing is actually an aerobic activity. It may not feel like it, but it's a lot of work for your body. Severe anemia, so, if you're extremely fatigued, you want to make sure that your hemoglobin is okay and that there are no thrombocytopenias or neutropenias or any other issues still going on. Worsening

or changing physical conditions such as a lymphedema exacerbation would be a time to stop exercising or during an active infection, in other words, a fever.

It's really recommended that, if you are not in that low-risk group, that you find yourself somebody who has expertise in working with cancer survivors. Again, I'm hoping that you, all, will get copies or access to these slides so that you can get these links and can find people from ACSM or from the APTA who can help you.

Okay, so exercise prescription basics, you're starting an exercise program, what do you do first? You want to figure out what your outcome is. Example, if function is an outcome, I want to be able to get on the floor and play with my grandchildren. I want to be able to go for a hike and not get winded. Figure out what your goal is and then start where you are. Start where you are with what you have. Start low. Progress slow. Let symptoms guide progression. That's your progression is, if you are still okay and not having an increase in any of your side-effects or symptoms, you can progress. Use what you have. If what you have is your feet and some sneakers, do laps around the house.

The other thing is you can do what you can when you can. Progression is important, but it's important that you do so in small increments, particularly while you're undergoing treatment or soon after treatment.

Two other things, and that is there needs to be awareness of the variability of exercise tolerance at different times when you're going through your cancer journey. There may be times when you can do less and just acknowledge that and honor your body. Finally, you want to have awareness of an adaption for any symptom changes that you have. Again, let symptoms guide your exercise and your progression.

Okay, last couple of slides on nutrition for the survivor. Being overweight after cancer is we know going to be an issue for the potential for bad outcomes overall, including a whole host of comorbidities not even having to do with cancer. Weight gain after cancer, not just being overweight, but then gaining weight after cancer can also lead to poor health outcomes, including just the ability to function in your life. Maintaining a healthy body weight is extremely important after breast cancer. We have increasing evidence that maintaining a healthy body weight is predictive of much better health outcomes for breast cancer survivors, a variety of different types of outcomes.

As a result, you should know your body mass index. You should know your BMI and maintain it in the healthy range of 18 to 25. If you don't know what your BMI is, you can type in, "What is my BMI?" in Google, and you'll likely be able to find a BMI calculator that will tell you what your BMI is. You want to work towards getting below 25. If you get below 18, that's not going to be great for your bone, so that's why we have a range, 18 to 25.

Maintaining a healthy body weight is the most important thing for you, having to do with nutrition. A lot of people want to believe that there is something that they can do, some Goji berry, some fish oil, some herb, some particular kind of one thing that might be particularly helpful to them. There is no single food supplement or nutrient that can be avoided or eaten that will be as influential on your recurrence of breast cancer as maintaining a healthy body weight. That is the most important thing to take in about nutrition after breast cancer.

In closing here, what I would offer to you then is that there is dietary guidance from the American Cancer Society. In fact, I would comment to you that cancer.org is an outstanding resource for you for those questions. If you decide, "Okay, I know she said that it was maintaining a healthy body weight, but I really do want to know about those Goji berries," they'll have something on it on the American Cancer Society website. I know this because I am the one they turned to for lymphedema and exercise. They go to the experts on particular issues and they ask them to write a few paragraphs for their website, and they're extremely up to date.

Again, the number one thing the American Cancer Society would tell you about dietary guidance after breast cancer is to achieve and maintain a healthy body weight, and then they talk about fruits and vegetables, whole grains, limit red meat, the other things that the American Cancer Society says that are generalities. All of the things that are below, achieve and maintain a healthy body weight, are things that are general recommendations from the US Department of Health and Human Services.

Okay, I'm just going to stop here and say thank you very much for listening and for tuning in as it were. If I can be helpful to you in any way, please do not hesitate to be in contact with me.

Shera Dubitsky: Dr. Schmitz, thank you so much. I imagine that there are many participants listening to tonight's teleconference who will now be drinking the exercise Kool-Aid because of the way that you delivered and shared the information.

I do remember listening to an oncologist once talking about nutrition and exercise, and he said that he went to medical school years ago and he's been in continuing education since then. Science sometimes changes, and scientific recommendations sometimes change, but he said, "What hasn't changed is that the message, that the most important thing is exercise and nutrition," and I think that that was your message loud and clear tonight, so thank you very much for that.

III. Personal Story

We will now hear from a Sharsheret caller, Marla, who had previously offered her insight on our blog and continues to be a wonderful volunteer and support to Sharsheret.

