

Yale CANCER  
CENTER

*answers*

WNPR Connecticut Public Radio



*Hosts*

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Professor of Medical Oncology

Physical Therapy and Support for  
Lymphedema

**Guest Expert:**  
**Scott Capozza, PT and Lou  
Friedman, PT**

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*Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is [canceranswers@yale.edu](mailto:canceranswers@yale.edu) and the phone number is 1-888-234-4YCC. This week, the doctors are joined by Lou Friedman and Scott Capozza, two physical therapists who specialize in working with cancer patients. Here is Francine Foss.*

Foss Can you start off by telling us a little bit about what lymphedema is?

Friedman I would be happy to tackle that one. It is an accumulation of fluid in a body part where it does not belong. Often with cancer patients it happens when lymph nodes are removed. The lymphatic system helps to drain fluid out of a limb, say back to the heart, and if lymph nodes are taken out, that pathway can become blocked up, and fluid that would normally drain back to the heart can accumulate in a normal leg or other body parts.

Foss So the lymph node system is different than the arteries and the veins?

Friedman It is complementary, but it is different, it is a third system. The arteries bring fluid from the heart to the extremities, or outward, and there are two systems for returning it; one is the venous system, or the veins, and the second is the lymphatic system. The lymphatic system, by design, is to get the bigger molecules out, some of the waste products, bigger proteins, and things other than fluid that the veins will not bring back to the heart.

Wilson Tell us about your backgrounds. How did you each become interested in this field?

Friedman I have been a physical therapist for 27 years, and started out doing orthopedics and musculoskeletal problems, and probably 10 or 12 years ago I took a class in lymphedema and enjoyed it and started doing more work in that area, and then what happens is you bring on more cases, things that are not related to lymphedema, but might be related to oncology. Say working with people after mastectomy, shoulder problems, and one thing leads to another and I was actually quite drawn to the area and seemed to do more and more with it and really enjoyed it. The opportunity came up recently to work full-time at Smilow Cancer Hospital doing outpatient, and I jumped at the chance.

Wilson Scott, how about yourself?

Capozza I have been a physical therapist for about 12 years now and I am also a 12-year cancer survivor. I worked mostly in pediatrics, pediatric physical therapy, but like Lou, I started to take some courses in oncology rehab, and it was in the summer of 2006 when the CT Challenge Survivorship Clinic was going to be opening, initially over at Howard Ave., now at Smilow and the medical director at

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that time, Dr. Ken Miller, approached me and said, I want a physical therapist to be on staff as part of the clinic, and I jumped at the opportunity because I thought that would be a good challenge and a good way to take my professional skills and my personal experience and be able to help fellow cancer survivors. I got involved with the Survivorship Clinic and have been doing that ever since.

Foss Is it unusual for a cancer hospital to have their own physical therapist?

Capozza I would say no. I think that some of the larger cancer hospitals do have a rehab component, physical therapy, occupational therapy, and speech therapy depending on what the needs of the patient are.

Foss When we talk about lymphedema, which is the topic of our show today, do we need to be concerned about lymphedema in any situation where a lymph node is removed, or is it only in the context of breast cancer and the breast cancer surgeries that we actually see this problem?

Friedman That is a great question, it is a broad question and it brings us to who is at risk for lymphedema, and honestly, having a lymph node or a couple of lymph nodes removed does not put a person at higher risk for developing lymphedema. It is when someone has multiple lymph nodes removed, and perhaps combined with radiation, that may put them at higher risk. And this can happen in breast cancer if the lymph nodes are removed from the armpit or it could happen in the leg, if lymph nodes are removed from the pelvic area, even folks with head and neck cancer, if they have a neck dissection, can develop lymphedema of the head and neck area. Each person is an individual. Even in the worst-case scenario the statistics might be that 30% to 40% of patients would develop it and I tend to be positive and say, well, that means 70% will not develop it and I tend to switch it around that way for patients because many patients are concerned about it. They talk about that and they are actually fearful, it is almost like they hesitate to have surgery for breast cancer because they are afraid of getting lymphedema, and that certainly should not be the case.

Foss Scott, do you see lymphedema in the setting of pediatric cancers as well?

