



Breast Cancer Rehabilitation: What You Need To Know

November 11, 2008
Richard DeMaria, PT

ELYSE S. CAPLAN, MA:

Welcome. Good evening, everybody. It's nice to see all of you at the end of a long day, I'm sure, especially now that we've turned out clocks; it gets dark out earlier, so it's hard. My name is Elyse Caplan. I'm the education director at Living Beyond Breast Cancer. Tonight we're going to learn more about breast cancer rehabilitation, some of the key points that are important for you to know.

On a personal note, I'll just mention that I was diagnosed with breast cancer in 1991, and I can tell you that 17 years ago, breast cancer rehabilitation wasn't really even talked about. The oncologists were busy taking care of us with their medical treatments, and the radiation oncologist with radiation, and the surgeons with surgery. But there wasn't as much focus on quality of life, and there wasn't as much focus on managing the side effects, preventing what we can. It was much more dealing with the effects of cancer treatment after it happens.

I'm happy to say that over the 17 years, I've been able to see the changing face of how people with cancer are treated and managed as it relates to their breast cancer, as it relates to quality of life . . . and what I've seen in the years I've been doing this work is that quality of life and the most effective treatment are pretty much up there on par. They're equally important.

We want to get women treated with the most effective treatment to take care of their breast cancer, but we also want to minimize and prevent as many side effects as possible. I'm sure many of you are here because you may be dealing with lymphedema or other side effects, such as fatigue or loss of endurance or stamina or all these things. You will be very happy to hear from our speaker, Richard DeMaria, and he will give a good overview in the time that he has to help you understand what rehabilitation can be, and how starting out, even before your surgery in many cases, can help you throughout the duration of your treatment and then in your post-treatment recovery period.

Let me tell you a little about Richard DeMaria. Richard has been a licensed physical therapist for over 30 years. He is a certified compression therapist with a focus on assisting people recovering from various forms of cancer and a special focus on meeting the rehabilitative needs of women and their families recovering from breast cancer. Richard's services include but are not limited to treating issues surrounding breast reconstruction, lymphedema, general debilitation and functional capabilities surrounding work and productivity. He is president and director of the Cancer Rehabilitation Program at Dynamic Rehabilitation Services, a multi-site provider of physical and occupational therapy services. Richard has served as a national officer and national membership chairman of the oncology section of the American Physical Therapy Association, and he has many other credits to his name. Without further delay, please welcome Richard DeMaria. (Applause)

RICHARD DeMARIA, PT:

Tonight we're going to briefly go through some different aspects of rehabilitation as it pertains to people recovering from various types of cancers. We'll quickly transition into the world of the applicability toward people with breast disease and then finish up with a bit about lymphedema. Several people in here have asked me about that tonight, and we will go over that a bit. In general, as Elyse said, I am a physical therapist. I have been practicing in the Philadelphia area for quite a while, and my clinical focus is exclusively on that of meeting the needs of people with cancer. Probably 50 percent of my caseload is women with breast disease, and the rest of the people I see range from limb salvage to hospice.

A rehabilitation team: If you were to look at this slide – this is kind of following the slides – it's made up of a lot of different people. At the start

– and the most important part – is the patient and their loved ones. Success in whatever we're doing transmits into making certain that loved ones and people who care about patients are incorporated into the system. That makes my job much easier, and it makes the job of the patient much easier.

Physicians: There are a myriad of physicians who take care of people with cancers. It could be radiologists, radiation oncologists, surgeons, reconstructive surgeons, medical oncologists and primary care doctors. Incorporating all of the physicians on the team into the rehab component is, quite frankly, poorly understood in the world of medicine.

Elyse said that 17 years ago – it's hard to believe that's when we met – it was just not understood or part of the program. That's evolving. It's improving, thank goodness. But physicians still have to be kept abreast very closely about what the rehab component is trying to accomplish. Then, there are usually physical therapists, occupational therapists and, in certain situations, speech pathologists. Certainly nursing is involved in it, social service, psychological services – because, remember, this disease impacts people's emotional state very, very much. Perceived threats are frequently dealt with by means of emotional upset. That needs to be addressed always. Also, aides and home health aides are dealing with it.

I'd like to briefly say what a physical therapist is. I am a physical therapist. I am a licensed-by-the-state, practicing clinician. Currently, to be a physical therapist you must have a master's degree. It's moving into a doctoral program at this point. There is clinical training that goes along with it. We have to be trained in doing a myriad of types of services, whether it is rehabilitation of orthopedics, stroke patients, hospital work. There are a lot of different types of services that physical therapists work in, and our initial training has to cover pretty much all of them.



Continuing education is required after that, and a lot of what we do is focused on what you want to do. I could treat a young child with cerebral palsy, I guess, but you really wouldn't want me doing that, because it's not what I do. My focus has been on taking care of the needs of people with various types of cancers. Then, there is credentialing in the world of physical therapists. There are clinical specializations in many types of fields. Oncology does not have that, but it is in the works. I'm on the committee to help develop the testing for that currently, so we're hoping that within the next several years, there will be clinical specialization in the world of oncology.

Then, there is also in the world of physical therapy the ability to be an independently practicing physical therapist, which means you do not necessarily need a referral from a physician. I am one of those. I've taken some additional study work, and we do that. But most all of the patients we see are coming directly through a physician.

Physical therapists can work in a lot of different places. It's really an awesome field. I can't tell you how much I love what I do. People can work in hospitals or healthcare systems. They can work in rehabilitation facilities like Bryn Mawr Rehab [Hospital] or ones in the city. They can work in outpatient settings, in the home, in schools, in sports medicine centers, in aquatic centers. And relatively recently, more and more physical therapists are working in the health and wellness arena. Gyms and private health clubs have rehab components to them.

There are a lot of different clinical focuses. Some of them are functional and disability evaluations. Physical therapists work to determine and quantify levels of disability in people. One of the cool things about this field is that you look at people for what they can do. You realize, "My knee doesn't work," but really what it translates into is, "I can't get up and down the steps, and I have to get up and down the steps to work, so consequently can or cannot do my job." We look at people functionally rather than just from a level of pathology.

There's a pediatric focus, cardiac rehab, geriatric, women's health. There's neurological, which is a big part of rehab in general, whether it's stroke or spinal cord patients. There's orthopedics. Everyone gets that. Orthopedists really understand what physical therapists do, whether it's in sports medicine, joint replacement, amputations, etcetera. Then there's also the world of oncology.

WOMAN:

Would that cover people who maybe like [inaudible] Arimidex, and you have joint pains and stuff? Would you cover it?

RICHARD DeMARIA, PT:

We would identify people who are on Arimidex who do have joint pains as well, but that's a byproduct of the medicine more than, like, if you had arthritis or a broken hip or things like that. But that's true, and a physical therapist could address some of the joint pains that people have with some of these medications. In the world of oncology, for years, when I would tell people I'm a physical therapist and I work with people with cancer, the response would usually be some dumb look, and they'd say, "Physical therapy for people with cancer? What do you do? What do you do?" People really didn't understand it. My response has turned into a relatively pat response, and that talks about the results of the medical model that helps people recover from cancer.

