Slide 1: Flexibility, Fitness, and Feeling Better
Ms. Lizette Figueroa:
Greetings. My name is Lizette Figueroa, and I would like to welcome you to The Leukemia & Lymphoma Society's Flexibility, Fitness, and Feeling Better Survivorship Education Program. The Leukemia & Lymphoma Society exist to find cures and ensure access to treatment for blood cancer patients. Our vision is a world without blood cancer.

For more than 60 years, LLS has helped pioneer innovation such as targeted therapies and immunotherapies that have improved survival rates and quality of life for many blood cancer patients. We advocate for patients, survivors, and their families, helping them navigate their cancer treatments and ensuring that they have access to quality, affordable, and coordinated care.

We're fortunate to have as our presenter Dr. Mark Gugliotti, PT, DPT, OCS, COMT.

Slide 2: Disclosures
Mark is an Assistant Professor at the New York Institute of Technology in Old Westbury, New York, where he teaches Orthopedic Manual Therapy and Massage. He has published in the peer-reviewed journals Rehabilitation Oncology and Journal of Manual and Manipulative Therapy. Mark has also self-published an autobiographical account of his cancer experience, titled Victor, Not Victim: My Battle with Hodgkin's Lymphoma.

Slide 3 – Flexibility, Fitness, and Feeling Better – Dr. Mark Gugliotti, PT, DPT, OCS, COMT
We appreciate Dr. Gugliotti volunteering his time and sharing his knowledge with us. Dr. Gugliotti, I am now privileged to turn the program over to you.

Dr. Mark Gugliotti:
Well, thank you so much, Lizette, and a special thanks to The Leukemia & Lymphoma Society for the opportunity to provide this information to your viewers. The topic I'll be presenting today will be pertinent for all survivors. It will focus on flexibility, fitness, and feeling better as it pertains to what I like to call the recovery from recovery. And what I mean by that is the time either during or after your active cancer treatments where you find yourself fatigued, weakened, or less able as a result of your cancer care.

The care you receive is necessary, but can take a toll on your body. Being a survivor myself, I understand this process and hope by sharing my story and the following information, it might make it easier for others. What I’d like to do now is just go over a few facts as they pertain to both blood cancers and cancers in general.

Slide 4 – Current Facts
So, let me just start out with some current facts as they pertain to blood cancers and cancers in general. You'll find one diagnosis of new blood cancer every three minutes in the United States, over 170,000 new diagnoses of blood cancer in the US for 2016, and over 1.2 million cancer survivors in the US currently, and overall over 15 million cancer survivors in the US.
Dr. Mark Gugliotti:

Slide 5

Now those are astounding figures, and the increase in survivorship is a direct result of the advances in cancer research and care. And here's where I have to do a “whoohoo!” to The Leukemia & Lymphoma Society, because as you know, their fundraising efforts go right back into funding local research for local survivors, and they do an amazing job at that.

Slide 6 – Hodgkin’s Lymphoma

My story starts off with Hodgkin’s lymphoma. As you would imagine, I was experiencing an onset of weight loss, night sweats, a nagging cough, and itchy skin beyond belief. And soon after that diagnosis, I was in active care. I started to look a little like this. I don’t look so much different than I did back then, but what has grown back are my eyebrows, my eyelashes, and a lot of the other hair around my body. And for those of you who are going under care and have lost your eyelashes, you can imagine how important they are on those bright, sunny days. And you know exactly what I’m talking about.

Slide 7 – 2007 B.C.

Now in 2007 BC, that’s before cancer, I was undergoing my initial diagnostics like any other patient. I had my pulmonary function test, my blood panels, my chest x-ray, my CT scan, my PET scan, and my biopsies. Here’s a small depiction of one of my chest x-rays. You can see that my heart is right in place, and with my wife’s name right across my heart where it belongs all the time.

Slide 8 – The C-Word

Now once I was given the diagnosis of cancer, I had a tough time with that C word, as many of you might be experiencing at the current time.

I actually felt more comfortable referring to it as a tumor in my chest. But, I knew sooner or later I had to come to terms with the diagnosis, and I even practiced saying, “I have cancer,” in the mirror just for reinforcement. And after a couple dry runs, I had it licked, and I knew at that point I was on my way to recovering. This is a depiction of the Reed-Sternberg cells, which are the hallmark signs of Hodgkin’s lymphoma.

Slide 9 – The Cancer Survivor

Now as I talk about cancer survivors in general or even just patients in general, I’ve always felt, and it was my experience, that it was comprised of four key components: a physical component, a mental component, an emotional component, and a spiritual component. And on any day, although if we’re talking about percentages, it would be ideal that each one was at 25%, totaling 100%. On any given day, you might have a decrease in any strength of these components. The one I think most people would associate with most easily is the physical component. Someday you might feel more weakened, more fatigued, less able to do things. Hopefully, those other components can help balance that out by maybe an uplifting e-mail that you receive from a friend, a card that you received last week that you read again and a smile came to your face, or even a song that you might have heard playing on the radio or from your iPhone that again inspired you to feel a little bit better, helping to bring a form of balance to all of those four components.
Dr. Mark Gugliotti:

Slide 10 - Chemotherapy

My treatments themselves consisted of chemotherapy, the traditional ABVD cocktail, consisting of Adriamycin® (doxorubicin), bleomycin, vinblastine, and dacarbazine. I was fortunate enough to not have to take, rather frequently, the antiemetics to combat any nausea, but because my white cell counts did drop, I had to engage in the use of Neupogen® (filgrastim) and receive my injections on every off week. I had eight sessions of chemotherapy that ran from the months of September to December. It was December 10th, those days that you don't tend to forget.

Slide 11 – External Beam Radiation Therapy (XRT)

Following my chemotherapy, I received 17 treatments of radiation therapy. The XRT utilizes ionizing radiation to control and kill cancer cells. Extreme care is given to mapping the treatment field, and all these dosages were determined by the radiation oncologist and my physicist. They were an amazing team of healthcare providers, and I am forever indebted to them greatly.

