



354 West Lancaster Avenue | Suite 224 | Haverford, PA 19041

Phone: (610) 645-4567

Fax: (610) 645-4573

Survivors' Helpline: (888) 753-LBBC (5222)

LIVING
BEYOND
BREAST
CANCER[®]

LBBC.ORG

Lymphedema: Prevention and Treatment Options

Wilma Morgan-Hazelwood, OTR/L, CLT-LANA

August 18, 2009

KATHLEEN KELLY:

Good evening, everyone, and welcome. Tonight's topic is "Lymphedema: Prevention and Treatment Options." I'd like to introduce our speaker, Wilma Morgan-Hazelwood. Ms. Morgan-Hazelwood has been a lymphedema therapist at Fox Chase Cancer Center for nine years, and has specialized in lymphedema for 12 years. She is board certified with the Lymph[ology] Association of North America, and represents the northeast region. She specializes in edema of the head and neck, arms and legs and trunk of the body. She was honored as Therapist of the Year by *Therapy Times* in 2007, and has lectured and taught courses on lymphedema.

Please welcome Wilma Morgan-Hazelwood. [Applause]

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

I guess everyone can hear me. I'm not used to talking like this, though. Please bear with me.

This is actually your program, so I'll try to make it as informal as you wish. You can interrupt me at any time, if you would like to ask questions or add to [my presentation]. Please be free, and then we can always ask the questions and everything later — so whatever you're comfortable with. But I'd rather have it as your program. . . .

We've already talked about some of the objectives. There are just going to be some signs and symptoms, the risks, precautions, some psychological effects, current modalities and things that are happening in the field, the role of the therapist, and the role of the patient.

A very fancy definition of lymphedema is "an abnormal accumulation of protein-rich fluid due to a low volume; mechanical insufficiency in the lymphatic system." Basically it's only a swelling of a body part, most often the extremities, caused by an abnormal accumulation of the lymph fluid.

. . . People always ask: What's the difference [between] regular edema and lymphedema? . . . Regular edema is just an accumulation of what happens naturally during the healing process, [if it's] subacute, [it] is an inflammation response [that] resolves usually in two to three weeks. Typical: You hit your knee. It swells to protect the joint. Within two to three weeks, you should see the swelling going down. Post-traumatic [injuries] sometimes deal with a little bit more involvement, or actually the flow of the lymph can last up to three months, [and then it resolves]. . . .

When it doesn't resolve, [when] the lymph or the actual edema stay there too long, that's when it switches over to lymphedema. The main reason . . . it switches over is that very little topical thing we said before — the protein-enriched fluid. The fluid is no longer filled with just water, but it actually changes into protein, where you get the changes in your skin, the densities and things of that sort. Once that occurs, it switches over to lymphedema rather than edema.

A little bit about our system here: What we have is what we call three peripheral nodes. They are your cervical nodes — and that's where most of our lymphatic system is posted, right here. Very typical when you were a kid and you complained of a sore throat and your mother [said], "Oh, look at your glands," [she was] actually feeling your cervical nodes. . . .

What we're really [focusing on] . . . today is . . . the axillary nodes, right here under the armpit. We actually have three sets of them — one, two and three — and then also the third peripheral node is right here. The inguinal nodes are going to be down here. These are the three that we can actually palpate.

Our body also has many other nodes. We have them deep in the sternum. We have them around most of our organs, and definitely [in our] deep abdominals. We have a couple in our knees, we have a couple in our ankles, a couple in our elbows,

and a few in our wrists. But that's basically the location of our nodes.

Lymphedema is actually brought into two different kinds of cases. One is primary — basically you can be born with [a lymphatic abnormality, and] develop [a form of primary lymphedema] later on. But there's no known cause for that lymphedema. What we're going to be talking about today is secondary lymphedema, where we know the cause is actually . . . the cancer [treatment] — if not the cancer itself — . . . the byproduct of it during surgery or radiation. In the United States, [cancer and cancer-related treatments are] the number one cause of lymphedema. In the world, it's the second [most common] cause of lymphedema.

[And here are a few] . . . cancer statistics: Approximately one in eight women will develop breast cancer in their lifetime. Breast cancer accounts for nearly one in three cases of cancer, next to skin cancer. [Breast cancer is] the second leading cause of mortality. One of the reasons why we do so much work with breast cancer right now is because we have the [high] survival rate. It's one of the cancers that we can actually do long studies for, which is fabulous. . . . We couldn't do [that] before. . . .

Most [often] in the United States, lymphedema [is diagnosed] unfortunately, . . . [among those who have had an] axillary node dissection . . . right now they're saying 15 to 20 percent of women will develop lymphedema. That is actually probably a little bit low. We probably feel it's more about 25 to 40 [percent], but a lot of times they're not diagnosed and the clarification of lymphedema is not always known. So there's a lot that goes undetected as to what. Approximately one in five [women with] breast cancer will develop lymphedema.

Luckily, [since] a couple of years ago, it's become much more successful now [to do] the sentinel [lymph] node biopsies, rather than going



with the axillary [lymph] node dissection. Initially, when [the sentinel lymph node dissection] came out, we really thought that was going to be the end of lymphedema, at least as we know it. We still are seeing some cases. We figure it's at least 7 to 10 percent [of] people will develop lymphedema from the sentinel [lymph] node biopsy. Is everyone familiar with the difference between an axillary node and a sentinel node? Sentinel node is when they actually use some dye, and the taping actually will see where the actual lymph nodes go into the tumor. They only remove [the nodes that are involved with the cancer]. When you actually do an axillary [lymph] node [dissection], you're usually [removing] number three and number two sections. That can [remove] anywhere from ten to 30 [lymph nodes], depending on each individual — how many nodes you actually produce. . . .

When we talk about lymphedema, I don't know how many people are actually familiar with it. This is basically what severe lymphedema would look like on an upper extremity. This is basically a moderate lymphedema.

. . . When I'm talking about lymphedema, I don't know how many people actually know what we're talking about when we talk about the lymphatic system. So I brought a little chart here. It gives you an idea of what we're dealing with and what — I don't know if you can actually see it. I'm giving a little IOI on lymphatics. The lymphatic system is actually with our vascular system. So you have your nice, big arteries. You have your veins right next to it. And the little skinny things in green are lymphatic systems. So they work very nicely together. You have your arteries that give the oxygenated blood into the system. The veins pick it up. What they pick up is only 90 percent of what is given to them by the arteries. The last 10 percent is picked up by the lymphatic system. So we basically only have about two liters of [lymph fluid] running through our bodies at a time. And that's what we actually produce.

The trouble with it, normally when we do arteries and veins, they can transplant them and everything else. We unfortunately can't [transplant] to the lymphatic system, because the [lymphatic system is] too frail. Basically . . . we're dealing with [follicles that are] basically about a thread size. Surgeries [have been conducted to] . . . try to hook them up, try to reconnect them, [but those surgeries have] . . . always failed. So we haven't been able to conquer that part.

So, actually, [the lymphatic system] runs pretty

deep into our system, midway through [and] into our muscles. The problem is . . . the receptors for the lymphatic system look like little trees that lie directly underneath the skin. So when we do any kind of therapy or anything like that, it's always very gentle, because it's a very light — what we want to do is move the skin. By moving the skin, we have these little receptors that take more, [and] bring it down into our systems [so we're] able to go through it.

So, what happens when you have an axillary node dissection? They don't actually count the little nodes that come out. That's always done in pathology. They do a scoop method. If they had to actually count your nodes, you would be in surgery ten hours. They scoop them out. When they scoop them out, they also scoop out the fine networking that comes [with it]. So not only are you removing the nodes themselves, you're removing the whole vessels with it and the whole capillary systems. So a lot of times after your surgery, they'll say, "Don't raise your arm," maybe for a few days, over 90 [degrees], or what's comfortable. It's because they want that capillary system to begin to fuse back, and work together. This is actually what a node does.