Capozza I have not seen it to be prevalent in pediatric cancers. I think you see it more in the breast cancer population, sometimes ovarian cancer, or prostate cancer.

Wilson The process of working with the patient, if we know that they are going to have surgery plus radiotherapy, and we are concerned that they are going to be at relatively high risk for lymphedema, do you start working with the patient prior to these procedures, in the midst of the cancer treatment, or afterwards? When do you like to get involved, when is it most beneficial?

Friedman Again, that is a broad question, and it depends on the clinic I think. There are some advantages to even doing preoperative assessments because it gives you your best baseline for someone who is going to have a problem, you have that baseline measurement. Mostly what we do in our

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outpatient physical therapy clinic, is we are working with patients during the course of their treatment. They are perhaps having radiotherapy or chemo treatments at the same time.

- Foss I imagine that there are some significant limitations to what you can do with those patients if they are fatigued from their chemotherapy or they have other side effects to deal with?
- Friedman You have to be creative, and it is a little bit of a challenge. Fatigue is certainly an issue. If it is after surgery, pain is an issue, and it is that right amount of aggressiveness between regaining function and not doing something that would disrupt say a surgical site or make it worse.
- Wilson What are some of the other functional problems that you have seen? Obviously, we have talked a little bit about lymphedema, but what other sorts of things are you involved with helping patients get better from?
- Capozza As Lou was referring to, I think cancer-related fatigue is one of the primary side effects from cancer treatments, and one of the things that we both try to educate our patients on is that cancer-related fatigue is something that can last for months, and sometimes even years after treatment is over. I think a lot of cancer patients will think that, oh, I finished chemotherapy three months ago, and so I should be feeling better right away, and that is not necessarily the case because the treatments are so powerful and so toxic to the system that it takes a long time to get all that out of your system. So, for us, a big part of it is education about fatigue and energy conservation as we move patients forward and to again educate them that it is not going to happen right off the bat, it is something that can linger for months and years.
- Foss There is the issue of overall fatigue but also there is the issue of actual muscle weakness, which we sometimes see, particularly in patients getting a lot of steroids as part of their therapy. How do you distinguish between those two and do you have a different way of approaching them?
- Friedman I would almost say that an even bigger issue, not to switch topics, but one of the bigger issues has to do with apprehension of movement, being afraid to regain function, being afraid to move, and as a result of that, getting muscle weakness from inactivity. One of the biggest things that we can do is educate the patient that, no, it is okay to move, and here are some certain guidelines to use so that you regain your strength and function, but don't overdo it. I think that is probably one of the biggest things that we do in physical therapy.
- Capozza I think that there is a very important point there, physical therapists and occupational therapists as well as the rehab team, are very important to help patients bridge that gap of I do not want to move, but really you do need to move, and you do not want to just cut your patients loose and say, okay, go exercise in a gym, you want them to work with a rehab professional to maybe give them some home exercise programs or something like that to build up their strength and work on posture and those types of things before they then go out into the rest of the world.

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- Foss I think another issue is that patients actually perceive the weakness and fatigue, and almost feel like they cannot get over that hump sometimes, and I know you probably see that a lot, so how do you deal with that?
- Friedman It is a really good question and I think it has to do with graded exercise in small bits and pieces, and I like to give feedback. Let's use something like an arm curl as an exercise and just for the sake of an example, say, here are 2 pounds and you did four repetitions, okay, the next time, there are 2 pounds but you did six repetitions, and that is an improvement. I track it so that the person can see those little gains adding up over time.
- Capozza And one of the things that I like to do is, we talk about having people exercise as a gold standard 30 minutes, five times a week, and a lot of people are not ready for that when they are right out of treatment, and likewise, I will break it down as well and say, okay, instead of doing 30 minutes all in one shot, maybe do 10 minutes in the morning and 10 minutes in the afternoon and 10 minutes in the evening if you can. Or even just do 10 minutes in the morning and 10 minutes in the afternoon, and that is a start, and like we said, then you build upon that. Rather than having it be this big thing that can be overwhelming for patients, you break it down and you make it a little bit more attainable.
- Wilson Generally, how often do you meet with patients and how long is a patient in the program, on average?
- Friedman That is going to be different for Scott and myself. In the outpatient physical therapy, we will see people anywhere from one to five times a week, and it really depends. If we have a real significant case of lymphedema, that person can be seen five times a week. If it is someone where we are trying to make sure they regain mobility and function, but maybe they have not had surgery all that long ago, I might see that person one time a week, send them off to do some home exercises and then monitor them and then upgrade the program. I think Scott will probably have a different answer for the survivorship.
- Capozza For the CT Challenge Survivorship Clinic, we typically see people for three visits that are spaced out 2 months apart. So, a survivor will come in for an initial visit, and then we will have them come in for a 2-month follow-up and then for a 4-month follow-up, so that way we can follow them along and see how their progress is going.
- Foss Lou and Scott, I am interested in knowing exactly what happens at a physical therapy appointment. A lot of people think about physical therapy as just being exercise, but I know you use a number of modalities like ultrasound and heat and a lot of other things as well. Could you take us through some of the things that you do and what a typical appointment would be like?