Slide 12 – Running

And even after all my treatments, and here's a small picture for inspiration to all of you, yes, after your treatments, you can make the voluntary choice to don a grass hula skirt and carry a pineapple on your hand if you're fortunate enough to participate in a Pineapple Classic, perhaps sponsored by your local Leukemia & Lymphoma Society.

Slide 13 – Treatment Strategies

I'd like to offer some treatment strategies. Adjust your current lifestyle. It's okay to modify your activities. I would encourage you to not fully disregard or do away with any of the activities that you're currently doing. I feel maintaining a certain lifestyle that's already familiar to you is helpful in maintaining your focus along your road to recovery. Try to stay engaged. A lot of people after their diagnosis have a tendency to become more recluse, and I could understand you may have those days every now and then. But, staying engaged is also important from a social component.

You'll have some inspiration given to you from sometimes those conversations with other people, and they're so very important. Try to also maintain an open line of communication. You can share with whomever you'd like to share, however much you'd like to share it with them. But, I think allowing other people into your circumstance and your active treatment can only help extinguish any unnecessary concerns they may have that they're just not aware of because perhaps you haven't shared with them or helped educate them on some of the things that you're going for.

So, maintain that open line of communication, not only with your family and friends, but also your doctor. There's nothing too small or too silly to ask and try to get better understanding with, and that's important. Try to stay informed. Again, going back to your primary health provider will be so important. What I found in the past and I even did this myself. I immediately went online and found a whole lot of information that sounded very threatening and disconcerting, but after reading through everything, I found that it didn't even apply to me. So,
Dr. Mark Gugliotti:  
try to stay informed from the best resources. Always have that line of communication open with your healthcare providers.

Try to continue to adapt a healthy mental attitude. Of course, you’re going to be dealing with a diagnosis of cancer, but it doesn't have to defeat you completely. It can carry a lot of bad meanings with that diagnosis, and it's important for you to look towards the lighter things from time to time to help you keep that positive attitude in going forward.

I might also recommend that you maintain and keep a journal. It was very helpful for me to reflect on different periods of my treatment at different weeks when I would look back and say, "Well, I wasn't doing so well at that point, but I'm actually now feeling a little bit better." Or, what I used to get me through that tough day, I'm going to use again, because it was successful and it got me over that hump.

Also, be sure to try to treat yourself and celebrate everything you possibly can. I mentioned before that there's nothing too small or too silly worth not celebrating. So, do it, and enjoy that. Make it easy on yourself.

Slide 14 – “Sometimes making the right choices…”
Now sometimes making the right choices can certainly be a challenge, and a challenge for anyone.

Slide 15 – “With a little guidance…”
So, keep in mind with a little guidance and effort, an improved quality of life is possible. And that's so important to keep in the back of your mind. Now how do you get there?

Slide 16 – Team Approach
One of the best approaches is to adapt a team approach, and that can include you. You'll be the forefront of that team. You're the most important team member, and I feel sometimes a lot of patients forget that. Of course, you'll have the advice from your physician or group of physicians that are handling your care. And then ultimately, when it's time to start that recovery from recovery, get in contact with the right PT, the trainer, the certified cancer exercise specialist who has knowledge of what you've gone through and can help you regain and reshape your quality of life.

In addition to these primary players, I would also recommend consideration and consultation with somebody who can give you nutritional or dietary information, helping to make sure that you're maintaining your right calorie count and you're making the better choices in food, as opposed to the less healthy choices in food. Sometimes also speaking to somebody about your emotional state or your mental health as well as your spirituality can help provide the direction that you're looking for, relying on individuals who are experts in the field of social work, and providing different family services for you that may be available to you within your own community, but yet you've never had to rely on those resources, and you were never aware that they were so close by home.
Dr. Mark Gugliotti:
Another key component is perhaps seeking advice and care at a sleep clinic. Very often, the effects of chemotherapy and the other treatments during your active cancer care can perpetuate loss of sleep. And it's very important that you're getting your rest so that your body can rehabilitate itself and make itself healthy again. Seeking cardiopulmonary care or cardiopulmonary physical therapy can also be beneficial in helping to increase your endurance levels again and putting a little bit more step in your stride.

And if at this point, you're still engaging in activities such as smoking, I would encourage you to get involved with a smoking cessation group. The decrease in smoking activity will not only have benefits in the short term, but certainly long term. And that can be beneficial for everybody.

Slide 17 – Team Approach (Continued)
So, in summary, your team approach really helps you in a lot of different dimensions. It can help improve your quality of life, maintain or improve your physical abilities, improve balance, thus reducing the risk of falls. There are a lot of secondary things that come about as a possibility of being treated for cancer. Sometimes having your balance off kilter just the slightest bit can result in an unnecessary fall. And the last thing you want to be doing after you've done so well with your cancer treatment care is now have to recover from a broken hip or a broken shoulder, just at the risk of a lack of balance.

Also, prevent mobility loss and atrophy. These are important in maintaining your overall strength and fitness levels. A team approach also helps to build your self-esteem and self-confidence, giving yourself that little bit of control that the diagnosis of cancer might have stolen away from you. And this is so important in restoring that self-empowerment that we often are lacking after a diagnosis such as cancer.

The team approach also helps to reduce anxiety and depression, and I'll show you that and the results of some of the studies I'm providing later. It also helps to control weight. That's very important. Oftentimes we're generally losing weight during our active treatments for cancer, but every now and then we'll see an actual weight gain. A gain in weight that can be considered an unhealthy gain in weight can also perpetuate other comorbidities, such as obesity, high blood pressure, the onset of diabetes. So, it's important that we're keeping track of that. And like I said, having some references or direction from a nutritionist or dietitian can be instrumental in that portion of your recovery.

Also, try to limit your exposure to infection. If you know that you're going out and you're going to be in tightknit places, surrounded by a lot of people who you're unfamiliar with or might be carrying a cold themselves, take caution with that. You can bring one of those little face masks with you if you want to go out to the movies or anywhere else so that you're just engaging in outside activities, but you're not putting yourself at risk.

