

Program Title: The Road Forward: Navigating Life After Cancer Treatments

Presented by: Support Connection, Inc.

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Guest Speaker: Mary Greco, MSN, FNP-BC, CBCN, CN-BP: Mary is a certified nurse practitioner with 30 years' experience in the area of Breast Disease. She is an Oncology Breast Care Nurse and a Breast Cancer Nurse Navigator, certified by the American Nurses Credentialing Center, the Oncology Nurses Society, and the National Accrediting Program for Breast Centers. Mary has worked in clinical practices and as a clinical research assistant in the fields of breast cancer and cell mediated immunity. She has been a nurse trainer for the NYS Dept. of Health Cancer Screening Program, has volunteered for the American Cancer Society for the promotion of breast health education, and belongs to multiple nurse and breast specialty organizations. At Northern Westchester Hospital, Mary serves as clinical coordinator for the Breast Institute.

Although finishing your cancer treatments (surgery, chemo or radiation) is a milestone to be celebrated, it can also bring anxiety, fear and uncertainty. The completion of treatment marks the start of adjusting to new and challenging physical and emotional changes. This program discusses how you can take charge and navigate this transition to the new normal of cancer survivorship.

Topics:

- **Recommendations for surveillance:** Which tests and exams do I need? Who do I need to follow up with? What's coming in the future regarding primary care vs. medical oncology?
- **Late and long term treatment effects:** Things you must know about such as lymphedema; cardiotoxicity; cognitive issues; bone health; pain.
- **Psychosocial issues:** Body image; depression or anxiety; fatigue. They are not all in your head!
- **Mind & body wellness:** The connections between the two.
- **Other concerns:** Sexual health, fertility and menopause; your ongoing treatment plan for long term health and wellness through nutrition, physical fitness, etc.

Marlene Stager: I'd like to welcome you all this evening to the webinar, The Road Forward: Navigating Life after Cancer Treatments. Remember that Mary is sharing her expertise. Any information from tonight or questions pertaining to individual concerns should be discussed with your own doctor. It is now my pleasure to welcome Mary Greco. Mary is a certified nurse practitioner with 30 years' experience. She is an oncology breast care nurse and a breast cancer nurse navigator certified by the American Nurses Credentialing Center, the Oncology Nurses Society, and the National Accrediting Program for Breast Centers. Mary currently serves as clinical coordinator for the Breast Institute at Northern Westchester Hospital.

Mary Greco: Thank you so much, Marlene. Can you hear me okay?

Marlene Stager: Yes.

Mary Greco: Great. I want to welcome everyone for participating tonight. I was quite honored when my friends at Support Connection asked me to do this presentation. They know how much I believe in reaching out with the knowledge that I've been lucky enough to gather in the last 35 years. So, having said that, The Road Forward: Navigating Life after Cancer Treatments. One of the things that I do here at Northern Westchester is, I am one of the survivorship nurse practitioners, so I do talk to and counsel survivors all the time. I'm not one myself, but I've been very close, as most of us have been, to people in my family. So, I have watched the journey from the sidelines, as they say.

I really want to thank Support Connection. For the last 20 years they really have stepped up for patients in terms of providing support for them in many different ways for patients who, believe it or not, some of

whom came from one of my hospitals in the Bronx that used to come up to Yorktown. And I have been delighted to have worked with them all the last 20 years.

I think before we get started, I think I really have to recognize that there are women, and men, for that matter, out there who do not have the advantages of health insurance. And we don't know where that's going to go currently. Hopefully, we'll get better and not worse, but certainly it is one of the things that we really do need to consider. For most of us, we have the opportunity to have healthcare and get treatment, but there are women who end up really being behind the game because they have had to delay treatment because of health insurance. So, hopefully, one day it will really be treated as a right rather than a privilege. And having said that, let's talk about what a cancer survivor, or who a cancer survivor is.

So, there are a lot of organizations out there who define these -- the American Cancer Society, the American Society of Clinical Oncology. So, we also listen to National Coalition for Cancer Survivorship, and they basically have called a survivor anybody with a history of cancer from the time of diagnosis and for the rest of their life, whether that's days or decades. And there are a lot of survivors in the United States, I am happy to report. If you look at this slide, you will see that this was taken from one of the organizations who were kind of predicting for the future where the United States is going to go in terms of survivors. So, we think by the year 2022, there will be 18 million cancer survivors in the United States. That's a huge, huge amount, and at least 20% of them will be breast cancer survivors.

So, when we talk about survivorship, about 10 or more years ago, the Institute of Medicine, knowing that these numbers were going to be so gigantic in terms of survivors in the United States, they had the foresight of talking about it and trying to put together some planning for patients who would need to have follow-up care but are not the normal primary care patient. They have a history of cancer, so there are certain special recommendations that are particular only to them. So, the Institute of Medicine put out a book called *From Cancer Patient to Survivor: Lost in Transition*, and it's actually on the Internet. You can download the book in its entirety. It's a couple hundred pages. And it really started focusing the medical community on establishing guidelines for planning long-term recommendations for survivors who we expect to live long and healthy lives after they've been treated for cancer. And out of that model actually spun a few things regarding how are we actually going to take care of all these patients? And it became apparent that institutions were really going to need to provide care for these survivors as they aged and as more and more survivors came into the population, because we do a better job at cancer treatment. And it was decided that primarily cancer survivors would need to be followed by primary care providers or medical oncologists. Seems reasonable.

This is continued into the Accountable Care Act, where a focus was kind of on providing the best quality care for the best cost. As we all know, there is a lot of waste in the medical health institutions, and we're trying to pay attention to that as we move forward to provide care for everyone. So, the emphasis is on quality care at a lower cost, and we needed to address supportive care, because this is what survivors say they don't really get. I think as a medical community we do pretty good at, we're pretty astute at taking care of some of the physical needs, but some of the issues that come into play that are really part of supportive-type care, we don't actually do a very good job at, and that's being told to us by survivors.