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Capozza I can tell you from the Survivorship Clinic, I do range of motion screenings and strength screenings, balance screenings, and then if somebody needs a home exercise program, I will give them a home exercise program. If somebody does have lymphedema, then I will refer them to Lou. Or if they need some more intensive hands-on treatments, then I will refer them on to Lou.

Friedman The outpatient physical therapy clinic is a little different, but basically all our treatments are based upon our initial assessment. We try to individualize each treatment based on each patient's individual needs. Whether it is range of motion and strength, if a person is coming in for lymphedema, we have an infrared scanner where we get lymph volume and girth measurements and, again, assess the lymphedema with our hands, whether it is soft or pitting, and it will depend. If we are working with someone for range of motion, say after mastectomy, this is going to be a combination of doing some hands-on care to stretch out the soft tissue, maybe mobilizing a joint, doing some exercises with them, and we are very big into education and home exercise and patient responsibility.

Wilson We are going to take a short break for a medical minute. Please stay tuned to learn more information about physical therapy for cancer patients with Lou Friedman and Scott Capozza.

*Medical  
Minute*

*It is estimated that nearly 200,000 men in the US will be diagnosed with prostate cancer this year, and over 2,000 new cases will be diagnosed in Connecticut alone. One in six American men will develop prostate cancer in the course of his lifetime. Major advances in the detection and treatment of prostate cancer have dramatically decreased the number of men who die from this disease. Screening for prostate cancer can be performed quickly and easily in a physician's office using two simple tests: a physical exam, and a blood test. Clinical trials are currently under way at federally designated comprehensive cancer centers, like the one at Yale, to test innovative new treatments for prostate cancer. The da Vinci Robotic Surgical System is an option available for patients at Yale that uses three-dimensional imaging to enable the surgeon to perform a prostatectomy without the need for a large incision. This has been a medical minute and more information is available at [YaleCancerCenter.org](http://YaleCancerCenter.org). You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.*

Wilson Welcome back to Yale Cancer Center Answers. This is Dr. Lynn Wilson and I am joined by my co-host Dr. Francine Foss. Today, we are joined by Lou Friedman and Scott Capozza, and we are discussing physical therapy and cancer patients. Gentlemen, tell us a little bit about exercises that might help reduce the effects of lymphedema, say in a breast cancer patient.

Friedman I will start with that one, and that really depends on where we intervene with the patient first, and it will depend on the severity of the lymphedema. Early on, even almost immediately postoperative, we want the person to do some deep breathing exercises, make sure they have good posture and not get caught in a kind of slumped posture, a protective posture, and even muscle pumping activities of muscles away from the surgical site. The last thing we want to do is disrupt the

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surgical site or if they have a drain in, to disrupt that, but we do want the body moving. Later on, it helps to regain motion and strength and get the muscles moving. There was almost a fear of doing weight training at one point and all the recent studies have shown that weight training will not increase lymphedema if done correctly, but it will help reduce lymphedema. The big thing there is to guide the patient on how to do it correctly, starting at a low level progressing slowly. If you have someone with more severe lymphedema, that is a case-by-case basis that has to be done with the use of compression and things along that line. That is going to be a more individual basis.

Foss On that note, can you talk a little bit about the lymphedema sleeve?