So, what happens is the 10 percent [of lymph fluid] that's left over, that the veins don't pick up, is primarily going to be water. It's also going to be a lot of bacteria, because this is [mainly] what the system does. It also picks up the cancer cells, which is what it's known for, which is why you always have them removed. It picks up the heavy protein cells. It's not the cells of protein that you eat, so it's nothing to do with diet. It's actually . . . in the byproducts of the cells. That's the protein that usually gets stuck and changes the texture of the skin when you're having lymphedema. So those are the things we're actually looking for.

So what happens when you have a [lymphatic] system that's a little sluggish — [that] hasn't completely repaired yet . . . — it leaves this fluid behind. And it works almost like a cesspool. You have these wonderful [home for] . . . infections sitting there, this heavy protein that's sitting there, and it's waiting for an infection. So [we'll be] . . . talking about how to prevent that, because that's the one [aspect of] . . . lymphedema [that can be deadly]. So, if you want more in-depth detail, I'd be more than happy [to provide that for you later on]. But [this has been] a little bit of [a] IOI [on the] lymphatic system, to figure out what we're talking about, and the system we're talking about.

WOMAN:

If you do have infection, would you know that you had it?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Yes. Usually the infection that you get is what we call cellulitis. It's usually very red, very hot, very rashy, very painful. And then there [is a second kind of infection]. You can get regular cellulitis that is still peripheral, and the other [one that] we worry about, [which] . . . can [be] very systemic. [It's called lymphangitis.] When that happens, it's like you have a flu. It happens immediately. Very quickly you run a high fever. You want to make sure you either get to the hospital or to a doctor, and you'll be put on heavy antibiotics. So that's what we usually watch out for.

We used to say, how you can prevent lymphedema? I don't believe we can prevent it. I believe if you're set up for lymphedema, you're going to have lymphedema. You will get lymphedema one way or the other. It doesn't mean you might not get it today, but you might get it three years down the road. What I like to do is risk factors, and some of the things to look out for; some of the things we might be able to ward off.

. . .

Some things we can control. And luckily you're here. We know surgery removes them. We also know radiation does a lot of damage, twofold. One, the radiation . . . changes the cellular makeup, and that's what's wonderful and keeps everyone living. But, unfortunately, it also produces a lot of scar-tissue — not only to the vessels themselves but also to the networking of the skin. A lot of times what happens is you increase your risk of lymphedema after radiation, because you don't have the free-flowing of the vessels that you had prior to it.

[Radiation is] also another cause of . . . lymphedema, [but it generally occurs] years down the road, [well after the radiation is completed]. I have a woman who just came in. It's been 15 years since her surgery. I have another woman who's 20 [to] 25 years post [treatment], and all of a sudden developed lymphedema. Usually when we see that, it's [from a combination of] . . . radiation . . . and . . . our aging process. As we age, all our vessels get a little bit thinner, a little bit [more] frail. And [after cancer treatment and surgery] . . . the [individual has] a system that the [fluids] just can't get through. So where [lymph flow] worked very



LIVING
BEYOND
BREAST
CANCER®

L B B C . O R G

354 West Lancaster Avenue | Suite 224 | Haverford, PA 19041

Phone: (610) 645-4567

Fax: (610) 645-4573

Survivors' Helpline: (888) 753-LBBC (5222)

marginally before for 25 years, now, with aging, it doesn't quite make the flow, and ... lymphedema [develops. But it's] a very low percentage, don't worry. [Laughter]

Some of the signs of radiation fibrosis — ... are things we're looking for because ... those areas ... can be very bound down, and [it's] harder to get the lymph to throw down [and reveal] ... [the symptoms of the condition]. Some [signs] are just [changes] the blood vessels. So you know you've seen changes in your skin. And you have to really [pay attention] to your radiation skin, because it doesn't move like it did before. It's not as elastic. It's much drier. ... So you always want to [have a] really good skin care [routine after radiation]. You want to protect it. It's not going to move as well, and you want to make sure you always [moisturize] the area.

Some additional risk factors [for developing lymphedema]: The number one thing is usually infection. That's one of the things we would like to prevent. Usually, if you do get infection, and you come down with a case of cellulitis, the chances of developing lymphedema are quite high. I'll be talking about those kinds of issues, and how to try to prevent that — any of the sarcomas, any of the tumor growths.

There's always an issue about weight. Years ago, they would always say, "You don't even have to worry about it. You are so thin. You will never develop lymphedema." We [have since found] ... that's [a] fallacy. What happens [is] it's not so much [what your] weight [is] ... going into your surgery, ... [it's more dependent on] the weight you gain after your surgery. The main reason why is ... the receptors. They're very tree-like and right underneath the skin. The other things that are right underneath our skin are fat molecules. When you gain weight, you don't usually get more fat molecules. Fat molecules grow. They're going to be much more aggressive than the actual capillaries for the lymphatic system. So what happens is [the fat molecules] push those little trees down further, not able to pick up as much fluid as before. So ... if you gain 15 pounds after your treatment, [it] probably is more detrimental than your actual weight going into it.

[Some risk factors are avoided with regular exercise, because it helps] avoid strain and weakening of the muscles. ... [If something] works with our lymphatic system, it works with our vascular system. ... The more you pump, the more you use your muscles, the more we increase

our blood flow, the more we increase the ... fluid that has to go out. So what happens — I don't know if anybody read the new article that came out in the [Philadelphia] Inquirer, the PAL study ... [read the newspaper article: http://www.philly.com/inquirer/home_top_stories/20090813_Study_changes_rules_on_breast-cancer_care.html or read the abstract at http://www.ncbi.nlm.nih.gov/pubmed/19171204?itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum&ordinalpos=2]. And it was wonderful [that this study was] ... done. I have a lot of patients who were in it, and I also worked on it. And what has been proven is that exercise is wonderful.

But it's how you do your exercises that matter. So it's a gradual increase. If you've never played tennis before, and you go out and you play seven hours worth of tennis; you have put so much vascular system into that [activity], and [so much] flow, that the system that's already a little bit depleted is not going to be able to take that fluid away. And that's why a lot of people [say], "Oh my goodness. I just came out with a very swollen arm." But if you do this very gradually, work on it 15 minutes at a time, the system works up with it. [In a weight-training program], you start with your half-pound weight, work to your pound weight, and [work up slowly and] gradually. So we find that exercise is very beneficial, but it has to be done on a gradual basis. ...

WOMAN:

Does it matter if you're ... water-exercising as opposed to regular [exercise]? Is there a difference in how your muscles react?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Actually, we love it more in the water for two reasons. One, because it's wonderful for the joints; you have a little bit of decrease in gravity. But, also, you have the pressure of the water. The more you put pressure onto that [vascular] system, it actually pushes down on those capillaries and makes them work harder. So we usually like that. The same thing, if you've ever gone into scuba diving, it's probably the best activity you could ever do; because you have all that wonderful, heavy, water-pressure. You'll never have any trouble with it. Later on, we're going to talk about the opposite — what happens when you fly — because it's less of a pressure, and what happens to the structures [is different]. But, actually, water is the best way you could ever do [exercise].

WOMAN:

[Inaudible] ... You're [talking about] causing muscle to be overloaded, or stressed. What if your lifestyle is very physically strenuous? You have your surgery, everything's fine. You do your chemo, your radiation. Can you go back to your strenuous lifestyle?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Yes.