And also, the team approach obviously nurtures independence, going back to that feeling of self-empowerment, building on that self-confidence, and building that self-esteem that we already talked about.
Slide 18:
Ms. Lizette Figueroa:
What is a physical therapist?

Dr. Mark Gugliotti:
A physical therapist is a licensed healthcare professional who studies upwards of seven years to be able to evaluate and treat different impairments of the body. Those can come in the form of orthopedic impairments or dysfunction, neurologic, can also work with special populations in the pediatric realm. And our other division is very dedicated to cardiopulmonary rehab. And we treat a whole host of individuals, from infancy all the way into their elder years at trying to recover their function, restore strength, restore mobility, restore flexibility, and improving quality of life. And we have many different means and methods of doing so. And we always tailor make the treatments for the individuals themselves.

Now historically, the field of physical therapy has not played a critical role in the care of this patient population. Medical referral for rehab was typically not considered due to the immediate health needs of the patient. And that's an important thing to keep in mind. The most important thing after that diagnosis of cancer is to address the cancer, address the disease itself.

As it becomes more manageable, under control, or hopefully even eradicated from the body, then it's time to start thinking about getting a little bit stronger, going back to that lifestyle you remember, and are just hoping to return to, and getting a little help along the way will only be helpful.

Slide 19 – Where do I start? Start with the right intentions!
So, where do you really start with that? Well, you start with the right intentions, and I love this article provided by Cancer Nursing, and it was published in 2006. It goes through three main criteria that you should keep in mind: and that's attitude, motivation, and control.

Now under the category of attitude, it's broken down into two other subcategories, and the more important of the two is that it's an instrumental attitude. A lot of people feel that engaging in exercise might be harmful. Understand that cancer is a disease process. Exercise will not cause it to worsen or spread. There's no need to be fearful. It's important to see the benefit of exercise, and this is widely publicized in how it can actually help you.

You also want the activities to be enjoyable. Nobody's ever going to engage on a regular basis of exercise if they're finding it unenjoyable. It's so important to find the types of exercise that you find enjoyable and that you're drawn to. It'll help stay with your commitment to the exercise. That brings me to the next criteria, and that's motivation. The motivation has to be yours and no one else's. Everybody has great advice to offer you about what you should be doing and why you should be doing this and this type of exercise that can be helpful for you.

But, if it's not coming from you, you won't commit if you're being forced or coerced into doing that. You need to be accountable for yourself, and this helps to always go back to that concept of self-empowerment and self-esteem building. And then finally, control, it's great that you go to
Dr. Mark Gugliotti:
a workout environment and you pick the machines that you want to do, making sure that you understand what your needs are. You can be best directed by somebody who has greater knowledge and can provide you some direction with that.

Slide 20 – Exercise’s “Core-4”
Very important, or what I always like to do is group my exercises. It's easier to conceptualize and for people to remember. And I refer to them as the “Core-4.” So, you want to have exercise that focuses on fatigue and fitness training, mobility and flexibility training, strength training, as well as balance training.

Slide 21 – Safety First
And it's always important to keep safety in mind, so safety first. Always listen to your body. Your body will tell you if something you're doing is not right or too much. That whole old adage, that concept of no pain, no gain doesn't exist here. And that's actually a pretty bad thing to live by. We don't advocate that at all as physical therapists, knowing that our body is very in tune with what's going on. You need to listen to it.

Keep hydrated. This sometimes becomes a problem for patients who are having those frequent trips at night to the bathroom because their bladder is so full. It's still important to maintain your level of hydration in your body, and I'd encourage you to keep up with it as opposed to shying away from it.

Keep your activities low impact so it minimizes the jarring in your bones and in your joints. You also want to remember to breathe during exertion. We've seen countless times in different situations that in order to overcome the load that you're trying to move, everybody does the same thing. They hold their breath. It's actually going to be harmful to the insides of your body by holding that breath, that internal pressure that you're creating. So, every time you're exerting or you're pushing an object or moving a weight or a resistant force, remember to breathe out upon exertion.

Also, make sure that you're very comfortable in the position that you're exercising in so that results in proper mechanics and greater support for the body, and it also acts as that protectant mechanism. Less weight, more repetitions, let's focus on bringing tone to the musculature as opposed to building bulk. There's plenty of time for that. Let's get started first by crawling and not running.

Also, avoid end-range movements. Avoid locking your knees out or locking out your elbows or going to the end of motion in your shoulders and hip joints. Keep it a nice, comfortable range. You don't have to go all the way to the end because this can also perpetuate some injury to your joints themselves.

Slide 22 – So what about all my other needs?
So, what about your other needs? Aside from general fitness, what about the pain that I'm experiencing, the fatigue, the stiffness, the weakness, the balance? All of that was supposed to
Dr. Mark Gugliotti:
go away after my cancer treatment, correct? No. These things can linger because these things affect everybody, not just active cancer survivors.

**Slide 23 – Break the “Pain Cycle”**
So, let's focus on pain itself. I want you to be careful not to blame everything on cancer, okay? All of us have aches and pains on a daily basis. They can be brought out by certain diseases or brought out from certain lifestyles or lack of activity.

So, the main thing is you want to identify that if you do have pain, you want to break the pain cycle. If you don't, it can snowball out of control. So, we start at the top and talk about pain and work clockwise around the circle; you'll see what I'm getting at. When somebody is in pain, they often go into a guarded position, especially if it's involving a certain body part or certain body region. This muscle guarding can end up in consistent and long-lasting spasm of the muscle and perpetuate the inflammatory cycle. This will often lead to restricted mobility, subsequent muscle weakness, eventually, loss of function of that body part, and then only adding to the anger, frustration, and feelings of helplessness that that individual already has.

Breaking the pain cycle, trying to get control over that pain in your body, is an important thing. Now whether you do it through the use of exercise or with prescription medication that would be prescribed by your appropriate physician, that's up to you and for your healthcare providers to decide. My focus today will focus a lot on just the use of easy, simple exercises that can be beneficial for many other reasons than just combating pain.

