

**Moving After Surgery:
Everything You Wished You Knew About
Lymphedema and Cording**

National Webinar Transcript

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Melissa Rosen:

Thank you for joining the conversation about postsurgical movement including range of motion, cording and lymphedema. My name is Melissa Rosen. I'm the director of Training and Education for Sharsheret. I'm going to be your host tonight. Before we begin, I have a few housekeeping items I would like to share with you. Firstly, I want to thank our sponsors for this important webinar. We are grateful for the following, Eisai, GSK, Merck, Seagen, the CDC and the Cooperative Agreements DP19-1906 and the Siegmund and Edith Blumenthal Memorial Fund. They generously enabled Sharsheret to continue to provide education and support surrounding genetics, breast and ovarian cancers.

A reminder that tonight's webinar is being recorded and will be posted on our Sharsheret's website along with the transcript. Participants' names and bases will not be a part of that recording. You may have noticed that participants were muted upon entry. Please maintain your mute status throughout the call. I have to say we received many, many, many questions before the call, a crazy number of questions. So you'll notice that some of these questions were combined. So be sure to listen for not your exact wording if you posted a question, but the topic that you were interested in. We expect additional questions now of course. Please use the chat box, which you can access at the bottom of the screen to ask any questions. And of course, any questions that we don't get to tonight will be answered via either email or a post on our website over the course of this week.

As a reminder, Sharsheret has been providing support services to the breast and ovarian cancer communities for 20 years. Our resources are 100% confidential and 100% free. In addition to our amazing clinical team that speaks to those impacted by these cancers and our many formal resources, kits, subsidies and programs to help women and their families navigate different aspects of the cancer experience, I want to remind you tonight of what you can find on our website. We have a wealth of information, a library of past webinar recordings and an entire section devoted to video demonstrations to help you with range of motion, lymphedema and other stretches and exercises. That link is actually in the chat box right now and we'll put that in our follow-up email as well. You see that's our Survivorship and Healthy Living section, scroll down the tiniest bit and click a box that says Exercise Resources.

As we move into the webinar itself, I want to remind you that Sharsheret is a national nonprofit cancer support and education organization and does not provide any medical advice or perform any medical procedures. The information provided by Sharsheret and tonight by our two guest speakers is not a substitute for medical advice or treatment for specific medical conditions. You should not use this advice or information to diagnose or treat a health problem. Always seek the advice of your physician or a qualified healthcare provider familiar with your case with any questions that you may have regarding a medical condition.

Let's get to it. We are so very fortunate to have two wonderful speakers joining us tonight. Jenni Rai, who holds a Master's of Science in Physical Therapy is the founder of mybreastiesays.com and received her master's degree in physical therapy from Ithaca College. She's a certified lymphedema therapist who completed her training with the Academy of Lymphatic Studies. She is also a reiki and cranial sacral practitioner and likes to combine elements of yoga, Pilates and mindfulness into our practice. Tonight, Jenni will be educating us about lymphedema and cording during the breast cancer experience.

Our second speaker is Caryn Shore-Genack. She holds a Master's of Science in Occupational Therapy and she is registered and licensed in that. She worked for over a decade in fitness as a group exercise instructor and a master personal trainer before returning to school to pursue a degree in occupational therapy. She received that degree from SUNY Downstate and earned all three of her American occupational therapy's badges in cancer rehabilitation. She will be speaking tonight about range of motion during the cancer experience. I am going to turn the screen over to Jenni who will be our first speaker and I know you're going to learn a lot tonight.

Moving After Surgery: Everything You Wished You Knew About Lymphedema and Cording

Jenni Rai:

Thank you so much for that introduction, Melissa, and thank you to everyone joining us this evening. Let's get started. I put together a PowerPoint and I have to say from the get go that this is going to be a lot to cover. These two topics, we could really do separate topics. So luckily, I am in Los Angeles, but I'm also a native New Yorker, so I'm going to do my best to speak as quickly as I can and get through the topics, hopefully as clearly as possible as well. So my goal for this first presentation about lymphedema is really to take a lot of fear about it by explaining to you really what's going on with the whole concept.

So, we're going to start with what is the lymphatic system because that's not really something a lot of us either learned in school, or if we did learn, we certainly don't really remember. So lymphatic system, its main focus is to clear junk from our body. Sometimes, we affectionately refer to it as the sewer system of our body. And when I say junk, I mean things such as old cells, excess fluid, lactic acid that stuff that causes the muscles to feel burning when we exercise and it does that using what I'm going to refer to as freeways to move the fluid through the body.

So just like our circulatory system moves blood through the body, it uses its own freeways, the veins and the arteries, the lymphatic system also has its own little freeways. And here, you can see the freeway. So if you can see my little cursor here, all of these green lines, those are the freeways, but then you'll also see these little dots.

Melissa Rosen:

Sorry, Jenni. Jenni, we don't see your screen.

Jenni Rai:

You don't see anything? You just see me?

