



# Cancer Survivorship Patient Education on Post-Treatment Care

## Lymphedema

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### *What is the condition?*

Lymphedema (Lim-Fi-DEEM-Uh) is a condition marked by swelling of the soft tissues due to accumulation of lymph. Lymph is a substance consisting mostly of water, but also containing proteins, chemicals, and white blood cells. Lymph is normally generated as fluid seeps out of small blood vessels into the soft tissues. It is collected by lymphatic vessels, transported through lymph nodes, and eventually returned to our bloodstream. When this process is interrupted – as in the case of surgery or radiation directed at treating cancer in the lymph nodes – the fluid cannot return to the bloodstream via its normal pathways. As a consequence, it collects in the soft tissues and results in lymphedema.

### *How common is it among head and neck cancer patients?*

Lymphedema is very common among patients who have undergone head and neck surgery or radiation therapy. Up to 75% of patients will manifest some signs and symptoms of lymphedema after treatment for head and neck cancers.

### *What are the signs/symptoms?*

Lymphedema is typically seen as doughy and diffuse swelling of the neck. This may be more pronounced over an incision or in the area under the chin. It can also be seen along the jaw-line, in the cheeks, and even in the eyelids. This is often worse first thing in the morning and after periods of inactivity. It tends to improve with being upright and mobile. Lymphedema can also occur internally – involving the mucous membranes of the mouth and throat. This often occurs at the same time as external swelling, but not always. When present, internal lymphedema can cause changes in voice, difficulty swallowing, a sense of something being “stuck” in the back of the throat, and, in severe cases, difficulty breathing or even with vision. Most patients with head and neck lymphedema will have both internal and external areas involved. Chronic lymphedema can lead to worsening inflammation and permanent fibrosis (scarring) of the tissues – leaving them stiff or even woody in texture.

### *How is it diagnosed?*

Lymphedema is a clinical diagnosis, but there are a number of objective scoring systems that your doctor may use to determine how severe it is. External head and neck lymphedema is most commonly graded on either the “Foldi” Scale or the MD Anderson Cancer Center Head and Neck Lymphedema Scale (a modification of Foldi’s system that is specific to the head and neck). Standardized face and neck measurements are often used to track progression of lymphedema. Your doctor may also use endoscopy to evaluate how severe the internal component of lymphedema is.

### *MD Anderson Cancer Center Head and Neck Lymphedema Rating Scale*

Stage	Exam Findings
0	No swelling, but a sense of heaviness in the neck
1a	Visible mild swelling without pitting. Reversible
1b	Visible mild swelling with pitting. Reversible
2	Firm pitting swelling that is irreversible. No visible tissue changes
3	Irreversible tissue changes with scarring and fibrosis



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### ***How is it treated?***

The most common and most widely accepted treatment method used for lymphedema is called complete decongestive therapy, or CDT. CDT is a series of techniques including (1) a form of massage known as manual lymph drainage (MLD), (2) compression bandages/clothing with special padding, (3) exercises to improve the flow of lymph, and (4) skin care of the affected areas. CDT has been shown to have lasting effects on the severity of lymphedema at all stages and to improve overall quality of life among lymphedema sufferers. Much of CDT may be performed at home by the patient under the guidance of a lymphedema therapist. 60% of patients with head and neck lymphedema can expect have significant improvement after CDT. The highest rates of success are seen among patients who consistently and properly use CDT at least 5x per week over a 3 month period.

### ***When should I call my doctor?***

Lymphedema can mimic other benign and cancerous conditions of the head and neck and thus it is important that you follow-up regularly with the health care professionals on your head and neck cancer team. A few examples of red flags that should prompt you to contact them between routine visits include:

- Swelling in the face or neck that is focal rather than spread out evenly
- Swelling/masses that continue to grow or become painful
- Swelling/masses that are accompanied by fever or drainage
- Swelling/masses that are associated with breathing difficulty/voice changes

### ***Where can I learn more?***

- <https://www.cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-pdq>
- <https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/lymphedema.html>
- Contact your hospital/cancer center's physical/occupational therapy department

### ***Selected References:***

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