So, how do cancer survivors move forward and where are we going to be going with regard to healthcare? So, primary care providers are really going to be the leaders in following cancer survivors long time, because we're moving towards managed care, as many of you probably belong to a managed care program, and the medical homes model. Medical homes model is kind of similar to the Mount Kisco Medical Group, where you have a group of physicians of all types, and you can stay within the system in order to get all the care that you need. They will be probably quite large, and it seems to be an efficient way to take care of patients.

The primary care clinicians are going to need the knowledge to follow patients, and they really are capable of providing excellent care. They're going to need to be educated, and there are some movements in the American Medical Association, the American Nurse Practitioner Association, to really make sure that everyone is knowledgeable on how to follow cancer survivors. And we need -- as patients, we need to be consumers of care. We need to know what it is that we need to know, and what it is that we need.

So, when survivors were interviewed, it was interesting that 70% of survivors, they thought that the oncologists followed them better than their primary care providers. But most of the survivors felt that neither group actually met all of their needs. So, there has been a lot of research done on, well, what actually are we not doing quite so well? And there are actually a couple of areas. We never in the history of man had so many patients, i.e., people, survive a life-threatening illness such as cancer and be alive to live to old age. So, it really is a new era for us as well.

So, how do we move forward? Well, the first thing that we need to do is, we need to get everyone's information to them. So, I say you want to get your story straight. As a survivor, just as any other patient with a chronic illness, you really need to know what you have been through, and you really do need to know the details of what you've been through. So, in terms of knowledge, a couple of different points. First of all, you need to know what is recommended for you, and these recommendations come from those organizations that govern the medical -- your medical care, or the standard of care -- American Cancer Society, American Society of Clinical Oncology, American Medical Association, all of those institutions who do a lot of research in order to determine what is the best recommendations and tests, etc., etc.

So, the first thing is, as a survivor, there needs to be surveillance for recurrence, meaning that the original tumor cancer is not coming back. There needs to be surveillance that there isn't a second primary breast cancer and/or ovarian cancer and/or melanoma, whatever it is that we're actually talking about, or gynecological cancers and ovarian cancer, etc., etc. And that is done by specific tests. We want to make sure that you're being covered for all of those tests in order to determine that none of this is going on.

The second thing is, we still need to pay attention to those other cancers. We still need to have colonoscopy. We need to make sure that you're following the right screening protocols for melanoma, for anything that may have occurred in the family that you may be at risk for.

The next thing is, we really need to assess and manage the physical and the psychological long-term and late effects of breast cancer treatment, of GYN treatment, of any sort of oncological treatment that has taken place.

The fourth point really is about health promotion. And I tell my patients all the time, you need to consider this as your last treatment protocol. When all of your treatment is said and done and you're finished with the five years of antiestrogen, or 10, by the way -- we'll talk about that in a minute -- it really is important for you to think about living a healthy and fit life to the best of your ability. We're not all able-bodied. Some of us have more health problems than others, but maximizing your fitness is going to be really your last treatment plan. The last thing is care coordination. I'll talk about that with just a quick slide later at the end.

So, we need to start with a survivorship care plan. A survivorship care plan is nothing more than a summary of all the things that happened to you when you went through your cancer experience. You can fill your own out, there are many online. The Lance Armstrong Society online has one that you can just fill out. You need to obviously have the information. And what is the most important part of having a

survivorship care plan? You need to know who is on your team. Believe it or not, we forget things all the time, people, places things. I don't know about you, but I have a lot of that going on these days. You need to know the diagnosis and staging, and the details really are important. You need to have a treatment summary. Believe it or not, you may not remember the exact names, the exact dates of the medications that you may have taken. You need to know that you have been assessed for familial cancer. So, if you haven't had a discussion with one of your providers about the genetic risks for breast cancer, ovarian cancer, pancreatic cancer, based on family history, should it be positive, that really is a discussion that should have taken place with you. If it hasn't bring it up with your primary care provider or your medical oncologist.

You need to know exactly what to expect from whom. So, for example, who is going to order your colonoscopy, your mammogram, your sonogram? All of these things need to be part of your plan and you need to know when you're going to have them. And that's the next point.

Often, we advise patients to have certain tests, and we usually are very specific about when they should have them. Being on schedule, particularly in the world of breast cancer, being on schedule is important. When we ask you to have your mammogram on a certain -- and it's usually an annual, a yearly basis, it is pretty important for you to actually have it around that time, as close to that month as possible. We know that for patients that have had cancer before, we are very strict with keeping those guidelines, because, of course, our job is to make sure that everything is okay.

So, what do the national guidelines say? And it depends upon which ones you look at, but basically if you look at this slide, they're pretty much the same. NCCN, the National Cancer Coalition Network, American Cancer Society say if you're a breast cancer patient and you've had surgery and treatment, you need to have a history and physical exam either every six months, depending upon what model you're looking at. For most surgeons, they're probably going to want to see you every three to four months for the first two years. After two years they want to see you probably at least every six months, annually after year five.

Labs and bone scans and chest x-rays, and things like that, they are not recommended for breast cancer patients. They really do not bring any value to the table in terms of early detection. Mammograms and sonograms do, and MRIs do when they are appropriate. They're not generally recommended for patients, but there are circumstances where an MRI would be an appropriate test for a patient.

And what about those patients who are status post treatment for ovarian cancer? Their surveillance is very, very critical, because, as we know, ovarian cancer is often diagnosed in a later stage because it doesn't present quite so obviously, and we don't have any really good screening tools. So, for ovarian surveillance, we want patients to be seen every two to four months for the first two years, annually until year five, but I can tell you that most GYN oncologists want to see their patients every six months. We do our markers in ovarian cancer patients, and if they haven't already been referred for genetics, they need to be. These patients do get bloodwork and chemistry markers and CAT scans, because it's a different type of cancer.

