

Cancer and Lymphedema

Webcast

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Introduction

Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr, and every two weeks we connect you with leading M. D. Anderson experts and inspiring patients. Today we are going to talk about a side effect that is something that follows lymph node removal for people who have had surgery for breast cancer and some other areas we are going to discuss, and that's lymphedema. And is not an insignificant concern, but yet not surprisingly there are folks at M. D. Anderson who specialize in it. I want to tell you what lymphedema is, and we will then meet someone who has been dealing with it for 13 years after treatment for breast cancer.

So lymphedema is a collection of protein-rich lymphatic fluid, usually in the arm or leg, so for women who have had breast cancer treatment often under their arm. It's caused by an interruption of normal lymphatic flow due to surgery, radiation, infection or trauma. Remember infection, we are going to talk about that. And it's the protein in the fluid that makes it difficult to treat. And the protein acts as a magnet, if you will, for more swelling and serves as a food source for infections. Now, there are interventions, and we are going to learn about that as M. D. Anderson, as you would expect, helps leads the way in helping people with that.

Now, one person who has been dealing with it is Debra Valentine. Debra lives in Houston. She is, if you will, a schoolteacher who makes house calls. She helps children with special needs from age 3 to 22. She goes to their home, and she is their teacher. She was diagnosed with breast cancer in her mid 30s. Now she is 49, still dealing with lymphedema.

So tell us, you had a lumpectomy I know, and chemotherapy, radiation, you had the lymph node removal. When did you notice, Debra, what became known to you as lymphedema? How did that show up?

Debra's Story

Debra:

I would say that I discovered my lymphedema about probably ten months after my surgery. I had also had chemotherapy followed by radiation, and I was sitting on a park bench one day with my arm propped up, and I noticed when I put my arm down a significant indentation in the arm, and that's when I contacted the M. D.

Anderson faculty and discovered that I did have lymphedema, and I was referred for physical therapy. And I've been going for physical therapy at M. D. Anderson on and off for the last 13 years.

Andrew Schorr:

All right. First of all, what does lymphedema feel like to you? Before you had any intervention, what did it feel like?

Debra:

At first it did not, it really did not hurt or anything. It was just kind of a troublesome area that seemed, the right arm was larger than the left. But then as time went on I did develop a little bit of a tightness in the arm, and I could tell because I had had some recurrent infections in that arm that when I was getting ready to get an infection it would get tighter than normal, and I would discover like little, red bumps that resembled mosquito bites on the arm one day, and within 24 hours those mosquito bite type things would develop into, it looked like a big, red angry sunburn on the whole arm. And at that time the arm would get hot, uncomfortable and really sometimes painful. It just depended on the severity of the infection, and that's when I would need to get on antibiotics.

Andrew Schorr:

All right. Now, so you go to M. D. Anderson, and you get connected with the folks in physical therapy there. And so your provider, if you will, who remains your partner, if you will, even now is our other guest, and that's Janet or Jan Scheetz, who is outpatient physical therapy supervisor in the department of physical therapy at M. D. Anderson.

So Jan, so lymphedema, how common is it related to breast cancer when someone has had lymph node dissection and also related to other procedures where someone with maybe another cancer has had it? How common is it?

Ms. Scheetz:

It's actually very common, more common than most literature says. We find that most of our patients who have the mastectomy and complete axillary node dissection will usually be at around a 40 percent chance of developing lymphedema. Other patients that we see that develop lymphedema is associated with maybe someone who has had melanoma who has had to have their lymph nodes removed, and that could either be on their back or their leg, and they have subsequent swelling in their leg or in their trunk.

Causes of Lymphedema

Andrew Schorr:

Now, let's understand. You know, I don't think we know much about lymph nodes, most of us. So you know, you think of let's say, I know people think of maybe

blood pooling in an area or something like that if there had been a wound, but lymph fluid, I don't think we really know what that is or understand what it does. So give us a little basic education on how this goes awry, if you will, when you have had lymph nodes removed.

