

**THE  
LARYNGECTOMEE  
GUIDE**

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## DEDICATION

The book is dedicated to my fellow laryngectomees and their caregivers for their courage and perseverance.

## ACKNOWLEDGEMENT

I am grateful to Joyce Reback Brook and Carole Kaminsky for their editorial assistance.

## DISCLAIMER

Dr Brook is not an expert in otolaryngology and head and neck surgery. This guide is not a substitute for medical care by medical professionals.

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## INTRODUCTION

I am a physician who became a laryngectomee in 2008. I was diagnosed with laryngeal cancer in 2006 and was initially treated with a course of radiation. After experiencing a recurrence two years later, my doctors recommended that total laryngectomy was the best assurance for eradicating the cancer. As I write this, it has been over five years since my operation; there has been no sign of recurrence.

After becoming a laryngectomee, I realized the magnitude of the challenges faced by new laryngectomees in learning how to care for themselves. Overcoming these challenges requires mastering new techniques in caring for one's airways, dealing with life long side effects of radiation and other treatments, living with the results of surgeries, facing uncertainties about the future, and struggling with psychological, social, medical and dental issues. I also learned the difficulties of life as a head and neck cancer survivor. This cancer and its treatment affect some of the most basic human functions, communication, nutrition, and social interaction.

As I gradually learned to cope with my life as a laryngectomee, I realized that the solutions to many problems are not only based on medicine and science but also on experience in addition to trial and error. I also realized that what works for one person may not always work for another. Because each person's medical history, anatomy and personality are different, so are some of the solutions. However, some general principles of care are helpful to most laryngectomees. I was fortunate to benefit from my physicians, speech and language pathologists, and other laryngectomees as I learned how to care for myself and overcome the myriad of daily challenges.

I gradually realized that new and even seasoned laryngectomees would probably improve their quality of life from learning how to better care for themselves. To that end I created a Website (<http://dribrook.blogspot.com/>) to help laryngectomees and other individuals with head and neck cancer. The site deals with medical, dental and psychological issues and also contains links to videos about rescue breathing and other informative lectures.

This practical guide is based on my Website and is aimed at providing useful information that can assist laryngectomees and their caregivers in dealing with medical, dental and psychological issues. The guide contains information about the side effects of radiation and chemotherapy; the methods of speaking after laryngectomy; how to care for the airway, stoma, heat and moisture exchange filter, and voice prosthesis. In addition I address eating and swallowing issues, medical, dental and psychological concerns, respiration and anesthesia, and travelling as a laryngectomee.

This guide is not a substitute for professional medical care but hopefully will be useful for laryngectomees and their caregiver(s) in dealing with their lives and the challenges they face.

## CHAPTER 1 :

# Diagnosis and treatment of laryngeal cancer

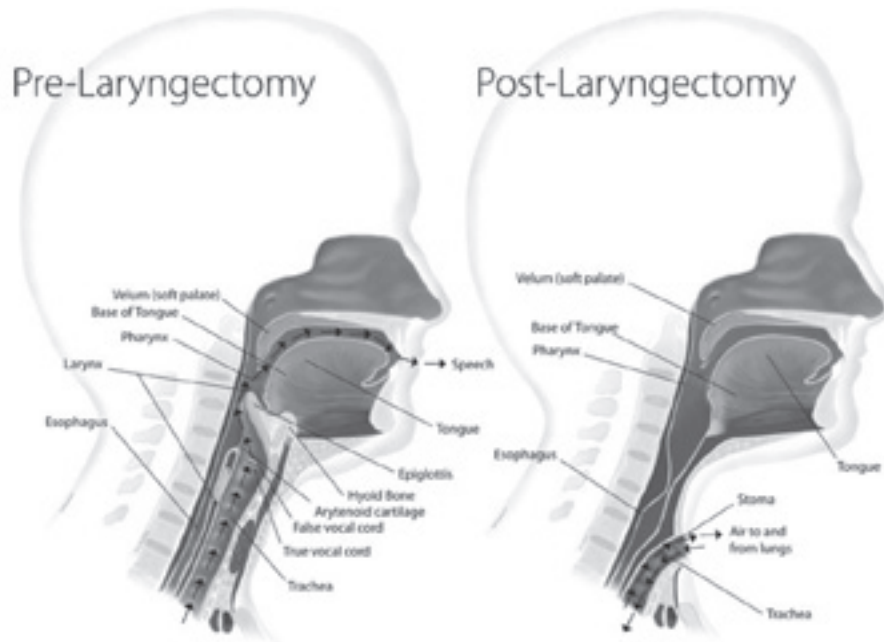
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## Overview

**Laryngeal cancer** affects the voice box. Cancers that start in the larynx are called laryngeal cancers; cancers of the hypopharynx are called **hypopharyngeal cancers**. (The hypopharynx is the part of the throat [pharynx] that lies beside and behind the larynx.) These cancers are very close to each other and the treatment principles of both are similar and may involve laryngectomy. Although the discussion below addresses laryngeal cancer, it is also generally applicable to hypopharyngeal cancer.

Laryngeal cancer occurs when malignant cells appear in the larynx. The larynx contains the vocal cords (or folds) which, by vibrating, generate sounds that create audible voice when the vibrations echo through the throat, mouth, and nose.