**Slide 24 – Fatigue and Fitness Training**
So, next I'd like to talk about fatigue and fitness training. The American Cancer Society suggests aerobic activity three to five times a week with a steady progression in duration. We're shooting for a total of 50 minutes of activity, but when you're just starting out, 50 minutes can seem like a lifetime, which is why I'll encourage you to start with five minutes. Increase it to seven minutes. Increase it to perhaps 10 minutes, 20, 30, and over the course of maybe six or eight weeks, eventually get yourself up to 50 minutes' worth of activity. And this can be as simple as walking. A great thing to be a part of every year, and it's a wonderful event is the *Light the Night Walk*. It's an incredible celebration of survivorship and those who are afflicted with cancer.

And again, gentle walking for that mile distance or whatever distance you're capable of is a wonderful way to kick off a great fatigue and fitness training program. You'll be surrounded by so many individuals. You'll just feel inspired, as so many do.

**Slide 25 – Therapeutic Fitness Fatigue and Fitness**
At this point, I want to delve a little bit into the literature, and I promise to just really highlight the important parts of this literature and not to go into so much great detail. So, the first study that I'd like to address is the one that starts with the exercise in reducing fatigue and improves mobility in cancer survivors. Now this was an amazing review, and it was recently published in 2016. It examined 42 studies and involved over 3,800 survivors. And they found after
Dr. Mark Gugliotti:
reviewing all of these studies, there was a significant relationship between the use of aerobic exercise, and primarily walking, in helping to decrease fatigue related to cancer treatments.

The next study that I'd like to bring to light is one where they actually determined the physical activity preferences for people living with multiple myeloma. Now they interviewed 24 survivors following autologous stem cell transplant. And it was interesting to hear that all of them really enjoyed engaging in different physical activities. But, the main thing is that they were all willing to. These activities involve walking, light exercise, gardening, bike riding, and they were supervised by a PT (physical therapist) or a nurse. They also preferred that the activities were tailor made for the survivor, again, going back to that concept of it being enjoyable for the individual, more of a tendency to commit to it.

And then finally, they also mentioned that they preferred a setting where other people were aware of their disease and their rehabilitative process. Some also enjoyed receiving care from healthcare providers in their home, and that's a possibility for many people, even in these areas.

The next study is a trial that looked at the effects of Qigong\(^1\) on fatigue and sleep quality for non-Hodgkin's lymphoma survivors.

It was a nice study involving 108 survivors that happened over the period of 21 days. Half the group was in active practice with qigong, and they noticed that there was a significant decrease in fatigue and an increased quality of sleep just by gentle, active exercise.

**Slide 26 – Therapeutic Exercise Fatigue and Fitness (Continued)**
The next slide will go on to examine the effects of aerobic exercises on cancer-related fatigue. This again was a study that looked at many studies. They examined 26 of them, which involved over 2,800 cancer survivors, and they found that aerobic activity which lasted 50 minutes, two times a week, had a significant improvement on reducing cancer-related fatigue.

The next study was a little bit special. It incorporated another form of therapy that I don't typically utilize myself with my patients. But, it was interesting, and it was, again, focused on cancer-related fatigue. So, it was the use of cognitive behavioral therapy in addition to physical training and physical therapy, and they compared it with no intervention. The interesting thing with this is it involved 147 survivors, and those people who engaged not only in physical therapy, but cognitive behavior therapy, which involves problem solving activities for stress, relaxation, and self-management, all noted a significant decrease in their cancer-related fatigue.

And then finally, the last article that I wanted to mention brings me back to something that I had said previously, how the effects of aerobic exercise was important to help maintain your current weight throughout your treatment. What sometimes can happen after treatment, active treatment of cancer specifically, is that it'll be an onset of weight gain. It's important to make

---

\(^1\) Qigong: [chee-goo ng, -gong] A Chinese system of breathing exercises, body postures and movements, and mental concentration, intended to maintain good health and control the flow of vital energy. Source: Dictionary.com Based upon the Random House Dictionary. © Random House, Inc. 2017
Flexibility, Fitness and Feeling Better

Mark Gugliotti, PT, DPT, OCS, COMT
January 18, 2017

Dr. Mark Gugliotti: sure that those gains in weight are healthy. If they're considered to be unhealthy, it can also lead to the onset of comorbidities such as obesity, hypertension, or even possibly diabetes.

Slide 27 – Mobility and Flexibility
The next grouping of topics that I want to address are those with relation to mobility and flexibility. Now on a daily basis, I'm doing many of the things shown in these pictures with my patients. I'm helping them regain mobility throughout their trunk or throughout their spine and their neck, helping to improve flexibility of their upper body as well as with their lower body. And quite frankly, I'm engaging often with the use of massage in my patients. And there's quite a bit of benefit to these, and I wanted to at least go over some of the details related to those.

Slide 28 – Manual Therapy Pain Relief, Mobility, and Flexibility
So, the first study revolves around the use of palliative care, which is also considered to be supportive care, versus direct care of the cancer treatment. And this was studied in the management of older patients who had undergone cancer treatment or were currently being treated for cancer. They found that it was very important to engage in aerobic activities, strength training, as well as flexibility training. It's important to maintain your flexibility and mobility, especially as you age, because it helps to maintain active mobility to allow you to do the day-to-day stuff and minimize the stiffening and the tightening of the musculature, which can often contribute to subsequent falls. And of course, some of the results from subsequent falls could be that fracture to the hip or fracture to the shoulder, so very important to maintain that flexibility as portrayed in this study.

The next two studies work along the same rationale, and that's the implementation of a more hands-on approach, the use of mobilizing the joints and mobilizing manipulation of the tissues to help regain mobility and function in individuals. This next one here I had submitted to Rehabilitation Oncology, and I'm happy to say that the individual is still doing well. I treated him some time ago, approximately five to six years ago. And I see him on a regular basis. He actually lives in the same town that I do, and his neck mobility has maintained ever since treatment, and he's doing very well.

It's sort of like that hands-on approach that could make a difference for individuals, like when you ask somebody to scratch your back because you can't quite get to that spot on your back. And the article also supplied by Clinton took a similar approach, and they even made more use of the strengthening and endurance and conditioning for their patient.