Ms. Scheetz:

Okay. Just think of the lymph system as a way of help managing your fluid balance within your body. As your arteries or your blood system is putting nourishment into your tissues, it puts in a lot of proteins and other fluids. Now, when it's being reabsorbed by your blood system, a lot of times those proteins are not being able to be transported back through the smaller venous system, therefore those proteins tend to be collected in the tissues, and we rely heavily on the lymph system coming in there and removing those. And when you have disruption of the lymph system by removal of the nodes, that crucial lymph fluid is being left behind, and it has a lot of protein associated with it.

Andrew Schorr:

All right. And then this protein can attract infections?

Ms. Scheetz:

Exactly. It sets up a very unhealthy environment, and it just feeds infections. And also the longer the swelling is within an area it actually starts to diminish the immune system as well. So we really wish to move that fluid as quickly as possible.

Andrew Schorr:

And, Debra, it was the infections that really have been your worry over the years, right?

Debra:

Yes, it is.

Andrew Schorr:

Okay. And so you have had courses of antibiotics that you have had to take to fight the infections?

Debra:

Yes. That is true.

Diagnosis and Treatment

Andrew Schorr:

All right. We are going to learn more about that. So, Jan Scheetz, let's understand. So first of all, you know, we know with cancer it's important to catch

it, diagnose it, and treat it early. With lymphedema what are the early indications, and how important is it to have early interventions? And then we'll learn what those early intervention are.

Ms. Scheetz:

Okay. It's very crucial to identify the problem as soon as possible. The first onset of signs are that the limb starts to become very heavy, very tense. Oftentimes a pins and needles sensation will reappear, and they start to lose the definition of their joints. They will look at the back of their hands and they may not be able to see their knuckles very well, or if they bend their elbows, they are not able to see their elbow as a finely sharpened point. So we tell our patients as soon as you have that sensation develop or lose the ability to see those joint contours is to contact us so that we can have early intervention.

Andrew Schorr:

Now, these indentations that I think Debra experienced, so how typical is that?

Ms. Scheetz:

It's very common in the first two stages of the swelling, and that's the result of the fluid being retained right underneath the surface layer of the skin. And at the beginning that fluid will be pushed out to the side with pressure, but as the fluid stays within the tissues for a longer period of time, in the later stages it no longer is able to be pitted or be pressured.

Andrew Schorr:

And these sorts of bee stings, red dots that she mentioned and the feeling hot, so is that the sign of an infection?

Ms. Scheetz:

That is a typical sign of infection, yes. They typically will have a red rash, feeling of a flu-like sensation, and a lot of our patients who initially have an infection, they will actually predict an infection the next time.

Andrew Schorr:

Nobody wants to get to that point, so let's understand if someone is diagnosed, if you will, with lymphedema as a side effect of their lymph node removal, then what do you do? How do you start? And take us through the stages of interventions.

Ms. Scheetz:

Well, initially what we do is we teach our patients that there are several activities that we would like them to be cautious of, and there is actually five of them. The first one is that they need to be very cautious of avoiding extreme temperatures such as heat, the ambient temperature in the air getting into saunas, whirlpool baths, and things of that nature. We tell them to either refrain or be very cautious.

The second thing is that we tell our patients to void trauma to the limb so that they will not add additional fluid to the limb as a result of the trauma.

The third thing is that we tell our patients not to do activities to the point of fatigue of the limb such as that they exhaust the muscle tissue.

The fourth thing is that we tell our patients when they do flying and do long travels is that they need to be taking frequent rests, be well hydrated, do a form of exercises while doing that activity so that they can mobilize that fluid.

And the fifth one is that we caution them that if they have any opened areas such as a needle stick or a paper cut or an insect bite is to take very good care of those sites because they stand to be at higher risk for infection.

Andrew Schorr:

Now, are you saying an open area let's say on the arm or under the arm?