So, as I said previously, if you're over 50, you need a colonoscopy. If you have a history of melanoma or a history of burns, you really need to see the dermatologist. The American Cancer Society recommends that everybody should be screened for melanoma. We are very much exposed to the sun, living in the Northeast.

Lung cancer screening. If you have a history of smoking, there actually is a low-dose CAT scan for the early detection of lung cancer.

Gynecological assessment. I know that the guidelines have changed in the past couple of years, but we still need to pay attention and we still need to be following the recommendations of our gynecologists and having PAP spears when appropriate.

So, now we get to the things that apparently the medical community doesn't do all that well, and that is really managing not only the physical but the psychosocial long-term and late effect of breast cancer. So, the physical functioning I think we've got down.

Anxiety or depression. Twenty percent of patient survivors of breast cancer will say that when they finish with their treatment that they are depressed. Sexual functioning is one of the things that is not commonly spoken about, and yet we prescribe antiestrogens for patients, which do terrible things, meaningful things physiological, but difficult things to libido and the physiological changes of having an instantaneous menopause.

Emotional and mental health. It's very hard to go through cancer. Some of us have better coping skills, better support systems than others. The memory or the concentration loss, both related to anxiety and related to treatment.

Weight changes. I often see patients who come into the office, and I always ask patients about their weight, and they'll say, "You know, I've gained weight; I've gained about 10 pounds." And my next question is always, "Gee, have you started on one of the antiestrogens?" And they always say yes. And then they tell me that their medical oncologist swears that it's not that that made them gain the weight. However, I tell them anecdotally that I see an awful lot of that, about 10 pounds. Something to pay attention to. Ten pounds may not seem a lot, but it may be a lot in someone.

The things on the right-hand side I'm not going to focus too much on. Insurance, of course, is a very complex issue. Smoking, we know at this time that smoking is detrimental and puts you at risk for all sorts of cancers, not just lung cancer. The financial assistance is only a topic that is actually coming to fruition now, as we realize that there are patients who cannot afford their treatment based on the insurance that they have. And, of course, all these other things that come into effect, including the last one, which is fatigue, because many patients think that the fatigue will be gone when they finish their treatment, and lo and behold, they're actually still quite tired for some time after treatment ends.

So, this is kind of the spectrum of side effects that we can have, the weight gain, depression, hot flashes, cognitive, sexual. The other second malignancy that we worry about, particularly endometrial, in patients that are taking tamoxifen. Osteoporosis, which is a side effect of an aromatase inhibitor, arthralgia or joint symptoms, which is also a result of often taking an aromatase inhibitor. Genitourinary symptoms, side effects of antiestrogen. Chronic fatigue, side effect of being a patient and taking many medications. And last but probably one of the most important, the cardiovascular effects of having treatment.

So, when we talk about effects, we know some become apparent during treatment, some may last months or years after therapy, some can be mild, some are severe, debilitating, even life-threatening. They can affect any body system, and some of them are temporary and improve over time. Some of them are permanent.

We talk about some of the common late effects. One-third of survivors questioned experienced symptoms after treatment that were just as bad as when they were getting treatment. Usually, the complaints are about menopausal symptoms, the emotional distress and anxiety and depression, the fatigue, the insomnia. And for anyone who may be having chemotherapy or in the midst of treatment, one of the things that we worry about in patients who are having treatment is insomnia. It's very, very

important when you are undergoing treatment for you to sleep, and we address this often with patients and make sure they sleep by giving them sleep aids.

The fear of recurrence. This is probably the number one long-term psychosocial effect that all patients with cancer have, but it's been particularly studied in breast cancer. It can last a lifetime, and there are a couple of things that I'll mention a little bit later that might be helpful with that.

The sexuality and the intimacy issue. Not only are they related to the psychosocial issues of having a change in body image, potentially having some very strong physiological changes in libido, but it's also something that up until recent years really has not been something that has been discussed because it had been put on the back burner as something that wasn't the most important thing, having had survived cancer. But there are a lot of side effects, and we'll talk about them, also, in a minute.

The two things that most survivors can appreciate that will probably go away will be the alopecia, the loss of hair, and the nausea and vomiting. And if those things are continuing after treatment has stopped, then that's something that you really have to bring to the attention of your physician. For most people, hair loss will recover and hair will come back. Interestingly, curly comes back straight and red comes back gray, and all different varieties as it returns. Nausea and vomiting should not be part of your everyday life if you're not on treatment. So, please bring them to the attention of your doctor should they be occurring.

What are the late effects of surgery? Well, lymphedema, one of the projects that I do here. Psychological distress. Just having had surgery, having surgery and having results that are not perfect, because you've had a surgical procedure. Even patients who have very, very good cosmetic results realize that it's not the original. Altered body image is really a big part of that. And pain. Pain is something as you probably already know, if you've been through the medical community, pain is one of the things that we consider a vital sign. We want to know about pain, we want to treat pain. We don't want people to be in pain, and yet some of the interventions that we use can cause long-term pain.

Lymphedema is the swelling of the arm that occurs when axillary nodes are removed from the underarm. Here in my practice at Northern Westchester, we do screen patients, and it could be as simple as taking some measurements of the arm to make sure that we kind of have a baseline before they go to surgery. We really want patients to know what the symptoms are, what the treatments are, and what the precautions are for lymphedema because lymphedema can be treated, and we really feel very strongly that we do not want women to have a lifelong sleeve be part of their life.

Staying fit is important, because it's the musculature of your arm that actually helps push the fluid back into circulation. So, we give exercises, and exercise in general moves body fluids through the body better. So, fitness is something that we encourage.

