**Discussing, Detecting, and Diagnosing Lymphedema**

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You're listening to the cancer assist podcast, wherever you are, in your experience, we are here to provide help and hope as you navigate cancer prevention, treatment and care hosted by Dr. Bill Evans and brought to you by the cancer Assistance Program. Help when you really need it.

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Well, welcome to the cancer assist show with Dr. Bill Evans. That's me. And we're delighted to have you listening today. And we're going to talk about a topic that doesn't get much attention. And that may be relevant to you or to a loved one. And so we hope you'll listen to this conversation about lymphedema and we'll explain what lymphedema is all about. Before I dive in, I do want to say a few words about the cancer Assistance Program. We do this show in order to make people aware of the services in the Hamilton region for cancer patients. And if you're a recently diagnosed cancer patient or caregiver to a cancer patient, you may want to know about those services that include things like free rides to the cancer center, free equipment loans, we have a vast variety of different pieces of equipment that can help keep your loved one safe in their homes. We have nutritional support, even food delivery to homes for individuals who need it can provide mastectomy, supplies, urinary incontinence supplies, free hair, pieces, and so on. So, we really want to make people aware of the cancer assistance program and one of the things we do is these podcasts to educate people about the services that are available about how cancers are being treated, hopefully to make people more informed so that they can ask their doctors and healthcare providers questions that will help them navigate, but is often a difficult cancer journey. And so I'm delighted today that we'll have our special guest Michelle Cardozo, who is a clinical specialist and radiation therapist at the Durban ski Cancer Center. And she's going to help us understand this lymphedema situation as I say, it's not something that is a common household word. I don't think most people in fact, understand what lymphatics are, or even lymph nodes. But it's all tied together. And so we're going to have this conversation and make it all crystal clear. So welcome, Michelle, and just delighted to have you here. For the podcast today,

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it's lovely to see you again, thank you. And it's true, nobody thinks about lymph nodes and lymph until they hear the conversation with their oncologist about removing lymph nodes or treating lymph nodes. So some of us can remember when we were children having the Doctor Feel our neck when we have a cold, and those little swollen glands in our neck are the same thing. But those are the lymph nodes. So lymph fluid is continuous with the fluid that bathes all our cells, the tissue fluid, every time our heart beats 1% of that fluid volume is trapped in the cells, and the only way it can come out is through the lymphatics. So it's another part of it kind of complements the circulatory system. So it's part of getting that fluid out of the body is a big part of what the lymphatics do. It's, it's responsible for fluid balance in the body. But so we know when you get swelling in your ankles after walking for a long, a lot of standing a lot, it's the same principle. But what happens when you have a cancer treatment, it damages the lymph nodes, so there's less available to help drain that fluid. So silicon fabric system is responsible for fluid balance in the body. It's also part of the immune system, there's a lot of white blood cells concentrated at various organs within the lymphatics, like the thymus, and spleen, and lymph nodes themselves. And it's also involved with fat transport as part of digestion. So we should talk about it more because it has a lot of jobs to do. Parallel

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vascular system, everybody understands, I think that we've got a heart and we've got veins and we got arteries and blood circulates. But nobody seems to realize there's a parallel system that is trans transporting fluid around our bodies, because there's an imbalance and pressures on the arterial side of the little vessels we call the capillaries is a tendency to push fluid into the tissues, right, yeah. And then it doesn't all get absorbed back. So if we didn't have a lymphatic system, I think in in a short time, we'd probably all blow up and look like the Doughboy or something. And so we need this system. And it's got to bring that fluid back into our heart, which it does through a rather large duct in our our chest called the thoracic duct and it dumps this clear fluid back into circulation the way it goes again. So it's an essential mechanism for keeping a balance of fluid in our tissues. But as you say, it also has this important immune system. And because the lymph nodes contain those many, many kinds of cells, but some of those cells are there to particularly fight viruses. bacteria, etc as well as cleansing of even things as simple as dirt gets in through a car. So it's

