Lymphedema of the head and neck is a build-up of protein rich fluid (lymph) in any areas above the shoulders and collar bone. It is the result of obstruction of lymphatic vessels or lymph nodes; or missing or damaged lymphatic structures. Lymphedema of the head and neck should not be confused with edema that can occur in the same areas. Edema, a buildup of excessive amounts of watery fluid in cells or intercellular tissues, is not due to lymphatic dysfunction.

There are many different causes for edema and treatment of edema is based upon treating the underlying cause of the swelling. This article will not address edema. Instead, it focuses on lymphedema.

Lymphedema in the head and neck region can be either primary, due to genetic and familial abnormalities, or secondary, due to trauma to the lymphatic system. Primary lymphedema seldom occurs only in the head and neck. It is usually accompanied by lymphedema in the limbs or trunk. Secondary lymphedema of the head and neck is more common.

Cancer patients who have had neck surgery, lymph node removal, plastic surgery reconstruction, tumors obstructing lymph flow, and/or radiation treatment are at risk for developing lymphedema. How severe is this problem? European literature suggests that 30% to 56% of all head and neck patients develop lymphedema regardless of type of treatment, a larger percentage than those with lymphedema associated with breast cancer. There are no statistics available for rates in the United States.

Non-cancer related trauma to the head, neck or mouth from surgery or accidents, also can cause lymphedema; as can medical conditions such as rosacea, an inflammatory skin condition.

**HEAD AND NECK LYMPHATIC ANATOMY**

The head and neck region of the body requires massive lymph drainage to maintain vital functions. Although small in percent of actual body area, 150 to 300 lymph nodes are located in the area. This is approximately one-third of the total number of lymph nodes contained in the entire body.

**ASSESSMENT AND DIAGNOSIS**

Similar to lymphedema occurring in other parts of the body, early diagnosis of lymphedema in the head and neck areas with prompt referral for treatment is critical to prevent or reduce the impact of distressing and potentially life threatening symptoms. However, assessment and measurement of lymphedema in HNC patients is problematic for many reasons. First, the shape of the head and neck do not lend themselves to easy tape measurement for treatment. There is no “gold standard” for measuring lymphedema in the head and neck areas. Recent attempts to develop a rating scale based on fluid distribution patterns (the number and types of internal body parts covered by fluid) seen during this procedure have been undertaken. The internal swelling is rated as normal, mild, moderate or severe based upon what structures it is covering in the throat. Results of this study were promising in that different clinicians were able to use the scale and rate the same patient’s lymphedema as being the same degree of
severity. CT scans may also be helpful in some situations.

When assessing and diagnosing swelling in the head and neck region, it is extremely important to determine if the swelling is pure lymphedema, edema, or mixed-edema. Diagnosis should only be made by a physician, as an accurate assessment of the cause of the swelling is necessary to make sure the correct treatment is ordered. Accurate diagnosis requires obtaining a complete medical history and may also involve drawing blood and/or having radiological tests. If you have swelling in your head or neck areas, it is important to cooperate fully with your physician during the diagnostic phase of treatment. This will help your physician best know how to treat you.

SYMPTOMS

Research about lymphedema occurring in the head and neck region is very limited at the present time. Therefore, most information about what symptoms or problems people with head and neck lymphedema experience come from clinical observations by healthcare professionals who care for the patients or from anecdotal reports by patients themselves. Symptoms related to head and neck lymphedema are generally believed to be many in number and to differ among patients. They are both emotional and physical in nature.

Lymphedema in the head and neck area is highly visible. It can distort facial features and, in some cases, make someone almost unrecognizable to those who have known them before the swelling began. Individuals with head and neck lymphedema can become emotionally distressed and depressed. They may develop social avoidance, a reluctance to be seen by others, particularly in public settings such as restaurants. Patients may have to change the type of shirts, blouses, or dresses they wear to accommodate the swelling. Family members and caregivers also experience distress and many state that they do not know how to help.

Physically, the location of the swelling influences the type of symptoms that develop. Swelling in the throat can make it hard to swallow, create a “full” feeling in the throat, cause problems with speech (hoarseness or difficulty speaking for more than a few minutes at a time), or a cough. Severe swelling can make it hard to breathe. It may be very hard to move the head from side to side or up and down. Eating and swallowing may also be a problem. Swelling around the eyes can make it hard to see and interferes with daily activities such as driving. Less noticeable internal swelling in the sinus areas can cause headaches, toothaches, blurred vision, scalp tingling or itching, and difficulty hearing. Occasionally, patients report feeling dizzy.

Since there is a lack of published information about head and neck lymphedema and the symptoms that arise with it, physicians and other healthcare professionals are not well-educated about this problem. They may not realize that symptoms are related to lymphedema and may fail to include referrals to lymphedema therapists in the plan of treatment. This lack of treatment can lead to increased difficulty with overall function, decreased quality of life, and worsening lymphedema which can, at times, be life-threatening.

TREATMENT

Lymphedema in the head and neck area can be treated. The current standard of care for lymphedema is manual lymphatic drainage (MLD). This treatment modality uses light massage techniques to open lymphatic pathways and move fluid into lymphatic drainage pathways and should only be undertaken by a trained, certified lymphedema therapist. Some patients may benefit from wearing compression garments in the head and neck areas. Care must be taken to insure that blood flow to the vital vessels located in the head and neck areas are not impaired.
emotional distress that can arise when lymphedema is present in the head and neck is critical. Patients and families should be made aware that this distress is common and they are not the only ones who experience it. If patients do not want to be seen in public or have signs of depression such as feeling hopeless or sad most of the time, they should be encouraged to seek support and professional help.

If you or a family member has head and neck LE, educate yourself about the condition. The NLN Network (www.lymphnet.org), Lymph Notes (www.lymphnotes.com), American Cancer Society (www.cancer.org), National Cancer Institute (www.cancer.gov) and Support for People with Oral, Head and Neck Cancer (www.spohnc.org) are reliable sources of information.

If you find yourself dealing with an uninformed healthcare provider, you may want to refer them to these resources for some self-education.

**CONCLUSIONS**

Early diagnosis and quick referral for treatment is needed to help reduce symptoms associated with head and neck lymphedema. Patient compliance with prescribed treatment is also of great importance. Individuals who experience emotional distress because of head and neck lymphedema may need to see a mental health professional for support. Lymphedema occurring in the head and neck area is a treatable condition, as are the symptoms that come with it.

![Image](image-url)

**REFERENCES**