Friedman The lymphedema sleeve is a form of compression, and compression is very important in the treatment of lymphedema, and there are many different types of compression. Basically, a lymphedema sleeve is something that you pull on; it is like a fixed stocking. If we are talking about something for the arm, it should be used with a glove or a gauntlet, and not alone. It really depends on the goal of compression. If you are trying to reduce lymphedema, there are actually better ways to do that than a sleeve, we use short-stretch bandaging and other types of materials in conjunction with a hands-on treatment. The best use of a sleeve is in prevention, if someone does not have lymphedema and you are trying to prevent it, let us say, they are going to be on an airplane, or after you are done with your treatment, you have reduced the swelling and you want to use something to maintain it, the sleeve is a wonderful way to do it. Basically, what it does is it squeezes the arm, and it makes less space for the swelling to accumulate.

Wilson That is interesting, Lou, that you made the mention about it should not be used alone, a sleeve. I have seen lots of patients, who have a sleeve on, and it is pretty effective at eliminating lymphedema in the arm itself, and then they have a gigantic hand at the end of that sleeve.

Friedman Because it is all based on pressure gradients. Let us say down at the wrist, you are going to have more pressure, and up at the upper part of the arm, you will have less pressure. So, the fluid is going to follow that pressure gradient. The problem is if you are squeezing at the wrist, the hand has less pressure as well, so the fluid tends to accumulate there, and unfortunately, I have seen a lot of it as well, people come into the clinic and say I have got this beautiful sleeve and I will say where is the glove, and they do not have a glove. That is the first thing we do is to get them to go out and get a glove or a gauntlet.

Foss Lou, are these sleeves custom-made for the individual patient?

Friedman They can be, but there is also what we call off-the-shelf sleeves. If it is to fit a certain size, they can be off-the-shelf. If the limb is misshapen in any way you have to go custom, and there are also different types of materials to use in a sleeve, and if you want to go with a certain type of material, like a flat knit, that is going to be a custom garment.

Foss And can woman start the process of dealing with their lymphedema during the course of their

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chemotherapy after their breast cancer surgery, or do they have to wait until the chemotherapy is done?

Friedman They can start right away, and sometimes it gets a little complicated with chemotherapy because that will affect the fluid balance in the body, and sometimes it is confusing as to whether the swelling is related to the chemotherapy, or is the swelling related to the lymphedema, but we try to sort that through as best we can.

Wilson Scott, have you noticed in your practice, patients deriving general benefits from physical therapy? Obviously, they may have a specific problem, you are seeing them and helping them with that, but just having patients get a sense of improvement and getting closer to their normal life baseline, do you feel that the program is helpful in general and has other benefits aside from the very specific problem you might be focusing on?

Capozza Definitely, when I see patients at the Survivorship Clinic, it is kind of the gamut, and as Lou was saying, it is very individualized. A breast cancer survivor will come in and she'll have a certain set of questions and then a gentleman who is a colon cancer survivor will come in and he has another set of concerns and questions, and so to be able to be there and work with them to give them exercises to do at home is critical. And again, I think the biggest piece that we do is education, and to be able to have that education piece there for patients is really critical, and then on top of that, not just myself, but the whole clinic is also staffed by a medical director, a dietician, and a social worker. So, when a survivor comes into the Survivorship Clinic, they see all four professionals, and they leave with a lot of information, not just from physical therapy but from those other realms as well because as we all know survivorship is such a broad topic and it hits on so many things.

Foss Scott, do you speak with the physician, with the medical oncologist, prior to seeing a patient in the Survivorship Clinic, or do you already know what the issues are for that patient? Do you assess them first and then meet as a group?

Capozza We get the records ahead of time. Our staff meets one hour prior to clinic starting and we go over everybody's medical record so that we have a general sense, and it gives each of us a good idea of what questions we need to ask. It helps us target those particular questions that we need to ask, and then once that initial visit is over, again, if they need additional follow-up say, for example, a breast cancer survivor comes in and needs a sleeve or needs lymphedema treatment, then I refer them to Lou. If somebody needs to have more labs done or needs to meet with the cardiologist, then our medical director makes that referral. Basically, whatever referrals need to be made from then on out can be controlled through the Survivorship Clinic.

Foss Lou, how often do you actually interact with the medical oncologists when you are treating a woman with say, breast cancer?