Melissa Rosen:

Your lovely face.

Jenni Rai:

Let's go back to ... Whoops, that was totally the wrong button. Let me go back to Zoom and share screen. Let's see. Interesting. It's saying that I'm sharing the screen, but no one can see it. Advanced sharing options, multiple participants can share, who can share and I am a host, so correct?

Melissa Rosen:

Yes. So I know that it's difficult to do this, but I'm going to ask if you can talk us through and do your best to present images verbally.

Jenni Rai:

I can. I have them all right here, so I can. All right, you got it. Here we go, ladies. Let's go on the fly. Thankfully, I've done this presentation a lot of times. So nodes are ... So what I was indicating, you couldn't see because I thought you can see cursor, the nodes are only in specific places in the body. So they are up here in our neck, in our armpits, in the groin and then they are connected by those kind of freeways. And then the lymph nodes act like the custom agents along the freeways, so meaning you're traveling along in your car and you go through the node and then the node checks to make sure what's going on. Meaning like, is the fluid that's coming through this node, is it okay? Does it have a bacteria in there? Is there a virus? Is it something suspicious?

If it is suspicious, it then alerts the rest of the immune system. It perks it up. So one way that we've all experienced that is when we say like, "Oh, my glands are swollen. I think I'm coming down with something." And those are actually lymph nodes that are in our throat and they've detected something that's coming through our nose or our mouth or something of that nature. So cancer treatment can disrupt this in two major ways. The first is by removing the lymph nodes and the second is through radiation treatment. What happens with radiation treatment is those pathways, just like I was saying, the pathways that the fluid travels, they can get damaged.

This can also happen with scars. So if you end up having really significant scars from treatment, that can also impede the pathway of the fluids as well. If you have a disruption in the flow of the lymph fluid because of radiation or what have you, that or as Noreen is saying to everyone also, or the cancer itself, the tumor blocking that pathway, the fluid will back up and that back up of fluid is we refer to as lymphedema. Now, lymphedema can form really anywhere there's a lymph node, really anywhere in the body. So the lymph nodes each drain a specific like a map of the body.

So, for example, the armpits drain the arm, the breast and then the shoulder blade, the opposite side of the breast, the backside. So if you had breast cancer and you had your armpit nodes removed, any of that area could become swollen. If you had ovarian cancer, a gynecological cancer, something more down into your stomach, that could lead to a genital lymphedema like swelling of the labia or leg swelling. And if you had a head and neck cancer, you could have swelling in your face, that as well, so it's not only in the arm.

I should also mention what we're talking about tonight is referred to as secondary lymphedema, meaning you were born with a robust healthy lymphatic system that was doing its job, going along fine and then it was insulted by these cancer treatments. There are some people who are just born without a lymphatic system that just can't keep up with the demands. They've never had cancer treatment. They just were born that way. That's primary lymphedema and that's a totally different story. So all of this is about cancer related.

So why don't we want to lymphedema? What are the negatives of lymphedema? The first one is probably the most obvious one which is just the look of it, the cosmetics, the asymmetry, maybe not being able to find a shoe that fits if it's in your leg or having one arm larger than the other. Your skin can also change in texture, so it can become bumpy or the color might change. It can get thicker. It can be different. Probably the most dangerous aspect of lymphedema, if we're to use the word danger would be that you could get infections or even recurrent infections that could land you in the hospital. That's because swollen skin is not as strong as regular old skin. And skin's main job, it's our largest organ and its main job is to keep all of the nasties in the world, the germs, the viruses, the fungus, etcetera, etcetera to keep them from getting into the inside of our body.

When we have a swollen body part, the skin stretches out, making it a little easier for those bad guys see it in there. Because of that, it's a lot easier to get an infection. Now for probably the million dollar question is how do I prevent lymphedema if I've had cancer treatment? And unfortunately, the honest truth is not 100% preventive. But what you can do and we're going to talk about this next, you can minimize your risk. So let's talk about what are the risk factors. So, there are four major risk factors ... Side note here, hopefully when we send out the follow up, I'm going to send you all my slides. They are so lovely and I'm bummed that you can't see them, but all of this will be on the slides. So don't worry about like taking notes. So you'll have all this info. I just want to put it out there.

But anyways, the four major risk factors, so put down your pens if you're furiously writing. In these four risk factors, the way we have come to land on these four is these are what the research has backed up. So you might hear from your neighbor like, "Oh, I heard so and so this triggered her." It may have for so and so, but what the research has shown are these four things. So the first one is radiation treatment.

The second one is the amount of lymph nodes removed. And the third one is an infection. And the fourth is obesity, so what your BMI is.

Now those first two, the radiation and the amount of lymph nodes removed, there's not much we can do about that. A lot of that is what your oncology team decides based on their experience, your cancer, all of those sorts of things. And since we're talking about the oncology team for a minute, a question that came up when someone asked ahead of time and it comes up often is, "Why doesn't the oncology team mention this? Why doesn't anyone talk about lymphedema?"