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removing waste from the cells, bacteria, viruses, all of that are removed into into the lymphatics. But it's not an efficient system. It's not like the heart at the bloodstream that has the heart pumping. It really relies on musculature in the walls of the vessels to help it move along in our movement to help squeeze the muscles against the skin to move those that fluid along. So, you know, once patients have had lymph nodes removed by surgery, or they've had radiation to the lymph nodes, or even taxing therapy can can contribute to lymph lymphedema. Once the that the burden is there of having those lymph nodes removed or damaged, it puts up stress on the remaining lymph nodes. So then what happens is the limb next to where the lymph nodes were removed, become swollen. So for breast cancer patients, which it affects the most, when they've had lymph nodes removed from the axilla, the armpit, they end up having swelling in the arm or even in the chest area. That's

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when we call it lymphedema. That's right. So we've talked about the lymphatic system and oedema just means swelling. So that's a swelling in the extremity. That's this accumulation of lymph fluid that should get back to the heart but can't. And so you get to a rather dysfunctional appendage could be an arm could be a lake. Yes, it could even be

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bad. Yes. Well, yeah, we

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jumped right into this. A little bit about you, because I always like to know a little bit about the people I'm talking to. And I'm sure listeners do too. And I know your radiation therapist. Yes, you've become somewhat specialized in this area as well. So

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I have Yeah, I have Margaret Forbes to thank for that. She's she's an advanced practice nurse, which is pretty spectacular human being. But she had a lot of wisdom and foresight, very much embraced into professional practice. And when she had an lymphedema clinic at the driveline ski cancer centers, there was so many people that that had to come and see her. And some of them just had education needs. So we developed a class, just to teach those patients and she got me involved with that. And it was just it was a wonderful experience, and so that I would teach the class and eventually, unfortunately, that clinic closed, Margaret has moved on since then. And so I've kept the class running. And I've tried to keep navigation, sort of at the forefront of what I do so that patients know who to go to, and what to do when they have any signs of swelling. But yeah, that's how I kind of fell into it. Yeah,

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well, I'm glad you did. Yeah, absolutely necessary service. So you touched a bit on on why people get lymphedema. And I guess it's kind of multifactorial, isn't it? It could be because the surgeon has had to cut those lymphatic channels and say, taking the lymph nodes out from underneath, in the armpit area or for say someone who had a melanoma or sarcoma on the lower extremity dissecting in the groin area. Yes, those those things have physical cutting, but then radiation and your radiation therapist, yeah. So oftentimes radiation has to be delivered to an area of the body and it has an effect on the lymphatics.

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Absolutely. In fact, it has a similar effect to having lymph nodes removed, like the similar risk factor, I guess you could say. So you know, compounding all of these things makes probably makes the risk much higher. So it's something that is discussed up front when the patient comes to consent for treatment. But you know, it's at that point, the focus is on just getting through the cancer. When when lymphedema appears after that, you know, it's very devastating for the patients because they feel like they've got past the cancer diagnosis, in many cases, and then now, now what Now what's this and it's quite devastating because Lymphedema is a chronic condition.

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And there's really no cure for or it's something you have to manage as a kind of chronic condition. Once it occurs.

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catching it early is very important because if you deal with it in the early stages, it never has to become I'm sure people have seen pictures of these big elephant limbs which are quite debilitating and difficult to deal with. But if you catch it early, you can keep it quite minimal. It is at the beginning. Shocking or and very difficult for patients to kind of wrap their heads around but if you become it becomes part of their daily practice, I wake up I do my skincare I will which we'll get into I think and put my compression sleeve on it or garment on and go about my day. Building an exercise as well in that day So you know, it becomes part of how they cope. And it doesn't have to be this this horrible thing. But yes, it's a compounding diagnosis, you've already had this horrible experience a traumatic experience. And now you're faced with a chronic condition. Having said that, there's lots of promise and exciting research coming out from Stanford. Stan Roxon has done some amazing work with his team. And they're thinking of it slightly differently. We always thought of lymphedema as sort of a traffic jam, some blockage or like, you know, diversion of the fluid. But he's saying what if it was an inflammatory process? So there's some exciting things going on. They did some mouse studies, now they're into human studies. Finally, you know, research is slow. But they're looking at this compound called ACE Billy stat, which is an anti inflammatory. We're targeting a pathway and they've the results already, the early results are amazing.

