“Lymphies Get Ready, Get Set, FILE! How to Work the New Lymphedema Treatment Law on Medicare & Medicaid Claim Platforms Beginning January 2024”

Judy Mittag
International Disability Rights Affirmation Conference 2023
November 10

[2023/11/10 12:31] LV (LoriVonne Lustre): Hello everyone.
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Some speakers may be using a text teleprompter tool for some or all of their presentation.
Transcriptionists will fill in any gaps and support the Question & Answer section at the end.
A little explanation about this service.
Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.
Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.
You will see the transcription in local chat.
Transcription is provided by Virtual Ability, Inc.
The transcriptionists are :
Lorivonne Lustre
Carolyn Carillon
The speakers will be identified by initials as they speak.
The following initials in the transcription record will identify the speakers:
JM: Judy Mittag (SL: Kirsten McLeod)

[2023/11/10 12:35] LV (LoriVonne Lustre): <<transcription begins>>

[2023/11/10 12:36] Shyla the Super Gecko (KriJon Resident): I am Shyla the Super Gecko, voicing for Minka Angel.
Good afternoon, and welcome to Virtual Ability's IDRAC 2023!!! My name is Minka Angel, and yes, I'm tiny so does anyone have a booster seat I can borrow? 🙂
Like many of you here, I'm living with a disability, which lead me to find Second Life. I've been here for 4 years now and learned that I can be whomever I want in here vs out there in the real world.
Here I don't have multiple sclerosis, here, I don't have a wheelchair, and in fact here, I have wings, and can fly. 🙂
In here, I don't need the $22,500 a month for just one of the medicines I need to take every week, that my insurance pays for, for me. In here it never dawned on me, there were conditions, diseases, illness with life threatening outcomes untreated that weren't covered by people's insurance. That they were having to fight tooth and nail for basic life saving

care. I thought if you had insurance you were good and they would take care of you. I learned that I live in a sheltered box, I am one of lucky ones.
I never had to fight for the medicines and things I need to live and flourish. I now know that's not the case for a lot of us....I find it disturbing that my medicines cost more than a house a year, and I have access to it, weekly, no questions, no arguments, and to find others with medicines that are extremely low cost in comparison and they can't get them at all.
It makes me very sad...So that's me, Princess Minka. One of the lucky ones. But I'm not why we're here today.
Today's session is on a topic that should never have to be fought for, but it was, so I would like to introduce you to someone who faced this, fought this, and won.
Here is the amazing Judy Mittag, to tell us about her battle, with her insurance company, and then taking the fight to Congress to bring about changes!

[2023/11/10 12:38] LV (LoriVonne Lustre): Lymphies Get Ready, Get Set, FILE! How to Work the New Lymphedema Treatment Law on Medicare & Medicaid Claim Platforms Beginning January 2024

JM: Can you hear me?
Thank you Minka and Shyla
This is the first time that I have come out in SL. I have been here for 6 years, but have kept this part of my life quiet
Dec 27 - 2022 I got the message! We did it!
We won our battle
Along the way we lost friends. People did not believe us that we could not get the help we needed. This is America, right?
When the legislation was written it only recognized people with lymphedema who got it from cancer. Even though 90% of people with lymphedema did not get it from cancer
Heather Ferguson in SC gave birth to twin boys, one of whom had lymphedema -- and they could not get the support and supplies needed.
Heather was a fierce mama bear and fought for her son. Taking him to Europe for treatment
She started organizing locally, then nationally
We decided to take on the US congress
2 people on the original team have died because they could not get the treatments they needed
I was lucky. I was found to be valuable enough to my company, so they told the insurance companies to help me
Do we have any kindred lymphies here in the auditorium? stand up
I do want to talk about this law. You can help someone who might not be readily diagnosed, especially if they do not have cancer
You may save their life

What is lymphedema?
Imagine your leg being the size of a tree trunk?
Doctors only told me to lose weight -- I had both legs affected
The problem is if you work out with lymphedema, you make it worse

I had a regular cardiac checkup and the doctor spotted it right away
The doctor said, you are not fat you are big. There is a difference
That doctor saved my life!
She got me in to see the lymphedema specialist. It took 3 hours to do the tests. 3 hours!
Nothing special about it.
People with acquired, secondary lymphedema make up 90% of patients. Of those, 70% have cancer
20% of people with secondary lymphedema do not have cancer, like me
The Lymphedema Treatment act becomes law in Jan 2024
We fought to get the services and supplies to stay healthy
Without treatment you can die

