

## WEBVTT

00:00.000 --> 00:13.300 Support for Yale Cancer Answers comes from AstraZeneca, a biopharmaceutical business that is pushing the boundaries of science to deliver new cancer medicines. More information at [astrazeneca-us.com](http://astrazeneca-us.com).

00:15.500 --> 00:47.800 Welcome to Yale Cancer Answers with Dr. Anees Chagpar and Dr. Steven Gore. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week, it is a conversation about lymphedema in cancer with Dr. Louis Friedman. Lou is a physical therapist and a certified lymphedema therapist. Dr. Gore is a professor of internal medicine in hematology at Yale School of Medicine and Director of hematologic malignancies at Yale Cancer Center.

00:48.200 --> 01:01.400 <vGore>Lymphedemas, I know a lot of people know about edema, it is one everybody worries about, swelling, but I am not sure that everyone knows what lymphedema is. Can you describe that for us?

01:24.400 --> 01:47.400 <vLou>I would be happy to. Lymph is actually a natural part of the circulation. Most people are aware that fluid comes back to the heart by veins, but there is a whole separate system called the lymphatic system that picks up and returns to the heart fluid that the veins don't and what can happen is that the lymph system can be interrupted whether it is by surgical removal of lymph nodes, radiation, or other factor. So that fluid tends to build up in the extremity, so in the case of breast cancer for example, the lymph nodes in the armpit are taken out, the fluid can build up in the arm, the breast area, chest wall. Even in head and neck cancer when they take out lymph nodes from surgery, the fluid can actually build up in the facial area of the head and neck.

01:48.400 --> 01:50.200 <vGore>Wow and I have also seen people who have lymphedema in the legs, right?

01:51.500 --> 01:55.600 <vLou>Correct, interestingly worldwide lymphedema is caused by a parasite, especially in third world countries, something called filariasis. In this country, it is due to the surgical removal of the lymph nodes. So if someone has had a gynecological cancer and lymph nodes are removed through the inguinal area, the groin, or the stomach, that fluid can also build up in the leg.

02:17.400 --> 02:19.800 <vGore>But not everybody who has lymph nodes removed will have lymphedema, is that right?

02:20.900 --> 02:29.600 <vLou>That is absolutely correct. The lymphatic system actually has a great deal of reserve capacity, so you can slow it down a little bit and it can still function well.

02:30.200 --> 02:42.400 <vGore>And maybe I am getting ahead of us a little

bit, but are there ways to predict in advance who is going to be at high risk for developing lymphedema with the particular surgery or is it just kind of hit or miss?

02:43.900 --> 02:58.700 <vLou>To some extent, it is hit or miss. We do know that in breast cancer for example, there are high risk patients, so patients who are overweight, with what we call body mass index near 30 at the time of diagnosis tends put them at risk.

02:59.300 --> 03:04.300 <vGore>And 30 is not that big in our society, really, I mean I realized it is considered obese but it is not super obese, right?

03:05.000 --> 03:23.800 <vLou>Correct and there are people that naturally tend up towards it, absolutely. When you start adding into that people who will be having a lymph node dissection and when they going to take a large amount of lymph nodes, in addition certain chemotherapies and the addition of radiation can also increase the risk slightly.

03:24.500 --> 03:36.700 <vGore>And is there anything that could be done prophylactically in such patients to try to prevent the onset of lymphedema or is there really nothing you can do ahead of time?

03:37.200 --> 04:31.400 <vLou>Great question and the issue is that trying to study that is very difficult. For example, we know in the case of breast cancer, someone who has had what is called a sentinel lymph node biopsy whether just taking one or two and checking that and then they do not go further. The numbers there are anywhere from 0 to 3 to 4% of those people might get lymphedema. When you start doing an axillary lymph node dissection that is where they are taking more lymph nodes than that percentage can go up to 25 to 30%. What we have found is best is if we can identify the group of high risk patients and see them and get a baseline and see them periodically, something we call surveillance. So that we are picking up real quickly if they are going to be developing lymphedema and intervening is the best we have at this point.