Slide 29 – Manual Therapy Pain Relief, Mobility and Flexibility (Continued)
The next series of articles I think everybody will relate to very well because it's often very comfortable. It's the use of therapeutic massage during and following their cancer treatments. The four articles listed here pretty much are all on the same page in suggesting that therapeutic massage and massage therapy helps significantly to reduce pain, fatigue, nausea, and anxiety. In the first one, there was a study done and performed with 58 survivors. All resulted in the same outcomes with their reduction in pain, fatigue, nausea, and anxiety. The next one examined 12 studies involving over 550 survivors, again all receiving a reduction in pain; important to break that pain cycle. Keep that in mind.
Dr. Mark Gugliotti:
The next study was just a simple review of literature, again validating the idea that there will be a reduction of stress, anxiety, and pain for individuals undergoing therapeutic massage and massage therapy. And then finally, the last article that I wanted to review with you is the one performed at Memorial Sloan Kettering Cancer Center. Over a three-year period, almost 1,300 survivors involved, all noted a 50% decrease in their overall symptom scores as it related to pain, fatigue, stress, nausea, and depression. So, again, massage has its place in cancer treatment, and it can be very beneficial for survivors.

I would just encourage you to keep in mind, often important to avoid direct pressure over a local mass or a tumor and also try to avoid radiated areas because of sensitivity to the skin in those radiated areas might not tolerate the massage therapy so well. And it will really be an individual by individual basis.

Slide 30 – Strength Training
With regards to strength training, the American College of Sports Medicine suggests resistance training two to three times weekly with a steady progression. Now many of you might associate well with this picture that I displayed, but I want you to know it’s not about the heavy weights. It’s really about the smaller weights and the repetition. The low load is really where you’ll find your saving grace. And you can see in the last picture that I brought up that many of these activities can be performed just using the weight of your body to get you started. But, two to three times a week with a steady progression can be most beneficial for individuals, particularly cancer survivors.

Slide 31 – Therapeutic Exercise beneficial for improving strength, endurance, mobility, quality of life
And here’s a few articles that will help validate what I’m mentioning. Exercise training in cancer survivors, this review of studies really helped to validate with the implementation of therapeutic exercise, you can decrease fatigue, demonstrate an increased quality of life, fitness, endurance, and also mental status. A study that I performed with one of my other research groups: we looked at nine studies overall and conclusively found that the implementation of aerobic exercise, strength training, and qigong can greatly help in the reduction of cancer-related fatigue.

And in the final article, over 132 survivors participated in physical therapy guided exercise involving aerobic activity, strength and flexibility training. [There was a] statistically significant presentation of decreased fatigue, increased strength, and increased quality of life.

Slide 32 – Balance Training
The other and most important training methodology that I feel is often overlooked but certainly needs to be implemented for the benefit of our patients is balance training. And it comes in many forms.

You can do balance training simply on a firm surface or a soft or uneven surface with the support of a chair to gain benefits from balance training; can be as easy as sitting on an unstable surface but working side-by-side with somebody to help maintain your safety; can be
Dr. Mark Gugliotti:
progressed of course to a rather uneven surface utilizing other objects, such as a weighted ball, to help train your balance. And then once you're getting really good, I suppose you can take this show on the road, head to your local beach, rig up a rope, and try your go at balance training in that sense. I would say let's focus on the other three before we get to that fourth.

Slide 33 – Balance Training
But, in saying all that, I do want to bring your attention to the final study I want to present to you, and that's this study. It's the effect of lower limb, closed kinematic chain, and that's just a fancy way of saying that both feet were on the ground at the same time. Exercise on balance with patients with chemotherapy-induced peripheral neuropathy. Now for those of you who are unaware of what neuropathy is, it's kind of a short-circuiting of the nerves in your body. And this happens a lot—can happen a lot, I should say—during active chemotherapy treatments because of the chemo toxins. They're killing the cancer, but they're also having an effect on other cells in your body. And some of those involve an effect on the nerves.

Now the nerves go throughout our body, and they often are affecting the nerves at the ends of our body, so in our hands and our feet. When it becomes a problem in the feet, you're unable to sense sometimes, very clearly, the surface that you're standing on, or if you're walking over something uneven or stepping over pebbles, or God forbid, something that can be considered harmful as a tack laying on the floor, you might be actually unaware that you're stepping on it and can cause further injury to yourself.

So, the importance of trying to overcome the peripheral neuropathy that's induced by some chemotherapies is rather important. And in many cases you can have a full recovery, but in some, it might be persistent. It all really depends on the exposure to the chemotherapy toxins that you're receiving during your active treatment. But, this was a great article that actually studied 25 survivors afflicted with chemotherapy-induced peripheral neuropathy. And they performed closed kinetic chain exercises, like I said, both feet on the ground at the same time, for 15 sessions for over a three-week period, so five days a week for three weeks. And all of them noted significant decrease in their symptoms and actually an increase in their balance.

The reason why I wanted to highlight this study is because I've been saying for many years that this is an important part, a key component to the recovery for patients who are undergoing active treatment for their cancer. And I was so pleased to finally come across a pilot study from the year 2016 that's actually taking that bold step forward.

Slide 34 – Reimbursement Concerns
Now of course, whenever you're introducing a new form of treatment to yourself, you always have to think about, “Well, who's going to pay for this?” And it always comes down to reimbursement concerns. For many of you who are on Medicare, treatments provided through physical therapy are part of your benefits. So, you can certainly engage and seek out care through the use of a physical therapist. I would just encourage to do a little research yourself, making sure that you're finding the right therapist to fit your needs.
Dr. Mark Gugliotti:
When you're shopping for healthcare, you are a consumer, and you want to buy the best product. So, it's important to sometimes talk to the therapist. Actually go, take a look at the facility. Take note of the type of care and the contact that you're going to have with your PT (physical therapist) or other healthcare provider or supportive care provider so that you're making the right investment in yourself. And if you do decide to engage in physical therapy, I will encourage you to ask your physician for a prescription and a referral, which includes both a medical diagnosis, which could be simply pain, gait disturbance, and there's many other that they'd be aware of, as well as a treatment diagnosis so that then the practitioner who will undertake your rehabilitation could enter it into their system and ensure that your benefits will pay for these services that are so necessary for you.