WOMAN:

Or should you lighten up on it because you might be overworking those muscles?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

I think if you were extremely always-active before [your surgery], you should be fine. I would still probably go into it a tiny bit gradually. But I think you should be ... fine. I had a tennis-pro who was playing tennis prior to her surgery, [got] lymphedema, and went back to playing tennis. That's what she was used to. ... She went back to playing five hours a day. But that was her quality of [life] before. We might have worked in[to it] a little bit, start with one hour and then we'll go up to our five [hours]. And that's something you have to do. I really believe you have to get back into your living and lifestyle. ... You might have to do it a little bit differently, and a little bit smarter. But, definitely, there's no reason [to not go back] to [an active] level [if that's how you lived before]. [Editor's Note: Always check with your doctor before starting or restarting physical activity. Your healthcare team can help you design a routine that will get you safely back up to speed.]

WOMAN:

I started with yoga right after my treatment, and [inaudible] ... really wanted to get back more into my active lifestyle. [So I] joined the dragon-boat team ... in Philly.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Wonderful.

WOMAN:

... Wearing a [lymphedema] sleeve, I've only had one flare-up. I've actually lost an inch in diameter in my arm. And it's a breast cancer survivor team, so I think the article even addressed that. It's been really good, and the [teams are] all over the world.



LIVING BEYOND BREAST CANCER®

LBBC.ORG

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Yep. It's wonderful, if anyone wants to join [Editor's Note: Here are two in the Philadelphia area: <http://www.philadelphiaflyingphoenix.org/survivorTeam.php> and <http://www.hopeafloatusa.org> and a list of teams in the United States and in Canada: <http://www.wavesofhope.ca/dragon-boat-teams>]. . . . Actually, there are three breast cancer teams that are paddling. And we also have some with [other types of] cancer. So we don't want to ignore anybody else who has different kinds of cancer. They can also paddle [inaudible]. . . .

[Speaking simultaneously]

WOMAN:

Our [team] is only breast cancer.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Only breast cancer. We have some only breast cancer, but we have — The Wellness [Community of Philadelphia, <http://www.twcp.org>] has a couple others. Yes, they're doing wonderful. In fact, next week one of my coworkers is in the World [Championships]. So she's going over to Prague to paddle for the dragon boating. I did it for about four years. But it's wonderful. You're wearing a LymphedIVAS [sleeve] [<http://lymphedivas.com>], so that's wonderful. It's very stylish. That is great.

WOMAN:

What's the time-period to build up [your activity level and get] back to normal? . . . At my work, I have to lift dogs and heavy things, and [the work is a] strain. So I was wondering, with anything, lifting and stuff like that, [how do I] . . . gradually build up to normal?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

. . . I can get you some of the publications of what happened over at the PAL study. It was a shame, because initially they said that you can't lift anything over five pounds, which really limits everything in life. You couldn't even [lift] a gallon of milk [with that as a requirement]. . . . I think you also have to be smart as to switching over [to a higher weight-limit], and things of that sort; and use good body mechanics. . . .

. . . When you're actually . . . doing some training, you want some key points. Okay? You want to take a little measurement, maybe, at your

wrist, some mole or something that's always going to be there, maybe [in] three different areas. So you want to keep an eye on that. Usually what you do [is] you . . . begin very gradually. You also want to [add] aerobic-type of exercising, which is wonderful, compared to say lifting or spot exercising. So you want to do a mixture of [activities]. You want to always start first with a good stretching program, a little bit of aerobics, and then go into . . . [working] some specialized muscles. Always do it without any weights, [at first]. Then you really want to work with that for about two weeks, and then gradually [do the same exercises, adding] maybe a quarter to a half a pound of weight — you're going to be using [the new weight] for two-to-three weeks — and then gradually [work up to] a pound. So it really is a [very] gradual . . . program.

Once they were [graduating to heavier weights within] . . . three months, and they actually trained at the Y[MCA]. . . . Some [patients] were lifting up to . . . 125 pounds. So they really got them into a wonderful program. But you want to make sure you're always protected, wearing the compression [garments specifically intended for lymphedema]. If you already have lymphedema, you want to make sure you're protected and have your garments on. And, take your spot-measurements, so you know you're doing the right thing, being able to handle it. Okay?

In your [packet], later on when you [review] it, [there's] a wonderful booklet on lymphedema that [LBBC] put out [called *Guide to Understanding Lymphedema*; [<http://www.lbbc.org/data/media/LBBCunderstandlymphedema.pdf>]]. They'll talk about some of the things that also I'm going to be talking about [ways to reduce lymphedema risk]. . . . [which is referred to] on page I4. . . . But the main thing is you also want to [protect] . . . that area [from] . . . infect[ion], to [keep it very] . . . clean. Moisturizing is wonderful, because what happens [is] you get those little cracks [that can increase the risk of infection, and] that's really deadly. So, as much as you can, moisturize . . . the area that's already been radiated. It's going to be much drier, and you want to keep all of that [skin moist, so it can] . . . move [well].

Things we usually recommend: [use an] electric razor [to avoid] getting a razor cut . . . [avoid] insect bites. One of the . . . fastest sources of infection are your cuticles, because [they have] a wonderful blood-supply. And [sometimes] . . .

I get a little hangnail, and the first thing I do is put it in my mouth and cut it off. And it's probably the worst thing that I could do for it. So it doesn't mean you can't get your manicures. You just want to make sure they don't cut your cuticles. Push them back. When you get those hangnails, the best thing you can do is [apply] a little Neosporin or tri-antibiotic cream, and put a Band-Aid on it.

So you don't want to make yourself neurotic. You get your little cut, or you get a paper cut, or something like that sort — just be smart. Wash it, [put] a little Neosporin and a Band-Aid [on it]. And that's really taken care of. If you know that you already have lymphedema, we really recommend you keep a little first-aid pack . . . in your [purse], so you have a little tube of Neosporin, a few Band-Aids, alcohol pads or one of the [purifiers] — Purell-type [sanitizing products]. And you can . . . clean [any cuts] right away.

Some of things that have always been no-no's are [taking] blood-draws and IVs [on the side(s) of your body where you had breast surgery]. The IVs mostly were due to infections. Needles have become much better. The gauges have [become] much better. So we don't usually see as much infection as we used to from IVs. But we still ask [people with lymphedema], "If you have your choice, please [ask your healthcare providers to] pick the other arm. Don't aggravate that one." The blood pressure [cuff] . . . works as a tourniquet, and actually does damage to the capillaries. That's why we usually recommend [against taking pressure on the affected side(s) of your body]. People who [have] bilateral [lymphedema], blood pressure's very easily taken in the leg. You don't have to worry, and . . . your [vaccinations and other] shots [can also be done in the leg].

WOMAN:

[Inaudible] . . . That's what you say to people when you go in to . . . get your blood drawn.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

And [sometimes] they're going to fight you for that tooth and nail, because they don't want to do it [in the leg]. They won't do it. And then you have to pick the best of the worst, and it's horrible. Have them use the smallest gauge needle as possible, and just make sure it's clean. And that's about the only thing [you can do], because that's the only thing you're really guarding against, is the infection-[risk].



LIVING BEYOND BREAST CANCER®

L B B C . O R G

WOMAN:

What if you had a prophylactic mastectomy on one side, and didn't have any lymph nodes taken out at all.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

You're fine.

WOMAN:

So you can still get blood drawn, and your blood pressure taken on the other [arm]?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Correct. You have no [increased] risk [of infection] whatsoever, which is good. We worry about the sunburn mostly right now, just because it's 95 degrees. But it's also a wonderful source of increasing fluids. [Inaudible] . . . As soon as you get a burn, the fluid just comes to that area. So what we're worried about is the fluid comes to that area, and . . . can't get away. Then you have a chance of the blistering, and a chance of infections and poisoning. . . . I'm not going [to tell you to] not go out in the sun. Everyone's going to go out in the sun. Just be smart. Put your [factor] 30-to-50 [sunscreen] on, or wear a light garment if you don't feel like putting protection on. So it's certainly not that you don't want to go out. It's just you have to be smart.