Marla?

Marla Friedman: Hello. Thank you. I just want to thank Dr. Schmitz for that really interesting information. A little reminder, personally, I actually have an oncology appointment tomorrow, and I'm going to ask my oncologist to test my calcium, vitamin D and iron, so I thank you for that. I think a lot of the things that you spoke about resonated with a lot of us.

My journey actually began with cancer in my 20's. I was diagnosed with thyroid cancer in 2001, just married, working, decided to start the South Florida Thyroid Cancer Support Group. After that, I had radiation, surgery, and I decided, "You know what? I'm going to do a 100-mile bike ride." I've never done a 100-mile bike ride. I thought it was a good idea. I continued to be a support for thyroid cancer. I was actually a guest speaker in Denver last fall for the Thyroid Cancer Survivors Association.

Now, fast forward to 2014, on my 42nd birthday, I was diagnosed with breast cancer. I actually got a call after a mammogram and a biopsy, and they were like, "Oh, don't worry. There's nothing to worry about." Following that, a radiologist called me. I'm in the grocery store parking lot. I'm holding the phone, and they're telling me I have cancer. I'm like, "How can this be happening again?"

A friend reminded me that this is really not the same as the last time because this is breast cancer. Now, I'm married with 2 children. I was married the first time, but I did not have kids. Now, I have young children. It's different. I had a double mastectomy at Sloan Kettering on New Year's Eve actually, and I had tissue expanders like many of you I'm sure and two reconstructive surgeries. The last one was actually in June of this year, so it's pretty recent for me. People always say, "Oh, you're in a fight. You're fighting cancer." I don't really think I'm fighting cancer. I'm just dealing with cancer. Right?

When I was recovering in New York City, because I live in South Florida, my sister-in-law flew up to help me, and she said, "Oh, you really should call this organization called Sharsheret." I had no idea what she was talking about, and I'm like, "Who knew there's this organization specifically to help Jewish younger women with breast cancer?" I mean that is a really specific target audience. I'm a marketing professor. I was like, "Wow, they really nailed it this time." They assigned me to a peer support person and they also sent materials to me, and they actually sent my boy Legos, which was really appreciated. I was really impressed. I think that this whole journey of connecting with others can be really powerful for recoveries.

Now, I'd like to touch on exercise. I appreciate all the comments the doctor mentioned about exercise. When I was diagnosed with breast cancer, I had always done yoga. I Googled "yoga" and "cancer." I actually found a local class for cancer patients specifically to do yoga that they can handle, and that has really helped with my recovery.

Also, I heard about this sport called dragon boating. I'm not sure if anyone out there knows what that is. Many years ago, I met a Canadian woman in business and she mentioned this dragon boating. I kept that in my head. I searched for teams. There were no teams where I lived, but they said, "Wait a minute, the woman who was on the team in Miami just moved to Palm Beach where you live, and she's starting a team this week." I mean what are the odds of that?

Dragon boating is kind of like a crew. If you're from the Northeast, you're familiar with rowing. There's a long, narrow boat. Two people are seated on each row only with one paddle. The boats are from 10 to 20 paddlers in length, so they're pretty long boats, and they have two people on each row. There's actually 150 teams around the world specifically of all breast cancer survivors. There's regular dragon boat teams and then there are breast cancer survivor dragon boat teams.

This became popular with the Canadian sports medicine specialists. This doctor realized that rowing is beneficial for many things such as physical health, emotional well-being, and then the medical community really has endorsed dragon boating for breast cancer patients specifically for reducing lymphedema, boosting self-esteem and breaking down scar tissues.

The camaraderie that we have in our team is amazing. I practice every single week, and we actually have races every few months. My team has only been around for a year. I've only been rowing for a year. I never rowed before this ever and, so far, we won a bronze medal, a silver medal. Just two weeks ago, my team took first place. We're actually going to the International Dragon Boating Competition in 2018 in Venice, Italy, so that's exciting.

That's my little piece on exercise. Nutrition, I'll go over that quickly. I've always eaten healthy and actually still got cancer twice, so I don't know about that, but we really have to be aware of our nutrition. The doctor mentioned eating vegetables, cutting out sugar. When I was diagnosed, my husband bought me a juicer. I started making beets and turmeric and apples, all kinds of crazy juices that I enjoy.

I happen to have a different sister-in-law in New York City who's a nutritionist. I can always go to her. It's nice to have an expert in the family. I use things like essential oil. If you feel anxious, I have lavender. I have peppermint oil for headaches. There are just so many things that we can use with foods, and then I actually received a really lovely cookbook from Sharsheret, and that cookbook has tons of recipes and ideas in there. That's great as well.