Now commercial insurances, such as United Healthcare, Aetna, and so many others, generally follow the same guidelines that Medicare dictates because Medicare has such stringent guidelines to follow. So, in most cases, you will be able to utilize those commercial insurances to your benefit as well. And there's always that last option of self-payment. It's not for everybody, and if it turns out that it is something for you, certainly work with the best practitioner that you can find available to you so that you're getting every bit of that investment on yourself back to you.

Slide 35 – “Take the first step”
Really to wrap this up, it's important that you take the first step. Commit to your self-improvement. Commit to reestablishing yourself as the individual you always knew that you were and that you're most familiar with. That feeling of self-empowerment is so important, so important. And please, talk with your family and physicians. These are the people who care about you, and they want to guide you in the best possible way to ensure the best outcome for yourself. I mean, I've had quite a privilege of a great support system. First off, my wife, my family, my friends, my colleagues, they were all very encouraging and were behind me 110%. And that makes such a difference on the days where you might be struggling to see if things are going really, really right.

Again, I'd like to acknowledge and thank The Leukemia & Lymphoma Society for all they do. As a survivor and volunteer for our Long Island Chapter, I have nothing but praise for the tireless efforts and commitment made to improve so many lives. It's truly heartwarming and inspiring, and I wish you well along your journey, and I thank you. This concludes my presentation.

SLIDE 36 – Q&A Session
Ms. Lizette Figueroa:
Thank you, Dr. Gugliotti, for your very clear and informative presentation. It's now time for the question and answer portion of our program. We have received some pre-submitted questions.

Our first question, Doctor, is, “How do you find a PT who is familiar with oncology patients?”
Dr. Mark Gugliotti:
Hopefully if you're working in a clinic or being treated actively in a hospital setting, you can ask for a referral from the physician him- or herself. Very often, physical therapists will make themselves known to the oncology physicians, and they'll often work close-knit with them in trying to ensure the best outcome for their patients. And I would say that would be one of your best resources to start with. You might also ask a friend who had a similar experience to you and where they utilized the services of a physical therapist or a trainer or a certified cancer exercise specialist. Sometimes that referral process can be very helpful and very comforting for many people.

Ms. Lizette Figueroa:
Thank you, and our next question is from our Information Specialists. They've spoken to many people who were very active before their diagnosis, and patients really wonder how long they would need to wait until they could resume that strenuous activity that they were used to prior to the diagnosis.

Dr. Mark Gugliotti:
That's a great question. I actually fell victim to that same approach. I was consistently maintaining a level of activity and exercise throughout my chemotherapy sessions, and then when I started my radiation treatments, because the fatigue was slowly easing from the effects of chemotherapy, I started going from brisk walking to running. And I overdid it a bit, especially towards the end of my radiation therapy.

What I'll encourage people to do is to just go at a slow pace. Slowly regain, slowly re-engage themselves into their activities, provided that they have consistent direction with that, utilizing a knowledgeable therapist or trainer, a nurse, nurse practitioner, or again, a certified cancer exercise specialist. To help tailor a program specific for that individual can be so important and so much more fulfilling to go through in starting without any obstacles along the way or regression in any way.

Ms. Lizette Figueroa:
Our next question is regarding how to avoid muscle atrophy.

Dr. Mark Gugliotti:
Muscle atrophy is often the result of lack of muscle use. One of the best ways to avoid muscle atrophy is to utilize the muscles that can possibly weaken over time. And a lot of people shy away from exercise because they have that misconception that exercise has to involve weight or resistance training or going to a gym or a location where many people are working out for their overall fitness and strengthening. Exercises to combat muscle atrophy can be simple exercises such as sitting from a chair and then standing from a chair and then sitting back down. So, if you're in a seated position in a chair, just simply stand and then come back down. You'll be actually utilizing and activating the muscles that tend to atrophy in most people, which are the muscles on the front of the thigh, and they're referred to as the quadriceps.

After the age of 60 years old, for every decade, you're losing 10% of the strength in those muscles alone; just simple activity such as standing from a chair and doing it in repetitions of 10,
20 repetitions per day. Going up and down stairs can be very helpful in helping to combat atrophy. And that's just one example of one muscle and one type of exercise. For every muscle there are better and more tailored exercises to target it, and again, I would always defer to working with somebody who has knowledge on that to best optimize your exercise efforts.

Ms. Lizette Figueroa:
And along that idea, what are some practical ideas for mild exercise, such as chair yoga?

Dr. Mark Gugliotti:
Chair yoga can be very beneficial. That will help add and combat--or help to safeguard against a loss of flexibility. I like to always have a balance of those core four. So, in addition to flexibility, with regards to fatigue and fitness, I would encourage gentle walking, and again, starting out at a comfortable pace in a safe environment and in an environment where, if you needed to stop, you didn't have to walk all the way around the building or whatever ring you're walking around to get back to your starting position. You could simply walk across and stop.

Also implement some resistance training as well as balance training. Keep it more of a holistic approach in hitting those four core activities. But, certainly armchair yoga is beneficial. Armchair aerobics, I've seen, armchair strengthening exercises. If you look hard enough on the web, you'll find just about anything, and provided that they're safe for the individual and effective, I'm in full support of that.

Ms. Lizette Figueroa:
And how do physical therapists deal with pain management?

Dr. Mark Gugliotti:
Well, we can offer many options to help break that pain cycle. We can do it through the use of some of the devices that we have in our practice. Some of them will be gentle applications of electric stimulation to just break that sensation of pain that the person is experiencing, through the use of massage, through the use of flexibility training and passive stretching that we'll perform with our patients, and also engaging them in low level active activities such as stationary cycling, walking on the treadmill. All can help contribute to decreasing the actual pain manifestation and helping to break that pain cycle.

Ms. Lizette Figueroa:
And we have a great deal of questions in regards to peripheral neuropathy. Can you speak about how to deal with peripheral neuropathy in the hands and feet, including how to gain balance if you have neuropathy in the feet?