So, the late effects of chemotherapy and monoclonal therapy, and that is primarily the drug herceptin, which has been new to the market for about the past 10 or 15 years. The one thing that patients are often surprised about is that there are associated cardiotoxicities with some chemotherapy drugs. Some are worse than others. There are some drugs that have very little cardiotoxicity, but many of our most effective drugs actually, in fact, do cause cardiotoxicity. They also can bring up your lipids, so many of us who are already on things like Crestor, atorvastatin, Lipitor, all of those, we need to be followed to make sure the cholesterol in our blood is actually being controlled.

Cognitive impairment is something that, when I first started in this business, it really wasn't taken seriously. Women would complain that they just couldn't remember anything and they felt like they were moving backwards in terms of their cognitive ability. But it is documented now and at least probably in

the last 15 years as being a real anomaly of having treatment. We call it chemobrain. So, it's defined really by a couple of different things, and it can be variable in most patients, and it can also depend upon the type of treatment that you've had.

One of the things, though, and it's reported in as much as 35% of patients who have had chemotherapy, survivors, executive function. Being able to balance a checkbook, verbal fluency, feeling like you're not as articulate as you used to be, or you can't find the words that you're actually looking for. Of course, for some of us, that may just be normal menopausal symptoms or age. Having a shorter attention span or not being able to concentrate as well as you have. Immediate memory and delayed memory loss, all of these things are part of the symptomology of chemobrain.

And what are the treatments? Well, there are not a lot of treatments out there. However, there is a little bit of research on the market about patients who use Lumosity. It's an online program of brain games, and there are some brain games for computers, you know, computer apps. And Lumosity and Sudoku have actually been tested and will improve memory in survivors who have had chemotherapy. All of us should be doing word games and math exercises and Jumbles.

The other very interesting thing that is coming into research now is that mindfulness-based stress reduction, such as yoga and meditation and tai chi seems to improve memory for some patients who are experiencing at least the memory, the recall for patients who have had chemotherapy.

So, all of these things are something that if you're feeling a little foggy after having chemo, something that you should try. We know that this can improve over time and over long periods of time. I've had patients who really worked very hard and improved over two or three years to kind of get back to their baseline.

Pain and neuropathy, very, very, difficult symptoms of being treated, do not always go away. I'm talking about peripheral neuropathy, which is the tingling and the pain that occur in your fingers and your toes, and it is a side effect of herceptin, which is a monoclonal antibody, as well as chemotherapy. And most recently, actually, we think that there may be some symptomology of neuropathy that comes from tamoxifen, because anecdotally we're seeing some patients who are complaining about this.

So, what do we do? Well, we always want to start with painkillers for pain, so we start with, you know, the NSAIDs, like Motrin and Tylenol. Physical activity is better. We want to improve circulation to the extremities. Acupuncture works for some people and not for others, but I recommend it for everyone, because until you've done it, you don't know if it's going to be helpful. And certainly the Eastern medicine has been using it for a long time with a lot of success. We refer to pain management. We use medical massage, so I don't want you to just think that you can go and see any massage therapist. If you have a history of cancer, it's important for a massage therapist to be trained appropriately to give you a massage, particular in the region that you had your cancer. And Cymbalta, which is a drug that is commonly being used and is very, very effective to at least eliminate the neuropathy and the pain, and allow patients to sleep.

So, chemo-induced menopause and fertility issues. You know, when we give a patient tamoxifen or an aromatase inhibitor like Arimidex, we are really blocking the estrogen, the circulating estrogen in your body. And as a result, of course, we throw many people into menopause immediately. So, the ovaries are no longer producing eggs. So, for patients who are coming in who are thinking that they are going to be using tamoxifen or going on chemotherapy, we often refer patients to fertility physicians, who will help them to discuss whether or not they want to have more children or maybe they haven't had any, saving their eggs. And there really are a lot of strategies to preserve fertility for patients that need chemotherapy or antiestrogen.

There is limited data about whether or not it's -- there is some impact on long-term survival for women who get pregnant after having treatment. When I first started in breast cancer, it was absolutely unheard of to have a pregnancy after you had breast cancer. I am happy to say that's not the recommendations today, but we still worry. So, we want patients to be followed very carefully, but we don't want -- we want to make sure that we preserve their fertility, because it's important to them.

Radiation, for those of you that have had it, you recognize the first thing here is fatigue. It hits at about two weeks, it can continue beyond radiation, when radiation therapy has stopped. Pain is one of those things that really is a phenomenon that can occur at any time after chemo, after radiation, after surgery. You can suddenly have pain five years after having all of your treatment. We don't have a good explanation for why pain is often residual after treatment. When it is persistent, we investigate it; when it is transient, we follow it. Those are generally the rules. Certainly, radiation causes burning when treatment is taking place, and as a result it causes skin changes. People who are very fair will be burned; people who have olive skin will be tanned; and women who have darker skin, darker brown skin, they often will get a very dark tanning effect from radiation. Some of those tans go away; some of them do not. Some of them may really last a lifetime.

Tamoxifen. So, we know that it's been around since 1978. It's been shown to decrease disease recurrence and increase survival. When it originally came onto the market, patients stayed on it forever. They were going to be on it for life long. It's still the standard of care for premenopausal breast cancer patients. It is associated with endometrial cancer and thromboembolism, which is [throwing] clots. I can honestly say that I've seen very few of these events in my 35 years. They do occur, however, and it's important for everyone to be on the lookout or be under surveillance for them.

Often patients come in and I talk to them very openly about vaginal atrophy. So, if you don't know what that is, vaginal atrophy occurs because the lack of estrogen -- estrogen is the hormone that, of course, supports our gynecological structures, including our vaginal wall. And without it, the wall begins to atrophy, just like when you don't use your biceps in your arms, your muscles can start to atrophy; the same thing happens here as a result of lack of estrogen. And what happens is, patients will often get irritation, they can get increased infections, they can get urinary tract infections. It can make intercourse quite difficult. It's not often talked about, but, of course, it should be talked about because it's important.