Today, what's going on with me today? I think we're all faced with decisions. They really can be overwhelming. Right? You have cancer. You've got to decide. Should I get radiation? Should I not? This doctor said I should have a mastectomy. This one said lumpectomy. Should I Take Tamoxifen? Which surgeon? What hospital? It's really super overwhelming, and I think we all struggle with those decisions.

What I'd do is try to find a place of gratitude. My hair is falling out. I don't know why exactly. I didn't even have chemo. It's just falling out. It ends up in my son's plated dinner sometimes. Sometimes, I look at the scars. I'm like, "Well, at least I don't need a bra," things like that. They tend to bother me, but then I have to like, "Well, at least I don't need a mammogram, right? I had a mastectomy. No more mammograms for me." There are things that we can find to be grateful for. Really, cancer hasn't ruined my life. I just think it's added to it. I have met a lot of great people in this journey.

Finally, this evening, I know you're anxious for questions. Here are my tips. Enjoy nature, things like the beach. I happen to live very close, within minutes of the ocean. Maybe if you have woods or mountains or rivers, something in nature is really, to me, therapeutic. Find something you do enjoy for exercise.

I'm also a tennis player. I like dragon boating now. I like yoga, whatever you can find, even walking, anything. Practice clean eating, plenty of fruits and vegetables and lean proteins. In yoga, they talk about breathing. You can do meditation. There's apps right now. If you can find the apps on your phone for meditation and just do five minutes, it's actually worth it. I took meditation for surgery into my mastectomy at Sloan Kettering, and I had headphones. For every surgery, I take headphones and meditate.

Be comfortable with your medical decisions. This is a tough one because we're all like, "Did we make the right decision?" Find support. Find support from Sharsheret. Join a team. Attend a support group. Lastly, be grateful. When you wake up each day thinking of one thing you are grateful for, it'll make your day better. Grateful people are happier people.

If you'd like to reach me, I do have a website called thegoodcancer.com. I'm writing a book right now with the same title. Thank you, all, for your support, attention, and I hope you enjoy tonight's seminar, and I want to see if anybody has any questions.

Thank you, Shera, for having me.

Shera Dubitsky:

Marla, thank you so much. I think, like you, I imagine that tonight's webinar will be a springboard to conversations with treatment teams all across the country. I also want to thank you for giving a shout out for the cookbook and the pedometer.

What Marla was referring to was the Thriving Again Survivorship Kit. We have one for women who are diagnosed with breast cancer, another one for women who are diagnosed with ovarian cancer. They could be tailored. We will be sending out a link if you are interested in ordering that.

IV: Question and Answer

Leo, would you like to give instructions on the question-and-answer?

Leo: Certainly. Please press "star," "1," if you'd like to ask a question. That is "star," "1" now on your touch-tone phone. One moment while we queue.

Shera Dubitsky: Okay, and we're also going to ask if you can keep your questions broad in nature so that everybody on tonight's call can benefit from the discussion. We have gotten some questions already.

Dr. Schmitz, the first one, we've done a nutrition teleconference several times over the years, and this one keeps coming up. "My oncologist told me to avoid all soy food as well as additives in food, soy flour, soy protein. Last week, I asked a nutritionist at the same cancer clinic if the same rule applies to flaxseed and it also contains estrogen. I was stunned when she said there was a pervasive misconception and continued that both soy and flaxseed are not only safe, but healthy even for estrogen-positive breast cancer survivors. Studies have shown that plant estrogen is not the same as human female estrogen and, now, both soy and flaxseed are being touted as beneficial in preventing many types of cancer, including breast cancer."

Thoughts?

Dr. Schmitz: Agreed. Yes, I agree. It's very difficult. It's one of those things not unlike what happened with my research with weight training after breast cancer faced with for so long with, "Don't do it. Don't do it. Don't do it," that changing it is really hard.

What happened is that there was a study that was done where there was a hypothesis. It makes sense. There's a hypothesis that there is this estrogen-promoting food, so that would be a bad idea. Right? Then they tested it, and the first studies came back saying, "Yes, there is a problem here," and so the advice was, "No. No. No. No. No. Avoid. Avoid. Avoid," but then there were people who were scratching their heads and saying, "Well, then why don't all the women in Asia have like rampant breast cancer and why isn't the breast cancer in places where people eat a lot of soy worse? Why don't they have more recurrence? More studies have been done of higher quality, and those more recent higher quality studies have shown that, in fact, it's quite the opposite, that, in fact, exactly as the question said, that the plant-based soy is not going to produce the same issue as a human estrogen, taking in a human estrogen.