Ms. Scheetz:

It's actually within the limb that they had the surgery on. It's not the whole entire body. So if it was breast surgery they would be cautious of the limb and their trunk area.

Traveling with Lymphedema

Andrew Schorr:

Now, let's talk about travel. So people come to M. D. Anderson from all over the world.

Ms. Scheetz:

Exactly.

Andrew Schorr:

Some come for breast surgery or melanoma surgery, as you mentioned, and then they are naturally going to go back on a plane. Should they worry about that as far as is there a lymphedema concern just going home?

Ms. Scheetz:

We are very proactive in that, and our surgeons actually send them to our clinic prior to their flight back home, and we give them instructions as far as the precautions, as far as their activity levels, and also do a prefitting for a sleeve so that they would actually wear that sleeve on the air flight back home.

Andrew Schorr:

All right. Now, as we think of lymphedema, though, when is it likely to show up? Is it on the way home? And, Debra, just asking you, when did lymphedema show up for you related to when you were actually diagnosed with breast cancer?

Debra:

I was diagnosed in June of '95, and then that was followed by chemotherapy from July through December of '95. Then that was followed by radiation January through March of '96, and it was in either April or May of that same year, '96, that I first discovered that I had lymphedema.

Andrew Schorr:

So it was a long time later. So, Jan, put us in perspective. I know it varies for people, but when can lymphedema show up?

Ms. Scheetz:

In the literature it actually says those who will develop it will develop it within the first two years of their diagnosis of their cancer after having the surgery. So about 75 percent of the people will have it within the first two years.

Andrew Schorr:

Okay. But it could show up later?

Ms. Scheetz:

It could, yes. The oldest person I have had was 40 years after her surgery.

Andrew Schorr:

Oh, my. Oh, my.

Ms. Scheetz:

And that was related to trauma to the arm and an infection.

Compression

Andrew Schorr:

Oh, my. Okay. You alluded to interventions, like you talked about this compression for people going home on the plane. So tell us how do you start? You talked about the things people can do themselves, and we are going to talk about heat in a minute because after all many of your people live in Texas where it can get quite hot, but we will get to that in a minute. But help us understand about compression. Is it sort of squeezing the fluid away or what about that?

Ms. Scheetz:

Well, basically what we are trying to do with the compression is just to raise the tissue pressure because as you know our skin serves that purpose. However, when

you start to have swelling, the skin is elastic so it tends to give in to the swelling. So what we have to do is to support that skin by putting it, containing it with a compression sleeve or a garment.

Andrew Schorr:

All right. Now, Debra, I understand that you have been managing this for 13 years, and you have had courses of antibiotics, but this idea of compression is something you do every day, right?

Debra:

I do. I faithfully wrap my arm every single night with the compression bandages that I received from M. D. Anderson, and then if I do not do that, if I skip a night, the next morning when I wake up my arm is very swollen and hard and somewhat tight and uncomfortable. So I do not miss a day of wrapping my arm.

Andrew Schorr:

All right. But you do that at night. Are you doing any kind of compression during the day?

Debra:

No. I do not wear a compression sleeve during the day. I know that that's highly recommended to do so, but I was one of the unfortunate few that developed a reaction to the compression garment.

Andrew Schorr:

All right. Jan, we are going to talk about how other people may handle it as well, because I know some people do do compression during the day. We are going to take a quick break, and when we come back, we are going to learn a lot more about the treatments that M. D. Anderson uses in helping people with lymphedema. After all, you want to fight the cancer and limit the effect of any side effects such as lymphedema, and fortunately there are interventions that can help.

You are listening to Patient Power brought to you by M. D. Anderson Cancer Center. We will be right back.

Andrew Schorr:

Welcome back to Patient Power as we continue our discussion about lymphedema, that swelling and lymphatic fluid build-up that can not only be uncomfortable and limiting in what you do, but it can lead to infection, and so it needs to be treated with interventions early. Unfortunately a significant percentage of women who have had lymph node removal and more aggressive treatment for breast cancer do get affected by lymphedema, usually in the first two years, but as you have heard it could be even later down the road. So we are visiting with Janet Scheetz or Jan,

who is the outpatient physical therapy supervisor in the department of physical therapy at M. D. Anderson, and also a woman who has been a patient for many years, Debra Valentine from Houston.