In general, surgery, chemotherapy and radiation are the primary types of interventions that help save people's lives with cancers. Think about what that does to you or does to someone. Rarely does somebody get done a series of Cytoxan and Adriamycin and say, "Man, am I pumped up. Man, give me a little more of that. I'm juiced from that." It frequently can be physically depleting and, consequently, emotionally depleting as well.

The very nature of people getting physically and emotionally depleted from the procedures to save their lives needs to be addressed. A lot of times, doctors will say, "Go out and walk." "I'm tired, I'm tired, I'm tired." "Go to bed" – that's another good one. Or, "Get out and walk." Well, they have no idea what kind of condition people are in. They have no idea if they're going to walk a quarter-mile, a mile, 12 miles, or they're going to just keep walking – the Forrest Gump approach. What we do is address the specific needs individually and do assessments of people's level of fitness and progress them. I like to say it is much better to maintain strength than it is to try to regain it.

If people know they're going to be entering a course of treatment that is going to physically deplete them, why not start right out of the get-go and exercise and try to stay strong – along with proper nutrition that we all understand, surrounding yourself with people who love you, all the important things that will help maintain you in a more fit and better way?

WOMAN:

What happens if they're already physically tired from all of the different treatments? Wouldn't it be kind of hard to make them go out and exercise or proper nutrition or talking to their treatment team on different exercising personally in the home or in the office?

RICHARD DeMARIA, PT:

Guaranteed, if someone is fatigued and they don't eat, they're not going to get stronger. So you have to encourage and motivate people to do the best they can.

WOMAN:

You have to [inaudible].

RICHARD DeMARIA, PT:

Consequently, if people are exhausted – often people say to me, "I am washed out. I'm exhausted." Well, you can't say, "Too bad; drop and give me 20." That doesn't work. But you have to encourage them to do some kind of intelligent, controlled exercise program, because fatigue will increase with rest. If you do too much, it will also increase the fatigue, which brings me to the point of why someone undergoing cancer recovery services needs someone to give them treatment or exercise or conditioning in a medical model.

Believe me, if you're washed out from having gone through weeks of chemo and surgery and radiation, and you go to the local gym and have some rock-head say, "I'm going to pump you up," you could be in trouble. There are a lot of issues. People have diminished hemoglobin levels; they have a lot of different issues that can impact their ability to properly exercise.

Physical therapists are experts in exercise, and we're experts in exercise as it relates to pathology. We look at the person; we understand the person's needs. We assess their current levels of fitness, strength, flexibility, endurance, and then design programs to help them get better, certainly maintain where they're at, and not get weaker.

General fitness: We're going to try to get to the breast stuff in a hurry, guys. By the way, if there are any questions, just shoot. The three components – primary components – of general fitness are strength, endurance and flexibility. We're going to talk about that as it pertains to several different issues tonight. But when you come right down to it, that's really what we're talking about: being strong, having the endurance to use that strength on a repetitive basis and having normal joint flexibility.



LIVING BEYOND BREAST CANCER®

L B B C . O R G

When it comes to strength, things we're looking for are, number one, symmetry. If someone has surgery on one upper quadrant of their body, we're looking by the time we're done with them to have similar strength on the right side as they have on the left. We're not trying to turn everybody into Arnold Schwarzenegger. We're trying to look at people, individualize what their bodies are capable of, which is frequently age, gender and body type. We're looking for symmetry and strength; that's an important key. Also, functional ability: If your job is moving pianos versus delivering mail, you need to be stronger if you're a piano mover. We look at what people need to do and then the degree of symmetry from right to left or top to bottom and calculate it like that.

Endurance: This is a very complicated part of what we do. The strengthening piece is much more simple, because you're either strong or you're not, and you know you have to load the muscles and make them lift weights on some level or lift resistance. Endurance is much more complicated, because it involves muscle usage, muscles' metabolism, of oxygen. It also involves your heart's ability to assimilate blood and strength, and a lot of different things, and your blood's ability to transport the oxygen and the nutrients to the muscles you need it in. These things can get wacky when you're undergoing these chemotherapeutic interventions.

From an endurance standpoint, we are very, very cautious when it comes to properly assessing people. We never have a patient come to one of the clinics and say, "Warm up on that bicycle for ten minutes." That doesn't work, because I've seen people who look like they are aerobics instructors get on a bicycle and their pulse shoots up through the roof, and I've seen people who look like they've never had a pair of sneakers on able to do it. In general, my rule is – especially if you have a diagnosis of cancer – I don't trust you. And we're going to test you before we put you on anything. And the way we do it, people can be tested – yes?

WOMAN:

I know if you've had radiation on the left-hand side, you're at high risk for having a heart attack. Am I saying it right? Would you give someone a strenuous exercise for that left side if they were having problems with that left side?

RICHARD DeMARIA, PT:

I'm not certain I've read a lot of literature that says if you've had radiation to the left upper

quadrant that you are at risk of a heart attack. But we would never exercise anyone without assessing their cardiac output, whether they've had radiation or not, because much more than radiation impacts the heart. How about some of these cardiotoxic drugs? Cytoxan and things like that affect the heart, which is why you need a MUGA scan before you get started on that chemotherapy. How about immobility? People have these surgeries, and they're not out jogging every day. They're lying around healing up. Immobility makes you more out of shape, so you can respond differently. In general, the answer to that question is that we would not have anybody exercise, regardless of the interventions they've had or are going to have, without properly assessing their ability to exercise. And that involves radiation.

One way to do it is to go to a cardiac lab and they do a full-blown, maximal stress test. What we primarily do are submaximal stress tests. We calculate what your age-predicted maximum heart rate is and then take you up to about 85 percent of it. Basically, people can go further than we're testing them, but we're looking for limitations that people have on the lower end of the cardiac output spectrum. Then we do functional assessments of them as well. If people say, "I can't do it; I can't do it," and I say, "But your pulse is only at 90," we listen to the, "I can't do it," because that's a very important consideration.

From that testing, we're able to write exercise prescriptions. An exercise prescription is an alternative to saying, "Get on that bike and pedal for ten minutes." We tell people to put on a heart-rate monitor. I want your heart rate between 110 and 130 for 15 minutes, and I want you to cross-train on an elliptical trainer and a bicycle so that we are safely exercising people within parameters that are safe for them. It's important. First off, I think it's important for anybody, but it's really important for someone who has had medical interventions that could impact their cardiac output and their ability to exercise. Any questions?

Now, flexibility is another component to this. That's starting to get closer to the world of breast disease, because frequently when women have breast surgery, it impacts the mobility, their availability of mobility in their arms. Once again, we're looking for symmetry. I had a new patient this morning. The woman was about 75 years old. She had a mastectomy. She did not have a reconstruction. When I asked her to lift her uninjured arm, she went to here. When I asked

her to lift her involved arm, she went almost as far. Normally, if I can lift my arm up to 180 degrees, that may be a very unrealistic expectation for that woman.