WOMAN:

Is that a "forever" thing? You know, once you've had radiation . . . as far as going out in the sun, be sure you're covered, and yadda, yadda. It's 95 degrees, and I don't think I want to have a long-sleeved shirt on. I'd rather be in the shade or something. I just want to know the length of time that you have to be so careful. I'm not suffering from lymphedema yet, not that I want to. But I want to know [if] that skin area [is] sensitive now. . . .

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Yes.

WOMAN:

And don't be in the sun for —

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Well, you can be in the sun. You just have to be smart. Put your protection on — your [factor] 15. And I think as you build up, regular sun lotion will [be enough protection]. . . . Of course, coming

from Fox Chase, we don't believe in any kind of tanning or anything else. [Laughter] So I have to promote that [notion of not sunbathing], or I'll probably get fired.

But you really want to be smart. You really want to enjoy the beach, you want to go swimming, and you want to [enjoy all of those activities]. But you just [need] to know how to be protected. . . . But because of that area, and because of change in the cellular structure, you will always have that tendency to [ward] radiation.

WOMAN:

Thank you.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Mm-hmm. Very typical things — and you also don't want to have a little tourniquet-effect with rings and bracelets. And that's just smart, that if you feel something's getting tight, just remove it.

Lymphedema will typically occur between the first and third year after treatment. You probably will start seeing it more often between six months and one year. . . . About 60 percent of people who are going to develop lymphedema will probably [develop it] within that [time-span]. The [remaining] one-third probably will be within the first three years. . . . And it's a very small percentage that will actually get it after that period.

It's sometimes very subtle. Sometime people say, "I went to bed, and all of a sudden I woke up and there it [was]." Other people — you really can't see it, and all they'll talk about is changes of sensation. All of a sudden, [an extremity will] get heavy. "I get a tightness." And those are all signs. I'll get into that a little bit later. We call that stage 0, where you actually can't see a difference, but you're already getting the changes. It's like everything else: the sooner [you get treatment], the better. If you can get to have that treated and have that looked at, [it will be] easier to deal with. So you're not going crazy when you say, "Oh my goodness. This arm just feels a little bit heavier. This breast is just a little bit heavier," things of that sort. It's sometimes the very precursor of what we're doing with lymphedema.

We always have trouble with diagnosing [lymphedema]. It's becoming much more popular [as an area of medical study] right now. Actually, lymphedema therapy training only began in the United States about 15 years ago. It was really well-known in Europe. It originally started in France during World War I. By World War II, it was taught in Germany. So most of the training now does

occur in Germany. [Lymphedema-therapy training] finally came over to the United States about 15 years ago. So it's relatively new, what we know here, compared to what's being done in Europe. I had a chance, luckily, to go over to Europe about a year and a half ago, and be trained . . . in the Földi Klinik, to see what they were actually doing. It was very similar [to what is going on in the United States], so it made me feel much better as to what was going on here.

So, we're actually doing more education for doctors now. Med schools are finally learning about the lymphatic system, and dealing more and more with lymphedema. So, hopefully, a lot of times we're educating the physicians.

WOMAN:

If your lymphedema is out of control, what are your chances of getting your limb or your arm back to normal? . . .

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

It does. The trouble is we can't cure lymphedema. And that's where we get into that whole emotional effect. You've gone through this process with cancer, and you finally have recovery and everything is wonderful, and now you're dealing with the system of lymphedema that's not curable. We can't put back the nodes, or the system, [or repair the changes that triggered the lymphedema]. We can get it pretty much close to size.

The trouble is you have to maintain it. And that's what we teach you. Okay? And I can go on, and I'll show you different kinds of garments and everything.

WOMAN:

[Inaudible]

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

So you have it, yeah. And it's a fight. We were just talking earlier. This type of weather, this humidity, is the worst weather [for lymphedema]. . . . It just makes everything blow up. It is tough. . . . And it's so ironic, because [the hot, humid weather is] when you need to wear your garments the most. And it's so hot, and it's so uncomfortable.

WOMAN:

. . . It is. I have it all [inaudible]. . . . I'm wearing the different ones. And different therapists fight against each other. What is the right way? Like there are two different ways. Some believe in the pump. Some do not believe in the pump.



LIVING BEYOND BREAST CANCER®

L B B C . O R G

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Correct.

WOMAN:

Which way do we go?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Well, except [doctors are warming to some therapies, because new, more effective products are] ... emerging. I was a non-pumper. [Laughter] I was a CDT [complete decongestive therapy, a treatment that combines compression bandages, skin care and exercise to promote lymphatic drainage]. I was a non-pumper. But there have been two new pumps — one is a Flexitouch — that we do believe in. [That device] actually pumps the entire [quadrant] — our [concern with pumps in the past was that they] ... didn't pump the entire quadrant. So [this device, the Flexitouch] ... pumps the entire quadrant and into the arm, and we find it very effective. So we are branching over. And there are some pumps that are very good out there. ...

WOMAN:

I'm [here today] with this lady right here in front of me, who's also a neighbor. [Laughter] ... Two things: Why [is the United States seemingly the last to try medical therapies that are used in other countries]? ... And the other thing is ... I've been suffering — it's almost four years — with this. And I know I'm over my normal weight, way over. I don't know if that has something to do with the fact that when I am getting physical therapy, it gets to a certain point and then I have a flare-up. This has been my frustration, is I get therapy, and either I get a flare-up, or I go to so many visits and the insurance company has to say, "Okay, you've had this many visits. You have to reevaluate."

And that happened to me recently. I had 17 days between the reevaluation and them okaying me [to stay in therapy]. And then I had a flare-up, so the doctor said, "Don't go to therapy." Well, then I [recovered and] went back for my first visit, and [my doctor] had to submit [the request for therapy to the insurance company], and I'm still waiting [for the approval]. How can they justify this? Is there some kind of help out there, [so that I can get] ... consistent therapy instead of [enduring all of these] interruption[s]?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

I think there is. It is hard. You have to be your own advocate, as you've found. But you have to go back to the Women's Act, the [Women's Health and Cancer Rights Act, <http://www.dol.gov/dol/topic/health-plans/womens.htm>] that says you're allowed to have any kind of treatment due to this disease process, including lymphedema.

WOMAN:

... Repeat that again.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

It's the Women's [Health and Cancer Rights] Act. I can download it, and I can give you copies. I didn't bring any today. By law, you ... must be treated for this kind of disability.

WOMAN:

So the reevaluations that they require, and the time in between that you're not taken care of, that could possibly go away?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Possibly. I don't know what's going to be happening with the new healthcare laws. But hopefully it won't.

The biggest difference, when you were talking about Europe, was not so much how it's being treated. Unfortunately, they don't believe in the pump and they go for very basic [treatments]. But they believe in holidays, so that once a year for four weeks you would go into the clinic.

WOMAN:

Oh, I'd love it. [Laughter]

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

And you'd be treated for four weeks every year, and that's your holiday. That's covered by the government. That's how it is in Germany. But that's what is being done over there, and that's how they look at it, for needing it. But we do have a long way to go with the insurance compan[ies]. ... Initially, when I first started 12 years ago, I had to educate almost everybody in the insurance field. They had no idea what I was talking about [regarding lymphedema]. So we have progressed, but I don't know if it's for better or for worse.

ELYSE SPATZ CAPLAN, MA:

We all have to advocate for ourselves and for our health care, and that means we've got to really press our physicians and our health providers — [the people that act as our] ... primary care providers — as it relates to our breast cancer treatment. And if it's an appeal letter, or some letter of support and medical necessity that needs to be written — and I'm sure you've tried it.

WOMAN:

Been there.

[Speaking simultaneously]

ELYSE SPATZ CAPLAN, MA:

I understand.

WOMAN:

— on the healthcare professionals.