04:32.100 --> 04:55.800 <vGore>Gotcha and how effective are the interventions, I mean in my practice over the years, I have certainly seen a number of patients who have really severe lymphedema either in the arm after breast cancer or in the legs and it is both unsightly and disabling for some patients, I mean it is a really scary stuff for some people.

04:56.300 --> 05:45.800 <vLou>Correct. Some of the studies show that the earlier you get it the better. So if you can get in breast cancer, again for example, if you can pick it up when the swelling first starts and a simple intervention something like a compression garment as well as showing certain exercises and possibly adding manual lymph drainage, but the studies show just adding a compression garment can significantly stop it in its tracks. The issue with the lymphedema is that it can be progressive and what they are finding in newer studies is that there is actually an inflammatory component to it. Initially, it was thought that it was just a blockage and a backup, now they are finding that

it can almost be a cell perpetuating condition and that is one of the reasons it can be very difficult to treat.

05:46.400 --> 05:50.400 <vGore>Hmm and I guess the lymphatics do not grow back, is that true, I don't know.

05:51.200 --> 05:57.100 <vLou>The lymph nodes will not grow back, the smaller lymph vessels what we call the initially capillaries, they will grow, it just takes a long time.

05:57.900 --> 06:08.400 <vGore> I see. So when you say compression garment, I guess we have all seen compression stockings, and people are familiar with that, is that the kind of thing you are talking about?

06:09.200 --> 07:24.100 <vLou>When we look at lymphedema care, we look at something called complete decongestive therapies, so that is 4 stages, one is a hands-on technique called manual lymph drainage, the other is compression, then we look at certain exercises, and then good skin care. So when we look at the compression piece of this, depending on where the person is at is how we decide. So if we can get someone initially, yes, it would be something like an elastic compression stocking. If we need additional compression, we use something called short-stretch bandaging which looks like an Ace wrap but is totally different type of compression that we wrap in a certain way on the extremity and that helps reduce the amount of lymphedema in the arm or leg. The vendors in this area have done a nice job, they are continually upgrading the quality of the elastic compression, there are also new products that you can apply with Velcro and we basically look at elastic and nonelastic compressions. So there are many different types of compression products that we would use. We always like to individualize that to the person.

07:24.600 --> 07:44.100 <vGore>And patients are often very reluctant in the case of either more conventional edema or lymphedema to put on a compression stocking for example, their experiences often been very painful or uncomfortable, so you know I have certainly found patients to resist that sometimes.

07:44.800 --> 08:16.800 <vLou>Well there are a few issues there, I have had many people who will go online and order something online. It really is advised to have a professional fitter, to take the measurements that you need and get into an appropriate compression, yes they can be difficult to put on especially for the legs where you might use higher compression, they can be very challenging to put on if someone has hand weakness or limited mobility and their body can be very challenging. So oftentimes, we have to enlist the help of family members.

8:17.100 --> 08:22.500 <vGore>Tell me about this manual compression thing. Are you actually talking about squeezing out the juice?

08:23.600 --> 09:46.800 <vLou>We call it manual lymph drainage and it is a very light pressure, the hands are over the lymph pathways, so we know what the lymph pathways are, we go towards the exit first, so by the neck is where all

the lymph fluid goes back to the veins and back to the heart, so we start there, we work our way outward on the lymph vessels. Depending on where we are, it might be a little bit deeper. Depending on where we are, it might be a little bit lighter. But we are essentially trying to stimulate the lymphatic system and also as we get into the area that has the swelling, we are trying to open and close those, what we call initial capillaries of the lymphatic system, small little vessels that once the fluid isn't there it is considered to be in the lymphatic system. Before it gets in there, it is not in the lymphatic system, it is sitting out there in what is called the interstitial space, so it is going nowhere, so stimulating the lymph system and physically moving it into the lymph vessels is what we are trying to do. We also know that the lymphatic system actually has some built-in muscle pumps, so by stimulating that you can actually increase the flow of the lymphatic system almost like you are increasing the vacuum effect, you are increasing the draw effect from that interstitial space.