So, what do we recommend? Well, we really recommend non-estrogenic vaginal lubricants, and I'm talking about Replens, which actually is a moisturizer, and K-Y Jelly, which is a lubricant. For some women -- you see the second point here on my slide -- for some women, yes, believe it or not, vaginal estrogens are actually recommended. There has to be a very good reason, but there can be severe atrophy of the vagina, which can cause genitourinary problems. So, in some women it really has to be resolved, and the only way to resolve it, really, is to replace the regional or local estrogen, so we use applicators or cream or an ESTRING, which is something also that provides that. There are some patients who get the opportunity to use vaginal testosterone. Not highly recommended for patients. Testosterone can be converted into estrogen, but it is recommended for some patients. And if you are using tamoxifen, you really need to be seeing the gynecologist.

For anyone who is having difficulty with the libido, the vaginal atrophy, intercourse, sexual dysfunction, I have a wonderful GYN who I refer many of my patients to. She is a gynecologist. This is -- her expertise is in talking with, treating and examining patients who have been through chemotherapy and it has affected their genitourinary and psychosocial sexual health. So, that is something that I'd be happy to provide if anybody needs that referral.

The other endocrine therapy, of course, is aromatase inhibitors, and whereas tamoxifen is a receptor blocker, aromatase inhibitor actually prevents the development or the transition of one compound into

estrogen. And they are also shown to decrease recurrence, as compared with tamoxifen. But now there is a new regimen that actually is being recommended by many oncologists, and that is to kind of recommend tamoxifen and follow it with an aromatase inhibitor. Those patients seem to get very good results in terms of long-term survival and decreased recurrence rates.

Now we're talking that there are some patients who should do five years of tamoxifen and five years of an aromatase inhibitor, or some combination of a 10-year plan. That is coming into fruition. I am happy to show you this one little item here called a Breast Cancer Index. There is actually a site on molecular test which can test your tumor for its likelihood that it is ultrasensitive to an antiestrogen. So, what that means is the tumor is actually sent to the laboratory, and tumors, of course, are saved from the procedure that -- the surgical procedure that's done. And there is a way of actually identifying those types of cancers that may benefit from 10 years of an antiestrogen. Conversely, it also identifies those tumors that will not benefit from 10 years of antiestrogen. So, this is something fairly new to the market. Some medical oncologists are using it, but definitely something to explore. At least ask your medical oncologist about it if someone is recommending that you go to 10 years of an antiestrogen.

This is oh, my aching bones, and this is aromatase inhibitors. They are notorious for decreasing bone mineral density, increasing risk of fracture. They cause bone loss. They cause osteoporosis, and for most people who are on them, they will be recommended to be on calcium, vitamin D. Some patients will be put on biophosphonates, like Boniva or Fosamax. But patients with osteopenia and osteoporosis, they can go on these medications as long as we support their bones. So, it's not a full contraindication; they are -- it's a risk-benefit analysis that really has to be done with you discussing it with your physician.

Bone density is very important, though. If you haven't had a bone density test and you are postmenopausal, you should have one. They should be tested, particularly the patients on aromatase inhibitors, like Arimidex, should have a test at least one year of starting it. Patients at baseline with normal bone density should at least be on calcium and vitamin D, and weight-bearing exercise is good for all of us as we go through menopause. We should all be doing weight-bearing exercises in order to keep our bones strong.

Patients with osteopenia need to be followed a little bit more carefully. Patients with osteoporosis, of course, need to be followed more carefully. And there is some six-month medications that a lot of people are on. There are actually some medications that actually are given once a year in order to improve bone. So, all these things really need to be considered. Certainly, everyone who has taken an aromatase inhibitor needs to be scanned regularly, every two years or every one year, depending on what the situation of their bones is with a bone density test. Once again, osteoporosis is not a contraindication to taking them.

This is -- there are more higher symptoms with AIs in terms of bones than with tamoxifen. We actually think that tamoxifen, within the first two to three years, may actually have a preventive bone effect, meaning it may actually protect your bones from the leaching of the calcium. So, generally, we're not as worried with patients that are on tamoxifen. We think it may actually protect them.

So, is there anybody else hot? Menopause, very distressing symptoms. We throw patients into it with surgery, with antiestrogen therapy, but it also causes some other symptoms. Depression is one of them. Hot flashes, night sweats commonly, the vaginal dryness often associated particularly with the tamoxifen. The pain with intercourse, as we talked about, with the vaginal atrophy. Insomnia. One of the things that I say to patients if they come in and they're actually still menstruating and they tell me that all of a sudden they have insomnia, I know that menopause is on its way.

We want people to sleep. Sleeping aids are important, as you know, if you watch the news. It's important for our work lives, our home lives, safety. So, insomnia is something that we want everyone to actually treat.

I think that we talked a little bit about this, 40% to 100% of cancer survivors report some sexual dysfunction based on estrogen deprivation.

So, how do we move forward? Get physical fit. Exercise like your life depended on it. No kidding. There is some recent studies that say that nutrition is -- that exercising is even more important than nutrition. Patients were put on exercise regimens between the ages of 60 and 90 years old. They didn't change their diet, we just got them up and made them move, and they actually improved their life expectancy just by exercising. We all have to get off the couch. I know, very easy to say, not so easy to do.

Obesity is a real problem. It puts us at risk for the development of cancer, particularly breast, but other gynecological, and it puts us at higher risk for recurrence of cancer. So, it's very hard, weight is a very difficult issue. As you know, if it was so easy, we would all be very physically fit. But it is something that we have to pay attention to, struggle every day to try to get to physical fitness and get your BMI down to what is a good BMI for you. We're not all the same. We know what the "government" wants us to be, but we have to do the best that we can.