ELYSE SPATZ CAPLAN, MA:

I'm not just talking to you. I'm just making this as a general comment. I think we're all in agreement in this room that this is a really challenging aspect of our health care. And in the United States, it's almost unconscionable to think that women and men with lymphedema have to struggle and fight so hard to get the medical care that they need. I was diagnosed 18 years ago. I get it. I completely understand. Eighteen years ago, they weren't even talking about lymphedema. It was just "Be happy that we took care of you. Be happy you're okay."

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

That's right. "It won't kill you, so don't worry."

ELYSE SPATZ CAPLAN, MA:

It's a whole different way of life. And I'm just bringing that up to say that I think we're all supportive, and in agreement, that there are definitely defects in the way physical therapy [is] covered, and how many visits you are able to get before you [have to be] reevaluated. This disruption in treatment, for people concerned about lymphedema, has a profound impact. So we're supportive of you and everyone else who's struggling. And I think as the programs and partnerships director at Living Beyond Breast Cancer, I just want to say we've got to keep pressing the doctors who are caring for us. To stand tall and do what is necessary as it relates to breast cancer care. I appreciate your frustration. And I'm sorry about that.

I'm going to move onto this question. If we have time at the end, we'll circle back.



WOMAN:

It's not a question. It was just [a] suggestion, perhaps — is one of your next seminars about navigating the system? I [wanted to know] if [LBBC offers] assistance [on how to] navigate the system [<http://www.lbbc.org/data/transcript-file/LBBCnavigatinghealthcare10.pdf>].

ELYSE SPATZ CAPLAN, MA:

Thank you. We have a lot of different programs throughout the year, but absolutely. We've got so many topics, and I know Kathleen mentioned our November 14 conference at the Pennsylvania Convention Center, at the beginning of our program. We actually have a workshop [featuring] Dr. Katie Schmitz from Penn. The principal investigator [for the] PAL study [[http://www.ncbi.nlm.nih.gov/pubmed/19171204?ordinalpos=8&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.SmartSearch&linkpos=I&log\\$=citationsensor](http://www.ncbi.nlm.nih.gov/pubmed/19171204?ordinalpos=8&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.SmartSearch&linkpos=I&log$=citationsensor)] is going to be doing a workshop that's going to address the research that she's conducted. So I would say [to] keep your eye out for the brochure, save the date, Saturday, November 14. You really will have an opportunity to learn more about that. So thank you for that reminder.

I'm not sure if you have more slides you want to get through and then come back to questions, or how you'd like to work.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

That would be—yeah, so we can go through a little bit.

Some of the things we actually do evaluate are going to be sensation, the skin quality and condition, measuring. And I don't know, many of you who have gone through the part about lymphedema and everything, as a therapist, one of the things we look at is just with our eyes. The next thing we do is we have to feel. And that tells us everything about where you are, your stage and everything else. So we're not being touchy-feely on purpose, but that gives us the information as to what's going on with your extremity. And they can range from anything. We have people with severe swelling with no pain, with no swelling with severe pain. It goes the gamut as to what the individual is.

... One of the things I wanted to stress today is [this]: Sometimes we get very hung up of only looking at the extremity — only the arm, only the leg. ... But lymphedema comes in a quadrant. It won't cross over. So people first think, "My

goodness. I have it in this arm; I might get it over here." And luckily we're divided by what we call watersheds. So it's not going to cross over. But it can be in the whole quadrant. So, a lot of times, what we only look at is the arm, [passing over] ... the breast, the trunk and the back. So a lot of the patients come in, and they don't really have a lymphedema in their arm. Where it is stemming from, a lot of times, is into the breast area — into this area here under the axillary — into the trunk, and into the back. So a lot of times, they come and they say, "I just don't know why. I just feel like there's a tennis ball, there's a golf ball underneath my arm." And those are the other things we have to look at. It's not just the arm. But you also want to check out the whole quadrant.

And these are some of the pictures. You can actually see some of the difference — of the imprint, of what's happening with the bra. But it's also all in through this quadrant. So we're not only treating here, but you also have to treat the whole individual. And here everyone looks at, "My goodness. Look what happened with the radiation damage. Look at this arm." But also, look what's happening to the whole body. So you just can't treat one thing. You have to treat everything to make it effective, because we know the real damage is occurring into here. So unless we can get this open and moving, it has nowhere else to drain.

And a lot of times they'll say — and I had this one individual, she was around 55 and she was wonderful. But she came in, and, and she said, "Look at this. I finally have a perky breast." [Laughter] And I said, "At 55 we don't have perky breasts anymore. It's perky because it's filled with fluid. If you had a lumpectomy, it should be smaller than the other breast." And so those are [what] we're looking at. We don't want perky breasts anymore. ...

We always went with stage I, II and III. The last year we added stage 0, which I talked a little bit about before. And that [stage just means there are] ... no visual signs of edema, but [there is a] change of sensation. Either pain, fullness, tight[ness], things of that sort. ... If you're dealing with numbness and tingling from your nerve damage, or things like that, that's something totally different. That's coming from nerve[s], and [is] not dealing with lymphedema.

Stage I is reversible or temporary. And that's usually what we see within the first one to three months after surgery. All of a sudden you might get a little bit of flare-up. But once the systems

have opened up and cleared, it usually dissipates. At those times, you don't usually have it recurring. Stage II is usually the stage [when] I see individuals coming in with [for] therapy. At that point, it's not reversible anymore, and the protein and the density in the hand and the arm or the breast has changed to a very — like a heaviness or a thickening. That's that protein [enrichment], and the change in the connective tissues. Stage III, the elephantiasis, [is] rarely ever, ever seen in the upper extremity. Those are the ones you usually see in the very lower extremities. ... But we usually don't see that with upper extremity. And that's what we were talking about, just the change of things.

Yes.

WOMAN:

A quick question: Did you say stage I was post-op, basically —

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Usually, you see — yeah.
[Speaking simultaneously]

WOMAN:

And the period after that, then it's pretty much irreversible?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Irreversible, or it doesn't change. If you have something that's going to be lasting more than three months, usually at this point it usually crosses over to a stage II.

Temporary is what we talked about. This can occur in approximately one [in] 20 women; that you're going to see, after your surgery, some swelling and things of that sort. But it's going to be actually dissipated. The irreversible, and that's really basically a change in texture [of the skin].

And this is the controversy. And you probably could — some of the women here could tell us a little bit about their therapy and on [their experiences] doing it. I've been trained to ... do ... complete decongestive therapy. It's usually [in] the four areas that we're looking at. One is going to be skin care, mainly because we want to prevent the infections and keep it as fluid as possible. Manual lymph drainage, which is a massage type of effect — it's very light, it's very soothing. What you're basically doing is not moving your hand around — the hand stays stable. You're moving [the] skin. And we know by moving the skin, we stimulate the receptors to be able to take more



LIVING BEYOND BREAST CANCER®

L B B C . O R G

fluid. And that's the whole purpose of the massage.

Compression bandaging: We know by adding compression into the area, ... [the fluid drained ... with] massage [is kept from getting] ... back in [the lymphatic system]. But also, by putting pressure on [the area], it makes the receptors work three to four times [harder than] ... usual. And it works as a little compression against the muscles. So you have your muscles pushing against the bandages, which actually pump out the fluid. So that's why compression, either through bandaging or through garments, is very effective. And then, of course, phase II [of the treatment] is when you're discharged, and that's [when] you practice [the treatment you received in the hospital] at home. ... I talk about bandaging and compression. Usually the [bandages used for compression to treat lymphedema] look like an Ace bandage, but they're a very low-stretch kind of thing. So they are much more comfortable [than the Ace bandage]. So don't use an Ace bandage on your arm.