The same thing with flaxseed. Yes, and it's a conundrum for the nutritionists out there. It's particularly difficult because, of course, the oncologists aren't reading that literature as voraciously as the nutritionists are. The nutritionists aren't seeing every patient, and so then the oncologists are continuing to give the old advice. Good catch.

Shera Dubitsky: That's very helpful. Thank you. Another question, Dr. Schmitz, can you give a little bit more information on weight lifting to prevent flare-ups from lymphedema?

Dr. Schmitz: Sure. Okay. In the PAL Trial, what we did, and I think what you're asking for is specifically what to do, so what we found was that, if we start with literally a one pound weight, like tiny, little pink dumbbells and do ... It's not magical exercises. It's the typical weight training program, so I don't need to tell you what the exercises work, but you start with very light weight and you really work carefully maybe even with a personal trainer to make sure that you're doing the exercises really very properly in terms of form and biomechanics.

A couple of weeks into it, you increase to two pounds. A couple of weeks later, you increase to three pounds, and you keep going. The sky is the limit. There's no limit on it as long as you're symptoms don't change. That's the protocol that we used, and what we found in a study of a 141 women with lymphedema was that, at the end of the year, 14 of the women who did the weight training had had a flare-up and 30 of the women in the controlled group had had a flare-up.

Shera Dubitsky: Okay, and I want to follow up I guess. Marla sort of got people interested in the dragon boat racing. Is that safe and okay for people who already have lymphedema?

Dr. Schmitz: Yes, it is. Here's the thing that actually is fascinating. I mean, dragon boat racing is sort of this mythological thing in breast cancer. It's been around for a long time, and there's a lot of women who do it, and so they come in and they tell their doctors they're really enjoying and they're having a great time, and so, if you asked the average oncologist was it safe to do dragon boat racing and the training for it, they'll say, "Yes," but if you ask them if it's safe to do weight training, and I'm talking three pounds in your hands, they'll say no.

Marla, I have tried dragon boat racing. It's very intense. It's sort of a funny thing that doctors will say no to one thing and then yes to something that's harder. What's interesting is that there has never actually been a randomized controlled trial to tell us that it's safe for women with lymphedema to do dragon boat racing and the training for it, but I think what we can go with is there is this preponderance of evidence of clinical experience of thousands of women doing this activity and not having a problem.

Shera Dubitsky: Okay. Marla, somebody asked if you can actually repeat your website.

Marla Friedman: Oh, sure, it's thegoodcancer.com.

Shera Dubitsky: Okay, and a question that came in for you. This is somebody who is physically active, but there are some days when the fatigue is taking over. She feels too busy and on the days that she's when she's like, "You know what? I can't do it," she starts to feel guilty that she didn't do the exercise and then she ... then it starts to snowball, like, "Does this mean that I'm falling off a regimen? Is this

going to increase the likelihood of a recurrence?" You know how that goes. Have you ever experienced that guilt, and, if so, how do you manage that?"

Marla Friedman: Yes, yesterday, I'll be perfectly honest. I had a practice and I was exhausted. I work full time. I have 2 young kids, a husband, a dog. I'm tired. I'm like, "You know what? I'm tired. I'm not going to row today," and I went and I walked on the beach instead. I think you really need to listen to your body. We've been through a lot, and, sometimes, we forget what we've been through as far as treatment and surgery and all of having cancer in the first place, so listen to your body. If you need to rest, you need to rest. Sometimes, going for a walk is really just as well as doing something a lot more strenuous.

Shera Dubitsky: Okay. Thank you.

We got a question, Dr. Schmitz, about that celiac can cause osteoporosis. This breast cancer survivor has that, and she want to know if you have any tips for bone strength for her or if there is anything that you can comment about that.

Dr. Schmitz: Yeah, she's right. What I can tell you is that this is a conundrum because, like I said, really, exercise is not going to do a whole lot for your bones unless you're taking in adequate calcium and vitamin D. I guess what I would ask is whether there is a form of calcium and vitamin D supplementation that the person with celiac can tolerate and that can be absorbed. Maybe there are even potentially injections. I know you can injections to B12. I wonder if you can get injections of vitamin D and calcium, and, if so, then that, combined with weight training, would be equally effective in somebody with celiac.