09:47.100 --> 09:52.500 <vGore>So you are saying that for an arm you are going from the shoulder out to the arm, is that correct?

09:53.500 --> 10:35.600 <vLou>So for the arm, we would actually start by the collar bones, work our way out to the shoulder, the armpit, and out into the extremity. I will tell you that if there has been a lot of lymph nodes taken out from one armpit, we can do what we call rerouting, so we can ask the fluid to go across the back to the other armpit or across the chest to the other armpit. There are these what we call collateral pathways, they are not really pathways but where the lymph crosses the midline, there are not a lot of valves, very small vessels, so we can encourage it to go, it is not perfect, it is not ideal, but any little bit of fluid that we can get out of the extremity and have go somewhere is what we are looking to do.

10:36.500 --> 10:39.800 <vGore> So when you are doing this, you actually watch the fluid move, I mean can you actually see fluid moving?

10:40.100 --> 10:56.500 <vLou>No, you can't, but you can feel a difference in the tissue tension of the arm. So if someone has a lot of fluid that tissue might be firm and as you do this, you can actually feel it soften up, so indirectly you do know the fluid is moving.

10: 57.600 --> 11:09.200 <vGore> I see, I see. So this is different than again the more usual swelling or edema that people know about where you can push like a Pillsbury dough boy, this is not usually like that, right?

11:10.400 --> 11:31.400 <vLou>Correct and you are not going to be able to monitor this like a Doppler, the intravenous flow, although there are some tests on the market where they can inject dye into the lymphatic system and track it now, so you can see that it is moving, although I will tell you these tests tend to be a little bit painful, cause you have to inject into the smaller lymphatic vessels.

11:32.800 --> 11:41.600 <vGore>Yeah, that does not sound very pleasant and

we used to do a radioactive version of that for staging of Hodgkin s disease that was a very unpopular test indeed.

11:42.500 --> 11:45.100 <vLou>Yes, absolutely, absolutely.

11:45.800 --> 11:55.600 <vGore>So how effective is this treatment for patients? I have seen people who have kind of thrown up their arms and some of them have been to lymphedema treaters.

11:56.900 --> 12:05.100 <vLou>Right. So I think if you have someone with established lymphedema and you are using complete decongestive therapy, I think you could probably expect realistically about a 60% improvement.

12:05.500 --> 12:06.500 <vGore>Oh, that is pretty good.

12:07.600 --> 13:11.100 <vLou> So I would tell you though that the earlier the better. There have been some studies done in conjunction with the NIH that look at this concept of surveillance, getting a baseline, and then rechecking and retesting and if they have an increase of volume of 3-4%, the patients are immediately put into an elastic compression stocking or garment if it is for the arm. They wear that daily for a month and then when they come back and retest them, they find that has resolved. So really the earlier the better and I think that a lot of that has to do with they are now finding is that there is an inflammatory component to it and once it is established, it is harder to get that under control. There is a physician in Sweden that has looked at the fact that lymph fluid can turn to adipose tissue and so again once it turns to adipose tissue, your success rate is going to drop.

13:10.500 --> 13:15.500 <vGore>And using anti-inflammatory drugs are not useful?

13:16.600 --> 14:07.800 <vLou>That was Dr. Roxan at Stanford University. In Japan for a long time, they were using a certain anti-inflammatory for oncology patients, as a side effect, they were finding it was helping with swelling. So Dr. Roxan brought that to the United States as a clinical trial, I think they called it the Ultra Trial. They recently stopped that. What they were finding, is they were using it to see if it reversed established lymphedema. They had some initial success with it, but it was not meeting their expectation, so they have stopped it. I think the hope is that they will revisit that because some of their findings were that there might have been some initial benefit for early onset or prevention.