Dr. Mark Gugliotti:
Yes. Well, first off, just to shed a small light on peripheral neuropathy, it's sort of, as I mentioned before, a little bit of a short circuitry of your nervous system. And it often comes about as a result of the exposure to certain chemo toxins that are used in chemotherapy. So, if you take the analogy of a lamp with a frayed electric cord, obviously we would unplug it, but until you realize that the cord is actually frayed, every time you turn the lamp on, the bulb might flicker. As you walk by a little more firmly, it shakes the lamp, and the bulb flickers.
Dr. Mark Gugliotti:
And the same kind of concept is happening with the nervous system. Our nervous system is kind of the electrical system of our body. And it's responsible for relaying messages from the world to the inside of our body and brain for processing, and then the brain does its best job at sending out the right and appropriate signal for that body part or the person in general. What can happen with exposure, as I said, to the chemo toxins in our body is that there's less of an activity or there's an impaired function of those nerves, particularly as they go further away from the central part of our body into our hands and into our feet.

And very often at times, it will cloud the judgment of the nerves in relaying messages back to the brain for processing, particularly those in the feet when it comes to balance. I was mentioning earlier in the program that if you were to walk on firm, level surfaces, it's usually less of a problem. But, because that sensory awareness has been taken away from you and the nerve is not functioning so well, as soon as you're going off those even surfaces, perhaps onto a carpeted rug and then onto a pathway that might now have some pebbles or some stones along the way, your body would normally recognize that and adjust for it. Well, in the cases of neuropathy, it's unable to. And you run the risk of potential becoming off-balance and then subsequently falling. With regards to the hands, sometimes the loss of sensory awareness might result in you reaching for something that you would normally recognize as being hot or too warm to pick up, and then you reach for it, and you end up burning yourself. So, being aware of your environment can be very helpful. Doctors can also prescribe you medication for that. We can also take you through various training sessions with various training tools to help you become more aware of differences in your sensory awareness with reaching into different bins. Maybe they contain rice or beans or something comfortable like a soft cloth, and you can start distinguishing between that. Also doing small activities with your hands, putting together simple puzzles or simple models, can also be another avenue to regain some mobility and awareness in your hands as a result of the neuropathy.

Balance exercises and gait training or walking training can be very helpful at regaining the balance in your lower extremities, and as a result of neuropathy in the feet. So, a lot of different avenues that we can work with our patients, and it's just trying to tailor make it to their needs.

Ms. Lizette Figueroa:
And as a lymphoma survivor yourself, I'm sure that you can relate. We do get a lot of lymphoma survivors asking about deep tissue massage, if that's okay after their treatments.

Dr. Mark Gugliotti:
It will be, and it's validated, like I said, in the literature that I presented. And that's one of the reasons why I wanted to certainly have the most literature with respect to massage available to individuals. It's proved to be beneficial. Now what some people sometimes make the mistake, and this is patients in general. It's not focused on any one patient. But, they will always say, "Well, can you push harder? Can you push deeper?" It really needs to be the objectiveness of the practitioner to decide how deep they really need to go with the tissues when they're trying to access deeper muscles that might be in a little bit of a spasm or a tightness.
Flexibility, Fitness and Feeling Better

Mark Gugliotti, PT, DPT, OCS, COMT
January 18, 2017

Dr. Mark Gugliotti:
What you want to do is always avoid harm to your patients. Now if you're pressing too deep, too hard, that can result in subsequent bruising. But, that would be available to any patient, which is why I often steer away from that approach. It doesn't have to be a “seek and destroy” mission just because your muscle is tight. You can provide a nice, good quality massage at the appropriate tissue depth and then support it by prescribing a stretching exercise to help maintain the flexibility that was gained through massage. So, I'd be cautious at what the patients are specifically looking for and try to work well with their healthcare provider at coming to the best approach for their appropriate treatment.

Ms. Lizette Figueroa:
Thank you. And many patients are asking if yoga is appropriate after cancer treatment.

Dr. Mark Gugliotti:
Absolutely. The use of yoga as well as many other exercise activities is very welcomed and also supported in the literature. So, I would encourage people to get involved, again always keeping in mind it should be enjoyable and it should be to their comfort level. I would strongly urge them to get involved with perhaps a group that is more familiar to them and be cautious that if they get into the situation where they're trying to attain a particular position but perhaps the muscle length in their body just won't allow them to get there that day, then keep working on the pose over the course of the next few days, the next few weeks, until you get there.

What I've often found that sometimes people will ask for that extra assistance and too much force is provided. So, whether you're going for active cancer treatment, cancer survivor, or any person engaging in yoga, you have to listen to your body and know when enough is enough and never trying to overextend, going further into a pose just because everyone else in the class is there except for you, all right? The use of blocks and the guidance of the yoga instructor to get you into a more comfortable position so that you can attain and achieve what you're hoping to achieve can happen a little slowly, but more safely over time.

Ms. Lizette Figueroa:
And many people don't necessarily consider their physical therapist as part of their treatment team, possibly since a physical therapist may provide services outside of a treatment center as well as in a person’s home. How do you really encourage open communication with patients’ oncology treatment teams?

Dr. Mark Gugliotti:
Well, this is again part of what I'm hoping will happen over the course of time, and I've really seen a nice transition in the last maybe five, seven years, where therapists are taking more of an active role in the treatment of cancer survivors, and their knowledge base is becoming broader, and their efforts as providers of care are getting more and more validated with the great research that's coming out. I think for so many times, and I've seen it happen in the past, that therapists and other healthcare providers, not just therapists, will shy away from treating patients, not really understanding the whole process that's involved in their care, just for the
sake of avoiding further harm to the patient. And it’s not really substantiated by much except for a gut feeling.