Shera Dubitsky: Okay. Thank you. We're back to lymphedema again. A participant asked that if she had lymphedema and had treatments 5 to 10 years ago, can the symptoms improve if they worked with a specialist?

Dr. Schmitz: You bet, yeah. Absolutely. That's what we found. I mean, we had women in our study that had lymphedema for 20 years, so yes.

Shera Dubitsky: Okay. Great. The last question we have of the evening, "If somebody has osteoporosis and is taking an Aromatase Inhibitor, but they don't want to take an osteoporosis drug, can you turn that around with exercise?"

Dr. Schmitz: No. You can help with exercise. Exercise is actually much more useful for prevention than for treatment of osteoporosis. I think the best you can kind of hope for is to be able to take a lower dose of the bisphosphonates or a lower dose of anything else that might be taken.

The analogy that I was given once about this was comparing exercise to the Bisphosphonates or the osteoporosis drugs is sort of comparing a Hugo to a Ferrari. They're just really powerful drugs..

Shera Dubitsky: Thank you. Thank you for these questions. They were very interesting and I think were beneficial to anybody who's listening on the call tonight.

V. Conclusion

Every webinar Sharsheret does is driven by conversations and feedback that we hear from you. You will be receiving an online evaluation, so please take a few moments to complete this because, again, your feedback is invaluable to us.

You will be access the transcript and audio of the webinar at sharsheret.org/resources/transcripts. I also encourage you to check out our other previous webinars and teleconferences that we've offered that may be helpful to you moving forward.

Again, I'd like to thank Amgen and the Cooperative Agreement DP14-1408 from the Centers for Disease Control and Prevention for their generous support in making tonight's program possible. I would also like to thank our speakers for sharing their expertise, their insights and their time that they'd put into preparing for this.

Lastly, I'd like to give a special shout out to Shira Kravitz, Sharsheret's Support Program Coordinator for all the time and work she'd put in to making this webinar such a success.

Finally, I would like to thank all of you for joining us this evening. If you would like to continue this discussion with a member of our support staff, please feel free to connect with us by calling the office, emailing us or going online. I also want to invite you to follow us on Facebook and Twitter. We are here when you need us, as you need us, and we would like to wish all of you a very happy and healthy New Year. Good night.

VI: Speaker Biography

Kathryn Schmitz, PhD, MPH, FACSM, is a professor at the Penn State University's College of Medicine. She is an exercise interventionist who has led multiple trials, including a large randomized controlled trial to assess the safety of upper body exercise among 295 breast cancer survivors with and without lymphedema (Physical Activity and Lymphedema Trial (PAL)). She has conducted dissemination research translate the PAL intervention to become more broadly disseminable. The program, now called Strength After Breast Cancer, has now been delivered to over 1,000 breast cancer survivors. An online educational training program to prepare exercise professionals and physical therapists to deliver the program has been delivered to over 200 outpatient rehabilitation specialists. Dr. Schmitz has published over 180 peer reviewed scientific papers (scopus h-index of 44) and has had continuous NIH funding for her research since 2001, including three R01s, two R21s and a TREC Center (Transdisciplinary Research on Energetics and Cancer). She has also received research support from the Robert Wood Johnson Foundation, Susan G. Komen for the Cure, and the Agency for Health Care Research and Quality. She has served on the expert panel for the YMCA/Lance Armstrong Foundation Cancer Survivorship Collaborative, wrote the cancer survivorship section of the recently published U.S. DHHS report of the Physical Activity Guidelines Advisory Committee, served on the ad hoc committee that developed the ACSM Cancer Exercise Trainer certification, and is the lead author of the ACSM Roundtable on Exercise for Cancer Survivors, which published guidance for exercise testing and prescription for cancer survivors in July 2010.

VII: About Sharsheret

Sharsheret, Hebrew for “chain”, is a national not-for-profit organization supporting young women and their families, of all Jewish backgrounds, facing breast cancer. Our mission is to offer a community of support to women diagnosed with breast cancer or at increased genetic risk, by fostering culturally-relevant individualized connections with networks of peers, health professionals, and related resources.

Since Sharsheret's founding in 2001, we have responded to more than 54,000 breast cancer inquiries, involved more than 6,900 peer supporters, and presented over 250 educational programs nationwide annually. Sharsheret supports young Jewish women and families facing breast cancer at every stage--before, during, and after diagnosis. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life. All Sharsheret's programs are open to all women and men.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer
- Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors
- Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus

- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare professionals

VIII: Disclaimer

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care professional. The document does not recommend the self-management of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

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