I think everybody knows about nutrition. I don't like to put in scientific slides, but I do want you to see this one slide. This was a group of women who were all eating 20% fat in their diet, and that's not a terrible amount of fat to be in one's diet. They were all breast cancer survivors. They were split into two groups. One group they said just eat exactly how you've eaten before, maintaining 20% fat in your diet. And the other group was put on 15% or less fat content of their diet. In five years there was a 24% reduction in recurrence of breast cancer for the patients who went on the lower fat diet. If that doesn't convince you, I don't know what will.

Physical activity, very important. Exercise like your life depended upon it. Here you see the recommendations, 150 minutes, 75 minutes of vigorous. The reality is, 10 minutes is better than nothing, 20 minutes is better than 10 minutes. Everyone needs to try to get up and move to the best of their ability. It makes us strong, helps us live longer lives, it's good for our heart.

The importance of care coordination. This is the bottom line. If you don't like your doctor or you don't like their offices, please pick new ones. No kidding. You need to like the people that are taking care of you. You're going to have a long-term relationship with them. I don't want you to be stressed while you're in their office.

The mind-body connection, very important. We have to incorporate the physical, what we say, what our thought patterns are. Pessimism is one of the things that is not good for us. I know that some of this is innate, but being a pessimist when you're going through treatment often is detrimental to your treatment outcome, and that has actually been documented in the research. Chronic stress, we know, is just not good for us. Stress in terms of immunity, it does terrible things to our immune system. I wanted to get towards the end, because I know we have questions.

Cancer, the mind-body relationship and chronic stress are the things that, if you haven't started thinking about them, you really should. I'm going to just move through here just a little bit.

Health and wellness. There are many institutions and there are many organizations that provide things like this for patients. They are wonderful for patients. Reiki, aromatherapy, acupuncture, massage, all of these things should be part of your wellness plan.

We are coming to the end, but this I just want you to take a look at. I think you're really familiar with all of this. Health maintenance, exercise and physical activity. Nutrition we talked about. Genetic counseling.

Fear of recurrence. I just wanted to go back to that for just a minute. One of the things that's recommended by clinical social workers for fear of recurrence, which is a very, very common psychosocial side effect, so-to-speak is, you know, you need to know what triggers you. Many of us have issues getting back into MRI machines or having mammography, or having GYN examinations, and you need to have a plan as to what you're going to do if you are triggered. Certainly, talk about it to friends, family members who understand. There are counseling groups, there are counselors. All of these things are going to be helpful. Also, be patient. You know, cancer is a traumatic life event. You're never the same after. We often talk about life before and life after, so definitely be patient. But certainly, we want to decrease your fear of recurrence over time. If it doesn't go down over time, you may have post-traumatic stress, and we want to help you treat that as well.

Finally, remember, there are more women today than ever before who survive and thrive. Early detection still not perfect, but it remains the best protection that we have. And, finally, I dedicate this to all of my patients over all the years. Their names remembered or forgotten, alive or departed, the fight continues, and we're all together in it. Thank you so much.

Marlene Stager:

Thank you very much. I am going to ask one question that has come in referencing, what about people with triple negative breast cancer?

Mary Greco:

Triple negative breast cancer is one of our more difficult cancers to treat. I can tell you that there is some research coming out that possibly, some of the antiestrogen may provide some benefit for triple negative breast cancer patients. Their main surveillance or survivorship treatment really is surveillance. They need to be followed quite closely. I know that triple-negative patients often feel that they are waiting, or that they're worried that they don't have that benefit of the long-term pills to take, like the patients who are able to take tamoxifen or the aromatase inhibitors. Certainly, triple negative is one of the cancers that we worry the most about in breast cancer. However, close surveillance with your physician, your surgeon, your medical oncologist is really the way to go. Keep looking at the Internet for some of the opportunities for some of the clinical trials that are coming out that are trying new drugs that will work similarly to long-term benefit on triple negative. Thanks for the question. It's very hard, triple negative breast cancer.

Caller # 1:

Okay, I had ovarian cancer in the dinosaur age of it, '76 through '80. I was on chemotherapy for a year. I was clear for 33 years and it came back after 33 years. But is there anything else you can think of that I can do?

Mary Greco:

Well, when they removed your -- when they removed the recurrence, did they check it for estrogens?

Caller # 1:

I don't know.

Mary Greco:

Well, there are actually some GYN oncologists who use similar drugs to what we use in breast cancer, antiestrogen. So, of course, it depends upon the characteristics of the tumor. But certainly that would be a question that I would ask your GYN. Are there any -- it's not that they're off-label, but they're not as mainstream as the chemotherapy and the radiation that is always recommended first. There absolutely may be some other modalities that you can try. May I ask where you're being treated?

Caller # 1:

Yeah, I'm in Whittier at Presbyterian Intercommunity.