14:08.500 --> 14:24.800 <vGore>Well this is really fascinating and very important for our listeners who are either worried about lymphedema or actually do suffer from lymphedema. Right now, we are going to take a short break for a medical minute. Please stay tuned to learn more about lymphedema and cancer with Louis Friedman.

14:25.600 --> 14:40.800 Medical Minute: Support for Yale Cancer Answers comes from AstraZeneca, proud partner in personalized medicine developing

tailored treatments for cancer patients. Learn more at [astrazeneca-us.com](http://astrazeneca-us.com).

14:41.400 --> 15:36.400 This is a medical minute about smoking cessation. There are many obstacles to face when quitting smoking as smoking involves the potent drug nicotine, but it is a very important lifestyle change, especially for patients undergoing cancer treatment. Quitting smoking has been shown to positively impact response to treatments, decrease the likelihood that patients will develop second malignancies, and increased rates of survival. Tobacco treatment programs are currently being offered at federally designated comprehensive cancer centers and operate on the principles of the US public health service clinical practice guidelines. All treatment components are evidence based and therefore, all patients are treated with FDA-approved first line medications for smoking cessation as well as smoking cessation counseling that stresses appropriate coping skills. More information is available at [YaleCancerCenter.org](http://YaleCancerCenter.org). You are listening to Connecticut Public Radio.

15:36.800 --> 16:06.800 <vGore> Welcome back to Yale Cancer Answers. This is Dr. Steven Gore, I am joined tonight by my guest, Louis Friedman and we have been discussing lymphedema in cancer. Lou before the break, you were telling me about a study from Stanford where they were using an anti-inflammatory medication to try to impact established lymphedema and you said that it was not really clear how effective it was, do you think in the future they will revisit?

16:07.800 --> 16:35.600 <vLou>They have been talking pretty highly about this for a while, so in my opinion, yes, I believe, the hope is that they will regroup and maybe look at a different clientele. I do believe it is very difficult to study prevention even though we have some numbers of who will get it as a group, we do not know that any individual will or will not get lymphedema, so it is very difficult to then say this person did not, therefore this medicine worked.

16:36.800 --> 17:04.500 <vGore>Right, but I guess if it was an relatively innocuous intervention, it was not likely to be harmful, you could certainly take people who are at high risk and maybe give them the drug or placebo in a big enough study should be able to measure that. I would think that this is a big enough public health problem that the NIH would be very eager to fund such a program, I would think if there was good science behind it.

17:03.400 --> 17:09.500 <vLou>It seems like there certainly would be some benefit in regrouping and going in that direction, so hopefully they will do that.

17:10.800 --> 17:18.100 <vGore>Yeah. Do you think there has been a decrease in the incidence of lymphedema over the years as certainly breast cancer surgery has gotten more conservative in general or am I just making that up?

17:21.900 --> 18:16.500 <vLou>No, I do. I think in particular breast cancer of all the groups, I do believe the breast surgeons are very aware of minimally invasive surgery, so it is standard practice now to do the sentinel lymph node biopsy which for those who do not know is they take 1 or 2 lymph nodes, they

send that to the lab immediately for what is called a frozen section and they can determine whether it has cancer or not. If it comes back negative, or no cancer, they do not have to take further lymph nodes and that has been a big benefit to folks for not developing lymphedema. Actually, in our practice, we are seeing, I would say less lymphedema over the years. So we still see a lot of musculoskeletal issues related to the surgery and other issues related to systemic treatment, but I actually think the prevalence of lymphedema is coming down.

18:17.800 --> 18:42.500 <vGore>Gotcha and since you are a physical therapist as well as a lymphedema therapist, maybe a subset of one of the other, I don't know. If patients referred to you or self-refer for the lymphedema, do you take a more holistic approach in terms of combining the physical therapy with the treatment of lymphedema, does that make any sense what I am saying?