That's just a little thing about the pump. Years ago, that's all they had. Fifteen years ago, ten years ago, you had the pneumatic pump, and that was given. What they found, and what the problem with it is [that] you would pump and you would put a sleeve on. And it's a nice little pressure. It start[ed] at your fingers and it work[ed] all the way up. But it stopped here. And so what happened was a lot of times you would get a very fibrotic ridge. So they would say, "Oh, my goodness. My pump was wonderful, but after a year or two it stopped working." And what happens, it brought up the fibrotic area and it didn't clear it. Or, what happens is it would clear it up to here, [and] it couldn't pass it any longer. You take off the pump, and within an hour or so [the fluid] would refill. Now they're finding if they do the whole area and clear the whole quadrant, it's been much more effective. So we're not poo-pooing pumps like we used to.

And some of these are the goals of treatment, as to what we're looking for.

Some contraindications: Of course, if you have infections, we usually ask to wait for at least three to five days [before using a pump] so the antibiotics [can] tak[e] effect. Once we know the antibiotic is working, usually after 72 hours, we can go back to treatments. Some physicians are very strong on [that waiting period], and they believe that you cannot use [the pump] at all until ... [the] full course of antibiotics [is] finished. We have other physicians who are the opposite: There's

nothing you can do about it; they're on antibiotics; start immediately. So we have one end to [either side of the debate]. But, usually a hospital follows the 72-hour rule. Of course, if you have any cardiac edema or congestive heart failure, the last thing we want to do is push any fluid into that area, and so we always have to watch about that.

We talked a little bit about the psychological impact [of lymphedema], because, [as] we said, this is a lifelong problem at this point, and it can be very frustrating. ... You get into the areas where Medicare doesn't cover garment costs, and that even gets into another huge issue. We have a lot of bills right now going through, trying to pass and trying to change things [legally]. And it's a fight — it's a long battle.

One of the things I get a lot of questions about [laughter] — I don't know if you can see it. She said her arm is going to blow up, and of course now she's taken [it] out. And a lot of doctors will write a script. "Oh, fit her. She's going on the airplane. Fit her for a garment." That has been a [point] of contention for therapists. You'll find as [many therapists for it] as ... against it. I can only tell you my rule, and it's only me, so take it for what it's worth. Usually if you have no signs of lymphedema — you've never had any kind of swelling, you've never had any kind of tightness, you've never had any problems with it — I sometimes [think] you can do more damage from wearing an ill-fitting garment than you can do from not wearing anything. The whole purpose of that is the barometric pressure changes. Just as the water in the deep seas adds pressure to the arm, now you have the opposite. The higher you go up [in an airplane], you have less air pressure, less pressure going into your arm, and so that's why everything expands. So a lot of people [cite these] typical [pieces of advice]: Don't take off your shoes when you're flying, because you won't get your shoes back on. Everything swells. So, of course, that arm is also going to have a tendency to swell, and you have less ability to actually get the fluid out. So that's the whole purpose of it.

What we find out a lot of times, it's not so much the [plane] taking off, but it's the landing [that leads to swelling]. ... So we always [suggest that] if you're going to wear your garment, if you're going to be bandaged, make sure you keep it on at least two to three hours after [the plane] lands. ... It's the equalization of getting out [of that low-pressure environment] that's going to create the problem. ...

Make sure [your garment is] fitted. And if you've [had a weight change], either gaining weight or losing weight, make sure the garments still fit you. The worse damage is going to be done from [an] ill-fitted [garment]. It's almost starting as a tourniquet. That's all you need once you get out there. So you really want to be careful with it.

If you have any signs of lymphedema, even if it was a year ago or two years ago, I would recommend getting a very light, class-one garment for flying, because [a higher compression class] ... might have a tendency to bring out lymphedema again. I've had patients [who] ... have developed their lymphedema after a flight. I've had some [with] ... no [challenges] ... whatsoever, [who] fly perfectly. ...

Make sure you're also aware that you will be stopped [by airport security] when you [wear your garments]. A lot of times they make you take off your garment. A lot of times they make sure you [examine] it. I don't know what they think you carry underneath that skintight thing [laughter], but usually everybody —

WOMAN:

Drugs.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

It must be drugs, because it can't be a gun. [Speaking simultaneously]

WOMAN:

That's what she —

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

[The airport security guard] said when she [asked you to remove your lymphedema sleeve]? ... [Drugs were] what she was looking for?

WOMAN:

[Yes. She said] ... "I'm looking," and [the other guard] said something ... [about drugs].

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Was it really? Because I couldn't figure what else you could put — I mean, it's skintight. What are you going to have?

WOMAN:

... The thing's real tight. You couldn't put any [drugs] in here.



LIVING BEYOND BREAST CANCER®

L B B C C . O R G

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

So I have a lot of patients, they carry their arm-sleeve. When they get into the opposite side, or after they get on the plane, they put it on, because they get tired of being stopped. I can't tell you what to do, but you want to make sure you definitely have it [in place] before you land, and [have it] on at that time. But you will usually be questioned [by airport security].

WOMAN:

Yeah, [the airport security interaction happened when I was flying] ... here.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Was it really? ... You must have looked very shifty. [Laughter] I'm telling you. But everybody gets stopped. I don't think I've had a patient who hasn't gotten —

WOMAN:

That was the first time [it had ever happened to me] ...

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

... We talked about this. The other thing is you want to make sure — it's not only the air-pressure when you're traveling, but you have that tendency to pick up that suitcase and carry it [around, and it may be very heavy]. ...

Really stay hydrated. It's one of the best things you can do. You really want to drink that water. You really want to get up and move. You might look very silly, but you can go right up and down, do little pumps up and down you're [arm]. ...

WOMAN:

But they also give you a lot of extra care when [you sit in first class]. ...

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

That's right. Ask for that first class [treatment]. [Laughter] All they can say is "no." That's right. You [usually] have to pay for that [first class treatment].

WOMAN:

They'll take your bag [for you so you don't have to load it into overhead storage yourself].

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Exactly. See? You take your pluses where you can get them. So, it's those things you also want

to pay attention to, [that will lessen the impact of lymphedema].

I don't know if anybody has ever had trouble with what we call cording or axillary web syndrome. That's a biggie. And [for] anybody who hasn't had it, it's a very severe tightness. It usually [occurs] when you bring your arm out to the side. Not so much up, but it's more out to the side. It's a beautiful tendon that pops. It is very painful, and will limit your range-of-motion. [Oftentimes, people get physical therapy to loosen it after cording occurs]. Sometimes [when it's corrected] you actually hear a pop. [But] sometimes they just [correct it with] ... stretching.

One of the things you really want to do if you've ever had this — or to prevent it — is you really want to stretch. I can't stress that enough. Th[e condition] will come back if you don't keep it open.

[Speaking simultaneously]

WOMAN:

[Inaudible]

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Yes, because you've gotten tight, and [the arm] automatically wants to pull in. And so if you can keep this area open — this is the area of injury. It might be swollen down here, but this is the area that's not doing anything. So one of the best things you can do for yourself is [to] do that stretch, if it's going back to climbing a wall and hanging there for five minutes. A stretch is low. It shouldn't be painful, and it should be prolonged.

... So the best things you can do for yourself are some very simple exercises, that stretch. If you do it to the wall — I don't want to do it here — if you're already up there and you say, "Oh, this is so easy," make sure where you're standing is the same, and then you're going to gently lean into it, until you can feel that stress, and hold it there. A minute is a long time. Two minutes and three minutes is a very long time. Do it when you're watching TV, something like that to take your mind off of it. Then, when you do it this way, turn sideways and do it horizontal, and do your lean. You really want to keep it open. You want to keep this area really open. So, I don't know, some of the beginning exercises were nice and open. You want to go back to them.

One of the best things you can do is the breast stroke, just in the air. Go out, flip and push. You'll feel it all through here, and you're going to keep

all that area really opened wide. Another really simple, easy [exercise] is keeping the shoulder intact. Pretend you're loosening a light bulb, about five rotations. Okay? It's great. It's great for that rotator cuff, to keep it open.

