

## Q&A Regarding Head and Neck Lymphedema

with Brad Smith, MS, CCC-SLP, CLT

### 1. Please tell us a little about yourself.

I have been a speech pathologist since 1988 and became a certified lymphedema therapist in 2006, specializing in management of patients with head and neck lymphedema. I was a senior speech pathologist and lead H&N lymphedema therapist at the University of Texas MD Anderson Cancer Center for 12 years, where we built a very busy and successful H&N lymphedema program. I gained extensive experience with a very complex caseload of patients with head and neck cancer and associated impairments, including head and lymphedema. I joined the team at Baylor University Medical Center in Dallas, TX in August, 2016 and continue to teach the HNL Evaluation and Management course offered by the Norton School of Lymphatic Therapy, which I have been teaching since 2009. I have been very blessed to be able to lecture and instruct extensively over the past decade and also to have the opportunity to co-author two journal articles and author or co-author three textbook chapters.

### 2. Why has there been such an increased level of interest in Head and Neck Lymphedema (HNL)?

Over the past 10-20 years there has been a dramatic rise in the number of cases of oropharyngeal cancer related to the human papilloma virus (HPV). HNL has been a common occurrence following surgery and radiotherapy for HPV negative head and neck cancer, typically associated with an older population with histories of heavy smoking and alcohol use. However, HPV positive oropharyngeal cancer typically occurs in a younger, healthier population, many of whom are still working. The treatment for their head and neck cancer often creates communication and swallowing impairments, neck and shoulder dysfunction, lymphedema, and other concerns in an otherwise healthy patient group. Since they often need to return to work and resume other social activities, there is a higher expectation that these deficits, including lymphedema, will be rehabilitated so they can return “normal” function and appearance.

With this increased demand for lymphedema management, many therapists tell me that they did not receive much training regarding HNL when they completed their CDT certification. With increasing numbers of HNL patients on their caseloads, therapists are now pursuing advanced training to be able to treat them appropriately. Interestingly, there has been an increasing push for the training of speech pathologists in the management of HNL since they are often the first discipline to identify it when they are working to address speech and swallowing concerns. I have been told by many therapists that the hope is that the SLP will manage the HNL patients since the lymphedema therapist is already overloaded with other cases or is not as comfortable with the population.

I have concerns regarding this pattern, since the majority of the SLPs who are pursuing training are not planning to become fully certified lymphedema therapists. Without the additional hands-on training that comes with a 135 hour CDT certification course or the benefit of other more experienced lymphedema therapists with whom to review treatment plans and brainstorm, the SLP is left at a disadvantage. Typically, the SLP will learn enough to perform basic treatment techniques when they attend a 15-20 hour course for HNL management, but not enough to perform complex problem solving or manage extremely complex cases that require more training. For that reason, I always encourage SLPs who come to my course that they should have a local lymphedema therapist available to them and

that if they will be seeing large numbers of patients or will be a solo practitioner, they should definitely pursue CDT certification.

3. You have said before that you believe HNL is different than edema elsewhere. How is it different?

Aside from the obvious anatomic differences and location of the swelling, edema that occurs following head and neck cancer treatment is generally located in areas that have been directly affected by surgery or radiation treatment. Unlike limb edema that occurs after nodal dissections but without additional insult to the actual limb, the areas that swell in the head and neck are often directly radiated or damaged by surgery. This means that manual lymph drainage and compression are usually applied directly to irradiated tissues that become fibrotic over time. We sometimes have to use heavier pressure during MLD in areas of increased tissue fibrosis in order to facilitate drainage. H&N lymphedema also seems to respond to treatment more quickly than edema in other locations.

4. Why do you feel HNL responds more quickly?

Perhaps this is because the volume of lymphatic fluid in the neck and face is less than the amount of lymph contained an extremity and it takes less time to soften and drain a smaller area. I think the onset of lymphedema treatment in relationship to cancer treatment may also have something to do with it. I think most responsive cases of neck and facial edema are treated within the first year after treatment, before it becomes extremely firm and hard, which is advantageous. Like extremity based edema, the earlier intervention begins, the easier it is to soften and reduce the size of the edematous region.

I also believe there is a gravitational advantage for patients with HNL since the head is not usually in a dependent position for prolonged period of time, unlike extremities. This allows the tissues of the head and neck to drain once we achieve an upright posture and the more mobile we become, the better the system drains due to increased lymphangiomotricity. Conversely, patients with facial edema struggle greatly when they are unable to maintain an upright head posture. It is not uncommon for patients to develop a kyphotic, "head down" posture after treatment for H&N Cancer. When this position is chronic, it becomes more difficult to drain fluid from the face, creating a literal "uphill battle" for drainage that makes it more difficult to drain edema that is more localized in the face than swelling primarily located in the neck. Not to say all neck swelling is easy to resolve, since the presence of severe surgical scarring or extreme tissue fibrosis following radiotherapy can certainly create obstructions that prevent drainage via optimum pathways.