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- Friedman It varies case-by-case. One of the things we do is if the person is not seeing the oncologist on a frequent basis, we can almost act as an extension of their eyes and ears. In other words, if things are going along well, they do not hear from us. If, in fact, we are having issues and we see something that does not sit well with us, then we contact them immediately or someone in that office and ask their opinion and do they need to see the person.
- Wilson The Connecticut Challenge Survivorship Clinic is obviously a special opportunity for patients, and an important part of our Yale Cancer Program. You mentioned it in the beginning, but give us some more details about how it first started and its background? Tell us what a typical visit is like for a patient when they hit the door. Who do they see and what is it like?
- Capozza The CT Challenge Survivorship Clinic was founded in October 2006, and it really was the idea of a local survivor named Jeff Keith, who as a childhood cancer survivor was treated at Dana-Farber and as an adult went back to Dana-Farber for a survivorship visit, and he realized that why should I need to go to Boston to have my survivorship needs met, there should be something here in Connecticut. So, through fundraising, through the Connecticut Challenge Bike Ride, which is an annual bike ride held every July, the funds were raised in order to open the first survivorship clinic in the state of Connecticut at Yale Cancer Center, which is now over at Smilow. The clinic has been in operation since 2006, and a typical visit would be that a survivor comes in, and again it is for a survivor of any cancer, breast cancer, colon cancer, ovarian cancer, any adult cancer survivor, they come in and like I said, they will meet with four healthcare professionals. They will meet with our medical director, our dietitian, our social worker, and myself, and it is a Wednesday afternoon, we block out 2 hours for those appointments and then you come back for a 2-month follow-up and you come back for a 4-month follow-up so that we can see how you are doing as far as the recommendations that we gave you moving forward.
- Wilson Does a doctor have to make a referral or can any survivor call up themselves and make an appointment?
- Capozza Both. We can have survivors' self-refer, and we can have a physicians' referral, and actually it can be even the APRNs or social workers, anybody who is part of the cancer care team can make a referral.
- Foss To what degree are you focused in the Survivorship Clinic on getting people back to their normal life, and to what degree are you focused on just kind of getting them through the trauma of all the treatment? Eventually, you want to get them back to their life.
- Capozza I am trying to do both, to be honest with you. Our social worker does a great job of helping people get over the psychological trauma of cancer and then whatever other events are going on in their life at that time. For me, I try to do both, a little bit of both. I try to pull from my professional expertise and my personal experiences as a survivor to help people get through what they are going

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through, and definitely I want people to walk out there with a plan. I find individually what each person wants. Do they want to be able to run a 5K? Do they want to just be able to get back to work? Do they want to be able to just be back to where they were beforehand? So, that is my goal, whatever is important to the patient is what we will work through.

Wilson Lou, you talked about the sleeve and gloves, specifically for lymphedema, tell us about what other materials or devices are at your disposal that you might incorporate into the rehabilitation for a patient.

Friedman For lymphedema?

Wilson Yeah, or just other things that you deal with in your daily professional life in general to help patients.

Friedman For lymphedema, it is really a comprehensive program called complete decongestive therapy that includes compression, manual therapy, exercise, skin care, and education. There are many, many types of compression sleeves that are on the market for nighttime use so that people do not have to wrap. The compression pump is something that is of interest. It has been around for years and really was the mainstay of treatment for venous edema, and I think it was incorrectly transferred over to the treatment of lymphedema, and oftentimes there is a bit of misuse, but it really has great use for someone who has, say, soft edema, non-pitting edema, and is looking for a way to manage their lymphedema at home on a regular basis. When it comes to dealing with just musculoskeletal issues, a lot of what we do is hands-on, and a lot of education and teaching, and we certainly have many modalities to use, like heats and ultrasounds, but with the oncology population, we tend not to use them and those have more of a use in the orthopedic population. We rely on a lot of teaching the patient to manage things. We get the families involved quite a bit. I teach family members all the time how to become therapists, within a certain range of things that will help their family member at home.

*Lou Friedman and Scott Capozza are physical therapists who specialize in working with cancer patients. If you have questions or would like to share your comments, visit [yalecancercenter.org](http://yalecancercenter.org) where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.*