The literature clearly shows and outlines the fact that we do make a difference for our patients, and so do other healthcare providers. So, it’s an important thing for the therapist to get out and market their skills to the neighboring oncologists and develop a great rapport so that then the patients have an option for referral if they do go to the oncologist and quite frankly ask for that. In New York State, physical therapists are actually direct access providers. So, the patients can come directly to us without the referral from the physician. However, I do think it’s important that the team work together. And that’s why that team approach slide is so important to reflect on. You’re always putting the patient first, and I think the more people on the team that are involved and knowledgeable of what’s going on for the patient, the more benefit to the patient.

Ms. Lizette Figueroa:
And as a Hodgkin's lymphoma survivor, what did you find the most challenging in getting back into the fitness status that you had prior to your diagnosis?

Dr. Mark Gugliotti:
I was able to kind of guide myself through some of the literature and get some of the information that's been very helpful. I do wish that it was more available to me and the studies that I spoke on today were available to me back then. But, I did take a gradual approach. I took the same approach with me as I would do with all of my patients.

There were some obstacles that I encountered along the way, but I was able to get over those obstacles because I was at least able to identify when my body was saying, you know, that was a little bit too much. You have to be a little bit more careful about that. I listened to my body. And that's the thing that I always instill in my patients. Listen to your body, and it will help guide you.

Ms. Lizette Figueroa:
Do you feel that a lot of patients that come to you have known that physical therapy can be an integral part of their treatment, or do you think that they were surprised to know that they could receive this type of service to help them in their survivorship?

Dr. Mark Gugliotti:
Actually, a lot of the patients who have come to see me in the past years were referred through their physicians. So, there was already a comfort level established before they were even contacting me. Most of what was necessary after they actually came to see me was to take time to listen to them and answer their questions, as many questions as they asked to the best of my ability, to help them understand that I was able to do something for them. And we took that approach throughout every session, and it was really beneficial for them to realize over time that they could actually do more than they thought that they could. And that is always great when they surpass even their own expectations.

Ms. Lizette Figueroa:
What are some of the concerns that your patients have had or have brought to you?
**Flexibility, Fitness and Feeling Better**

Mark Gugliotti, PT, DPT, OCS, COMT

January 18, 2017

**Dr. Mark Gugliotti:**

One of the major concerns is that they're worried that they're going to engage in some kind of activity with me that's going to make their cancer worse. And as I mentioned before, with the help of the literature and going over the information with them as best as I can, the benefits, the benefits from these activities are so great and so significant and so well documented that there really should be no concern. It kind of goes back to the article that I was mentioning about motivators and criteria for engaging in exercise. It's the attitude, and it needs to be a positive one, a positive instrumental attitude, understanding that these exercises are not harmful and that cancer is a disease process. And it will follow its course as such, and it's treated in that way. And under no circumstances would the participation in activities influence that at all.

And that also then segues into the other concern or at least the presentation of feeling so helpless, without direction, or without guidance. And they're always genuinely very appreciative of just taking note of the some of the examples that I bring to their attention right away that they are actually here. That was the hardest part of actually getting here in the clinic or in my presence or me being at their home to starting to take that step forward with so many people unable to even do that. Just get out of bed just to do some of the basic things that they were already capable of doing, and bringing that to light so they can actually see that they are accomplishing something and hopefully use that as a platform to get more motivated.

**Ms. Lizette Figueroa:**

And here at The Leukemia & Lymphoma Society, we have a lot of patients saying that they are so fatigued from their diagnosis, from their treatment regimens. And we often let them know that exercise does help with the fatigue. And many wonder how can they exercise if they feel so fatigued?

**Dr. Mark Gugliotti:**

Regularly. That's something that's brought to my attention regularly. And as I mentioned before, a lot of people have this ill-conceived idea that exercise has to be “no pain, no gain”, or it has to be with every last breath that you were engaging in some form of activity such as running or cycling that you're just completely exhausted. No, the start of the right types of exercises starts with taking the first step. And that's initiating some form of exercise. And it can be up to five minutes.

There's a great program through the American Cancer Society where they start out a program over six weeks where the initial meeting is mostly all talking and education, and then they do five minutes of walking. And then in the next meeting, they up that duration of walking from five minutes to 10 minutes. And then as you go through the entire program, by the time you're at the end of six weeks, you're talking minimally in a seated area with regarding dispensing education, but actually walking for 60 minutes by the time everything's over.

We actually have a special program at the Long Island Chapter called “Survivors in Motion”. It's abbreviation is SIM. It was actually one of the slides earlier, and I forgot to mention it. But, it's a great way to meet with other survivors and help reengage them into regular activities. Activities
that we do, aside from an education component where we all talk about a particular subject, we turn that subject to the focus of the activity. So, we've actually talked about peripheral neuropathy and gone to shoot pool where you have to hold the cue stick and maneuver the stick with the balls on the table, much as anyone would be familiar playing pool.

We talked about the importance of balance, and we went to the bowling alley, and we started with some light balls and that assistive ramp to get people actually engaged in bowling. We have a paint night where somebody comes in and helps guide us through painting the chosen picture of the evening. We've often incorporated Tai chi, fitness, and exercise training in a weight room. We're actually on the slate to also incorporate beginning tennis, all in a nice, controlled environment, low key, low stress, and just full of enjoyment.

So many people have come to me later because I'm one of the facilitators of the group and say how they're just continuing to do these activities. Somebody who had bowled for so many years was so thrilled to pick up his bowling ball again and just get to the alley when he wants to. He actually does Tai chi every day now. And it's just wonderful to see that embracement of getting back into a regular lifestyle.

Ms. Lizette Figueroa:
Thank you, Doctor. That concludes the question and answer portion of our program. Thanks again to Dr. Gugliotti for sharing his knowledge with us.

Slide 37 – Resources Slide
If you have additional questions, please call a Leukemia and Lymphoma Society Information Specialist at 1-800-955-4572. Information Specialists are available to speak with you from 9:00 AM to 9:00 PM Eastern time, or you can reach us by e-mail at infocenter@LLS.org. We can provide information throughout your entire cancer journey about treatment, including clinical trials, or answer other questions that you may have about support, including questions about financial assistance for treatment. LLS Information Specialists can also talk to you about our free personalized nutrition consults.

On behalf of The Leukemia & Lymphoma Society, thank you for listening, and we wish you well.