Ladies, as we continue, Debra, you were just mentioning that you do the wrapping at night. I just want to understand other things that you do that work for you.

Methods for Managing Lymphedema

Debra:

What I do I've been doing for the last approximately five to six years is water exercises. I am a member of the Y, and I get in the swimming pool about five out of seven days a week, and I move my arms about, not enough to fatigue them but enough to get the fluid going and everything. And I definitely have seen an improvement since I have been doing water exercises almost daily. I drink lots of water, as Jan mentioned. I try to be cautious with my arm. I baby my arm. I try not to pull or tug on things. When I am carrying groceries in, I try to do any heavy lifting with the other side and not much of that if possible.

I do carry antibacterial ointment with me. If I get some little cut or something on my right arm during the day I will put some of that on. That seems to be helpful. I do go in periodically for physical therapy, which is the manual lymph drainage, and then I wrap my arm every night faithfully. Those are the main things that I do.

Andrew Schorr:

Now, we were talking a couple of minutes ago about heat. So Houston gets hot where you live. So what do you do about that?

Debra:

Well, what's ironic about that question is that we just came through Hurricane Ike, and so we were without power from the morning of September 13th. Well, by Sunday night, September 14th, I was starting to see some little red spots on my arm, so I did have to go to the pharmacist and get my prescription of antibiotics. But what's ironic about it is that it had been since Hurricane Rita in 2005, about three years ago, that I had an episode with an infection. And both were related to A, I was in heat, I was perspiring, I was doing things I normally would not be doing like trying to help bring things in from the wind and so forth, and it was totally out of my routine. I was not babying my arm. And both times in my opinion it was related to heat and the things that I was doing that was not appropriate for a lymphedema patient.

Andrew Schorr:

Okay. So taking care of yourself, air conditioning, or moving to Alaska or someplace like that for cooling. Okay. Well, let's continue with Jan Scheetz. So Jan, so wrapping doesn't really work for Debra during the day, but for other women is there some kind of compression during the day that's helpful?

Ms. Scheetz:

Yes. And that's either the custom or off-the-shelf compression sleeves that are available. And depending on the stage of the lymphedema, we choose the correct sleeve for that patient. But we do recommend the patient wear a compression sleeve during the day, actually taking it off at night and then applying the compression bandages for the nighttime, and then in the morning starting the routine over again by reapplying the compression garment.

Andrew Schorr:

Okay. I think the point of course that we heard as we listened to Debra is that people are different, and so working with you and other providers there, you see what's right for this patient. Well, let's go on, though. Massage was mentioned. How does that work?

Ms. Scheetz:

Well, it's actually a technique that comes over from Europe. It's called manual lymphatic drainage, and it was developed back in the 1930s. And it basically helps to stimulate your own lymph system to work at a faster pace. Because the lymph system is a very passive system that needs to be encouraged all the time, and by doing this systematic massage and a directional massage we are able to transfer fluid that is being congested in one area of the body to other areas that have a perfectly healthy lymph system, and it gets and returns that fluid back into our blood system where it's reprocessed or excreted out through the urine.

It's done by the therapist. They need to be certified in the technique. And we will either see patients on a daily basis for a three-week period of time or three times a week for at least four weeks and take specified measurements to make sure that we are reducing the size and then getting them into a compression sleeve to maintain it.

Andrew Schorr:

Now, can anyone, a spouse or a partner or friend, be trained to help out with this?

Ms. Scheetz:

Yes. It's a crucial part of their home maintenance that they themselves will do a self-massage, or we train a family member in the simple technique of the self-massage. However, we do stress that they spend no longer than about 15 minutes on the massage itself because we wish them to do it on a daily basis and either doing it themselves or having a family member do it for them.