I have an answer. There was a study done in 2011 that said, at that time in medical schools, physicians learned 30 minutes about lymphedema. So on all of medical school, they spent 30 minutes. Now if you compare that to, to become a certified lymphedema therapist, we spend 135 hours, so that's a huge difference. And I don't know why that is in this country. In Europe, it seems to be much more accepted in part of treatment. So although your radiation oncologist is the expert in radiation, your oncologist is the expert in which chemo you need, they are experts in their field, but lymphedema is just one field they're not great at [inaudible 00:16:33]. So that's why you just find your lymphedema therapist for that one. So not their fault. They just weren't taught that. And again, this is 2011. Who knows what they learned when they went to school in whatever decades they went to school in?

We're going to go through the two risk-producing behaviors that we do have control over, which is again infection and weight. So we'll start with infection. Like I said before, if you have a swollen limb, that could make the skin easier to get a germ inside, but say you don't have a swollen limb, you're just living your life, you're missing some lymph nodes, "Why should I worry about infection?" Well, it's possible that after you've gone through chemo or radiation, I know it's not uncommon to have your immune system compromised for a while. Even if your immune system is doing fine, just take the precaution. And if you get a paper cut, don't do, "Huh? Paper cut, okay," just actually instead go to the sink, wash it with soap and water, put a little Neosporin, put a Band-Aid on it, go on with your day.

Now, I should say in the paper cut example, that's assuming I had breast cancer and it was on this side. If I got a paper cut on the other side, it doesn't matter. If I had ovarian cancer on my left side, that would pertain to my left leg. It goes with the limb we worry about is the limb that correlates to where the lymph nodes or the original cancer was. If you had breast cancer to where you got stepped on glasses, I don't want anyone to step on glass, but don't worry that you're going to get lymphedema because you hurt your foot. You're not going to get lymphedema in your arm because you hurt your foot, if that make sense.

So, some other things to think about, you may have heard a prior common breast cancer warning was, "Don't get manicures." And it's not that nail polish itself is going to trigger lymphedema, it's just that being in the salon, if it's not clean or we've all seen that expose on 2020 where there's fungus everywhere or they're reusing the products and the tools. So just make sure that if you do get a manicure and you're at risk for your arms, bring your own tools or maybe ask them not to cut the cuticles because cuticles are where ... Mine always bleed at the nail salon. That's where like you could get a little cut and then the germs could enter, if you've had ovarian or any other gynecological cancer, stomach cancer. So that would apply to pedicures. Anything, if you're at risk for leg lymphedema, if you go get a pedicure, just be extra careful that it's extra clean and there's no risk of getting any sort of infection because infections certainly is at risk for getting lymphedema.

I'm not going to comment on all the chats, but someone just asked about blood pressure. Blood pressure, that falls into one of that category of things we think make a difference, but there's hasn't been any research that really backs it up. So yeah, If you're at risk, you had cancer on the right side, try to do your blood pressure on the left. Because we only have control over so many things and it could

literally make you crazy, we're sticking to the things that research backs up and will make a big difference.

So that's why I'm not mentioning blood pressure today, but that's probably one a lot of you have heard is, "Don't do blood pressure on that." But the thought is it can cut off the flow, it's also very temporary. You don't walk around with a blood pressure cuff on your arms for an hour and a half. So that's basically the idea behind avoiding infection. Also, try to avoid sunburns. If you're in the sun and for a million reasons, we should be wearing our sunscreen. Bug bites, do your best to avoid getting bug bites on the involved area and that is that.

So, our second risk factor that is under our control, sort of, is our weight. And they have found that if your BMI, so that's body mass index, if it's over 25, you have an increased risk for lymphedema. I'm sure more than half of you are like, "Oh, man, I have literally no idea what my BMI is." So if you're sitting here thinking that, if you type into a Google or any search engine BMI calculator, it will pop right up. And as long as you know your height and weight, it will tell you what your BMI is. So it's easy to figure it out. But now's the time where I step on a soapbox for a moment. If you find that you're like, "Oh, man, my BMI is really not where I would like it to be now that I've done the calculations," ask for help.

And I feel so passionate about that because losing weight is not easy on a good day and less easy when you are recovering from a major illness and let alone a major illness that if you've got breast cancer or even ovarian cancer that may have put you into menopause. It makes me nuts when doctors, even if it's not cancer related, it's like, "Oh, you're at risk. You're on the border for diabetes. Go exercise." It's not that simple. So either speak with a nutritionist, it'd be great if there's someone like if Sharsheret could recommend someone who works with people who have cancer or talk to functional medicine people or different dietitians. Physical therapists are great. We love to help you get an exercise routine.

And I know there's also probably some of you on here who are like, "Oh, my personal trainer is so good," and we probably are, but also, I'm going to put a pitch in, if you are on Arimidex, tamoxifen, any of those estrogen suppressors, they can increase your risk for some joint pain and those sorts of things. So you might want to work with someone who has a little bit more education than your personal trainer like a physical therapist. So find your local PT. They are more than happy to help get you pointed in the right direction. So stepping off the soapbox about that one.