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Well, that's really exciting to hear. I hadn't, I was unaware of that. And I kind of assumed that that progress hadn't been made against lymphedema because it's it's been around for so long. And it seems to me we've been limited to compression massage exercise a few other things that we should talk about a little more depth before we maybe dive into that. Also important to make mention of the fact that the cancer itself can cause lymphedema, clogging up the the lymphatic. So there's really those three things that treatment with surgery, the treatment for radiation and the actual tumor itself. You know, over my career, I've seen a gradual decrease in the amount of lymphedema occurring, partly because surgeries become a lot less aggressive. We've been talking about breast screening and finding cat and breast cancers early so. And with sentinel node biopsies, you don't have to have these big operations to clean out all the lymph nodes in the axilla. So the risk of getting our Medina is less even in melanoma, same sort of approach and much less radical surgery. So is this actually the case? I'm assuming? Yes. I've seen fewer patients who need care for lymphedema.

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Yeah, it's we do. And even with our modern radiation therapy techniques, we're trying to limit those to the normal tissues. And we're very, very, very careful with planning. But, you know, also we're finding other lymph nodes that we need to treat, for example, with breast cancer, where our local regional treatment is coming across the midline a little bit more to to include internal mammary nodes, which we didn't do many years ago. So you know, that the you know, we win some we lose, in a way, but, but the knowledge is there and we try to let patients know upfront what they can do. We never used to think of lymphedema as preventative, but that there is, in fact, some evidence growing to say, some of the same practices that you were advising to do in the post surgical recovery period, are also valid valid in unfortunately, as lifelong intervention, so you'd have to do, but you can go a long way in preventing just just knowing what you can and can't do. I don't know if you're ready to go into those things. But infection prevention, for example, because sometimes if you have an infection in the limb, it can provoke lymphedema to begin so just looking out for signs of infection, treating it early, that sort of thing.

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Maybe before we delve there, yeah, maybe just to describe for people who maybe don't know what we're talking about. What would a lymphedema this arm or leg look like? Yeah, and how is it? How does it affect the person's quality of life and what they can do?

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Yeah, so in the beginning, when, when the swelling starts, it's really only the patient that's aware of it. And it's just sort of a heaviness and achy feeling, and in the arm or leg, typically, as it as the swelling starts to accumulate, it's typically for breast cancer patient in the forearm and the hand for lower extremity they can see it and maybe in the ankle, and the feet, more so then other parts but it can be anywhere in the leg or the arm. And it starts to be very apparent, you can't bend your fingers very easily your toes and shoes become uncomfortable if it's lower extremity, you know, clothing becomes little tighter rings don't fit those kinds of things. Yeah.

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And so, variety of functions per day for their hands, or how much we use on a daily basis can be really impairing activities of daily living. And then there are you can as it progresses gets thicker and thicker and yes, tissues get really quite Yeah. The Hardys if

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you left it alone, it continues to accumulate and unfortunately what then happens is collagen fibers Start to be late and fibrosis happens. And then fat gets deposited in between those layers. It's like a network of fibers that the fat gets in there. And then it becomes very difficult to reverse at this point in fact and maybe starts to be impossible to reverse and then that that's when you see this giant limbs are very swollen, very painful and and limit the movement.

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And this is why you're saying it's very important to identify it early. Absolutely. Early. Yeah. And when it is advanced like that there's a lot of risk of infection because the skin is so yeah, and so easily injured like scratching it or mental trauma can produce infection. That's a hard infection to treat, and also makes the edema so much worse.

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Yes, a skin infection. cellulitis goes hand in hand with lymphedema diagnosis. Often, the infection might come first and trigger lymphedema to begin. But for people who already have lymphedema, and they and they get a skin infection, and cellulitis, often that becomes a vicious cycle of repeat infections. And they're horrible infections, they end up you know, often needing to have hospitalization for that. So definitely the earliest sign of a cut or scrape on your on your limb that's adjacent to the lymph nodes that were removed next to the lymph nodes that are removed, you want to treat those immediately. So you want to you know, if at home Polysporin go or if it's red or warm, you want to go and see your doctor and get some antibiotics

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and treat it seriously, as opposed to some awesome, red or unintended. That really can't be an important thing. I certainly recall from earlier in my career, I don't think we had the knowledge that you're imparting. Now, people who've got quite marked infections and very stubborn to try and clear up and often requiring intravenous antibiotics because he just can't penetrate the antibodies that didn't penetrate into the tissue to fight the infection that was there. So, so early intervention, so what are some of those early interventions and how should people be managing lymphedema?