The larynx is divided into three anatomical regions: the glottis (in the middle of the larynx, includes the vocal cords); the supraglottis ( in the top part, includes the epiglottis, arytenoids and aryepiglottic folds, and false cords); and the subglottis ( the bottom of the larynx). While cancer can develop in any part of the larynx most laryngeal cancers originate in the glottis. Supraglottic cancers are less common, and subglottic tumors are the least frequent.



**Figure 1: Anatomy before and after laryngectomy**

Laryngeal and hypopharyngeal cancer may spread by direct extension to adjacent structures, by metastasis to regional cervical lymph nodes, or more distantly, through the blood stream to other locations in the body. Distant metastases to the lungs and liver are most common. Squamous cell carcinomas account for 90 to 95 percent of laryngeal and hypopharyngeal cancer.

Smoking and heavy alcohol consumption are the main risk factors for laryngeal cancer. Exposure to human papilloma virus (HPV) has been mainly associated with oropharyngeal cancer and to a lesser degree with laryngeal and hypopharyngeal ones.

There are about 50,000 to 60,000 laryngectomees in the USA. According to the Surveillance Epidemiology and End Results (SEER) Cancer Statistics Review of the National Cancer Institute, an estimated 12,250 men and women are diagnosed with cancer of the larynx each year. The number of new laryngectomees has been declining mainly

because fewer people are smoking and newer therapeutic approaches can spare the larynx.

## Diagnosis

Symptoms and signs of laryngeal cancer include:

- Abnormal (high-pitched) breathing sounds
- Chronic cough (with and without blood)
- Difficulty swallowing
- A sensation of a lump in the throat
- Hoarseness that does not get better in 1 - 2 weeks
- Neck and ear pain
- Sore throat that does not get better in 1 - 2 weeks, even with antibiotics
- Swelling or lumps in the neck
- Unintentional weight loss

The symptoms associated with laryngeal cancer depend upon its location. Persistent hoarseness can be the initial complaint in cancers of the glottis. Later symptoms may include difficulty in swallowing, ear pain, chronic and sometimes bloody cough, and hoarseness. Supraglottic cancers are frequently diagnosed only when they cause airway obstruction or palpable metastatic lymph nodes. Primary

subglottic tumors typically present with hoarseness or complaints of difficulty in breathing on exertion.

There is no single test that can accurately diagnose cancer. The complete evaluation of a patient generally requires a thorough history and physical examination along with diagnostic testing. Many tests are required to determine if a person has cancer or if another condition (such as an infection) may be mimicking the symptoms of cancer.

Effective diagnostic testing is used to confirm or eliminate the presence of cancer, monitor its progress, and plan for and evaluate the effectiveness of treatment. In some instances, it is necessary to perform repeat testing if a person's condition has changed, a sample collected was not of good quality, or an abnormal test result needs to be confirmed. Diagnostic procedures for cancer may include imaging, laboratory tests, tumor biopsy, endoscopic examination, surgery, or genetic testing.

The following tests and procedures may be used to help diagnose and stage laryngeal cancer which influences the choice of treatment:

**Physical examination of the throat and neck:** This enables the doctor to feel for swollen lymph nodes in the neck and to view the throat by using a small, long-handled mirror to check for abnormalities.

**Endoscopy:** A procedure in which an endoscope (a flexible lighted tube) is inserted through the nose or mouth into the upper airway to the larynx, enabling the examiner to directly view these structures.

**Laryngoscopy:** A procedure to examine the larynx with a mirror or a laryngoscope (a rigid lighted tube).

**CT scan (computed tomography):** A procedure that generates a series of detailed radiographs of body sites, taken from different

directions. A contrast material such as an injected or swollen dye enables better visualization of the organs or tissues.

**MRI (magnetic resonance imaging):** A procedure that uses a magnet and radio waves to generate a series of detailed pictures of areas inside the body.

**Barium swallow:** A procedure to examine the esophagus and stomach in which the patient drinks a barium solution that coats the esophagus and stomach, and x-rays are obtained.

**Biopsy:** A procedure in which tissues are obtained so that they can be viewed under a microscope to check for cancer.

The potential for recovery from laryngeal cancer depends on the following:

- The extent the cancer has spread (the “stage”)
- The appearance of the cancer cells (the “grade”)
- The location(s) and size of the tumor
- The patient's age, gender, and general health

Additionally, smoking tobacco and drinking alcohol decrease the effectiveness of treatment for laryngeal cancer. Patients with laryngeal cancer who continue to smoke and drink are less likely to be cured and more likely to develop a second tumor.



## Treatment of laryngeal cancer

Individuals with early or small laryngeal cancer may be treated with surgery or radiation therapy. Those with advanced laryngeal cancer may require a combination of treatments. This may include surgery and a combination of radiation therapy and chemotherapy, generally given at the same time.

Targeted therapy is another therapeutic option specifically directed at advanced laryngeal cancer. Targeted cancer therapies are administered by using drugs or other substances that block the growth and spread of cancer by interfering with specific molecules involved in tumor growth and progression.

The choice of treatment depends mainly on the patient's general health, the location of the tumor, and whether the cancer has spread to other sites.

A team of medical specialists generally collaborate in planning the treatment.

These can include:

- Ear, nose, and throat doctors (otolaryngologists)
- General head and neck surgeons
- Medical oncologists
- Radiation oncologists

Other health care providers who work with the specialists as a team may include a dentist, plastic surgeon, reconstructive surgeon, speech and language pathologist, oncology nurse, dietitian, and a mental health counselor.