What we're looking for, again, is some degree of symmetry. We want the right side to match up to the left. Got that? It can be age-related. Even though there are established norms for range of motion – a normal range of motion and forward flexion is zero to 180 degrees straight up – but that's age-related and pathology-related. So we look toward the symmetry when it comes to all parts of the flexibility.

[Inaudible Question]

Now, that's a very good question. She asked if one side has a problem like arthritis and the other one does not. No. We would probably look a little more closely at how much available motion could be made on the arm that does not have the arthritis. Or how about if somebody had a big surgery on one of their shoulders and their arm didn't work properly, and then they had a mastectomy on the other side? Just because they could only lift one arm up to 90 degrees does not mean we're going to be satisfied with that on the other. That was a very good question. Symmetry does not always rule.

WOMAN:

My question is if your mobility is impacted when you have physical therapy after breast surgery or reconstruction, with physical therapy will you ever gain that symmetry back again, or will it still always be slightly off?

RICHARD DeMARIA, PT:

It should come back pretty much to the norm. She said if you have restricted motion – and I assume if we're talking about breast disease we're talking about post-breast surgery and the limitations in motion in your shoulder. It has been my experience that almost always we can regain full mobility, unless the people are like, "Well, I had surgery five years ago and I haven't lifted my arm up for five years, and now I want you to get it better." That turns into the "tear and swear" of physical therapy. We do the tearing; the patient does the swearing.

The reality of the situation is that if you get into it in a timely basis, there is really nothing wrong with the shoulder joint complex. The problem is with the muscles that surround it, and it's soft tissue, and you can usually overcome that.

Now let's talk about physical therapy as it



pertains to people with breast disease. When one looks at someone who has had surgery for breast disease, the main impact that we see that people have would be from surgery, chemotherapy and then radiation – not in that order, and not always all three. The primary thing I see as a physical therapist is people who have had some sort of surgical intervention: a lumpectomy, a mastectomy, a mastectomy with various types of reconstructions. The most comfortable way for somebody to hold their shoulder after surgery, regardless of the [shoulder], is like Napoleon, which makes it much more difficult, eventually, to hitchhike. Rapid intervention and getting mobility in the shoulder has become the rule.

We're seeing more and more times now – I've been doing this a long time, and it used to be that people would come to me postmastectomy, 20 years ago, and they would have these capsular patterns where they couldn't move, because no one in the hospital would tell them, "Walk the walk, get your arm up, do whatever." That's much more the standard of care now, so people are coming to see us with better admitting mobility in their upper quadrant. What we're frequently seeing is imbalances between the multiple joints in the shoulder complex.

The shoulder is the most complicated joint in the body. A knee is like a dum-dum joint. It's a hinge. A shoulder is made up, really, of four joints, but primarily two, one being where the humerus rotates in the scapula, and the other being where the scapula rotates on your ribs, where there's a natural relationship between both of those joints to have full usage of your arm. We frequently see people who are good with the gleno-humeral joint, but the scapular-thoracic motion doesn't work, so we look very closely at the whole complex of the joint and make sure it's working in a normal fashion.

What we're looking for on women who have had breast surgery – whether it's a simple lumpectomy, a mastectomy with no reconstruction or a mastectomy with many types of reconstructions – is, number one, posture. Chest is connected to the shoulder, shoulder is connected to the neck, etcetera. We frequently see people with protracted shoulders, uneven posture, protracted neck, because it's all about being comfortable after the surgery. The last thing you want to do after you've had breast surgery is this, so frequently people will assume postures that are more comfortable, and it results in restrictions in motion.

Then we look at flexibility. We always look at adjacent joints as well. We don't only look at the shoulders. We look at the elbows, and we look at the neck and spine as well. Because the shoulder bone is connected to the neck bone and such, you have to look at the whole system.

We check strength, once again looking for symmetry, and then we check function to see what they can do. I've seen people who are so strong and so flexible, but after surgeries like this, they just can't get it together to use their arms correctly. They have coordination issues and problems with this. It could be because they're guarding, because they're scared. It could be because they're still in pain. It could be a lot of things. So we look at posture, flexibility, strength and function, not necessarily in that order.

WOMAN:

What happens if a person has other elements, like maybe back or whatever? How can they assess whether they're doing what they can or overworking themselves to impress the physical therapist?

RICHARD DeMARIA, PT:

To impress the physical therapist? Well, we demand that. (Laughter) We insist on our patients trying to impress us. The reality is that frequently, as difficult as it can be to motivate someone to do something, we've had many patients where you have to throw the lasso on them and say, "Slow down and do less." It's very common in people to have various types of comorbidities. Arthritis is a big one. Bad backs are huge. We see tons of bad backs. One of my missions is to educate plastic reconstruction surgeons to try to avoid TRAM procedures, which is a type of breast reconstruction, if a patient has a bad back because it just magnifies the whole system. It destabilizes your pelvis, and it affects your back.

We look at the comorbidities, and we look at those things and incorporate it. Although I like to be impressed by patients – I like that; trust me, I do – but the reality is that we're not letting you trick us and say, "Oh, I'm going to do more than you asked me. If I hurt my back, it's on me." That doesn't work with us. We try to control the system and look at people individually and make sure we do the best we can without having them injure themselves, even if it's at the sake of not impressing me.

WOMAN:

In general, is there a critical time when the rapid intervention is most useful?

RICHARD DeMARIA, PT:

In general, rehab services should be incorporated right away. It has always been my dream that the diagnosis of cancers – and not only breast disease – would unfold something like this: "I hate to tell you this, but you have cancer. But here's what we're going to do for you. We're going to get blood work. We're going to get CAT scans. We're going to get this. We're going to send you to a nutritionist. We're going to send you to a family counselor because there are impacts on your family. We're going to send you to rehab because we don't want you getting weak with this. We're going to send you to the radiation oncologist and surgeons." But to incorporate it right away, so that it's in the loop – it's very, very hard to get docs to get that.

WOMAN:

Do you think there is reluctance on the doctor's part to recommend physical therapy? I had breast cancer and a double mastectomy, but I'm also a fitness instructor for breast cancer survivors. I see a lot of people coming in months later, as you're describing, with very limited range of motion. And they say their doctors never said anything to them. I don't know if it's the doctors who are reluctant to, or is there something with insurance? What can we do to encourage doctors to make these recommendations?

RICHARD DeMARIA, PT:

One of the issues is that, in general, physicians don't necessarily understand the applicability of physical therapy or rehabilitation services. A lot of these guys are molecular biologists, and while they say they preach the concept of, "We believe in quality of life," what they're really doing is looking at lab studies a lot, and they're really trying to save your life and do things a physician would do. In fairness to most physicians, I don't think, other than surgeons, that they necessarily get it.