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So those mainstays of that you mentioned of lymphedema care, skincare exercise, watching your body mass index, and engaging with lymphedema provider in the community, there are lots of providers. So skincare is is something we can all do at home, it's looking, you have to inspect the limb daily, you're looking for any signs of cuts and scrapes and so on, and then moisturize you want to keep the skin clean first, and then moisturize the moisture helps the skin to retain its integrity helps it stand up better to infection. And then once that's done, you know it's something so simple, but it's a sort of becomes a daily habit. And we actually want patients to continue that from the time of surgery. And as a preventative with the other, the other part of that is looking at exercising the limb. So if you exercise, there's limb specific exercises, actually we have on our website if people need to look at that. And it helps to drain the fluid as well. Because what happens is the muscles push against the skin, the counterpressure have that is what the compression garment would do as well. And that helps the limp to drain, in addition to that, body mass index is another important thing to look at. And so that's a ratio of your height and your

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weight. How does that influence my so? Yeah,

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so the thing is, we want to keep our body mass. So the body mass index ratio of the height and weight, you can actually go online and look at a BMI calculator. I tend to go on there and I'll just type in my numbers. And if I don't like them, I just change them till I like them. But I'm not suggesting that everyone changes. But you want to keep that number in less than 30 to be out of the sort of the risk group for lymphedema. By doing that what happens is when you have that extra layer of fat between the muscle and the skin, it kind of reduces the efficiency of the pumping action of the muscles helping the fluid to drain.

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Okay, that makes sense. Because people need to understand that the lymphatics, these little channels, they have valves in them. Yes, when you compress then the fluid will move in the right direction, right, go backwards. Yes. So the exercise is helping to keep them moving through your system the way it's supposed to. If there's too much in the way, like fat, you won't move as much. You will have less ability to clear the lymphedema. It makes sense. Yeah. I've learned something. Yes, there you go.

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There's lots of exercise that's really good. You know, and we but we really need to emphasize that we want people to go low and slow. This is not a no pain, no gain kind of situation. We want you to start with where you are after after Having all the treatment you may not be as up for exercise as you were before, to start slowly, the limb specific exercises are really important. But also general exercise is great to just, it does so many things, it also gets the lymphatics going. And it's for well being, it's for all of those things. Cancer Care, Ontario recommends 150 minutes of exercise over three to five days. So worked out about 20 minutes of exercise a day, so you can do what I tell patients to start with walking. Walking is fantastic. You know, and you know, you can set goals for yourself and you know, whatever you're doing today do a little bit more tomorrow, I found having a Fitbit or a pedometer very motivational to get going.

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Is there lessons for all of us? For those of us Yeah, lymphedema, right? Yeah,

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I started with a friend of mine. Malini gave me a pedometer, it's like a cereal box kind of one. And you just clip it on your waist is not high tech at all. But it will count your steps. But there's a powerful connection between the brain and having this pedometer that just motivates you and keeps you going. So it's a great way to start. Yoga is fantastic, because it combines deep breathing with exercise. So the deep breathing is key because at the diaphragm, at the bottom of the lungs, you have the last major reservoir of lymphatic fluid resistant a child which is so when you do these deep breathing exercises, you kind of stimulate that reservoir and help push that last stretch of lymphatic fluid upwards through the chest into the neck and then it drains to the heart. That fluid then goes to your kidneys and you excrete that up that

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was good to hear about yoga. I know nothing about them. Don't practice yoga that maybe, but an explanation about the breathing and how that would affect lymphatic system makes perfect sense to me. So there's a few other things that we want to talk about in terms of things people can do, but maybe we'll take a brief break now. And come back and talk to Michelle's further about things you can do if you have lymphedema, and also the special month that's focused on lymphedema, so we'll be right back.