Treatment options depend on the following:

- The extent to which the cancer has spread (the “stage”)
- The location and size of the tumor
- Maintaining the patient's ability to talk, eat, and breathe as normally as possible
- Whether the cancer has returned

The medical team describes the available treatment choices to the patient and what are the expected results, as well as the possible side effects. Patients should carefully consider the available options and understand how these treatments may affect their ability to eat, swallow, and talk, and whether these treatments will alter their appearance during and after treatment. The patient and his/her health care team can work together to develop a treatment plan that fits the patient's needs and expectations.

Supportive care for control of pain and other symptoms that can relieve potential side effects and ease emotional concerns should be available before, during, and after cancer treatment.

Patients should be well informed before making their choice. If necessary, obtaining a second medical and/or surgical opinion is helpful. Having a patient advocate (family member or friend) attend the discussions with the medical team is desirable as they can assist the patient in making the best choice.

It is suggested to ask the following questions of the medical team:

- What is the size, location, spread, and stage of the tumor?
- What are the treatment options? Would they include surgery, radiation therapy, chemotherapy or a combination of these?

- What are the expected side effects, risks and benefits of each kind of treatment?
- How can side effects be managed?
- What will be the sound of the voice with each of the above treatments?
- What are the chances of being able to eat normally?
- How to prepare for treatment?
- Will the treatment require hospitalization and if so for how long?
- What is the estimated cost of the treatment and will insurance cover it?
- How will the treatment affect one's life, work and normal activities?
- Is a research study (clinical trial) a good option?
- Can the physician recommend an expert for a second opinion regarding the treatment options?
- How often and for how long will there be a need for follow-ups?

## CHAPTER 2 :

# Having surgery: types of laryngectomy, outcome, pain management, and seeking a second opinion

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### Types of laryngectomy

Treatment of laryngeal cancer often includes surgery. The surgeon can use either scalpel or laser. Laser surgery is performed using a device that generates an intense beam of light that cuts or destroys tissues.

There are two types of surgery for removal of laryngeal cancer:

**Removal of part of the larynx:** The surgeon takes out only the part of the larynx harboring the tumor.

**Removal of the entire larynx:** The surgeon removes the whole larynx and some adjacent tissues.

Lymph nodes that are close or drain the cancerous site may also be taken out during either type of surgery.

The patient may need to undergo reconstructive or plastic surgery to rebuild the affected tissues. The surgeon may obtain tissues from other parts of the body to repair the site of the surgery in the throat and/or neck. The reconstructive or plastic surgery sometimes takes place at the same time when the cancer is removed, or it can be performed later.

Healing after surgery takes time; the length of time needed to recover varies among individuals.

## Surgery's outcome

The main results of the surgery can include all or some of the following:

- Throat and neck swelling
- Local pain
- Tiredness
- Increased mucus production
- Changes in physical appearance
- Numbness, muscle stiffness and weakness
- Tracheostomy

Most people feel weak or tired for some time after surgery, have a swollen neck, and experience pain and discomfort for the first few days. Pain medications can relieve some of these symptoms. (See **Pain management**, page 101)

Surgery can alter the ability to swallow, eat, or talk. However, not all such effects are permanent, as discussed later in the guide (see chapters 6 and 11). Those who lose their ability to talk after surgery may find it useful to communicate by writing on a notepad, writing board (such as a magic slate), cell phone, or computer. Prior to the surgery it may be helpful to make a recording for one's answering machine or voicemail to inform callers about one's speaking difficulties.

An electrolarynx can be used to speak within a few days after the surgery. (See **Electrolarynx**, page 47) Because of neck swelling and post surgical stitches the intra-oral route of delivering vibrations with a straw-like tube is preferred.

## Preparing for surgery

Prior to surgery it is important to thoroughly discuss with the surgeon all available therapeutic and surgical options and their short and long term outcomes. Patients scheduled for surgery may be anxious and under a lot of stress. It is therefore important to have a patient advocate (such as a family member or friend) also attend the meetings with the surgeon. It is important to freely ask and discuss any concerns and request clarifications. It may be necessary to repeatedly listen to explanations until they are fully understood. It is useful to prepare questions to ask the surgeon prior to the meeting and write down the information obtained.

In addition to consultation with the surgeon, it is also important to see these medical providers:

- Internist and/or family physician
- Any specialist one sees for a specific medical problem (i.e., cardiologist, pulmonologist, etc.)
- Radiation oncologist
- Medical oncologist
- Anesthetist
- Dentist

- Speech and language pathologist (SLP)
- Social worker or mental health counselor
- Nutritionist

It is also very useful to meet other individuals who have already undergone a laryngectomy. They can guide the patient about future speech options, share some of their experiences, and provide emotional support.

## Getting a second opinion

When facing a new medical diagnosis that requires making a choice between several therapeutic options, including surgery, it is important to get a second opinion. There may be different medical and surgical approaches and a second (or even third) opinion may be invaluable. Getting such an opinion from physicians experienced in the issues at hand is judicious. There are many situations when treatment cannot be reversed. This is why choosing the course of therapy after consulting with at least one more specialist is very important.

Some individuals may be reluctant to ask for a referral to see another physician for a second opinion. Some may be afraid that this will be interpreted as lack of confidence in their primary physician or doubts about their competence. Most physicians encourage their patients to get a second opinion and will not feel insulted or intimidated by such a request. Furthermore, many medical insurers welcome it.