I've done this sales pitch for years and years and years, and when I used to promote my practices to physicians, I would say, "Please send your patients to us. We are good. We know what we're doing. We have clinical focuses of cancers." And they would look at me and say, "Physical therapy for people with cancer? What do you do?" Before physicians can understand that they would send it to clinicians who know what they're doing



LIVING BEYOND BREAST CANCER

L B B C . O R G

about it, they have to understand that they should be sending them to them. It has been my experience that most surgeons are more mechanics, and they get it a little more. Also they've been impacted, perhaps, by lymphedema more, which has been treated by therapeutic interventions more.

The medical oncologist should be the number-one referral source to this, because they are seeing the physical and emotional depletion of these patients, the gradual weakening of them, and it has been my experience that our referral mechanism, in the world of cancer doctors, they're the least willing to refer. Unless we get these wonderful referrals that say, "Rich, I'd like you to go see this guy. He can't get out of bed. Three months ago he was walking pretty well, and we've really been bombing him with heavy-metal chemo and whatever, and now the guy can't get out of bed."

WOMAN:

[Inaudible] to be persistent about how bad the pain is, how bad the – they don't have the mobility. Is that how you say it? So sometimes the patients have to be persistent with the doctor for the doctor to realize that it is bothering them like that to [inaudible].

RICHARD DeMARIA, PT:

Consumerism is very important in medicine. The smarter the patient is about getting services, the better they will be. But in fairness to patients, they frequently don't get it. The main conduit to services is that of their physicians. People do not come to me and say, "I had a mastectomy. My hand is swollen. Come to me." They go to their physician, and then their physician directs them to them.

Another answer to your question is it's not that common for a physician to be able to send a patient to someone who is adept at taking care of the special needs of people recovering from cancers. I've seen some funny things happen in my career, especially in the world of HMOs, where they dictate where one needs to go to get rehab. They could end up at a rehab place that's great if you have a broken hip, but it hasn't done a lot of work with people with cancers.

If I were a physician referring somebody, I'd be a little bit careful. Remember, rule number one is do no harm. You don't want to send somebody to a place where they don't know what they're doing. I think that plays into it as well.

Hopefully, as we move more in the direction of clinical specialization – we currently have clinical interests. In the world of physical therapists, we have the oncology section. I was a national officer and the national membership chairman in there for about six years. That is a group of physical therapists who are dedicated and interested in continuing education as it comes to dealing with people with cancers. But in general, most physical therapists do not do that. It's not quite as glamorous as treating athletes or taking crippled children and getting them to talk. It's not quite as glamorous as that. But it's more ...

ELYSE S. CAPLAN, MA:

Richard?

RICHARD DeMARIA, PT:

Yes?

ELYSE S. CAPLAN, MA:

Can I just add one thing? I'm just thinking that a lot of physicians across the disciplines have been trained – at least older generations – to fix things that are broken. That proactive, preventive approach isn't integrated across the continuum across the United States, where some physicians or health professionals are more tuned in to prevention and referring women with breast cancer early, postoperative or preoperative for those having reconstruction, to see how they can strengthen their muscles, how they can maintain endurance to get through treatment and beyond. We hear often at Living Beyond Breast Cancer that they don't get to physical rehabilitation until they're depleted or there is a problem.

The other end of that, which I think you brought up a little bit, is that many women, I think – and what we hear – may not be disclosing to their doctors when they go in for their checkups, because they feel pressed for time. They feel rushed. They feel like the doctor has seven minutes to spend with them. They have other "more important questions," so that their swollen hand or their tingling arm or their exhaustion may not be on the top of their list. I think we have to work harder to educate women about the possible effects. We need to be better at telling our providers what's going on.

RICHARD DeMARIA, PT:

I think that's true. I think in general the world of breast disease has done a pretty good job of that. We're seeing much better utilization of rehabilitative services in the world of breast disease,

but if you compare it to the lymphoma patients we see, the utilization rates are much, much lower. They wait until people get much more depleted. But there are all of these wonderful organizations – LBBC is one – that educate people into saying you don't have to get weak. You don't have to have restricted mobility. You need to be your own advocate. If you're not an advocate for yourself, we [as an organization] can advocate for you. I think that's marvelous. The whole world of cancer, I think, would benefit more if they understood that a little bit better.

By the way, I think the whole world would be better if we incorporated a little more intelligent exercise into the whole thing. You don't have to be sick to take care of yourself. The concept of saying, "I have to eat, I have to sleep, I have to take a vitamin and I better exercise some," is a smart move. Many, many people don't get it.

WOMAN:

Another thing: People, after they have surgery, maybe they do need to go to physical therapists and sometimes even to a psychiatrist, because when this happens to them, sometimes it can be a shock to their mental system. ... Some of the doctors who do this surgery – they are surgeons, and when they finish what they do, they don't go beyond that point with the patient, because it's like an assembly line: "She puts in one part, and I do another." When he's finished with the surgery, then he's done with the patient. He's not thinking any further. To him, it's the next patient, and he has to do surgery. That's why it is important that the patient has to address the doctor.

RICHARD DeMARIA, PT:

I also think it's up to clinicians the way they want to practice. I run a very warm-and-fuzzy business. It's very touchy-feely with patients. I am very interested in emotional well-being. I have never seen a patient with whom we do not address whether they're experiencing anger, fear or sadness, or how they are functioning in the dynamics of their family or loved ones. I like that stuff. I'm married to a psychologist, a marriage and family therapist, for 30 years, so I'm very in tune with that aspect of it. Trust me: It would be a lot easier to treat sprained ankles all day, where you put them in a whirlpool and you have no idea about them. But I am not interested in that.

I think clinicians who are focusing on doing more and more work with people with cancer are doing better at that, because patients need that. It's



LIVING BEYOND BREAST CANCER®

LBBC.ORG

not physical. The first slide I put up here, the first slide we had talked about physical depletion and emotional depletion. It's huge and must be addressed. You have to surround yourself with people who love you.

WOMAN:

I'm a therapist, but I was going to say that the other thing that I've found really interesting is that women who have come to me are scared to move. Or they'll feel pain and they'll think their cancer has come back. Or they'll think that means something bad. The doctors aren't very good about educating them about what to expect.

RICHARD DeMARIA, PT:

Don't lift more than five pounds – that's a great line we hear.

WOMAN:

I think it's even just saying, "No, that's okay; it's normal. You're going to feel ..." that kind of thing.

RICHARD DeMARIA, PT:

Permission to do activities as well as restrictions or limitations on activities is a very important part of what you have to do, because people will frequently err on the side of doing less rather than more.

In the world of an irradiated chest wall, we look at all of the same things: flexibility, strength, posture and function. We also examine skin integrity. When you're stretching your shoulder, the skin can cause breakdowns and things like that. Frequently, postradiation or even during radiation, we see a lot of that, and that needs to be addressed. I'm trying to fly through this, guys.

In postmastectomy patients, we look at the same four things. When you think about it, the breast is superficial to the musculature in your body. Your body is basically made: skin, breast, muscles, ribs, lungs. When a mastectomy procedure is done, it scrapes the breast off of the muscle. In reality, functionally your arm should work the same way it did with or without the breast, for the most part. But frequently women will guard, or they'll have problems moving it.