How expensive is treatment?
$500 for one pair of stockings on sale. [$800 otherwise]
Treatment is done by a certified lymphedema specialist. They won't come to you as they know you don't have insurance coverage
The night garments are very expensive [$1500]
I finally had to leave my job -- and so lost my insurance
The stockings need to be replaced regularly. I also learned to do lymphatic massage
I remember meeting Wisdomseeker here in SL
My alarm went off and I spent 5 minutes on my elliptical.
I am advanced stage 2. Without treatments and exercise I can move into stage 3 very easily
If caught at stage 1 or early stage 2, there can be complete recovery
There is no medicine. And therefore no pharmaceuticals to sell -- not enough profit
Questions before we move on?
[2023/11/10 13:03] Gentle Heron: I'm just shocked and horrified

[2023/11/10 13:03] Minka Angel (Saraminka Nova): What was your daily routine, your 'normal?
[2023/11/10 13:03] LV (LoriVonne Lustre): JM: the first part of getting ready is knowing what you need
I remember being body shamed
Just 4 weeks ago
By a doctor
I asked her if she knew about lymphedema
And she said she didn't' care
My son had come with me
He looked at me and shook his head no
She said I don't know if you're going to follow through
I wrote the address of a website
And told her to learn
And then we could talk
I was tired of it (sigh)
My son told me he didn't want me to see her
And I thought the next person may get lucky with her

You just have to grin and bear it
You just try to figure out a way
I emailed her some brochures that I'll show you
I mail them and I don't do anything more
If they don't read it, I don't need them as my doctor
[2023/11/10 13:07] Minka Angel (Saraminka Nova): I don't understand how they cannot see the facts in front of them, I am so sorry to hear you had a doc like that =(
No you don't, you need a doc that works for you, not against you
[2023/11/10 13:07] Sasy Scarborough: it is disgusting that any Doctor would say they do not care, when someone puts forth a reason for something, even if they are ignorant of what that thing is in full
[2023/11/10 13:07] James Atlloud (Lloud Laffer): Thank you for this talk. I have a friend in SL who has Lymphedema.
Thank you so much. Will tell her about you.

[2023/11/10 13:08] Carolyn Carillon: JM: this is how it is for people who don't have cancer
You're a very easy group to talk to
This is my first time being this open in SL
Like I am in RL
It's scary but you're all so nice!
This is the URL
You'll see the symptoms in someone else
Ask them
Some people just think they're fat like I did
https://lymphedematreatmentact.org/
This URL will take you to the front page
You'll see the navigation panel that's up here on the slide
Go to FAQ
You're going to learn
How to recognize to help other people
We'll look at the tools
You can print the brochures if you want
The last one is the get set part
We want to leverage this new law
So that everyone is treated the same
My cardiologist is cheering for me to make it to Jan 1 to get my stockings!
He just keeps going with me
I need those stockings
It will help my heart a whole lot
Go to that site
It's a robust site full of information
Just tell people about it
Have you all gotten a notecard?
There's a lot of info but it can be condensed
[2023/11/10 13:12] iSkye Silvercloud (iSkye Silverweb): sending out [notecard] now - Judy, you might get one too (sorry)

[2023/11/10 13:12] Carolyn Carillon: JM: glance at the topics
It will give you the basics
Ask me what you want to talk about
My favourites are #4
The answer is YES!
[2023/11/10 13:13] Gentle Heron: I was going to ask which one you think is most important

[2023/11/10 13:13] Carolyn Carillon: JM: not everyone is on Medicare
The insurance companies follow what Medicare covers
#4 and #6 are most important
Those are my favourites
Because it means I can get help now
I have my paperwork done and I'm ready to go!
I'll be submitting my first claim on Jan 2

[2023/11/10 13:14] Sasy Scarborough: I was wondering if these stockings are something that are only costly in the US? are they cheaper in other countries?

[2023/11/10 13:14] Carolyn Carillon: JM: have you all looked at the topics on that notecard?
Is there one topic you're curious about?
[2023/11/10 13:15] Lady Tigress Bonded (pet Karu): #13. What about coverage for other items currently not covered, such as surgery, custom shoes, etc?
[2023/11/10 13:16] Carolyn Carillon: JM: On that one, #13, those things are already covered under DME
[2023/11/10 13:16] Gentle Heron: durable medical equipment
[2023/11/10 13:16] Lady Tigress Bonded (pet Karu): ah, thank you
[2023/11/10 13:16] Carolyn Carillon: JM: for example, if you have a prescription for those, your doctor will know how you can file
They can file that for you
It's all the other things
That have never been covered before
It didn't have to be included in the LTA
But if you didn't have lymphedema due to causes other than cancer, you couldn't get a prescription
Is there another question you'd like to know more about?
[2023/11/10 13:18] Lorin Tone: How does it feel to be an absolute hero?