The second doctor may agree with the first doctor's diagnosis and treatment plan. Conversely, the other physician may suggest a different approach. Either way, the patient ends up with more valuable information and also with a greater sense of control. Eventually one may feel more confident about the decisions he/she makes, knowing that all options have been considered.

Gathering one's medical records and seeing another physician may take some time and effort. Generally, the delay in initiating treatment will not make the eventual treatment less effective. However, one should discuss any possible delay with the physician.

There are numerous ways to find an expert for a second opinion. One can request a referral to another specialist from the primary doctor, a local or state medical society, a nearby hospital, or a medical school. Even though patients with cancer are often in a rush to get treated and remove the cancer as soon as possible, waiting for another opinion may be worthwhile.

## Pain management after surgery

The degree of pain experienced after laryngectomy (or any other head and neck surgery) is very subjective, but, as a general rule, the more extensive the surgery, the more likely the patient will experience pain. Certain types of reconstructive procedures, where tissue is transferred (a flap) from the chest muscles, forearm, thigh, jejunum, or a stomach pull up are more likely to be associated with increased or prolonged pain.

Those who have a radical neck dissection as part of the surgery may experience additional pain. At present, most patients undergo a "modified radical neck dissection" when the spinal accessory nerve is not removed. If the spinal accessory nerve is cut or removed during surgery, the patient is more likely to have shoulder discomfort, stiffness, and long term loss of range of motion. Some of the attendant discomfort of this procedure can be prevented by exercise and physical therapy.

For individuals who experience chronic pain as a result of laryngectomy or any other head and neck surgery, evaluation by a pain management specialist is usually very helpful. (See **Pain management**, page 101)

## CHAPTER 3:

# Side effects of radiation treatment for head and neck cancer

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Radiation therapy (RT) is often used to treat head and neck cancer. The goal of RT is to kill cancer cells. Because these cells divide and grow at a faster rate than normal cells, they are more likely to be destroyed by radiation. In contrast, although they may be damaged healthy cells generally recover.

If RT is recommended the radiation oncologist sets up a treatment plan that includes the total dose of radiation to be administered, the number of treatments to be given, and their schedule. These are based on the type and location of the tumor, the patient's general health, and other present or past treatments.

The side effects of RT for head and neck cancer are divided into early (acute) and long term (chronic). Early side effects occur during the course of therapy and during the immediate post therapy period (approximately 2-3 weeks after the completion of a course of RT). Chronic effects can manifest any time thereafter, from weeks to years later.

Patients are usually most bothered by the early effects of RT, although these will generally resolve over time. However, because long term effects may require lifelong care it is important to recognize these in order to prevent them and/or deal with their consequences. Knowledge of the radiation side effects can allow their early detection and proper management.

Individuals with head and neck cancer should receive counseling about the importance of smoking cessation. In addition to the fact that smoking is a major risk factor for head and neck cancer, the risk of cancer in smokers is further enhanced by alcohol consumption. Smoking can also influence cancer prognosis. When smoking is continued both during and after RT, it can increase the severity and duration of mucosal reactions, worsen the dry mouth (xerostomia), and compromise patient outcome. Patients who continue to smoke while receiving RT have a lower long-term survival rate than those who do not smoke. (See **Avoiding smoking and alcohol**, page 115)

## 1. Early side effects

Early side effects include inflammation of the oropharyngeal mucosa (mucositis), painful swallowing (odynophagia), difficulty swallowing (dysphagia), hoarseness, lack of saliva (xerostomia), orofacial pain, dermatitis, nausea, vomiting, and weight loss. These complications can interfere with, and delay treatment. To some degree, these side effects occur in most patients and generally dissipate over time.

The severity of these side effects is influenced by the amount and method by which the RT is given, the tumor's location and spread, and the patient's general health and habits (i.e., continued smoking, alcohol consumption).

## Skin damage

Radiation can cause a sunburn-like damage to the skin which can be further aggravated by chemotherapy. It is advisable to avoid exposure to potential chemical irritants, direct sun and wind, and local application of lotions or ointments prior to RT that might change the depth of radiation penetration. There are a number of skin care products that can be used during radiation treatment to lubricate and protect the skin.

## Dry mouth

The loss of saliva production (or xerostomia) is related to the administered irradiation dose and the volume of salivary tissue irradiated. Drinking adequate fluids and rinsing and gargling with a weak solution of salt and baking soda are helpful to refresh the mouth, loosen thick oral secretions, and alleviate mild pain. Artificial saliva and constant wetting of the mouth with water may also be helpful.

## Alterations in taste

Radiation can induce changes in taste as well as tongue pain. Such side effects can further decrease food intake. The altered taste and tongue pain gradually dissipate in most patients over a six month period, although in some cases taste recovery is incomplete. Many individuals experience a permanent alteration in their taste.

## Inflammation of the oropharyngeal mucosa (mucositis)

Radiation, as well as chemotherapy, damage the oropharyngeal mucosa, resulting in mucositis which develops gradually, usually two to three weeks after starting RT. Its incidence and severity depend upon the field, total dose and duration of RT. Chemotherapy can aggravate the condition. Mucositis can be painful and interfere with food intake and nutrition.

Management includes meticulous oral hygiene, dietary modification, and topical anesthetics combined with an antacid and antifungal suspension ("cocktail"). Spicy, acidic, sharp, or hot food should be avoided, as well as all alcohol. Secondary bacterial, viral (e.g., Herpes), and fungal (e.g., Candida) infections are possible. Control of the pain (using opiates or gabapentin) may be needed.