So next point here, "How do I know if I have lymphedema?" So I'm going to teach the ladies, so if anyone who have had breast cancer, I'm going to teach you very quickly how you monitor yourself. And what you do is you basically just get to know your arms. You're going to look at your wrists. So you look here and think, "Oh, yeah, I see tendons. I see veins, looks the same." Then you're going to flip your hands over. See those tendons, that looks the same. And then the third way is if you were to bend your elbows and then look in the mirror that way, sometimes the lymphedema, like this one, will just hang out there. So you might see like one side is a chubbier than the other. That can also be a way.

So, I would encourage you just to get into a habit of doing that. So you know what's a baseline. So if at one point you're like, "Oh, yeah. I actually can't see the crease on my wrist as well," that's a sign that you're catching it super early. You also might notice that there's a feeling of heaviness in that arm. Before you even notice anything. I read somewhere once that women can tell that there's one before sometimes our tape measures can even tell if you're aware of your body. Typically, pain is not associated with lymphedema and I have a little asterisk to that statement.

So, if I hear from someone, "Oh, my god, my shoulder is killing me. Do you think it's some edema?" as a physical therapist and lymphedema therapist, my first thought is it probably is, it's probably not. However, I've worked with enough women over the years who do report some pain and discomfort with swelling. So in this school they say, "No, no, no, no pain," but I'm not going to discredit their experience. So some women do feel aches and feel some pain with lymphedema, but typically, that's not your first

signal. I would rule it could be cording which will talk about in a minute, but it's probably not lymphedema. So usually not painful.

And so, then what happens if you do discover like, "Oh, yeah, this is different," one wrist does not look the same as the other or one leg doesn't look the same as the other, please don't panic. There's no need to panic and I'm going to show you why. I promise you this, you will never ever go to bed with two normal-looking arms, two normal-looking legs and wake up with one gigantic elephant arm or elephant leg like you saw when you googled lymphedema on the internet. It doesn't work that way. Those pictures we've seen on the internet, God bless Google, those are people that for whatever reason could not get treatment for months, possibly years.

You guys are all at this webinar, you are all clearly motivated to monitor for this stuff. You are interested, you have the wherewithal, you won't be that person. So please, just I hope that takes some of the stress away about lymphedema. It starts slowly. You'll start to notice like, "Hmm." It typically will start where you might notice, like if it's your hand, you might notice, "Oh, this ring isn't fitting," but then the morning it does fit again. By the end of the day, it feels tight. Or with your feet, if you're prone to leg swelling, you wake up, everything looks fine. By the end of the day like, "Oh, God, that's weird. My left foot is swollen, but my right foot isn't swollen."

If you ignore that, typically what will happen, and I can't tell you why because it's different for everyone, it could be three months, it could be a year and a half could be five years. At some point, it will stop getting better on its own and you'll wake up and it's the left foot swollen and you'll go to bed and the left foot swollen and then it can get bigger and bigger from there. The other reason I want to say to hopefully take some of your pain away is lymphedema, it's not permanent in the way you may have been led to believe. It's talked about as if it's a tattoo. Once you get lymphedema, you can't ever get rid of it. And that's also very frightening, but what I would suggest you is maybe think about a little bit more like back pain, right? And this is why.

So back pain, you get to certain age, it's common. So same with me, if you have cancer, it could be common, but there's some risk factors. Some people are more prone to it than others and people's experiences with it are very different. There are some people who have back pain once and then are debilitated for the rest of their life. It's something they're constantly managing. They may end up with surgery for it. Every morning, they do their stretches. There are other people where, "Yeah, I've had back pain," and then they're fine for a few years and then it flares up and they go to the physical therapist and they address it and they deal with it and then it's fine again.

And lymphedema is very much like that. How you are going to fall in that spectrum, it's anybody's guess, but it's not a guarantee that if you get it, the rest of your life will be devoted only to managing your lymphedema. There's a lot of gray in there, so it breaks my heart. It's funny when I started practicing as a lymphedema therapist was in 2005, at the time, a lot of my patients, I was the first person introducing lymphedema as a topic. As the years went on, women were coming into me like, "Oh, my God, I don't want to lymphedema. What something ... Do I have to have ... How am I going ..." this fear and it just breaks my heart.

Jenni Rai:

So I'm looking at these cancer warriors with like, "Good God, you guys have faced down pretty scary things and don't let this stupid little thing like add to it. You guys are warriors," and so again soapbox, but it just breaks my heart that this stupid thing is causing so much fear. So try to take some of its power away, off the soapbox. So what happens if you get lymphedema, and I'll try to like get through this, we'll talk about cording. So you come visit someone like me, lymphedema therapist. We just figure out where

you are with your swelling. If you are someone is very really early, you caught it early, you've been checking your ankles or wherever, all you might need is just some education.