WOMAN:

I have a torn rotator cuff. That's why I wear

[Speaking simultaneously]

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

[Inaudible]

WOMAN:

... exercise for that. That's what they use.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

That's what they use, yeah, so not too far off. [Laughter] You're doing everything [you need to do], but it's so important ... to keep that area open. You want that flow to keep going. That's basically what we were talking about.

These are some studies that I just put in ... seeing the severity of the lymph nodes. Some of the statistics are what increases — a lot of times they feel that if you had ten or more nodes [removed], the chance of having lymphedema increases. Some of the other studies, they feel it's purely genetic, because we have somebody who's had 30 nodes [taken] out, radiated to heck, and [that person has] never had lymphedema in [her] life. We have somebody who had a sentinel node dissection, had two nodes [removed], no radiation, and comes down with lymphedema. Genetically, they really had a very marginal system to begin with. All they needed was one thing that tipped the scale, and they [end up with lymphedema]. A lot of times, you'll see that genetically through the family. "Aunt Irma always had that large foot. We don't know why." [Laughter] Her systems weren't working too well.

One of the studies they're doing now with drugs — because that was our issue, is what some of the newest research [is]. ... And what they're trying to do through the drug companies, is they're developing something to try to stimulate the growth of the capillaries in the lymphatic system, so [those capillaries] can be built up. They actually have done that in some of the studies [with] mice and rat[s]. They have not tried that with the humans yet. But, to me, that's very exciting, because I think that's where it has to go.



LIVING BEYOND BREAST CANCER

LBBC.ORG

If we can build up enough of those capillaries that have been removed or damaged, we can actually get the flow back again. So those are some of the studies and some of the work that's actually being done nowadays into the actual pharmaceutical end of it.

There are some surgeries that they're doing up in Mass[achusetts] General [Hospital]. That seems to be a little bit more successful. But we don't see it, so far, too much past that area. So I'd like to see more studies — ... with trying [to repair] lymphatic systems, actually through surgery. ...

And that's just a little bit of our peripheral. I don't know him personally. ...

ELYSE SPATZ CAPLAN, MA:

I'd just like to jump in. Excuse me for one second. I think what I'd like to do is thank you for your time and your expertise. I think the show-and-tell is a great way for us to wrap up. But I also wanted to more formally say we can move into questions and answers. We really like to capture your questions on the microphone, so that people who listen to this after tonight [can hear] ... the question, and the answer, [so that it] makes sense to them.

So, thank you for your attention. Thank you for an amazing presentation. You touched on so many important areas. [Applause]

And as I said, [at] our November 14 conference, you can learn even more about some research being done on weight-training, and exercising, and physical fitness as it impacts lymphedema, [as well as] so much more. We've got lots of workshops and great keynote presentations [planned].

So, with that, [please] ... raise your hands so that we can go around [the room]. If you had any concluding remarks, you can certainly feel free to jump in.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

I'm going to wrap it up just in case — I know some people might have to leave [before the program is over]. ... I want to thank you so much [for coming today]. A lot of it is just an education. [We're just bringing people up to speed on recent information and upcoming research]. Please don't lose your drive, and [keep striving to better-understand] ... what needs to be done [in your situation]. [Another goal we have today is to] bring awareness of [lymphedema], that it can actually

go into the different quadrants, and [that healthcare providers need to] ... check the rest of your body, not only just the hands and the arms. ... It can also go into the chest wall, and things of that sort. It's a little pet peeve of mine, that I teach people whole body, and not just one area. ...

It is a passion of mine. I do believe we are continuing to make strides, and with that a lot of push into development [of new treatments and discoveries — that's what] really needs to be done, [as well as] ... education [for lymphedema sufferers] and [helping them to consistently incorporate their treatment at home]. Thank you. [Applause]

WOMAN:

Is it ever too late to start therapy?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Oh, never, never.

WOMAN:

I've had lymphedema for 15 years. [I] did therapy in the beginning, and then for various reasons — now my kids call this my Popeye arm — but it's hard to get clothes to fit. [That's] one of the hardest things.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

It is. Some of the department stores are realizing that. Nordstrom's will put [appropriate clothes], with bras and things like that ... [inaudible]. ... They also will sell shoes different sizes for people who have [edema] in the lower extremities, because that becomes a huge problem. You get very creative with dressing. And [dressing with a lymphedema condition] is a whole area [of knowledge]. But we are seeing some changes that are occurring, [more organizations becoming aware] as to what is happening.

But it's never too late. There are also new ideas on how to handle [lymphedema] with different kinds of [foam padding] ... and things of that sort. [Things] that we didn't have before, that we're using now for treatments. So we are getting educated and trained along the way. ...

KATHLEEN KELLY:

... Wilma? We have a question back here, if you don't mind.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Sure.

WOMAN:

Hi. When I moisturize, and I do that every night because I bandage every night ... I was always told not to use anything that had a fragrance in it. Why is that?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Right. And we still say that, [to use] a non-fragrance [moisturizer], because it changes pH level. Once you add a fragrance, it changes the pH level, and you have a little bit more chance of getting an infection. We like the base-level of the pH to be more flat. That's why we usually recommend the non-fragrant.

WOMAN:

I'm also a certified massage therapist.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Good.

WOMAN:

I'm refreshing my courses, and we're starting to do trades [in class], where we practice [massage] on each other. I'm just nervous. Is there anything for me to avoid? Is there any contraindication on me, when I get worked on? And, is there anything for me to be concerned [about] when I work on someone else, [when doing] deep tissue and anything like that?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Right, because a lot of my patients, they can have massage. And unless the massage therapist knows about the lymphatic system, or the manual lymph drainage massage, I usually say [the massage therapist should] stay away from the [affected] quadrant. The rest of the body is wonderful, but I do worry about that deep massage. [Deep tissue massage can] ... do damage to capillaries, and that's the only thing I worry about.

WOMAN:

I guess [my question is related to] ... her question, was the massage. What about chiropractic? [Are there any contraindications with chiropractic work?]

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Usually that's a manipulation, and sometimes it can be very, very good ... if they know what they're dealing with. Usually, if you're dealing with a joint or manipulation, it's going to be a little bit



different than what we're dealing with, with the lymphatic system. But I think you just have to be smart. [Editor's Note: Ask your healthcare team for a referral to a massage therapist or chiropractor who has experience with people with lymphedema.]

WOMAN:

Where can I find a therapist? I just got started. I don't know where to begin.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

... A lot of times it can [involve] going back to your hospital, or going back to your physician. There is a Web site called LANA, L-A-N-A. It's the Lymph[ology] Association of North America [http://www.clt-lana.org]. What's listed there are the therapists that [the organization has] certified. ... We had to have so many hours of training, and then we had to sit for an examination. [You choose a therapist from that list, and] at least you have qualified [therapists], because anybody who's taken a three-hour course can call themselves a lymphedema therapist. ... So that's the way be basically got [listed on that site]. ... If you go on th[is] Web site, it [lists therapists] ... according to the states, and it has all the therapists in your states that have been certified. ...

WOMAN:

Are you aware of any current recommendations for a woman who's having surgery? Let's say she's having a mastectomy with the sentinel lymph node [biopsy]. I've heard that people are getting [their arms] measured in recovery. Is that a recommendation? Is there a standard for that or not?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

There's not [a national standard of measurement]. Even in our hospital, we're trying to make [measurement] a standard [for our physicians]. We have not achieved that yet. Some of the hospitals are a little bit more advanced. What they do is ... pre-body measurements, so you know where to stand for [later on, in case things change].

One of the newest studies that was done at NIH [the National Institute of Health], and down at Bethesda Naval Institute, [involved] measuring individuals prior to surgery, and then every three months [post-surgery. If a patient showed a] ... change of 3 percent, [an] increase, they [were]

automatically started [on] compression therapy. And what they found was it was a very typical amount. They still had 20 to 25 percent of the women increasing to those 3 percent. They were given the garments, [and advised to] wear the arm-sleeve and glove for one month, then remove it [and] only use it as necessary. [The result was that their condition] never developed into lymphedema. They were actually [able] to reverse [the process].