- Mary Greco:** Okay. I would -- the next time that you are doing your follow-up or at least make a phone call. Find out of there, based on the characteristics of your tumor, are there any other modalities that could be offered to you at this time.
- Caller # 2:** I don't live in New York; I live in Washington State. You talked about the effects of the chemo and everything on your sex life, and unfortunately I am one of those people. I brought it to the attention of my gynecologist and he didn't either -- well, anyway, he didn't understand or have knowledge about, I guess, the effects. How do I find someone who maybe can give me some treatment, because it certainly has a negative impact on your marriage and how you feel about yourself?
- Mary Greco:** It absolutely does, and it can be a very, very serious situation in marriages that have had wonderful, robust, intimate sex lives where all of a sudden --
- Caller # 2:** And we did.
- Mary Greco:** -- or have no sex lives, so that really is an issue. I actually have a colleague here who has been to all the national -- because this is her training -- who has been to all of the national conferences on this. If you want to contact me through Support Connection, I would be happy to find someone out there who is part of that network of GYNs. They have special certifications, and they don't deliver babies anymore. They're not OBs, but they primarily deal with women who are having sexual dysfunction, which includes libido and physiology. I mean, the two of them together and are treating with recommended guidelines, who are treating patients to really try to get back to their pretreatment lives.
- Caller # 2:** Thank you so much.
- Caller # 3:** I have a question regarding, I'm an ovarian cancer survivor of about six months, and I'm 74 years old, and my doctor recommended that I go on Arimidex. But I have osteoporosis in my left hip, and I'm not too sure that there is a lot of studies as to whether the Arimidex actually helps. What is your experience with ovarian cancer and the hormone-blocking therapy? I mean, how (inaudible)?
- Mary Greco:** Yes, it's actually being commonly used now. Tell me about your hip. Is it -- have you had a fracture of the hip?
- Caller # 3:** No, but I've had osteopenia for quite a while --
- Mary Greco:** Right.
- Caller # 3:** -- and kept telling my doctor about it, so finally he did a bone scan --
- Mary Greco:** Right.
- Caller # 3:** -- after my chemo, and found that, I guess, that maybe the chemo pushed me into osteoporosis, I don't know.
- Mary Greco:** That can be built back up again with the biophosphonates. So, even though he may be recommending an aromatase inhibitor for you, the biophosphonates, and there are a couple of different ones that are really very powerful, may actually be able to prevent that hip from getting any worse and may actually be able to maybe reverse it a little bit. So, it will be a combination of medications, but the aromatase inhibitors are being used in ovarian cancer patients such as yourself.

- Caller # 3:** Okay. I had, but not all -- from my reading I heard that not all tumors or all types of ovarian cancer respond to it. Mine was low-grade serous, Stage III.
- Mary Greco:** It's not so much about -- that's correct. There really are more characteristics of the tumor that are making him make that recommendation. And one of the things I tell patients, too, you know, you can always stop a medication. If you are not -- and my concerns about aromatase inhibitors is that there are many women who don't feel well on them. They hurt, they ache, they feel like they have aged 20 years in just a couple of weeks. So, it can't hurt to try it.
- Caller # 3:** I've been on it for four months and I have --
- Mary Greco:** How are you feeling?
- Caller # 3:** Well, I feel okay, except that I notice that my hair is not growing like it should be, and my eyebrows started coming out again.
- Mary Greco:** Yeah, that is a side effect.
- Caller # 3:** Yep, and so this part bothers me a lot, and so I'm wondering at my age, I mean, how many hormones do I really have that it can block?
- Mary Greco:** Well, you could have quite a bit, by the way.
- Caller # 3:** But I thought they were supposed to test you for the estrogen levels and (inaudible) --
- Mary Greco:** Well, not necessarily. Remember, it's not circulating estrogen that they're actually worrying about; it's actually the sensitivity of a tumor that, although it may be grabbing the little tiny bit that you have of estrogen and using that to proliferate.
- Caller # 3:** Okay, even though you've had a total hysterectomy and all the tumors have been removed?
- Mary Greco:** Yes. Remember that estrogen doesn't just come from a GYN. It's created in your adrenals, so there are other mechanisms of estrogen production. So, he wants to make sure that he's really blocking every bit he can.
- Caller # 3:** Yeah. Well, it was my choice. He gave me a choice, and he said that there was a lot of research done on it, and that some oncologists, gynecologists don't agree with him.
- Mary Greco:** Correct. I have to tell you that here in New York I'm seeing it be used, and we're talking about its use in tumor board with ovarian patients.
- Marlene Stager:** Okay, do we have any new questions?
- Caller # 4:** Mary, quick question. You had mentioned that you recommend sleep aids for insomnia because it's important for us to sleep.
- Mary Greco:** Yes.
- Caller # 4:** So, what do you recommend?

- Mary Greco:** Well, the first -- if you go to the over-the-counter products, they all contain Benadryl, and Unisom and anything that has PM after it, it's all Benadryl. The problem with Benadryl is that there are some people that have an opposite reaction to Benadryl. So, for example, there are some people who take Benadryl and stay up all night. The first, probably the first and the least harmful, if you don't have a contraindication to Benadryl, would be to take a product that has Benadryl in it. If you're in pain, then Motrin PM or Tylenol PM, one of those. We do often tell patients that trying melatonin can be very helpful. Melatonin is an herb which actually has a neurotransmitter. It's very helpful for a lot of people, but not for everyone.
- Caller # 4:** Do you recommend any prescription ones, because sometimes those things don't work for me?
- Mary Greco:** You know, there are several prescriptions on the market. Ambien is a rough medication because it has a lot of --
- Caller # 4:** No.
- Mary Greco:** Yeah. It it's a good drug for sleeping, but it can have a lot of side effects, including nightmares, sleep eating, sleep driving, walking. So, it's difficult. There is actually another drug on the market which is called Lunesta. This is a much less toxic sleep aid. So, people find it more tolerable than Ambien. And there is actually another drug that is not so new to the market, but it's for people who wake up in the middle of the night. It's designed to be very short-acting, so that it actually will put you back to sleep but not have you have a hangover when you try to get out of bed at 7:00.
- Caller # 4:** And what is the name of that one?
- Mary Greco:** I can't remember it off the top of my head, but physicians know about it.
- Caller # 4:** Okay. All right, thank you.
- Mary Greco:** Lunesta is a great drug. Ambien, you know, Ambien is not my favorite drug. I certainly don't like to use it. I don't like to use it in patients that are over 70, because the physiology changes throughout the lifecycle, and there really can be some cognitive changes associated with it as well. You don't want to be on it long-term. If you haven't tried Benadryl, it may be really effective for you.
- Caller # 4:** Yeah, I've tried that, too, but, okay.
- Mary Greco:** Not working?
- Caller # 4:** Sometimes --
- Mary Greco:** Yeah, but not all the time.
- Caller # 4:** -- but it doesn't sustain me.
- Mary Greco:** Yeah. You know, some people who use Xanax, a little bit of Xanax, will keep you asleep, but it will put you to sleep. Ativan, little doses. I mean, I'm always thinking that less is better, so a little bit of something that will at least help you to get to sleep. If you stay asleep, then try to go with something less. I would try, if you have an option, I would think about or at least do some research on Lunesta. It's a really good drug.