Andrew Schorr:

All right. Let's carry on. What if it's more serious? I have heard of things like pumps, and I know in extreme cases there even can be surgical interventions. Tell us sort of where we go beyond massage and compression and sometimes courses of antibiotics.

Ms. Scheetz:

Right. At this time the pumps are rather controversial. In fact they have been really controversial the last, maybe the last decade. The research is there that basically they are removing the water content of the tissues, not the protein. And when you gave the definition of lymphedema, it's actually the accumulation of protein in the tissues. So basically with the pumps, we are actually dehydrating the tissues. With our management we actually rely on the massage, which has been shown to remove the protein. So in our practice we really do not recommend the patient be provided the pump.

Andrew Schorr:

Okay. Well, that knocks out the pumps from the point of view of M. D. Anderson and I go with that, but beyond that then when do you need to step up the intervention? And I mentioned surgery. I have read somewhere that that can come into play sometimes.

Ms. Scheetz:

It can. We do have a plastic surgeon who has been doing the procedure for about the last year and a half, and he actually takes lymph vessels and reconnects them to the venous system within the limb, and he has gotten fairly good results with this process. We have found that if we direct the patient there in the earlier stages of lymphedema he has greater success in teasing out those vessels to reconnect them to. When they go into a later stage where we have a lot more tissue changes, where the tissue becomes very hard and very fibrotic, he is not able to find those vessels very easily and reconnect them.

Exercise

Andrew Schorr:

All right. Now, so we talked about massage. And Debra mentioned along the way exercise and going to the Y. So tell us about exercise. Is it good? Is it bad? I would think the cool water, cool water, that's a good thing, but what about exercise?

Ms. Scheetz:

Well, exercise, what we encourage, we encourage several forms of exercise. The first one is lymphedema exercises. These are geared towards increasing the rate at which your lymph fluid is being removed. And again it's a very passive system, so

by doing diaphragmatic breathing or gentle exercises of just contracting and relaxing the arm muscles by bending the elbow back and forth, by raising the arm over the head, doing the wrist in circles and so forth helps to stimulate that natural lymph flow to work at a faster rate. So we greatly encourage those.

The next form of exercise we encourage are flexibility exercises. After you have had surgery, a lot of times you will have a lot of scarring associated with that, and that scar acts as though it's an artificial barrier for that fluid to travel across. But by doing flexibility exercise they get the full mobility of the tissues back, and it allows that flow of fluid across that scar tissue. Also we are encouraging that muscle pump action to help with fluid control.

The third type of exercise we encourage greatly is aerobics, and anything ending in -ing, i-n-g, is aerobic, and we greatly stress water aerobics because of the three factors. One, you have the water pressure on the tissues helping to increase the tissue pressure and allowing those vessels to open and close and to remove the fluid. Also the coolness of the water. And a third is that you are allowing the arm to move through the resistance of the water.

And the other one that we encourage is getting these patients much more active, getting them into a walking program or a running program or anything that they actually would like to do after the surgery that they have done prior to their surgery.

And then the fourth exercise program that we stress is strengthening. Now, again this is also controversial because originally back in the 70s when I first started to practice they said oh, if you did that, you would actually create more fluids, and you would actually aggravate the lymphedema. Well, that has since turned around with literature and research is that we want to prepare those muscles to be stronger so that they will be able to have the stamina to do activity so they don't fatigue quite as rapidly. So in fact we are actually benefitting the patients by getting them stronger. But we show them in a systematic way of how to develop the program and to monitor the program so that they always have positive outcomes.

Andrew Schorr:

Well, that's what I hope for. Now, here's an e-mail question we got from Karen from Lake Charles, Louisiana, and she writes in, "I had a lumpectomy early in the November followed by ten sessions of brachytherapy where the catheters were put in for local radiation of the breast." She said, "Everything went smoothly. Now I have developed some edema in the same breast. My doctor says we'll watch it. It's not uncomfortable yet." But here's her question. "Will a sports bra keep it from getting worse? And does activity like raking and working out make it better or worse?" And we were talking about that. What about the sports bra thing?