You might need to learn how to do some specific exercises, some massage. Maybe we'll get you a compression garment and then do a few visits, you're on your way. If you are someone where you come in and you're like, "You know what? It's just bigger than the other side. In the morning, it's bigger. By the evening, it's still bigger. It's not going back down, if you were that person, then we do what's called complete decongestive therapy. It's the gold star treatment for lymphedema. It involves some sort of compression. It's almost like wearing a cast. We wrap up the limb, either the arm or the leg. You wear that like it's a cast 23 hours a day, come into the clinic, take it off. We do a special massage, the manual lymph massage where we reroute the fluid.

So, if lymph nodes are missing here, we help the fluid come over to these lymph nodes where they're all still there and happy and working. We do that until, it can take up to three to six weeks for the arm depending on how long you've had the fluid. We do that until the arm gets as small as it can, ideally back to the size of the other arm. Once it's gotten to be that size, we then get you into a compression sleeve, the ones you've probably seen, the over-the-counter. Sometimes, they're over-the-counter. And then you probably have to wear that sleeve for a while.

So, there are pumps out there that can do the massage. For some people, that's helpful. They are expensive. I personally like the hand version better because you can work around the scars. But for some people, if your insurance covers it, it can be nice to just throw that thing on, if it's something that you have to do every day. That was a question someone had asked, so I'm just answering that now, case-by-case basis. Almost done, almost done on lymphedema, I'm going to talk about compression sleeves and airplanes because that's also a hot topic. You probably have heard maybe from your surgeon, "All right, you've had your lymph nodes removed, time to get that sleep for the airplane," that's old news. That's not actually super accurate anymore.

I believe it was 2012, the National Lymphedema Network, which is the United States governing body of lymphedema, they did a big literature review and they put out a position statement saying, "Guys, we actually don't know if that helps." There's some thought that the way they cram us in sardines these days that if you have an arm sleeve on your arm and you are seated like this, that maybe you're cutting off your own flow. So here's the new more up to the minute, up to the date recommendations, if you have a history of swelling, 100% wear that sleeve on the plane. If you are at risk for swelling, but you haven't developed it yet, then it's like maybe talk to your lymphedema therapist, is the hitch. Then talk to someone.

When I'm having that conversation with my patients, we base it on like, "What are your other risk factors? How many other factors do you have? What's your personality?" I've met people who are just like, "I didn't want to think about it. I just want to put this thing on," or conversely, "I actually don't want to think about it all. I don't want to put that thing on." We just talk about it and come up with a decision that everyone's comfortable with. So lastly is we'll just talk quickly about lymphedema surgery because that's also a new thing. Again, when I did my certification in 2005, at the time, all the surgeries were not good. They were mostly some version of liposuction which just remove all the excess skin and stuff, but damage some of the lymphatic systems that were left there. And undoubtedly, the limb would swell again and now will be harder to treat. It was just bad news.

Again, like I said, I'm in Los Angeles, and in the last five years, I'm starting to see more patients. There's two main types. I've seen more of what's known as the lymph venous anastomosis bypass or LVA. People who are good candidates to have either the stage one which is where you wake up in the morning and things are okay and then it gets swollen at night, but then you wake up and it's better again or stage two where it's not getting better in the morning, but it's not too bad. And what they do there is

instead of ... When your lymphatic system is working well, working normally, eventually all of the lymph fluid ends up getting dumped around here into your veins.

What they do for your arm, for example, they connect the lymph system to the veins like out here somewhere. So now it's connected to your veins out here and then travels. It just bypasses all these lymph vessels by going directly into your veins. I've seen a few patients, maybe a handful. It's not a cure. It's definitely not a cure. You still have to wear compression sleeve. I have not had enough experience yet to say like, "Yes, I would definitely do it." I can't help it. When I'm in the clinic, I always play the, "Would I do that if I have this?" game, and jury's still out for me personally if I would do that. I think I need to see more.

The second one is the vascular ... Let's try it for the third time, vascularized, vascularized lymph node transfer, VLNT. That's for stage two or for the people who had the first surgery that it didn't work for them. I know one person who had this. She had really bad, she got infections, infections all the time of her lymphedema. And what they do is they take a clump of lymph nodes from somewhere else in your body and put it where you're missing lymph nodes. So I haven't seen enough of that to have a comment, but in general, I'm always a little bit skeptical of those robbing Peter or pay Paul kind of surgeries, but-

Melissa Rosen:

Jenni, this was so much great information, but we do need to move forward. So, I think what I'm going to ask is if you could talk for just five minutes....

Jenni Rai:

I could do really fast with cording.

Melissa Rosen:

About cording, but I want to get to Caryn and there are questions also. If there's not enough time, we can always create a blog about some of this information.