We look at all of the same things in a postmastectomy patient that we would in any kind of a shoulder. That is, again, looking at their posture, their strength, their flexibility and how well they function.

Now, we're moving toward the concerns we have with women who have had a mastectomy and then a reconstruction. Most

of the work I do in the world of breast disease is dealing with reconstructed chest walls. The last slide here has our home page [<http://www.dynamicrehabilitation.com/>] on it, and [the slide has] all of the protocols we use for all of the different types of breast reconstructions, which include giving people permission to do things, restrictions and encouragement to do things in a time frame for the normal person, whether it's a simple reconstruction or a much more complex one.

The major types of reconstructions we see, going from the simplest to perhaps the more complicated ones, are a subpectoral expansion, where the breast is removed and the expander bag is put beneath the pectoralis major muscle, expanded to give an elevation on a chest wall, and then switched out with a permanent implant. That big-time affects the way the shoulder works, because this pectoral muscle used to come straight across the ribs, and now it's coming up and over an inflated bag. It alters posture, it alters motion and it alters the physics of the anterior chest wall muscles so that it will basically make them weaker with the same amount of muscle functioning.

Once again, we look at posture, strength, flexibility and functioning, then to get them to basically have similar strength or the same strength and motion on one side as they have on the other.

Now, in the case of a bilateral procedure – we see a lot of women who have had bilateral procedures – we look at established norms: the norms of 180 degrees, trying to get a four or a four-plus out of five strength grade on them. We look at it a little differently if they've had both sides affected. We also see the same kind of procedure where muscle flaps are incorporated. We do a lot of work with women who have their latissimus dorsi muscle resected from the back into the front. That has all the same considerations that an expansion reconstruction does, but now one of the major muscles that controls your shoulder, most or sometimes all of it, is put around to the front. Once again, it affects the impact of strengthening it, the flexibility of it and the way you posture people.

Then we see people who have TRAM procedures – we're seeing fewer and fewer of them – where they take the rectus abdominis muscle, kind of like this tie, cut it off your pelvis and make a breast out of it. It's a muscle flap with no artificial things in it, and that has all of the impact – or a little less impact – on your shoulder, but a

lot of impact on your pelvis, because that muscle was there for a reason, and now it's making a breast. It affects the stability of your pelvis, and your spine sits on your pelvis. We also see free flaps and tissue transfers.

WOMAN:

Can they remove the breast and not remove the muscle?

RICHARD DeMARIA, PT:

Yes, they can remove the breast and not remove the muscle, but some methods of having the breast replaced, reconstructed after they remove the original breast –

[Inaudible Question]

No, no. When a woman has a breast removed, a mastectomy, she has options. One option is to not have it reconstructed and to have a flat chest on one side. If she chooses to have a breast rebuilt on that side, one of the procedures is to take the muscle from your stomach area and make a breast out of it. It's a different muscle. That's called a TRAM, which stands for transverse rectus abdominis muscle. We're not seeing as many of them as we used to. We're seeing many, many more basic expansions, and some latissimus flaps, especially if the patient has been previously irradiated. It adds a slightly better contour to the inferior part of the breast, and it gives it a more natural look.

We also are seeing more and more patients who do not have breast disease, because the same doctors who are reconstructing breasts are also doing cosmetic augmentations. The cosmetic augmentation, where a woman wants to have a larger-volume breast, they're getting a very similar type of expander bags, putting them under the pectoralis major muscle on top of the ribs, and they're having some of the same issues – shoulder issues and postural issues – as women who are having reconstructed breasts. That's going to be a growing part, because more and more of those procedures are being done.

Now, let's talk quickly about lymphedema. Lymphedema, as most of you may know, is where lymph nodes are affected. Lymph nodes are tissues in your body that help get germs and lymphocytes out of your body. They come in by the blood and go out by a separate tract, and they get swollen when they're working. They're all over your body, but they're in particular in your armpit area as it relates to breast disease. Frequently, if someone has breast cancer, the breast cancer will spread into



the adjacent lymph nodes, so that when they're surgically removing the breast or even a lump from the breast, they will look at the adjacent lymph nodes and sometimes surgically excise them, sometimes check them with dye, and assess them to make sure the cancer has not spread from the breast glandular tissue into the nodes.

The nodes are there for a reason. When they are resected out, it puts people more at risk of developing lymphedema. In an oversimplification, lymphedema is where certain protein-enriched fluids come into your arm and they can't get out, or it's difficult for it to get out normally. If you have normal lymph nodes, lymphocytes come in and they come out. They come in and they come out, and everything works nicely, and you don't end up with swollen hands or swollen arms. But when you have either a surgical or an irradiated approach toward lymph nodes, it can impair their function, and the system can back up and get swollen. And the arm can get swollen.

Our personal goal in dealing with people who have lymphedema is that of self-management and self-control. We want people to be able to take care of themselves, and we try to arm them with all of the things they need to do to take care of it themselves, because they could have it for a long time. They could be at risk for it for the rest of their lives. Or they could have it off and on or keep it for a long time. We don't want them coming into the office Tuesdays and Thursdays for the rest of their lives or for years. We want them to know how to take care of it.

For us, the first approach we use is that of education. We want people to understand what it is. If they don't understand what lymphedema is, their ability to be compliant with their own self-management is impaired. So we spend a lot of upfront time with videos and talking and handouts describing what lymphedema is, certain dos and don'ts, avoidance strategies and things like that.

Then, the treatment support we use – and literature supports that a comprehensive treatment approach is the most effective. There's a study that came out of Stanford University... and it talks about the most effective treatment for lymphedema being a comprehensive approach that involves pretty much everything that is out there to treat it. When you treat lymphedema – and we'll talk about this quickly – it has a lot to do with applying a compressional force to put the fluid out. But it has to be a very controlled

compressional force, and there are a lot of different ways to do it. We'll talk briefly about what they are.

Early intervention is always important. If people come to me and say, "Oh, my gosh, my arm has been swollen for nine months," and you feel it; it's hard, and their ability to decompress it and get that fluid out of there is much more compromised than if someone had come to me and said, "This came on three weeks ago. I don't know what it's about. My doctor put me on antibiotics, and it didn't work, and he sent me to you." Their ability to be successful in decompressing the arm or diminishing the volume in the arm increases with early intervention.

Aggressive treatment needs to be initiated. In Europe, it's awesome. If you come down with lymphedema, they put you in a spa for a month, where you get rubbed and squeezed and worked on all day long for hours. Well, it doesn't work like that here, but we try to get people in aggressive treatment of decompression, exercise, elevation, manual drainage, pneumatic drainage, as quickly as we can to try to nip it in the bud.