5. Can you describe your typical approach?

My evaluation usually entails a thorough interview where I review their medical history, determine their current overall level of function in terms of communication, swallowing, etc, determine their need for other disciplines, as well as determine any contraindications to treatment. I perform a visual and tactile assessment, intra-oral exam, and obtain photos and tape measurements of the face and neck. If adequate time remains, I will either fabricate foam pads to be worn with an "off-the-shelf" compression garment or I will instruct them regarding basic manual lymph drainage techniques they can start performing some type of self MLD that day. I like to bring them back in for a series of instructional sessions so I can then instruct them fully in a home MLD program and the use of a compression garment and their padding. The number of sessions depends on the complexity of their situation, their

availability, and their ability to learn the home program. If they present with severe edema and/or need additional assistance for some reason, I will request they come for a series of intensive outpatient treatment sessions and have them implement their home program as well as they can.

Manual Lymph Drainage (MLD): I typically instruct patients to perform a self-MLD routine they can perform while sitting upright, decongesting the trunk first, followed by the neck, and then the lower, mid, and upper face as needed to open the drainage pathways to the axillary nodal basins, in most cases. The route to mobilize the fluid from the congested head and neck to the axillary region will depend on the extensiveness of any surgical scars that may block direct access to the drainage pathways in the lateral neck, beneath the ear. If this is not a viable route, a more posterior route over the ears will be required. Be aware that the performance of a neck dissection to remove lymph nodes does not preclude use of the neck as a drainage target. There are approximately 300 lymph nodes in the neck so there are large numbers of lymph nodes available, as well as a dense lymphatic capillary network in the neck, even after a large neck dissection. Once the MLD sequence has been completed from bottom to top, I ask them to reverse course and perform the sequence in reverse order in an effort to complete the drainage process. When performed properly, the sequence should take 20-30 minutes. In more severe cases with extensive facial or intra-oral edema, additional time may be required.

Compression: All my patients with HNL are asked to wear a compression garment in combination with MLD. If kinesiotape is used, it will be used as an adjunct rather than as a substitute for either strategy. For most patients who present with edema of the anterior neck and lower face, I will have them order an off-the-shelf, non-custom compression chinstrap and add a custom made compression pad to enhance the fit and maximize the drainage. If there is pitting edema present, I ask them to wear an irregular softening pad (Schneider Pack) for 30 minutes before MLD to soften the firm fibrotic tissues and make them more responsive to MLD. In cases of soft non-pitting edema, I do not have them use the first compression pad but I do ask all my patients to wear a custom cut flat ½" gray foam pad beneath their non-custom compression chinstrap for a minimum of 3-4 hours after MLD. Longer time frames are preferred and result in longer carryover before tissues refill. However, it is sometimes difficult for patients to wear these garments all night while sleeping.

If they have a firm stage 2 edema, I may have them use the same Schneider Pack and before and after MLD to apply sufficient pressure to the tissue. If patients have anterior facial edema, I typically prefer a custom made facemask based on their specific measurements. Regardless of garment type, I do not apply compression if they are actively undergoing radiotherapy, have undressed wounds, or have massive facial swelling. I prefer to wait until the skin has healed after radiotherapy before applying compression. In cases of massive facial edema, improperly fit garments can worsen edema. As previously stated, custom garments are typically preferred for edema in the mid or upper face, lips, or eyelids. I typically try and reduce the edema initially using MLD and a short stretch bandage or an inexpensive garment in an effort to prevent to the need for resizing or purchasing a second custom garment. I do not recommend non-custom full coverage facemasks, since the opening for the eyes, nose, and mouth were not cut specifically for your patient and cannot be guaranteed to fit properly. If they do not fit properly, edema can be forced through the openings, worsening their condition.

Using this system of compression and MLD once daily, I ask patients with mild cases of edema to perform the routine for 4-6 weeks then return for reassessment. If good results have been achieved at this first assessment, they should begin weaning the program by 50% every two weeks. More

commonly, I ask them to perform the routine for 2-3 months on a daily basis. Once they begin to notice much less tissue refilling and visible difference in the edematous regions, they can start the weaning process. For example, patients are often able to decrease from daily treatment to 4 days per week for 2 weeks, then 3 days per week, then twice weekly, etc but they will usually experience an increase in edema once they reach a certain level. If that occurs they should resume the previous level of frequency for 2 more weeks then re-attempt the weaning protocol and continue until they are satisfied with their level of edema and frequency of intervention. Of course, there are differences when patients receive palliative treatment, have severe facial edema, etc.. The likelihood of treatment cessation in those cases is limited.