Jenni Rai:

Yeah, I'm going to give you my quickest down and dirty about cording. Cording is this weird thing that happens. Usually, we see it in the armpit after axillary node dissection when you have lymph nodes removed. It can also happen, I've seen it in women who have ports here. It is one of three things. It's either like scar tissue or it's lymphatic tissue or it's veins. And I say it's one or three because literally, it's different in each person, it could be different within your own arm. It's three different things that happen. And you know you have it because you come in, like my patients will come in and they'll say like, "Oh, I have this pain," and it's not like, "It's tight here," It's like, "It is tight right here."

And it doesn't feel like, "Oh, my calf muscle is tight. I'm going to stretch it." It's like, "It feels like if I move, something's going to tear inside." It can come all the way down into your hand. It is not dangerous. It will eventually go away on its own. It has nothing to do with lymphedema. If you had a seroma, you're more likely to have it. Seromas aren't dangerous. They're just like pockets of fluid that can happen after surgery. If you have lots of nodes removed, that can be make you more apt to have it. It usually happens for weeks after surgery. It eventually goes away on its own.

Someone asked, said their PT was working on stretching. It shouldn't hurt to get rid of them. It should be very gentle. It definitely can come back. Usually, I see in the clinic it goes away within like three to four months, but then something will happen. Usually, radiation can make it come back or they start working out a lot and that can make you come back. Eventually it goes away. If you, have it, don't worry about it

and it just know there's nothing to do with the recurrence of lymphedema. Keep moving your arm. Keep stretching. Motion is lotion, as Caryn will mention. And you can read my whole PowerPoint for more info, but that's the down and dirty about it. It's weird, but it's not dangerous. Just don't be scared of it.

Melissa Rosen:

And that's a perfect segue as you talk about motion to have our next presenter come. And she's going to actually talk about range of motion and show us a few things that we can do. So Caryn, welcome to the screen.

Caryn Shore-Genack:

Thank you so much for having me. Really, I feel genuinely privileged to be able to speak with Jenni. My grandmother, suffered in her life from a variety of cancers including breast cancer. And when I was single and I would attend breast cancer walks, this would be me. I'd be running up to anyone in a pink t-shirt, "Congratulations, you're my hero," and then off to the next one. So it's genuinely a privilege to be able to serve this population. I want to clarify my role as an occupational therapist in general and in treating patients with breast cancer, either prior or post some type of resection.

All occupational therapists are trained in upper extremity. Physical therapists are also trained in upper extremity depending on the school, the degree to which there is an emphasis. Usually the degree is much higher for occupational therapists than for physical therapists when it comes to upper extremity. Likewise, some therapists continue in a path, for example, during the day I work in pediatrics, but I work in a hand clinic in the evening and I've had multiple rotations in hands in particular. With that said, I do not treat cancer patients. And I often remark in my education to develop competency in treating cancer patients, "Why not? Where are they? Where are they going? Are they being sent anywhere?"

So, the exercises that I'm going to demonstrate to you are the exercises that I would teach you if you came into my clinic. They're the exercises I would recommend as a home exercise program. You should communicate with your doctor in the course of your recovery when is it appropriate to incorporate these exercises. There's been some discussion about fatigue. There's been discussion in the chat about pain. We're obviously talking about edema and cording, so all of these exercises are not only safe, but they've been proven efficacious to treat all of those things.

So, cancer-related fatigue, like secondary lymphedema, can come about from not moving. And when we have scar tissue that's tough, it can be frightening to move. It can be painful to move. And we want to honor that pain. We want to take it to the edge of the discomfort, but the pain is a warning to back off. So I may recommend, "Oh, you know what would be beneficial? Do five minutes of this five to six times a day," but where are you going to start? You're going to start with 10. And if 10 doesn't feel good, you're going to start with one. And if 10 feels good, but you could only go an inch, that's where you're going to start. So the first range that we're going to take, and I like to use a towel.

Melissa Rosen:

Caryn, before you continue, can you move the mic a little closer to your mouth?

Caryn Shore-Genack:

Yes, is that better?

Melissa Rosen:

We'll see. Keep going.

Caryn Shore-Genack:

A towel or a paper towel. The reason is that you want to create some slip on the surface to give yourself a boost. So I do this particular exercise with both hands, even if only one side is affected and the other hand acts as a helper. We're going to get the whole trunk involved. You're going to also feel this in your abs. We're going to push forward, forward, forward and back, back, back. Forward, forward, forward, and back, back, back. Now, like I said, we're going to start, we'll do 10 at a time, maybe 10 times three. And as you progress, we could do as much as five minutes at a time, five to six times a day.

Now, let's say this is my affected side, take back, we're going to do circles. And you want to make that circle as big as you can. So we're starting with 10, 10 times three, up to five minutes and then the opposite direction. So going out would be external rotation, going in would be internal rotation. These exercises can also be done on a wall. If you're feeling that you want to progress and you're looking for something more aggressive, so I would take either my towel or my paper towel and literally wipe the wall. You can wash the window or you can use your fingers as an assist and simply climb the wall like a ladder as far as you can go to the point of discomfort but never pain.