Another very, very, very important thing is that of making accurate assessments. A lot of times, people come to me and say, "My rings didn't feel right. My rings feel tight on me. I must have it." We take very accurate assessments, because you have to know what's working in the treatment. Some people respond beautifully to compression garments. Some people have to be manually drained. Some people can work well with pumps. Some people can do whatever. There are a lot of different ways to do it. But if you're not assessing to see whether what you're doing is working, it's more complicated.

We take volumetric measurements based on sequential girth measurements. We also have liquid volumetry units, which you put your arms into like a water thing, and it displaces the water. We also have – which I don't think is very effective – a bioimpedance unit that assesses the level of resistance to an electrical current in your extremity. In theory, the more swollen you are, the less resistance you'll have, because of more fluid. We primarily use volumetry, which is displacing water, and girth measurements. Sometimes we use calipers, where we'll take actual measurements of how wide something is, as well.

We need consistent re-evaluation. Literature supports that if you go to a physical therapist or a clinician or an occupational therapist and a

different person measures your arm on subsequent visits, the chances of reliability diminish if it's not the first person. We all try to do it the same way, but there are variations. We have checked it within my own organization, and even if you pull on the tape the same way by holding the spring, the reality is that people do it differently. A suggestion would be in subsequent reassessments to have the same clinician do it, because it will help to better standardize the results. The better the results are, the better the chances are that you'll know what's working or, more importantly, what's not working. You'll stop doing what's not working and start doing what is working, because you want to get rid of this.

WOMAN:

[Inaudible] the blood pressure cuff you get put around your arm. Can that cause lymphedema?

RICHARD DeMARIA, PT:

It cannot cause lymphedema, but it can affect the lymphedema from exiting your arm. That's one of the things that doctors frequently tell people who have had a lymph node [removed]. They'll say, "Do not get blood pressure checked on that arm, and don't get needles on that arm."

WOMAN:

Suppose you've had lymph nodes taken out on both sides.

RICHARD DeMARIA, PT:

We do blood pressures on the leg. Think about it: It compresses those lymphatics, and they can't get out if you squeeze them.

WOMAN:

[Inaudible] other people say that [inaudible] you have to have it ... go ahead and have it [inaudible]. But I've noticed that the cuff makes it feel very, very tight. When I had it, it made my hand swell up some.

RICHARD DeMARIA, PT:

If you have lymphedema and you compress the musculature ... think about it – a blood pressure cuff, they pump it up to 160 millimeters of mercury. It collapses the lymphatic vessels, and lymphatic vessels are not the same as blood vessels. Blood vessels are like a garden hose. You kink it, and as soon as you unkink it, the water runs. A lymphatic vessel collapses, and while it will reinflate or reopen up, it's not pressurized in the same way. You don't want to do it, just like you don't want to lift heavy weights and let the muscles compress those lymphatics.



LIVING BEYOND BREAST CANCER®

L B B C . O R G

The reality is: Lifting weights or [getting your] blood pressure [checked] will not cause lymphedema. Lymphedema is caused by a germ being in your body and white blood cells coming there and not being able to get out.

Our number-one intervention when it comes to lymphedema is meticulous skin care. We encourage people to wash their hands up to their elbows three times a day with soap and water for about 60 seconds to kill germs. Keep your skin moist, and look for any kind of break in the skin – a cuticle nip, a mosquito bite, an irritation. And one should put a topical antibiotic on it right away. And if it gets red, they need to address the fact, because antibiotics can be their best friend. But meticulous skin care. Yes?

WOMAN:

A patient who does not have lymphedema but has had a bilateral mastectomy, is it safe to do a blood pressure reading on her arm?

RICHARD DeMARIA, PT:

We recommend to anyone who has had a nodal dissection – an axillary nodal dissection – not to do blood pressure on the arm. Just because you don't have visual swelling in the arm or documentable swelling does not mean that you do not have static lymphocytes in your arm. So my recommendation is if you have had a lymph node dissection, do not squeeze it on that side.

[Inaudible Question]

No, because that's a break in the skin, and it allows the potential for germs to get in.

[Inaudible Question]

You need to be your own advocate. The literature is a little bit mixed with regards to people who have sentinel node [biopsies]. A sentinel node, in theory, does not put a person at risk of having lymphedema, but I know surgeons who say, "Take the blood pressure or the needle on the other side."

ELYSE S. CAPLAN, MA:

Rich, we have 20 minutes and a lot of questions. Do you want to do some wrap-up, and then we'll go to questions?

RICHARD DeMARIA, PT:

Yes.

ELYSE S. CAPLAN, MA:

Great.

RICHARD DeMARIA, PT:

I'm on the last slides anyway. In the comprehensive approach, besides patient education, we use exercise, low-level exercise, and

then compression. The concept is to squeeze the fluid out of the arm but to do it in a fashion that is consistent with not collapsing the lymphatics. We recommend 40 millimeters of mercury or less. Think about a blood pressure cuff – it goes up to 160 millimeters of mercury. It will collapse everything.

The types of compression that can be done are manual drainage, which is massage – basically pushing you from the hand to the shoulder. There are garments – a lot of different kinds of static garments. There is wrapping with wraps. There are gradient sleeves. There are ReidSleeves. There are all these different kinds of static compressional garments. They must be fitted properly, because if they're too tight or there are pressure points on them, it will result in an increased pressure over those lymphatics and problems with that. There is also pneumatic pumping, where you have these machines that pump your arms.

There is also elevation. There are a lot of different things people use to incorporate gravity, to incorporate pressure to get the fluid out. There's a lot of controversy among my peers in this. Some people believe we only manually drain them. Some people say we never manually drain them. Or we do this. The literature clearly supports – and it's irrefutable – that a comprehensive approach that incorporates all components of decompression is the most effective.

We move from a conservative model to a more aggressive model using manual drainage as our last effort, because people must come in for manual drainage. It's very expensive to the patient and to the insurance company, and it's a huge intrusion on someone's life who is already maybe going back and forth to a lot of meetings. So if a simple garment will decrease it or a simple garment and exercise or elevation or whatever can decrease it, we try to avoid having them come in all the time, and we move toward the more aggressive program.

One last thing I want to say is we determine within the organization then, in my organization, a 7 percent girth differential as being significant. We measure arms, divide the bigger one by the smaller one, and if it comes up with a 7 percent girth differential – there are certain variances that people have. My left arm is a little bigger than my right arm, but it's not 7 percent bigger, unless all I did was lift weights with this arm or something like that. So that's how we determine significance – at 7 percent differential.

ELYSE S. CAPLAN, MA:

With that, I'm going to say thank you for a quick overview of so many different aspects of cancer rehabilitation. We only have 15 to 20 minutes left. I know there are a lot of questions, so if you'll bear with me, we'll start, and we'll try to go from side to side.

WOMAN:

I would like to know if it's true that you can develop lymphedema 20 years from now or immediately. I've read literature that said you could have never had lymphedema, and 20 years down the road you could develop it. Is that true or false?