Mucositis can lead to nutritional deficiency. Those who experience significant weight loss or recurrent episodes of dehydration may require feeding through a gastrostomy feeding tube.

## Orofacial pain

Orofacial pain is common in patients with head and neck cancer and occurs in up to half of the patients before RT, eighty percent of patients during treatment and about one third of patients six months after treatment. The pain can be caused by mucositis which can be aggravated by concurrent chemotherapy, and by damage from the cancer, infection, inflammation, and scarring due to surgery or other treatments. Pain management includes the use of analgesics and narcotics. (See **Pain management**, page 101).

## Nausea and vomiting

RT may cause nausea. When it occurs, it generally happens from two to six hours after a RT session and generally lasts about two hours. Nausea may or may not be accompanied by vomiting.

Management includes:

- Eating small, frequent meals throughout the day instead of three large meals. Nausea is often worse if the stomach is empty.
- Eating slowly, chewing the food completely, and staying relaxed.
- Eating cold or room temperature foods. The smell of hot or warm foods may induce nausea.

- Avoiding difficult to digest foods, such as spicy foods or foods high in fat or accompanied by rich sauces.
- Resting after eating. When lying down, the head should be elevated about 12 inches.
- Drinking beverages and other fluids between meals instead of drinking beverages with meals.
- Drinking 6- 8 ounce glasses of fluid per day to prevent dehydration. Cold beverages, ice cubes, popsicles, or gelatin are adequate.
- Eating more food at a time of the day when one is less nauseous.
- Informing one's health care provider before each treatment session when one develops persistent nausea.
- Treating persistent vomiting immediately, as this can cause dehydration.
- Administering anti-nausea medication by a health care provider.

Persistent vomiting can result in the body losing large amounts of water and nutrients. If vomiting persists for more than three times a day and one does not drink enough fluids, it could lead to dehydration. This condition can cause serious complications if left untreated.

Signs of dehydration include:

- Small amount of urine

- Dark urine
- Rapid heart rate
- Headaches
- Flushed, dry skin
- Coated tongue
- Irritability and confusion

Persistent vomiting may reduce the effectiveness of medications. If persistent vomiting continues, RT may be stopped temporarily. Fluids administered intravenously assist the body in regaining nutrients and electrolytes.

## Tiredness (fatigue)

Fatigue is one of the most common side effects of RT. RT can cause cumulative fatigue (fatigue that increases over time). It usually lasts from three to four weeks after treatment stops, but can continue for up to two to three months.

Factors that contribute to fatigue are anemia, decrease food and liquid intake, medications, hypothyroidism, pain, stress, depression, and lack of sleep (insomnia) and rest.

Rest, energy conservation, and correcting the above contributing factors may ameliorate the fatigue.

## Other side effects

These include trismus (See page 24) and hearing problems (See page 27).

## 2. Late side effects

Late side effects of RT include permanent loss of saliva, osteoradionecrosis, ototoxicity, fibrosis, lymphedema, hypothyroidism, and damage to neck structures.

### Permanent mouth dryness

Although dry mouth (xerostomia) improves in most people with time, it can be long lasting.

Management includes salivary substitutes or artificial saliva and frequent sips of water. This may lead to frequent urination during the night, especially in men with prostatic hypertrophy and in those with small bladders. Available treatment includes medications such as salivary stimulants (sialagogues), pilocarpine, amifostine, cevimeline, and acupuncture.

### Osteoradionecrosis of the jaw

This is one potentially severe complication that may necessitate surgical intervention and reconstruction. Depending on the location and extent of the lesion, symptoms can include pain, bad breath, taste distortion (dysgeusia), “bad sensation”, numbness (anesthesia), trismus, difficulty with mastication and speech, fistula formation, pathologic fracture, and local, spreading, or systemic infection.

The jaw bone (mandible) is the most frequently affected bone, especially in those treated for nasopharyngeal cancer. Maxillary involvement is rare because of the collateral blood circulation it receives.

Tooth extraction and dental disease in irradiated areas are major factors in the development of osteoradionecrosis. (See **Dental issues**, page 117) In some cases it is necessary to remove teeth before RT if they will be in the area receiving radiation and are too decayed to preserve



by filling or root canal. An unhealthy tooth can serve as a source of infection to the jawbone, that can be particularly difficult to treat after radiation.

Repair of nonrestorable and diseased teeth prior to RT may reduce the risk of this complication. Mild osteoradionecrosis can be conservatively treated with debridement, antibiotics, and occasionally ultrasound. When necrosis is extensive, radical resection, followed by microvascular reconstruction, is often used.

Dental prophylaxis can reduce this problem. (See **Dental issues**, page 117) Special fluoride treatments may help with dental problems, along with brushing, flossing, and regular cleaning by a dental hygienist.

Hyperbaric oxygen therapy (HBO) has been often used in patients at risk or those who develop osteoradionecrosis of the jaw. However, the available data are conflicting about the clinical benefits of HBO for prevention and therapy of osteoradionecrosis. (See **Hyperbaric oxygen therapy**, page 119)

Patients should remind their dentists about their RT prior to extraction or dental surgery. Osteoradionecrosis may be prevented by administration of a series of HBO therapy before and after these procedures. This is recommended if the involved tooth is in an area that has been exposed to a high dose of radiation. Consulting the radiation oncologist who delivered the radiation treatment can be helpful in determining the extent of prior exposure.