Let's talk for a moment about scarring. So let's say you have wounds. Now this is applicable for cording, this is also applicable for a surgical scar. We talk about scar massage from the perspective of when this scar is dry, but again you want to consult with your surgeon when is it appropriate to implement this type of activity. So in our clinic, we use a cocoa butter with vitamin E. You could use anything. You can use that cucumber melon from Bath & Body Works, but the cocoa butter, the shea butter, the vitamin E, the vitamin Z has all been proven efficacious for improving the quality of your skin, so you're just going to take a little again to create some slip and I like to work it in.

Then what I do from one end, to the degree that I can tolerate the pressure, you're going to massage in circles, approximately 10 times and then move the finger over another 10 times. When you get to the end, you're going to work backwards. Now, if you have the ability to use two hands, you can use two hands for the next series or you can simply use one. We're going to zigzag. So up and down, up and down, up and down, up and down and backwards. Finally, you're going to actually pinch it. The purpose of pinching it, the purpose of all of this, is to prevent adhesions. So if the skin is crossing a joint and it adheres to the soft tissue underneath, it's going to impact your range of motion.

So, the exercises themselves will stretch the scar. More directly, we're going to manually mobilize that scar. So you would literally pull up the skin. And in the beginning, it might really resist you, but when I have patients that come into the clinic, I joke with them, I can tell who's been aggressively doing their home exercise because it's so supple under my hands. Something else that you can do again that's a little more aggressive would be a manual massager. Some come with only one set and some come with multiple settings, so you can grade the intensity. We have our patients to five minutes of manual massage on a small scar. So remember, if you have a large scar and you're using a small head, five minutes is not a lot of time on each particular spot, so you may want to invest in a larger size massager if you can tolerate the vibration.

When you have scarring or you have radiation that's resulted in like a neuropathy or you're having cording that's presenting as a neuropathy, it's not uncommon to have paresthesia or other numbness or patchiness of just uncomfortable unusual sensation. Maybe you're in the shower and it feels uncomfortable, the water on the wounds. Maybe certain fabrics are distressing. So what we do is we have a variety of fabrics on sticks. You don't actually need a stick. You can just cut different pieces of fabric or you can make a pile of laundry and take between one and 10 types. So I tell people, "Start with something really soft like a silk or velvet, a corduroy. Work your way up to a terrycloth towel, maybe like a denim.

And what you're going to do is simply take the fabric and rub it directly on. So we say for each fabric, you're going to spend about one minute as tolerated. You might have better tolerance for the softer fabrics and then you might want to spend more time on that and build up to the more intense fabrics. Likewise, you might have decreased sensation and you may not be detecting the degree of touch. You may not be synthesizing that information. So it's very important to always take a look. So if you're someone who sunburns easily or if you press on yourself, you get red really quickly, you want to be extra cautious. But all of us, all of us who are perhaps experiencing [inaudible 00:48:43] sensation, you want to use your eyes as a backup to make sure that you're not chafing your skin unnecessarily. It's not part of the therapeutic process.

For the bigger limbs like the hands or the feet, if you're having an actual neuropathy, what we recommend is between five and 10 minutes in rice. Do you see what I'm doing? I'm very active. I'm digging. I'm letting it cover my hands. I recommend that you purchase the least expensive rice. Cheap rice is very starchy. So the more that you manually handle it, the softer it gets, was actually very pleasant over time. To increase the complexity, I'd like to throw in glass marbles. If you have a stash of buttons, different-shaped buttons and textures. And then to challenge yourself, distinguish them from the rice, a little bit more intense than the rice would be corn.

Still speaking about the scars, an option that you can also have, and this is available with a prescription or over the counter, would be what's called a scar pad. And the scar pad is actually the size of this box. So it would be very usual to have a scar quite this size. You can cut this pad to size and store the rest for another time. Then you would take either like surgical tape or a sock and net or cut the top of a sock to hold on the pad in place. You can use the pads several days in a row. You can then wash the pad and let it air dry. You can use it as long as you see that it's still adhering. Eventually, you'll see that the silicone starts to rub off and it needs to be replaced.

We do recommend if you have pets in the house that you keep it at a high surface that they can't reach because it smells like you, so it makes it appealing to them, but it could be a choking hazard. Different than a scar pad, they also sell over-the-counter scar gel and you can use that for your massage instead of the vitamin E. The occupational therapist that is not certified in lymphedema is not supposed to do lymphedema drainage on a cancer patient. So let's say if I had a traditional biomechanical injury, I would definitely do retrograde massage, similar to what Jenni was describing, but not to the same expert level, but I would not do that if you came into my clinic.

What I could do though is measure you for the compression garment that would be appropriate, and we can talk about different positioning. So there was a participant that mentioned in the chat that sometimes she elevates her limb on a pillow and that's very helpful. So we can talk about, well, elevation, when is that relevance? Well, are you keeping your hands in your lap? Are you keeping your hands on the table? Can you take breaks throughout the day, raise your hands in the air and pump to bring circulation to the affected area? When you're sleeping, are you waking up and feeling numbness? How can we utilize pillows?