RICHARD DeMARIA, PT:

The answer is "true." However, if you look at intervention or initial onset of lymphedema, it happens primarily – like, if you're going to get it, about 70 percent of people who get it get it within the first five years. They have an initial onset. That does not mean if you've had a nodal dissection or radiation that you're ever not at risk. But most people who get it will get it sooner rather than later, and sooner could be up to five years.

WOMAN:

The other thing I would like to say to the audience is that you must be your own advocate. If they say they want to take your blood pressure on your left arm, you tell them no, and be emphatic about it. If they say they want to draw blood on your left arm – I'm just saying "left" because of me. I had open-heart surgery, and I went in there with a red band around my wrist telling them what they were not allowed to do. I'm telling everyone, if you are not your own advocate, they will kill you in the hospital. (Laughter)

ELYSE S. CAPLAN, MA:

Is there a question over here?

WOMAN:

Thank you. Hi. Bilateral mastectomy. Don't know which reconstruction – tissue or free. It's been called both. You didn't differentiate there, so I don't know which. I have terrible pain where my left natural breast was. It's been 14 months. That wasn't discussed at all. I haven't found it discussed anywhere. I haven't been able to find it in any books, and I haven't met any other women – I think there's a woman here with bilateral, because we have the same issue, when you don't have any side at all for the cuff, or at least that's what I thought. The pain intellectually is identical to the pain that led to the diagnosis, so I wanted to talk about that or hear about that.



RICHARD DeMARIA, PT:

I think chronic pain post-breast reconstruction is not the norm. You should assess what is causing it. The best person to start with, I would suspect, would be your reconstructive or plastic reconstructive surgeon, whoever did that procedure. While I guess I have seen people who have had chronic pain after these surgical procedures, there are things that can be done. That should not be expected at all.

Pain is a very complicated issue. I've seen people have nerves blunted. I've seen people have injections to deaden nerves. I've seen a lot of different things be done with people who have had prolonged pain. Prolonged pain might be two or three months postsurgery, and once the stretching and all the rehab – painful – part is done. But I would be very comfortable saying that chronic pain post-breast reconstruction is not the norm, and I would start looking for your doctor to help you get out of that. If your doctor cannot do something with that, there are many, many people who would probably be able to see you and help you. It's not the norm.

WOMAN:

I had breast cancer 16 years ago, and I developed lymphedema in three organs: my left arm and leg, and my right arm. I've had all of these treatments done two and three times, but I suffer from cellulitis. I've had 12 bouts of cellulitis since I've had so much lymphedema. The doctors now feel like, since I had it so long ago, just go home, send me home. I'm in and out of the hospital, consequently, with cellulitis. I do the cleaning issues, the nails, everything. Now they don't even halfway want to treat me, because it's been 16 years now, and I don't know what to do. I have to fight for everything I have now, since it's been so long. What do I do in reference to getting help? These doctors now really don't understand about, like you said, taking the blood pressure, because it's been so long. They maybe feel like, "No, she's all right now." But I'm constantly in and out of the hospital with cellulitis.

RICHARD DeMARIA, PT:

Cellulitis is another issue as it relates to lymphedema. I would be persistent in trying to get the right clinicians to help you. The good news is that in Philadelphia, there are many, many clinicians who have focused on doing this kind of work. There are a lot of physical therapists with advanced training to help take care of this. The

reality is that you may not be able to completely recover from it. But in general, lymphoma is progressive, and doing nothing will work in the other direction, and it will probably get worse. So staying vigilant and doing what you can do to help it will be in your best interest.

WOMAN:

But I've had three doctors at Fox Chase [Cancer Center in Philadelphia].

RICHARD DeMARIA, PT:

Yeah, I know.

WOMAN:

Physical therapy for the back problems – I've had it two or three times.

RICHARD DeMARIA, PT:

I understand.

WOMAN:

But I'm still suffering. They don't want to treat me now.

RICHARD DeMARIA, PT:

Who's "they" don't want to treat you?

WOMAN:

My doctors. I'm at Jefferson. I've been there about 15 years, and I've had [inaudible]. Now they just feel like, "Okay, lose the weight and we'll just give you the compression." It's even harder for me to get the wraps and stuff now since I've had it two or three times before. But it's like a fighting issue [inaudible] needed this [inaudible]. The past ten years, I feel like [inaudible] it's getting worse.

RICHARD DeMARIA, PT:

I'd stay vigilant with it, because it will progress.

WOMAN:

Oh, it has. It has.

RICHARD DeMARIA, PT:

It doesn't always, but it can. I would stay vigilant to make sure that you get what you need. Also, be realistic with your expectations, because not everyone gets better from it, from the treatment.

WOMAN:

So I'm going to go through cellulitis again [inaudible].

RICHARD DeMARIA, PT:

I didn't say that. I have no idea what you're doing or what you're going through, but it would not be unheard of for someone to experience chronic lymphedema and not be able to completely

get rid of it. However, if you do nothing, it will probably get worse.

ELYSE S. CAPLAN, MA:

Keep doing what you're doing, press on and contact us at LBBC. We have Helpline volunteers, women who have been diagnosed and treated for breast cancer, who give peer emotional support. We definitely get a lot of calls on our Survivors' Helpline [(888) 753-5222] from women who are dealing with lymphedema and just feel comfort talking to another survivor, another woman who is going through a similar experience. Just keep in mind that it's a toll-free number you can call to talk to someone else if that would be helpful to you. [Editor's Note: Read LBBC's *Guide to Understanding Lymphedema* for more information. You can download it free at <http://www.lbcc.org/data/media/LBCCunderstandlymphedema.pdf>]

WOMAN:

I have a question. You did answer part of it when you told her not to have sticks on either arm, because I had a mastectomy 16 years ago and a mastectomy a year ago. My doctor said getting blood drawn from your leg has a greater risk of a deep vein thrombosis than having blood drawn from the arm with less lymph nodes taken out.

RICHARD DeMARIA, PT:

That is more of a question that I would address with the people that are drawing the blood. Remember, having a mastectomy will not preclude you from having blood drawn on an arm. It's a question of having a lymph node dissection and/or radiation to that side, which will make you more suspect. I would go by what the doc says. If he's cautious about drawing blood out of your leg, especially with the concern of a deep vein thrombosis, I would listen to him, because that's something you really don't want.

[Inaudible Portion]

ELYSE S. CAPLAN, MA:

I'll just offer, having had a bilateral mastectomy myself, about a year apart, that, again, it's very individual. I think that's what Richard has been saying all night. That's what we at LBBC and what I would say also. It's very individual. You really have to have dialogue with your doctors. I know I have had blood pressures and blood draws on the side – the oldest side of surgery, not the more recent side. Talk with your doctors about their thoughts, their options. It's your individual anatomy. It's your



other medical concerns, health history. It's complicated, and I've had blood draws in the groin when I didn't have other places to draw. It's really a challenge for a lot of us who are dealing with ...

[Inaudible Question]

Yes. Is there a question over here?

WOMAN:

I don't have lymphedema. But I heard that once you've had lymph nodes removed, if you're flying you should wear a sleeve, because the pressure that builds up in the airplane can present a problem. Is this true?