Ms. Scheetz:

The sports bra, we actually encourage sports bras because they actually have a wider chest band that goes around their chest area. But one thing about a sports bra, they don't have enough pressure that can be applied to the tissue. So what I would actually do is to be fitted with a sports bra, but actually line that sports bra with additional foam that would actually increase the tissue pressure, and that will provide her much more of a relief for her. But I do stress the fact that she do flexibility exercises and do a lot of diaphragmatic breathing.

Words of Encouragement

Andrew Schorr:

So, Debra, I want to ask you, so you have been dealing with this for 13 years.

Debra:

Yes.

Andrew Schorr:

And being a 13-year breast cancer survivor is a good thing, but unfortunately you have had this side effect that you have had to deal with, and I know that's troublesome. It sounds like you have got a system going on. What would you say to people listening who are either concerned about it or maybe starting to notice it as far as encouraging them that things can improve?

Debra:

Well, it can be managed. Of course you have to be proactive. And if you are just now discovering that you do have signs of lymphedema, I would strongly encourage you to contact your doctor. I don't know if all of the ones listening are necessarily M. D. Anderson patients, but I do know that that would be your first avenue is to contact your medical provider, and they can point you in the right direction. I know that for me the physical therapy has been essential. And I go in periodically for that, pretty much on a yearly basis, and it's been very manageable.

I do know that you have to be careful when you start seeing warning signs such as a red rash developing, tenderness, painfulness, heat in the arm, etc., and as time goes on you will be more and more cognizant of exactly when you are in trouble with your arm. But I would just suggest staying very, very on top of things, very proactive, and having a good relationship with your medical practitioner.

Andrew Schorr:

And in your case watch out for hurricanes.

Debra:

And watch out for Hurricane Ike.

Andrew Schorr:

Or Rita, as you said.

Debra:

Or Rita.

Andrew Schorr:

There you go. So Jan Scheetz, just to wrap up from you then. Should this discussion about lymphedema be part of really every woman's discussion about intervention for breast cancer, to be aware of it as a possible side effect, be educated about what to look for, and then if there is concern either right away or within the first year or second or even down the road that there is this active discussion as they go in for check-ups?

Ms. Scheetz:

Exactly. In fact here at M. D. Anderson basically with the breast clinic, our department has set up a program of exercises to do while they have the drain in, and then also those exercises to do while the drain has been removed, and also a set of exercises as far as the warning signs of lymphedema and what type of activities they need to avoid or modify so that they don't have problems with lymphedema. This information is actually given to them at the time that they see their medical provider at their first appointment in the surgeon's office.

Andrew Schorr:

Well, I know you and your team and some of the nursing staff have really helped lead the way nationally in the discussion of interventions for lymphedema, and it sounds like you have helped a lot of people. So, Jan Scheetz and the department of physical therapy, I want to thank you and the other providers there for what you do in educating us further today. Thank you for being with us, Jan.

Ms. Scheetz:

Well, thank you very much.

Andrew Schorr:

And Debra Valentine, being a teacher who makes house calls and really continuing your work there and learning how to manage the lymphedema and then go on hopefully as a very long-term breast cancer survivor, I want to thank you for sharing your story with us today.

Debra:

Thank you. It was a pleasure.

Andrew Schorr:

Well, I want to tell you that this is what we do every two weeks with our Patient Power programs on mdanderson.org. And in two weeks from now on October 21st



we will have a live discussion. You can call in with questions, and it's going to be on advances in the treatment of cervical cancer. So if you know someone who is concerned about that you will want to listen live, e-mail in questions, call in, we would be happy to get you the answers you need to have better health. That's two weeks on October 21st.

Thank you for joining us for Patient Power brought to you by M. D. Anderson Cancer Center. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all.

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