## Fibrosis and trismus

High doses of radiation to the head and neck can result in fibrosis. This condition may be aggravated after head and neck surgery where the neck may develop a woody texture and have limited movement. Late onset of fibrosis can also occur in the pharynx and esophagus leading to stricture, and temporomandibular joint problems.

Fibrosis of the muscles of mastication can lead to the inability to open the mouth (**trismus or lockjaw**), which can progress over time. Generally, eating becomes more difficult but articulation is not affected. Trismus impedes proper oral care and treatment and may cause speech/swallowing deficits. This condition may be intensified by surgery prior to radiation. Patients likely to develop trismus are those with tumors of the nasopharynx, palate, and maxillary sinus. Radiation of the highly vascularized temporomandibular joint (TMJ) and muscles of mastication can often lead to trismus. Chronic trismus gradually leads to fibrosis. Trismus impedes proper oral care and treatment and may cause speech/swallowing deficits. Forced opening of the mouth, jaw exercises and the use of a dynamic opening device (Therabite™) can be helpful. This device is increasingly used during radiation therapy as a prophylactic measure to prevent trismus.

Exercise can reduce neck tightness and increases the range of neck motion. One needs to perform these exercises throughout life to maintain good neck mobility. This is especially the case if the stiffness is due to radiation. Receiving treatment by experienced physical therapists who can also break down the fibrosis is very helpful. The earlier the intervention, the better it is for the patient. A new treatment modality using external laser is also available. There are physical therapy experts in most communities who specialize in reducing swelling.

Fibrosis in the head and neck can become even more extensive in those who have surgery or further radiation. Post radiation fibrosis can also involve the skin and subcutaneous tissues, causing discomfort and lymphedema.

Swallowing dysfunction due to fibrosis often requires a change in diet, pharyngeal strengthening, or swallow retraining especially in those who have had surgery and/or chemotherapy. Swallowing exercises are increasingly used as a preventing measure. (See Swallowing difficulties, page 91) Partial or total oropharyngeal stricture can occur in severe cases.

## Wound healing problems

Some laryngectomees may manifest wound healing problems following surgery, especially in areas that have received RT. Some may develop a fistula ( an abnormal connection between the inside of the throat and the skin). Wounds that heal at a slower pace can be treated with antibiotics and dressing changes. (See **Pharyngo-cutaneous fistula**, page 98)

## Lymphedema

Obstruction of the cutaneous lymphatics results in lymphedema. Significant pharyngeal or laryngeal edema may interfere with breathing and may require temporary or long term tracheostomy. Lymphedema, strictures, and other dysfunctions predispose patients to aspiration and the need for a feeding tube. (See **Lymphedema**, page 37).

## Hypothyroidism

RT is almost always associated with hypothyroidism. The incidence varies; it is dose-dependent and increases with time since the RT. (See **Low thyroid hormone and its treatment**, page 105)

## Neurological damage

RT to the neck can also affect the spinal cord, resulting in a self-limited transverse myelitis, known as “Lhermitte sign”. The patient notes an electric shock-like sensation mostly felt with neck bending (flexion). This condition rarely progresses to a true transverse myelitis which is associated with Brown-Séquard syndrome (A loss of sensation and motor function caused by the lateral cutting of the spinal cord).

RT can also cause peripheral nervous system dysfunction resulting from external compressive fibrosis of soft tissues and reduced blood supply caused by fibrosis. Pain, sensory loss, and weakness are the most commonly observed clinical features of peripheral nervous system dysfunction. Autonomic dysfunction with resultant orthostatic hypotension (an abnormal decrease in blood pressure when a person stands up) and other abnormalities can also be seen.

## Damage to the ear (ototoxicity)

Radiation to the ear may result in serous otitis (otitis with effusion). High doses of irradiation can cause and sensorineural hearing loss (damage to the inner ear, the auditory nerve, or the brain).

## Damage to neck structures

Neck edema and fibrosis are common after RT. Over time the edema may harden, leading to neck stiffness. Damage can also include carotid artery narrowing (stenosis) and stroke, carotid artery rupture, oropharyngo-cutaneous fistula (the last two are associated also with surgery), and carotid artery baroreceptors damage leading to permanent and proxysmal (sudden and recurrent) hypertension.

**Carotid artery narrowing (stenosis):** The carotid arteries in the neck supply blood to the brain. Radiation to the neck has been linked to carotid artery stenosis or narrowing, representing a significant risk for head and neck cancer patients, including many laryngectomees. Stenosis can be diagnosed by ultrasound as well as angiography. It is important to diagnose carotid stenosis early, before a stroke has occurred.

Treatment includes removal of the blockage (endarterectomy), placing a stent (a small device placed inside the artery to widens it) or a prosthetic carotid bypass grafting.

**Hypertension due to baroreceptors damage:** Radiation to the head and neck can damage the baroreceptors located in the carotid artery. These baroreceptors (blood pressure sensors) help in regulating blood pressure by detecting the pressure of blood flowing through them, and sending messages to the central nervous system to increase or decrease the peripheral vascular resistance and cardiac output. Some individual treated with radiation develop labile or paroxysmal hypertension.

**Labile hypertension:** In this condition the blood pressure fluctuates far more than usual during the day. It can rapidly soar from low (e.g., 120/80 mm Hg) to high (e.g., 170/105 mm Hg). In many instances these fluctuations are asymptomatic but may be associated with headaches. A relationship between blood pressure elevation and stress or emotional distress is usually present.