18:43.800 --> 19:46.500 <vLou>Yeah, it does. So let me answer. So we do work on referral, and so oftentimes, the referral is going to be for a specific issue, so the person might report to their provider that they are concerned about lymphedema or they are concerned about limited range of motion or pain. When they come to us, we look at them holistically, so even if they come in for the diagnosis of lymphedema, we are going to look at their ability to move their arm, their strength, any pain that they are having. Conversely, if they come in with just the diagnosis of limited range of motion or pain, we are going to look at their lymphedema as well. We are going to go ahead and get a baseline limb volume and also educate them as to not to get anyone paranoid, but you know there is a slight risk of you getting lymphedema, here are the early signs of lymphedema, so please keep an eye on it and then if you do see anything develop, then obviously let your medical provider know. It is just a different focus of intervention.

19:47.800 --> 20:26.500 <vGore> Provider-wise, who do you think is the best physician to be monitoring this? I mean our patients, so many of them have had curative surgery or surgery and radiation and I do not know really what the practice is, are they seeing their surgeon regularly, is the surgeon kind of responsible for looking at it, is it their radiation oncologist, is it their GYN or internal medicine, primary care provider, is it on the patient's shoulders to monitor herself or himself?

20:27.800 --> 22:30.100 <vLou>Yes, Steve, that is a very broad question. I think it really depends on where they are in the course of care. Let's just take an example of someone who is having surgery for breast cancer. Early on they are going to see the breast surgeon fairly frequently that will then become less frequent. During the course of that care, they may be seeing their medical oncologist and again depending on where they are, they may be seeing, even if they are going through the course of chemotherapy, they will be seeing the medical oncologist as well as the nurses who give the chemotherapy. At some point, they might be seeing radiation oncology. I can tell you here at Yale, at Smilow, everyone in that team is aware of lymphedema and knows what to do and is looking for it. What happens generally, well let me back up, those high

risk patients, we are starting to do preoperative assessment to get the baseline and setting them up on what we call a surveillance program or physical therapy clinic or rehab clinic to maybe see them once a month, every 3 months, every 6 months depending on how they are doing. Again, our goal is to try to pick up as early as possible if there are any issues. The issue I think becomes late on, they might be done with their oncology team, hopefully during that time, they have been educated enough. Some primary care physicians are aware of it and some are not, and again not to talk negatively, but if someone is not aware of it, they don't know. So educating primary care physicians is a great way to go. We think educating the patient is a great way to go, so that they can then say, I have lymphedema or I believe I have lymphedema and therefore I would like you to send me back to either again, the medical oncologist, the breast surgeon, or if they had been in our system and the rehab team send them back, so we can remeasure them.

22:32.400 --> 22:44.500 <vGore>Is there a period of time after treatment beyond which the risk of lymphedema is gone if the person has not developed it or is it sort of an ongoing risk overtime?

22:47.500 --> 23:21.300 <vLou>That is a great question. There is no timeframe. I can tell you that the majority of people who are going to get lymphedema, it will happen probably within the first 18 months to 3 years. Now after that, the rate of which people will get lymphedema is much lower, but there is evidence that people can get it 20 years after. It is just that it is a much lower rate. So you know, I tell people generally if you can get through the first 3 years, your chances are pretty good of not getting it or pretty good, but don't ignore it and do keep an eye on it.

23:22.100 --> 23:28.500 <vGore> Gotcha and are there clinics similar to yours broadly available in many places or is the setup that you guys have kind of unique?

23:29.100 --> 24:02.100 <vLou>Yes and no, there are more and more clinics available now, there are more and more therapists that will be coming interested in oncology care and are getting their certified lymphedema therapists. Most all of them are outpatient clinics, so if you look at Europe, their setup is different, they have a lot of inpatient clinics where the patients can go for this intensive rehabilitation that we talked about earlier the complex or complete decongestive therapy. Here in the United States, it is mostly setup as an outpatient.