22:09

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We're back talking with Michelle Cardozo about lymphedema and how it's managed. And we were talking about exercise and yoga as ways of sort of naturally stimulating lymphatic flow. But then there are other things that patients can do. And in my reading, I didn't know anything about this before I read about it, that sort of manual self massage, as as a technique and the use of compression. Bandages. So tell us a little bit more about those sorts of techniques and what patients should know about them. So

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sorry to step back for a minute. If you have some swelling, the first thing you should do is see your physician really what you want to do, whether it's a family doctor or your oncologists who seeing you, you want to rule out other causes of swelling, it could be blood clot, it could be cancer recurrence, unfortunately, it but yes, but often, it will, it looks like a duck walks like a duck, it's a duck. Often it's lymphedema and and then the pathway becomes a little bit murky because people don't necessarily know what to do and that's what I try to do in my in my role is try to navigate patients to services. So in the community, I would say start with your lymphedema specialist. And there are many and we have a list of providers on our website for the Hamilton Health Sciences website they're fantastic people their background is massage therapy or physiotherapy most often some some we have one that's an occupational therapist, but they've gone on to specialize in complete decongestive therapy, which is so they had the initial CDT after their name. So what they do, yeah, I heard that before. Yeah. So what they do is a complete and thorough assessment of the patient. So above and beyond probably what we would do is in terms of we would never measure limb circumference so we go around and how big is the limb and we use a measuring tape, which is a very basic way of doing There's much more efficient and technology, technologically advanced ways. But they, they look at the limb volume, they look at pain, they look at your mobility, all of that they give a very detailed education, similar to what we're talking about, but more tailored to the individual and an exercise plan. And then manual lymph drainage, as well. So manual lymph drainage is a light touch massage, is just enough to move the skin. And it's not deep tissue massage, which actually can be kind of damaging in certain situations. So for people that know a massage therapists already, or I'd like to go and see their familiar face to do that, I would caution that you really want to go to somebody who knows what they're doing, because you can move that fluid anywhere with with some not so great results. So, and definitely some of those massage techniques can be taught at home, the for you to do at home. So self massage becomes part of your daily practice as well at home. Yeah. And

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then apart from that, then the use of sort of compression.

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Yeah, sure. So when you when you go, yeah, so when you go for Lymphedema Therapy for swelling, there's an initial intensive phase where you go one to two times a week perhaps. And then gradually that sort of decreases once once the volume has been shrunk as much as we can possibly bring it down to normal. Then you want to go into this maintenance phase of treatment, where are you maybe going every six months to see the therapist? What compression does is maintain? Stable? Yes, yeah, any but any reduction that you get, the compression garment helps to keep it there. So I don't see compression as a standalone. It does. It does work to some extent on in certain situations, like if you're exercising, and you have swelling, definitely wear a compression sleeve. If you have lymphedema, but really what it's what it's designed to do is keep the benefit that you've achieved through the therapy. So I would start with going to see a therapist because actually the sleeves are quite expensive. sleeves can be anywhere from $30 to $300, depending on how tailored they need to be for you. So really, everybody's different and you're limited lymphedema specialist will sort of navigate that process and help you decide which way to

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go. This is really important to know because I again, things have obviously changed since I was seeing women with breast cancer who had lymphedema, that seems to me we just sort of said, Oh, get a compression sleeve. Without the the whole idea of going to see someone who could help you basically decompress it, get it down to the maximum amount he could and then get an appropriately sized compression bandage that would keep it at that level. So I think that's it's really important for people to understand that there are the specialists out there who really know how to compress the, the tissue of the fluid,

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they do say, you know, if they were patient went out and got the compression garment versus not wrong, it probably is better than not doing anything at all. But what happens is, what that they come, they got a patient will go for therapy, and we're able to then reduce the limb volume and other garment doesn't fit.