**Paroxysmal hypertension:** Patients exhibit sudden elevation of blood pressure (which can be greater than 200/110 mm Hg) associated with an abrupt onset of distressful physical symptoms, such as headache, chest pain, dizziness, nausea, palpitations, flushing, and sweating. Episodes can last from 10 minutes to several hours and may occur once every few months to once or twice daily. Between episodes, the blood pressure is normal or may be mildly elevated. Patients generally cannot identify obvious psychological factors that cause the paroxysms. Medical conditions that can also cause such blood pressure swings need to be excluded (e.g., pheochromocytoma).

Both of these conditions are serious and should be treated. Management can be difficult and should be done by experienced specialists.

More information about complications of RT can be found at the National Cancer Institute Web site at:

<http://www.cancer.gov/cancertopics/pdq/supportivecare/oralcomplications/Patient/page5>

## CHAPTER 4:

### **Side effects of chemotherapy for head and neck cancer**

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Chemotherapy for head and neck cancer is used in conjunction with supportive care for most patients with metastatic or advanced recurrent head and neck cancer. The choice of specific systemic therapy is influenced by the patient's prior treatment with chemotherapeutic agents and the general approach to preserve the effected organs. Supportive care includes the prevention of infection due to severe bone marrow suppression and the maintenance of adequate nutrition.

Therapeutic options include treatment with a single agent and combination regimens with conventional cytotoxic chemotherapy and/or molecularly targeted agents, combined with optimal supportive care. Chemotherapy is given in cycles, alternating between periods of treatment and rest. Treatment can last several months, or even longer.

A Web site that lists all the chemotherapeutic agents and their side effects is at: <http://www.tirgan.com/chemolst.htm>

Chemotherapeutic drugs which are usually given intravenously, work throughout the whole body by disrupting cancer cells' growth. Chemotherapy for the treatment of head and neck cancers is usually given at the same time as radiation therapy and is known as chemoradiation. It can be given as adjuvant chemotherapy or as neoadjuvant chemotherapy.

Adjuvant chemotherapy is used for treatment after surgery to reduce the risk of cancer returning, and to kill cells that may have

spread. Neoadjuvant chemotherapy is administered before surgery to shrink the size of the tumor thus making it easier to remove.

Chemotherapy administered prior to chemoradiation treatment is known as induction chemotherapy.

## Side effects of chemotherapy

The kind and type of possible side effects of chemotherapy depend on the individual. Some have few side effects, while others have more. Many individuals do not experience side effects until the end of their treatments; for many individuals these side effects do not last long.

Chemotherapy can, however, cause several temporary side effects. Although these may be worse with combined radiation therapy, they generally disappear gradually after the treatment has ended.

Side effects depend on the chemotherapeutic agent(s) used. These occur because chemotherapy drugs work by killing all actively growing cells. These include cells of the digestive tract, hair follicles, and bone marrow (which makes red and white blood cells), as well as the cancer cells.

The more common side effects are nausea, vomiting, diarrhea, sores (mucositis) in the mouth (resulting in problems with swallowing and sensitivity in the mouth and throat), increased susceptibility to infection, anemia, hair loss, general fatigue, numbness in the hands and feet, hearing loss, kidney damage, bleeding problems, malaise, and balance problem. An oncologist and other medical specialist watch for and treat these side effects.

The most common side effects include:

## Lowered resistance to infection

Chemotherapy can temporarily reduce the production of white blood cells (neutropenia), making the patient more susceptible to infections.

This effect may begin about seven days following treatment and the decline in resistance to infection is maximal usually about 10–14 days after chemotherapy has ended. At that point the blood cells generally begin to increase steadily and return to normal before the next cycle of chemotherapy is administered. Signs of infection include fever above 100.4°F (38°C) and/or sudden feeling of being ill. Prior to resuming chemotherapy blood test are performed to ensure that the recovery of the white blood cells has occurred. Further administration of chemotherapy may be delayed until recovery of blood cells has taken place.

## Bruising or bleeding

Chemotherapy can promote bruising or bleeding because the agents given reduce the production of platelets which help the blood clotting. Nosebleeds, blood spots or rashes on the skin, and bleeding gums can be a sign that this had occurred.

## Anemia

Chemotherapy can lead to anemia (low number of red blood cells). The patient generally feels tired and breathless. Severe anemia can be treated by blood transfusions or medications that promote red cells production.

## Hair loss

Some chemotherapy agents cause hair loss. The hair almost always grows back over a period of 3-6 months once the chemotherapy has ended. Meanwhile, a wig, bandana, hat or scarf can be worn.

## Sore mouth and small mouth ulcers

Some chemotherapy agents cause sore mouth (mucositis) which can interfere with mastication and swallowing, oral bleeding, difficulty in swallowing (dysphagia), dehydration, heartburn, vomiting, nausea, and sensitivity to salty, spicy, and hot/cold foods. These agents can also cause chemotherapy-related oral cavity ulcers (stomatitis) that result in eating difficulty.

Nausea and vomiting can be treated by anti-nausea (anti-emetic) drugs. Regular mouthwashes can also help. These side effects can impact swallowing and nutrition. Accordingly, it is important to supplement one's diet with nutritious drinks or soups. A dietitian's advice may be helpful to maintain adequate nutrition.

The cytotoxic agents most often associated with oral, pharyngeal, and esophageal symptoms of swallowing difficulty (dysphagia) are the antimetabolites such as methotrexate and fluorouracil. The radiosensitizer chemotherapies, designed to heighten the effects of radiation therapy, also increase the side effects of the radiation mucositis.