24:03.800 --> 24:10.500 <vGore>So in Europe, they actually check-in to a spa or a rehab facility and do that for a week?

24:10.900 --> 24:16.500 <vLou>Yeah, could be a week, 2 weeks, 3 weeks depending on how long they need to get the lymphedema under control.

24:17.600 --> 24:36.500 <vGore>Wow, well you know this long history in Europe of testing the waters, I know some of the national health services in Europe at least recently would pay for like a spa, what seems as a medical benefit, it is



not a bad thing, not sure it is cost effective?

24:37.100 --> 24:54.400 <vLou>Well as far as lymphedema goes Europe has really been ahead of the curve, they have been doing this more since the 1920s, whereas it is kind of later in this country where we have been focusing on it.

24:55.100 --> 25:11.200 <vGore>I see. I won't ask you why you might think that is because I agree there are some political issues, I suppose, but once you have had this decongestive therapy, does it just stay away or is there maintenance that is required?

25:12.100 --> 26:13.100 <vGore>So you can look at the complete decongestive therapy in 2 phases, you can look at the intensive phase which would be all the things we talked about earlier, the manual lymph drainage, the compression, exercise, skin care. Doing that to get the maximum reduction you can and there is a maintenance phase which most likely would involve an elastic compression stocking, I am a big believer in teaching patients the exercise, teaching them how to do self-manual lymph drainage, teaching family members to do if they are able and willing to do it and then it is a matter of monitoring. So it depends on the clinic, it depends on the patient, getting back in for periodic rechecks is important, elastic compression needs to be replaced periodically, generally we will tell people you know every 6 months, the elasticity in the materials would degrade, so you want a new compression stocking to give the most elasticity you can get.

26:12.800 --> 26:17.500 <vGore>And are people wearing the compression stocking 24/7?

26:18.100 --> 26:47.500 <vLou>So generally speaking, an elastic compression is worn during daytime hours. There are providers that do advocate for 24 hours a day. I think you can do that as long as someone has no arterial issues. If someone has any arterial compromise, we certainly do not want to have an elastic compression stocking on them, especially when they are sleeping and they are not aware of it.

26:47.900 --> 26:52.100 <vGore>Okay, but these people are going around with the compression sleeve or stocking on.

26:52.800 --> 28:01.600 <vLou>There are always new fabrics coming out, thus I believe the vendors, the manufacturers are doing a great job of different types of compression products, different types of material, some that breathe more than others, so there are definitely options, there are some materials that you can put on, for example there is a what we call a nonelastic compression wrap that applies with Velcro, so that can be put on and taken off a lot easier, that is something that could be used for daytime or night time use, so that often gives a client or patient a little bit more flexibility. We have to look at whether they are being covered by insurance or not and that itself is a tricky issue, as is that intensive care that we talked about, trying to get someone in 4 or 5 days a week to do that, oftentimes, we find very difficult, whether it is trying to work

around their work schedule, copayments, parking, getting transportation, so we are always trying to adapt and fit the care to the patient as well.

28:02.900 --> 28:06.100 <vGore>So insurance does not cover all of these?

28:06.800 --> 28:15.600 <vLou>Some will and some won't and the best way we do is we will ask the vendor to do a preauthorization, so take the person's insurance information and just check with the insurance to see if it is covered or not.

28:19.200 --> 28:21.800 <vGore>Similarly for the visits for your manual decompression right?

28:22.800 --> 28:41.100 <vLou>The visits are generally covered pretty well and there might be some limitation to them as with all insurances, but a lot of that has to do with if the person is making progress, we can demonstrate the benefit, and also demonstrate the need, I would say that these days most insurance companies are very good about covering it.

28:42.900 --> 29:06.400 <vGore>Louis Friedman is a physical therapist and a certified lymphedema therapist. If you have questions, the address is cancer-answers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. We hope you will join us next week to learn more about the fight against cancer here on Connecticut Public Radio.