[2023/11/10 13:18] Carolyn Carillon: JM: I'm happy to get notecards or email later on
What will be covered?
Bandaging, compression wraps
This is the only way we can treat our lymphedema
There's no medicine
Even if you've experienced a reversal
You'll still be aware
You have to stay vigilant

How often do we get them?
3 sets of daytime garments every 6 months
That's pretty good
You can make your stockings last
It's not ideal
But you can manage
You can provide evidence it tore and you can get a replacement
You get 2 sets of nighttime garments every 2 years
Bandaging
I measured
You use 4 layers of different media to bandage your legs or your arm or midriff
900 ft on each leg
When I finished bandaging
[2023/11/10 13:22] Minka Angel (Saraminka Nova): good lord, that is crazy
[2023/11/10 13:22] Sarvana Haalan: OMGoodness!!!
[2023/11/10 13:22] Carolyn Carillon: JM: the first layer is a thin gauze
You have to wrap each toe a certain way
Then you take that gauze up your foot
It needs to be wrapped in a certain direction
I had to go to the top of my thigh
Then you have surgical cotton
Same thing
It has to go in a certain slant
That's why it's so much yardage
Then it's short stretch bandaging
You're doing each toe
The short stretch bandaging is different widths
It takes hours
You have to wash them a certain way
Then you need to lay them out
My house was covered with short stretch bandaging
You needed two sets
You were always bandaging, washing and drying
It's hard to work at the same time but I needed to if I wanted to keep my insurance
Once I could put on my stockings, those would take me ~30 minutes to put on
They're painful in the beginning
You grin and bear it
It takes 3 months to get used to the pain
You tell yourself you're getting better and you're going to live
I would get mad (Laughs)
I'd change doctors
And I'd have to explain everything all over again

Then I'd lobby
I can share that if you want
In the first few years I went to the staff briefings in Washington

I was their example
There were others there too
One young man
He looked like he needed a sling to carry his belly
I don't know where he got his courage
He'd had surgery
As a result, he has lymphedema
He said you probably think I should lose weight
I still cry for this young man
He said I'm not fat
I have testicular lymphedema
These are my testes
Everyone in the room looked at the floor
This man wasn't afraid
He let everyone stare at him
My story was easier
Then I couldn't travel anymore
That happens often
There was one woman who didn't make the journey
She couldn't travel
She knew the senator
She used the political connections
I listened to her reports
Louise Thyman
She had primary lymphedema
She could have lived
But didn't see anyone who would recognize her lymphedema
She suffered for years until she was diagnosed
She didn't make the journey
She died
I thought I know the ins and outs of DC
I know how to find out things!
So I decided to take what Lois had done
I saw who was having trouble getting their senator on side
I would do the research on the staffers
That's how the offices work
We are running out of time for this sessions
I'd find a common denominator
I'd tell others to jump on it
Only one senator defeated me (Laughs)
I succeeded for so many
They got appointments to talk
Not my senator
He didn't give a darn
I couldn't make it work
If you drop me a notecard, I can send the slides to you

We've made templates to make it easier
Nothing here is copywritten
Thanks for your attention
You're not so scary :)
You're really very nice
Thanks so much

[2023/11/10 13:32] Sasy Scarborough: thank you so much for sharing ♥
[2023/11/10 13:32] Gentle Heron: Kirsten, thank you for "coming out" in SL and sharing this important advocacy process with us today.
For more information on Lymphedema, check out the poster set on Healthinfo Island.
http://maps.secondlife.com/secondlife/Healthinfo%20Island/24/23/30

[2023/11/10 13:33] iSkye Silvercloud (iSkye Silverweb):
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[2023/11/10 13:33] Elektra Panthar: ♫♪♫♪ Applauds ♪♫♪♫
[2023/11/10 13:33] Lorin Tone: Brilliant work!
[2023/11/10 13:33] Basona Melody: Thanks so much Kirsten!