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Exactly. So we spent $300 Yes, yes. So

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it's better to start with them, they become the quarterbacks in care, they will send the patient to a appropriate garment fitter. So there are lots of people involved in in the care of lymphedema. So there is some financial support available for compression sleeves. It's through the assistive devices program, the Ministry of Health. It's a little bit of a cumbersome process out of pocket expense. Usually, when you want to buy the garment you would have to wait then it needs a doctor's signature on the ADP form. But again, the lymphedema therapist can help you get all of that going. Yeah, yeah. And you need to have an authorized provider for lymphedema care and an authorized fitter. So and but and they're authorized by the Ministry so that they're all identified. So if you go to a resource, let's say like the lymphedema association of Ontario, it will tell you who has authorization. Also, our list of providers is quite clearly demarcated, who has that and who doesn't. So they're great. It's a great service that they offer. The Lymphedema Therapy itself is also quite costly, just like physio and massage therapists. So some people have benefits that we'll cover that across the board, I would say it's $100 an hour but they tried to do it. They tried to their initial appointment certainly will be an hour, but beyond that, they try to make it a little bit shorter. So that And they'll work with with patients, if they say there's a financial hardship or they don't have benefits, they'll try and make a plan that's affordable, and so on. And what I love about the ones that we have networked with, and you'll see on our provider list is, they're not interested in keeping a patient forever. They want to give them the tools to help them manage their disease themselves, and go on and be productive and happy in their lives and be able to, you know, offload them, really.

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So, it seems like there's a lot of resources out there. Yes, I wasn't aware of Yeah, or an even in association for lymphedema. So if edema association of Ontario, they have a website where a lot of this would be readily available to patients and educational materials. And the jersey Cancer Center and handle Health Sciences has a lot of this for a region listed. Yeah. So

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if you go to Hamilton Health sciences.ca And you go to the section on cancer care, there's a there's a kind of a bulleted list that comes out on the side, it's community services. If you click there, there's a lymphedema drop down with all the arm axis, upper upper body exercises, lower body exercises, list of providers and a general kind of information pamphlet about lymphedema.

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Now there's one group of patients I wonder what you do about it? And those are the people who have had neck cancers often have extensive neck surgery disrupting all the Yes. And they can get swelling that affects their speech and their swallowing. Yeah, what are the things we can do for those? Yeah,

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very challenging. But treatable, like you know, we can reduce the volume, the lymphatic, lymphatic, sorry, lymphedema specialists can reduce the volume with the lymphatic drainage. And also there are specialized garments for head and neck cancers, which actually wrap around the face and head. So I mean, you know, in that situation, I think with with any of the compression sleeves, the difference between lymphedema and cancer is it's out there and people can tell. And unfortunately, with the head neck compression, it's quite noticeable. So people tend to wear them, you know, more privately than outside. But the idea with any compression garment is to wear it as much as possible during the daylight hours.

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We've covered a lot of ground about this. And actually, you've educated me and educated a lot of listeners. Are there any other things that we haven't talked about? We didn't you did mention to us before we started the podcast about March being a special month with focus on lymphedema. What what happens during

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this world lymphedema Day on March 6, and it is a way of sort of creating awareness because there really isn't very much awareness for lymphedema. We're really trying to bang the drum and make sure people know what to do if it happens to them and where to go. Also, we would like if if the ministry on down could could understand and support patients who have this debilitating condition a lot better than it is it is very challenging to navigate right now. I'm

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hoping that this podcast is beating the drum.

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For the one group I should mention as well, sorry, I'll be in trouble if I don't. Whenever we make a diagnosis of lymphedema at the cancer center, we also refer to the psychosocial oncology program. We have a amazing group of men, mental health workers, social workers, psychiatrists, mental health nurses, psychologists, because there is that aspect of the disease as well to consider that feeling the emotional impact of the compounding diagnosis. Patients do need support and navigation and for the financial peace to at that they're able to the social workers can step in. So by all means, we want patients to present themselves to PSO. Or we can do that for them to make sure they're well supported through through managing lymphedema.

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Well, as I said, I've learned a lot about this. And I think the whole purpose of having the podcast is to educate those who are listening about what the options are for treating aspects of cancer. And this is one aspect of cancer management, I think has been under discussed may be under researched. And you mentioned earlier some very interesting research coming along that may make a big difference to people's lives. So I really want to thank you, Michelle, this has been a very, very interesting conversation. I think, very enlightening for those who've joined us. So thank you.

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Thank you. Thank you is wonderful.

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