RICHARD DeMARIA, PT:

There is very, very inconclusive evidence toward that. However, I don't think a week goes by that I don't have someone say to me, "I'm flying. Should I wear a sleeve?" If one really looks at the literature, it does not necessarily support that people who have never had lymphedema who fly will get lymphedema. It suggests – and it's not even really conclusive – that people who have lymphedema will worsen their lymphedema if they fly for prolonged periods. I have taken the path of least resistance. I'm not fighting the airplane battle anymore. If someone is flying, we will give them a slice of Tubigrip to put on and say, "Wear this before you get on the plane, during and after."

WOMAN:

[Inaudible] is it a [inaudible]?

RICHARD DeMARIA, PT:

It's like a small compression wrap. We give that to them, and I'm not certain it does any good. It certainly makes them feel better.

WOMAN:

What is it called?

RICHARD DeMARIA, PT:

We use something called Tubigrip. It's just a basic elastic-y kind of tube that you put your hand into that's like a garment. It's what [basketball player] Allen Iverson used to wear on his arm. We put that on. We give that to people because it makes them feel better. But if you really read the literature, especially out of the National Lymphedema Network [<http://www.lymphnet.org>], it does not support that people who have never had lymphedema, when they fly, will have a higher incidence of getting it. Remember, it's not the pressure that causes it; it's the germs. But if you have it, the pressure can kind of – might – make it get worse.

WOMAN:

I don't have it, but [inaudible] she was a dance teacher. We were having therapy. She said she had been a cancer patient 20 years prior, and she took a flight, and she did not have lymphedema. She said when she got off the plane in California, her arm swelled up twice the size, so she suggested that we [inaudible].

RICHARD DeMARIA, PT:

It may not be lymphedema. If you take a long flight, your feet will swell, too. That's not necessarily lymphedema.

WOMAN:

I'd like to get back to exercise postsurgery. I would love it if everyone did have personal assessment so we knew and we could be evaluated and have an exercise prescription. Given that we don't have that at this time, I believe the next best thing is to at least be equipped with good information. So one of the handouts I received through the American Cancer Society was on exercises after breast cancer. Is this a useful tool? Are there any other tools like this, some documents, that might even be better, guidelines that might be better?

RICHARD DeMARIA, PT:

I have not reviewed that one. I'd be happy to ... I will. (Laughter) You can call me, and we can talk about it. In general, we use procedures that come out of not only the American Physical Therapy Association but also the American Academy of Sports Medicine. They do submaximal testing on people, both resistance- and endurance-wise. They do not differentiate between people who have had cancer or who have had polio or who have had anything. They look at people as a generalized population and determine what a normative response to exercise is. That's what we do.

By the way, people you know who have gone through this recovery phase of cancer, they really, really should be assessed properly before they start exercising. This business of, "Jump on that treadmill and start running," it's dangerous. We don't do it.

I know most of my peers in the world of physical therapy do not monitor vitals, do not use cardiac monitoring when they do exercises. We, in my own organization, never have anybody exercise without pulse meters on them at the very least and pre and post vital assessment.

Vital signs for us are blood pressure, pulse oximetry and monitoring targeted heart rates while

they are doing it. We do not do EKG strips. We just look at rates. That is an indication of cardiac output, and it can be really impaired. It's not only chemotherapy that can do it. It's the generalized debilitation. How about the anxiety? "Oh, my gosh. They're putting me on a treadmill. Am I going to be able to do this?" All of a sudden, somebody goes up to 200 beats per minute. I don't want them having heart attacks on my watch. I don't go for that. We take the conservative approach, and no one exercises without that in my organization.

WOMAN:

I understand. That's terrific, but that's not the reality we're living in. We get most people who are released from the hospital, and they're not leaving with any kind of information. They're not given prescriptions. They're not being told by their doctors to see a physical therapist. So my question is, is this a helpful thing or not to hand out to people?

RICHARD DeMARIA, PT:

I don't know. I'd have to look at this. I only know that I'd be – you talk about being an advocate, making sure you get the services you need. Make sure the services you get are what you really want and what you need. You do not want to have some rock-head at some gym pumping you up. That might work once you get clearance to do that. But cancer survival strategies – chemo, radiation, surgery combined – have long-lasting impact on people. We see diminished hemoglobin levels, which is the ability to transport oxygen to the muscles, six, eight months postsurgically. Now, that doesn't mean they're totally anemic and can't get out of bed. But there are residual impacts from these procedures long-term.

I think you need to be very, very cautious. You have special needs. People who are recovering from cancer have special needs. It's not like a 13-year-old who wants to go on a bicycle and ride down to the shore. You have special needs.

WOMAN:

How about water exercises?

RICHARD DeMARIA, PT:

They're great. Water is great if you don't have any open things on your skin.

WOMAN:

We're diabetes educators, and I'm also a dialysis nurse, so I sympathize with the lady – nobody touches your access arm. My question is with



blood sugar testing: If it's one side, you can use your other side for doing blood sugars. But if you're bilateral, what are you going to do with blood sugars? We don't recommend the feet because there's a higher incidence of infections and stuff like that also. Even if you do your arms, because the new meters ...

RICHARD DeMARIA, PT:

Why is it a higher incidence of infection in your feet versus your hand?

WOMAN:

Because there is less circulation down there, so it's an open wound, neuropathy and all that kind of stuff.

RICHARD DeMARIA, PT:

I don't know what the right answer is.

WOMAN:

And infections, yes.

RICHARD DeMARIA, PT:

I will tell you that ...

WOMAN:

Less circulation also.

RICHARD DeMARIA, PT:

I don't know what the right answer to that is. But I will tell you that any breach in the skin where you've had compromised lymphatic systems does put you more at risk. It's interesting you would say that. I have a patient I got last week who was a dialysis patient with a fistula in his upper arm, and we're using a compression pump on him.

WOMAN:

(Gasps)

RICHARD DeMARIA, PT:

Wait a minute. I cleared it with the surgeon. I cleared it with the nephrologist. We're going 35, 30, 25, nothing, so it is pushing it with no pressure over that, because there are graded segmental programs so you can decrease that. He has experienced about a 15 percent diminishment in volume already.

WOMAN:

All I can think is meticulous hand-washing and skin care.

RICHARD DeMARIA, PT:

Oh, yeah. That's important.

WOMAN:

That's the only thing I can think of.

ELYSE S. CAPLAN, MA:

At this point, we're at our stop time. I know if Richard had a few more minutes, some of you may be able to ask questions. But we do like to start things pretty much on time and end things on time at LBBC. I want to, first of all, thank Richard for coming out at the end of a long day and, once again, supporting Living Beyond Breast Cancer's educational programs. (Applause)

We've had him a number of times before, and it's a pleasure to work with him. I also want to thank each and every one of you for making time for yourself for coming out tonight and being empowered and being educated. We're here for you, so stay in touch. Thanks so much, again, for coming and sharing your time with us.

[END OF TRANSCRIPT]