[2023/11/10 13:33] Carolyn Carillon: <<transcription ends>>

ATTACHMENT: Judy Mittag's FAQ:
1. Can I read a copy of the bill / law?   YES
2. What does the LTA do, and why is it only about compression supplies?
3. Does a Medicare beneficiary need to be diagnosed with lymphedema in order to qualify for coverage?   YES
4. Will the LTA cover patients with primary lymphedema and non-cancer related lymphedema? YEPPERS!
5. When will coverage begin? January 2024
6. What about patients not on Medicare?   Protocol and process for them as well including Medicaid
7. Will this cover patients with Lipedema?   YES Lymphedema Not One Disease Slide 14
8. Will this cover patients with Venous Insufficiency?   YES
9. Will this cover both standard-fit and custom-fit compression garments?   YES
10. Will compression garments for all parts of the body be covered, or only arms and legs?   YES
11. Will the bill allow for patient choice in regard to brand? SHOULD
12. Will other compression items such as bandaging supplies, low stretch (Velcro) garments, nighttime garments, etc. also be covered?   YES
13. What about coverage for other items currently not covered, such as surgery, custom shoes, etc?

14. Will this affect coverage for lymphedema therapy/MLD (manual lymphatic drainage), and will it affect which providers can bill for lymphedema therapy? NO
15. Will this affect coverage for lymphedema/pneumatic compression pumps? NO under DME
16. Will this affect the coverage I am receiving due to the Women's Health and Cancer Rights Act (WHCRA) of 1998? NO
17. Will this affect coverage for compression supplies used in wound care? NO Established different category
18. Will I need a prescription? YES
19. Will I have to see a CLT (Certified Lymphedema Therapist) before I can order my compression garments? UNLIKELY
20. Will there be criteria that must be met in order to receive custom-fit versus standard-fit garments? Determined as Medicare implements the program
21. How many compression garments will I be able to get at one time and how often will I be able to replace them? COVERED on LTA FINAL RULE COVERAGE SLIDES 7 – 11
22. What will my out of pocket costs be? Depends on your supplemental insurance Plan
23. Will there be an insurance cap on lymphedema compression supplies? Unlikely Again Medicare Implementation
24. Will insurance companies make you jump through hoops to get this coverage? And that's why we are going to GET SET! Slide 12
25. Will there be any retroactive coverage? In other words, could I buy a compression garment in 2023 and submit it for reimbursement in 2024? NO
26. Where will I be able to get my compression garments, will online purchases be allowed, and can I choose the brand I want? Let me give you the concise answer … not a yes no thing
27. What will the reimbursement rates be? In other words, what will the suppliers who sell compression garments be paid by Medicare for providing these items? Let me give you the concise answer … not a yes no thing
28. What will the terms of coverage be for patients receiving home health services? Let me give you the concise answer … not a yes or no thing
29. Will facilities be compensated if the garment is supplied while the patient is in a skilled nursing facility, long term acute care, or inpatient rehabilitation? See response to 28 above
30. What if I need to replace my garments sooner than what is allowed, or want to get more at one time than what is allowed? Let me give you the concise answer … not a yes no thing
31. If an item that can be refurbished (for example, a Reid Sleeve) will Medicare cover refurbishment? Again, Let me give you the concise answer … not a yes no thing
32. What if Medicare is unwilling to cover everything that I need, or all types of compression products currently on the market Let me give you the concise answer … not a yes no thing
33. What if Medicare incorrectly denies the claim, is the provider then able to bill the patient? Let me give you the concise answer … not a yes no thing
34. What if new compression products are developed that are different from the choices available today - will they be covered? Essentially yes with following qualification
35. What can be done if a non-Medicare insurance plan still fails to cover compression garments and supplies after the Medicare coverage has gone into effect? There are

many other steps that can be taken to remedy this if the need arises, and we will share information on how to pursue those actions if necessary

36. . What is involved with the CMS process and timeline, and what can I do to help in this process of implementing the LTA? Allow me to read the concise answer

37. What can I do to help after the LTA is implemented? Many lymphedema patients will not know about the LTA and how its provisions affect them. Would a longer-term public education campaign be possible to spread the word among providers, patients, insurers, etc.? Hang on for Slide 16

38. Will any new diagnosis or billing codes be added as part of implementing the LTA? Slide 10

39. Will any credentialed Medicare provider be able to bill for lymphedema compression supplies, especially bandaging supplies applied during therapy, or will only Medicare participating DMEPOS vendors be able to bill for compression supplies? Allow me to read the concise response

40. Will there be a way to submit the bill directly to Medicare for reimbursement if my provider is not enrolled in Medicare? Yes, brief description of that familiar process . . .