Caller # 4: Okay. Thank you very much.

Mary Greco: You're welcome.

Caller # 5: I'm actually taking an aromatase inhibitor. I take letrozole, the generic Femara. I don't take the tamoxifen because I have a history of blood clots. And I find that I have a lot of osteoarthritis to start with. I've had joint replacements. I'm 65, I had those when I was in my 50s, so I do have a lot of osteoarthritis, and I find that it really makes my joints even that much stiffer. I feel like I'm 95. But I also find that I'm starting to have some balance problems. Is that -- I've read online that that can be part of the aromatase inhibitor, but maybe not. Do you see that as a side effect with letrozole?

Mary Greco: Yes, we do. And one of the issues is actually a combination of the musculoskeletal with the balance. So, as an arthritic person myself, we do change the way we move when we have arthritis. And the way that the human body moves is a delicate ballet of motion, so part of, I think, what may be aggravating your balance is the fact that you are -- you're feeling kind of lousy in terms of your musculoskeletal system. You're having arthritis symptoms, right?

Caller # 5: Right, true.

Mary Greco: Yeah, you know, it's kind of a combination effect. There would be -- how long are you on it?

Caller # 5: I've been on -- well, my surgery was two years ago, so I've been on the aromatase inhibitor for a year and a half. But I did take a vacation for a while, like six weeks off, because of the arthritic symptoms and I felt much better. But the oncologist doesn't think that that's a reasonable thing that I just go off of it.

Mary Greco: Are you on any of the other aromatase inhibitors besides the letrozole?

Caller # 5: No. The oncologist said they all have similar symptoms. I mean, as far as the (inaudible) --

Mary Greco: I mean, I've seen patients who have tried two and, you know, Femara actually seems to be the most tolerable. However, everybody is different. I have many patients who started on one, move to another, couldn't tolerate either of them and moved to a third and actually felt a little bit better. So, it's not beyond reason to see if you would get less side effects from one of the other aromatase inhibitors, and it actually is -- it is a reasonable suggestion for you to bring up with your oncologist. Certainly, 30 days of a different drug or six weeks of a different drug will tell you right away whether or not you have the same side effects on a different brand.

Caller # 5: Okay. Is there anything to help with the balance problem?

Mary Greco: Sure. There is actually, there is balance training. Are you doing anything such as yoga or pilates or tai chi, any of that?

Caller # 5: No.

Mary Greco: Tai chi is the answer to balance. It really helps improve balance. You can actually pull it up online. There is some excellent YouTube videos of people doing tai chi in order to improve their balance.

Caller # 5: It can be kind of dangerous when you fall down.

Mary Greco: It can be pretty dangerous when you fall down. And the good thing about the tai chi is that you can do it holding on -- if you're doing on at home or even in a class, you can do it holding onto the back of a chair. I

mean, you also don't want to be in a tai chi class and fall down, but it really does improve balance and it's not anecdotal, it is true. So, you should really be some sort of movement class.

Caller # 5: Okay. All right, well, great. Thank you very much.

Mary Greco: You're welcome.

Caller # 6: I have a quick question. I think it was osteoporosis you said --

Mary Greco: Yes.

Caller # 6: -- limit ETOH. What is that?

Mary Greco: Oh, alcohol, yes. I'm sorry I didn't mention that. Alcohol is a real risk factor for breast cancer. It also is a drug, as we probably all realize, and interacts with anything else that you're putting in your system. So, we really want patients to refrain. Now, I'm not talking about having a couple of glasses of wine a week, but we know that seven drinks a week, which really could be the equivalent of having a glass of wine every day, has been considered to be too much. So, we really all should be watching how much alcohol we're consuming.

Caller # 6: And I have just one more, quick one. I have my memory and I really want to deny it big time about it came from the chemo. And when I meet people and they say, "Hi, it's great to see you," and it's like who the hell are they?

Mary Greco: Who is that and am I supposed to know their names?

Caller # 6: How do you handle it? Sometimes I don't ask, sometimes I do. I just feel embarrassed. I just --

Mary Greco: Besides calling everyone hon. You know, it really is tough. We do know that if you're not -- if we're not exercising our memory, we're not going to be able to improve it. So, any little thing that you can do in terms of memory recall, that could even include things like crosswords and stuff like that, is actually going to be helpful. I don't have an easy answer for that, because I suffer from that myself and it is very difficult. But from what I'm reading about all memory, regardless of cancer or any other chronic illnesses, when you don't use it, you really do lose it, and that includes memory skills, like the games that kids play, like Concentration and stuff like that. All of those are really very helpful. If you have a cell phone, you can pull some of those apps onto your cell phone and they could actually help you.

Caller # 6: Concentration, things like that?

Mary Greco: Yeah. Concentration was that game that kids play when they match colors or match cards. They have that for cell phone apps, and they really are very helpful in exercising the memory skills.

Caller # 6: Fantastic. Thanks so much.

Mary Greco: You're welcome.

Marlene Stager: Okay. At this time we're going to conclude the presentation. If anyone has questions that they did not have an opportunity to ask, please feel free to call the Support Connection office tomorrow, and we will see about -- we'll get the information for you, okay? I want to thank Mary, again, for your time, your expertise and dedication --

Mary Greco: Yes, Marlene, thank you.

Marlene Stager: -- and an absolutely fabulous presentation.

Mary Greco: Thank you. Stay well, all.

Marlene Stager: Okay. Thank you. Everybody, have a good night.