6. Why is the treatment regimen for H&N lymphedema commonly focused on self-MLD, with less intensive outpatient treatment?

The head and neck region is much smaller and more accessible for the patient than the areas of the body that must be addressed with lymphedema of the extremities or trunk. As a result, it is much easier for many patients with HNL or their caregivers to perform self MLD to the neck or face. This allows greater potential for self-care and increases the likelihood of strong carryover. My goal is always to try and make the patient and his caregiver as independent in the treatment as they can be. If I can teach them adequately and they demonstrate proficiency in 3 visits, that saves them the need to come in to my clinic, pay for parking, and incur the expenses associated with my office visits. However, if they require 10 visits, I am also glad to provide that degree of assistance if needed. I feel like a patient who is invested in his treatment will be more likely to comply with recommendations so I prefer to teach them to perform the routine themselves if at all possible, rather than be dependent on someone else to do it for them

7. How is compression for the H&N different than other types of compression garments?

I think there are several differences.

- a. Compared to the options available for the limbs and trunk, few vendors offer specialized options for the head and neck and those that are available are custom made and expensive. As a result, most therapists have limited exposure to the less expensive garments that are available and will work fine for the majority of the patients they will encounter. As a result, patients sometimes receive a garment that is overkill for a very mild edema. In fact, there are many off-the-shelf compression garments that are used for plastic surgery applications that will do well for most edemas present in the neck and low face. Most compression garments for the H&N are elastic garments and most are not fabricated for lymphedema at all. However, they will work fine as “pad holders”. I never use them without compression pads to help disperse pressure to the tissues and compensate for the fit of a garment that is not made specifically for your patient. Most of these garments are available for less than \$75.00 online, compared to several hundred dollars for a custom device that may not be necessary.
- b. Compression garments for arms and legs are often a lifetime commitment. Some patients wear both daytime and nighttime garments to provide 24 hour compression. While not an easy task to convince patients to wear garments for extended periods of time, it is less obvious and more acceptable when they can be camouflaged beneath clothing. Facemasks and chinstraps cannot be hidden and are not typically considered socially acceptable for public wear. Because of this, it is more difficult to convince some patients to wear facial compression garments for extended periods

of time during the day. This often means the only way to achieve extended use (greater than 3-4 hours) is to wear it at home at night. Some patients tolerate these garments well while sleeping, while others do not. My anecdotal observations have been that if they can wear the pad and chinstrap or their custom garment for 6-8 hours per night, the results of treatment will be accelerated and reductions will be greater.

8. Do you really see patients who can stop performing their home programs and not experience worsening edema?

I do, especially in cases of mild to moderate edema without surgical scars. I have seen many patients be able to greatly reduce both the edema stage and size using a simple program of MLD and compression over a 3-6 month period of time. By weaning from a daily program by 50% every two weeks, many patients are able to limit their need to perform the routine to weekly, semi-monthly, or not at all. In these cases they also do not typically develop increased size or firmness unless they develop recurrent disease or severely progressive radiation fibrosis. Obviously, patients with severe scarring and severe, fibrotic edema will typically experience more chronic edema in the upper neck and face that are more difficult to resolve. In those cases, the hope is to reduce the severity of the edema and its effect on function as much as possible. However, in those severe cases, the time frame for performance of the home program is almost always long term, with the objective of maintaining maximum edema reduction and prevention of worsening edema. These patients may not be able to wean from treatment at a more frequent interval.

9. How do you get your patients to “buy in” to the program? It sounds like it is time consuming.

It is time consuming and I explain that to them in the first session because if they are not willing to work with me I do not want to waste their time or mine. I explain that the most time consuming aspect is the compression after MLD. However, I also tell them that if they had edema in a limb, they would have to wear their garment for 16 hours a day and with their situation I am only asking them to wear it 4 hours. I always try to stay positive and keep my patients motivated. I am honest and tell them I do not know how long it will take and I also let them know that their compliance is directly related to their success. However, I also do not tell them things that will “de—motivate” them. I never tell them that there is no cure for lymphedema and this will be a lifetime problem, regardless of our intervention. If I tell them that, why should they bother trying? That quickly demotivates them. I would rather tell them we can likely reduce the edema and the degree of severity and their consistency with the routine will dictate how long they have to perform their program. So far, this approach has been very effective.

10. How can someone reach you if they have additional questions?

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