What we find is ... the classification now is [a change of] 5 percent [in the measurement before and after surgery]. ... What it's trying to do is pick it up in a very early stage, and [treat it]. So that's one of the newest studies that has been out, and will be published in the next couple of months [http://www.ncbi.nlm.nih.gov/pubmed/18428212].

WOMAN:

[Inaudible] ... occupational therapist that they would visit every three months?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Usually it's done at different places, at different things. It's also being done now in General Mass, they're doing a lot of work. The radiology department is the one that measures them. Bethesda, Maryland, it was the physical therapy department that measured them. In Texas, it was the surgeon himself. The surgery department actually measured them. So each different department of each facility picked who was going to be the keeper of the measurements. Then, once it did, they sent it over to the therapist. So it was the different facilities as to where it was going to be done.

WOMAN:

Just a quick question: The lymphedema that I have, I find that at the end of the day my ankle is swollen. But when I wake up in the morning, it's normal. Obviously that's a good thing.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Yes, because you still have a reversible stage. It means it dissipates at night with elevation, and unfortunately with gravity it just fills. That's why they recommend having some kind of compression, even support-hose and things of that sort.

WOMAN:

I do have a stocking to use. But in the beginning, I was wrapped. They did wrap me, and

they taught me the massaging. But I massaged my entire body. They feel as though you should work —

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Well, we usually open up the nodes in the different areas to say, "Hey, come on. Help us out. Take a little bit up here." ... In reality ... the lymph node that's down here is certainly not going to get up there. But we like to think it does, so — [Laughter] It can't hurt.

And what happens is some of the best things you could actually do is: Everything drains into our thoracic duct.

WOMAN:

Yes.

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Okay. So it everything comes up in here, except for the one over here, comes right into it. It goes up to our thoracic duct into our aortic arch, around the [cardio]vascular ... system and basically out into the kidneys. One of the best things you can do is diaphragmatic breathing, where your yoga comes in, because what happens is [that] by doing diaphragmatic breathing, which is meaning when you inhale the diaphragm opens, [when you] exhale it decreases, it stimulates the thoracic duct, and it works as a vacuum. So it pulls all that wonderful fluid that we want.

WOMAN:

So the massaging should be done every day ... [inaudible]?

WILMA MORGAN-HAZELWOOD, OTR/L, CLT-LANA:

Actually, we usually tell people two or three times a week. If they want to do it every day, that's wonderful.

WOMAN:

Two things: Do you advocate hanging your arm upside — straight up and down? I had that [done] to me in the hospital when I had cellulitis. Also, the last time I was in the hospital, it was last December, I noticed — it was just like a light bulb went off — I was in a different hospital, and I went in through the ER [emergency room]. They put me in a room, and they insisted I had to stay at least 72 hours, because the arm was really bad. ... I just put my arm on a pillow, just for the fact, I guess, that I was on the IV antibiotic, [and] my arm [swelling] actually went down on its own.



But what do you think about this hanging? Right now, I have terrible pain. I was told I have a tendonitis. I just can't hang it. But I'm also afraid of the water leaving, but whatever's left behind [is] going to stay there if you just hang it up in the air. I don't know. What is your opinion?

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Yeah. Gravity assists us. So, having it hanging ... [is] still hard. You have to worry about your other joints, and what else is happening with your arm. So, so-much elevation is all you need, at a basically higher-than-the-heart level.

We also find, if you're compressed, if you're wearing your garment, or if you're wrapped, elevation does not help [at all]. Usually, we say if you're wrapped, or if you have any kind of compression, elevation is basically not necessary. It won't assist one way or the other. ... So ... if you do it, have it raised. [And getting into] ... a comfortable position has usually been beneficial.

WOMAN:

But as far as the cellulitis with the antibiotic, I can't understand why it just went down. It was so much better on its own, without even being touched. Is [there] that much goop in there ... [inaudible]. [Laughter]

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Yeah. It's like a swamp, yeah. It's goopy.

WOMAN:

Just let me understand something you talked about earlier with bilateral sleeves and flying. If you've had a double mastectomy, but just the radiation on one side, you don't think it's necessary to wear bilateral sleeves, like on your good side?

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Did you have axillary node dissection on the good side?

WOMAN:

No. But you said there's —

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Did you have sentinel node biopsy? [Speaking simultaneously]

WOMAN:

On the one side, no.

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

If you haven't had any node dissection and no radiation, the chances of lymphedema is no greater than anybody else.

WOMAN:

Just because of what was classified as extensive surgery and scooping out our breast tissue, etcetera, etcetera, that does not —

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Correct.

WOMAN:

Okay.

ELYSE SPATZ CAPLAN, MA:

That would be a simple mastectomy.

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

It would be a simple mastectomy.

ELYSE SPATZ CAPLAN, MA:

A simple mastectomy, meaning the breast has been removed but no lymph nodes have been surgically affected. It doesn't put you at the same risk [for lymphedema] as someone who has a sentinel lymph node biopsy or an axillary lymph node dissection.

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Right.

WOMAN:

Even if there have been multiple surgeries on that side.

ELYSE SPATZ CAPLAN, MA:

Correct.

WOMAN:

Okay.

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Because your lymph system should be still intact.

WOMAN:

... But can you wear antiperspirant?

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Yes. I mean, some people get into crystals and some people — I guess I'm a bad person to ask about that. But I'm a therapist. I'm usually in there. So I usually say "thank you" if you do. [Laughter]

And that's, a lot of times, up to your radiologist. Your radiologist will usually tell you what you are allowed to use, and what they recommend in your positions.

ELYSE SPATZ CAPLAN, MA:

Not before a mammogram, right? They always tell you no antiperspirant, no deodorant before you get a mammogram.

Well, I think everybody has asked a lot of really important and good questions. Clearly, at Living Beyond Breast Cancer, quality of life is part of our mission. It's what we do. It's why we do it. And I think we're very sympathetic and sensitive to the fact that having breast cancer is a life-altering experience. Having breast surgery, chemotherapy, radiation therapy, hormonal, biologic therapy — you name it — [all are] life-altering experience[s]. And to move into your recovery from your treatment, and [then] have to deal with lymphedema, can have a profound impact on your daily life.

So, keep talking, keep asking questions. Press your health providers. Come to our programs. Call our toll-free peer support Survivors' Helpline (888) 753-LBBC (5222). We have Helpline volunteers, women who have been diagnosed and treated for breast cancer, who want to give back, who want to give peer emotional support. They'll help you think through the questions to ask your doctor. And, many of the women who serve as volunteers on our helpline are living with or have dealt with lymphedema. So you really can be matched to someone who may have experienced something similar to [your experience]. And sometimes that's really helpful, to get that peer support from outside your immediate network, from a more objective source, from someone who's not going to judge or give their two cents, so to speak, but just be there for you, to listen and to support you.

So I'd like you to keep that in mind. And I think there might be a card in your bag with our Helpline number. But if not, it's on our Web site, call our office. But I do encourage you to get support in the variety of ways that you can. Getting more knowledge is really key and important, but getting that girl-talk can sometimes make a really big difference, too.



**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

We do have a support group at Fox Chase that I run [<http://www.fccc.edu/patients/support/groups/lymphedema.html>]. And anybody is more than welcome to come. [You] can bring significant others; [you] can bring friends. I'm making a little bit of a plug. . . .

ELYSE SPATZ CAPLAN, MA:

. . . So thank you once again.

**WILMA MORGAN-HAZELWOOD,
OTR/L, CLT-LANA:**

Thank you.

ELYSE SPATZ CAPLAN, MA:

And everybody have a safe trip home. . . .
Thank you.
[END OF TRANSCRIPT]