Sometimes an outside person can brainstorm in a way that you yourself couldn't figure out, but you know this is an area that that can be improved upon. Similarly, some occupational therapists can talk too about energy conservation and time management or maybe your environment. For example, if you're spending a lot of time in the kitchen and you're not able to reach things or you're having trouble with bathing because you can't raise your arm to wash your hair or you're having trouble dispensing soap, what kind of modifications could you make in the meantime without altering your environment permanently to be able to reduce some of that tension?

Melissa Rosen:

Thank you so much for that information, Caryn. It's clear that there are so many ways that work to address some of these issues. And that's amazing. It's amazing information, very practical.

We're going to just ask two quick questions and then we will get more information out to in a follow up. So a couple of things, I know that you said, Jenni, that cording goes away on its own. So there were some questions about lymphedema, will it always progress? Is it possible with minor interventions with the massage or the compression sleeves that it will stay where it is or even go away? And then finally, why is it and is it true ... Sorry, lots of questions. Why is it and is it true that 15 years after surgery, after not having lymphedema, something can happen and somebody will then get?

Jenni Rai:

that last question, your guess is as good as mine, but that does happen. And there doesn't really seem to be any real good rhyme or reason why that happens. So even if you're like, "I'm six years out, so I'm cool. I've never had lymphedema. I'm never going to get it," unfortunately, there is statistics that the longer time goes by, there is less of a risk, but you could be that 1% who gets it that it never goes away completely and we don't know why. But yes, two things that when we do the chats I wanted to emphasize, when I talk about swelling, lymphedema is asymmetrical.

So, a lot of the medications can make people swell. Someone I saw said, "Swelling is neuropathy in your ankles," that's actually not accurate. Neuropathy is the pins and needles feeling, but if you do see both ankles are swollen or both hands are swollen the same, that's probably not lymphedema and probably from a medication or the heat or something. But yes, 100% lymphedema does not have to progress to a big mess like a big giant body parts. It can stay in a smaller like a medium thing, it can go away.

Melissa Rosen:

Perfect. Last question is, if possible, could you talk a little bit if there's something different about it, about truncal lymphedema or lymphedema of the breast?

Jenni Rai:

Sure. To talk about that quickly, one, the way you would monitor for that, because it's not as easy as comparing side to side, but I would say if you wear a bra, the easiest way that I even look at my patients is I have them keep the bra on and not to be like a weirdo. If this is my bra, but where the skin squidges over the bra, if it looks asymmetrical, or if you have someone at home who can look at the back, you can feel it. There's a lot of times my patients will say, "I just feel like there's more tissue here," but what's tricky is a lot of times their sensation is a little messed up from surgery. Then when I feel it, I'm like, "It feels the same to me," but it feels funny to them because of that. It's better to look and see if there's a swelling. We treat it the same way. We do the special massage.

But obviously, we wouldn't bandage you the same way and we find again some sort of compression garment that could look like a Spanx top or they make special kind of bras that have compression. So you would treat it with compression as well, the same kind of thing. And that same if you have breast edema as well, you treat it that same way like finding a special bra.

Melissa Rosen:

Thank you both very much. We are mindful of the time. So I promise you, additional information to answer some other questions will be sent out, but I want to take a moment to thank both Jenni and Caryn for all they shared. It wasn't just informational, it was incredibly practical. So that's wonderful. Thank you again to GSK, Eisai, Merck, Seagen, The CDC and the Siegmund and Edith Blumenthal Memorial Fund. Please take a moment, there is a link to an evaluation survey in the chat or will be in

one second. Please take a second. There it is. It's so quick and it really does inform future programming. I do want to remind you that Sharsheret is here for you and your loved ones to provide emotional support, mental health counseling and other programs and resources to help you navigate the cancer experience. Again, all are free and completely confidential. You can reach out to us on our website or by calling us.

And finally, I want to let you know that we have several exciting webinars on a wide range of topics scheduled for this month. An email went out yesterday, I believe, with a list of several upcoming webinars, but you can also explore and register for the upcoming webinars on our website and I just saw that link posted. So you have several ways of doing it. Again, I want to thank you for joining us tonight and wish you all a great evening.

Jenni Rai:

Can I say one thing fast? I'm so sorry.

Melissa Rosen:

Sure.

Jenni Rai:

If anyone has questions, this is all in my stupid slideshow, please just email me. It's in the chat box jenniraipt@gmail.com. I love to answer your questions individually.

Melissa Rosen:

And we'll get that slideshow out as part of the follow-up email in a couple of days.

Jenni Rai:

Yay.

Melissa Rosen:

Thank you very much. Have a great night.

About Sharsheret

Sharsheret, Hebrew for “chain”, is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret’s Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

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

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

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Moving After Surgery: Everything You Wished You Knew About Lymphedema and Cording

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