## Tiredness (fatigue)

Chemotherapy affects different individuals in different ways. Some people are able to lead a normal life during their treatment, while others may find they become very weak and tired (fatigue) and have to take things more slowly. Any chemotherapy drug may cause fatigue.

It can last for a few days or persists through and beyond completion of treatment. Drugs such as vincristine, vinblastine, and cisplatin often cause fatigue.

Factors that contribute to fatigue are anemia, decrease food and liquid intake, medications, hypothyroidism, pain, stress, depression, and lack of sleep (insomnia) and rest.

Rest, energy conservation, and correcting the above contributing factors may ameliorate the fatigue.

More information can be found at the National Cancer Institute Web site at:

<http://www.cancer.gov/cancertopics/pdq/supportivecare/oralcomplications/Patient/page5>

## CHAPTER 5:

# **Lymphedema, neck swelling and numbness after radiation and surgery**

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### **Lymphedema**

The lymph vessels drain fluid from tissues throughout the body and allow immune cells to travel throughout the body. Lymphedema is a localized lymphatic fluid retention and tissue swelling caused by a compromised lymphatic system. Lymphedema, a common complication of radiation and surgery for head and neck cancer, is an abnormal accumulation of protein-rich fluid in the space between cells which causes chronic inflammation and reactive fibrosis of the affected tissues.

Radiation creates scarring which interferes with the function of the lymphatics. The cervical lymph nodes are generally removed when the cancer is excised. When the surgeons remove these glands, they also take away the drainage system for the lymphatics and cut some of the sensory nerves. Unfortunately, most of the severed lymphatics and nerves are permanently cut. Consequently it takes longer to drain the area, resulting in swelling. Like flooding after a heavy rain when the drainage system is broken, the surgery creates a backup of lymphatic fluid that cannot drain adequately, as well as numbness of the areas supplied by the severed nerves (usually in the neck, chin, and behind the ears). As a result, some of the lymphatic fluid cannot re-enter the systemic circulation and accumulates in the tissues.

There are two types of lymphedema that can develop in patients with head and neck cancer: an *external* visible swelling of the skin or soft tissue and an *internal* swelling of the mucosa of the pharynx and larynx. Lymphedema generally starts slowly and is progressive, rarely painful, causes discomfort in the form of a sensation of heaviness and achiness, and may lead to skin changes.

Lymphedema has several stages:

**Stage 0:** Latency stage – No visible/palpable edema

**Stage 1:** Accumulation of protein-rich edema, presence of pitting edema that can be reduced with elevation

**Stage 2:** Progressive pitting, proliferation of connective tissue (fibrosis)

**Stage 3:** No pitting, presence of fibrosis, sclerosis, and skin changes

Lymphedema of the head and neck can cause several functional impairments.

These include:

- Difficulty in breathing
- Impairment in vision
- Motor limitations (reduced neck motion, jaw tightness or trismus and chest tightness)
- Sensory limitations

- Speech, voice and swallowing problems (inability to use an electrolarynx, difficulty in articulation, drooling, and loss of food from mouth)
- Emotional issues (depression, frustration and embarrassment)

Fortunately over time the lymphatics find new ways of drainage and the swelling generally goes down. Specialists in reducing edema (usually physical therapists) can assist the patient in enhancing the drainage and shortening the time for the swelling to decrease. This intervention can also prevent the area from becoming permanently swollen and from developing fibrosis.

**Treatment** of lymphedema includes:

- Manual lymph drainage (face and neck, deep lymphatics, trunk, intra oral)
- Compressive bandages and garments
- Remedial exercises
- Skin care
- Elastic therapeutic tape (Kinesiotape)
- Oncology rehabilitation
- Diuretics, surgical removal (debulking), liposuction, compression pumps, and elevation of the head alone are ineffective treatments.

Neck tightness and swelling due to lymphedema generally improve over time. Sleeping with the upper body in an elevated position can use



gravity to speed the process of lymph fluid drainage. A lymphedema treatment specialist can perform and teach manual lymph drainage that can help in reducing edema. Manual lymph drainage involves a special type of gentle skin massage to help blocked lymphatic fluid drain properly into the bloodstream. Movement and exercise are also important in aiding lymphatic drainage. A head and neck lymphedema therapist can teach the patient specific exercises to improve the range of head and neck motion.

A head and neck lymphedema therapist can select non-elastic bandages or compression garments that are worn at home. These place gentle pressure on the affected areas to help move the lymph fluid and prevent it from refilling and swelling. Application of bandages should be done as directed by a specialist. There are several options, depending on the location of the lymphedema to improve comfort and avoid complications from pressure on the neck.

There are also exercises that can reduce the neck tightness and increase the range of neck motion. One needs to perform these exercises throughout life to maintain good neck mobility. This is especially true if the stiffness is due to radiation. Receiving treatment by experienced physical therapists who can also break down the fibrosis is very helpful. The earlier the intervention the better.

A new treatment modality that reduces lymphedema, fibrosis and neck muscle stiffness using *external laser* is also available. This method uses a low energy laser beam administered by an experienced physical therapist. The laser beam penetrates into the tissues where it is absorbed by cells and changes their metabolic processes. The beam is generated by the LTU-904 Portable Laser Therapeutic Unit. (<http://www.stepup-speakout.org/Laser%20Brochure.pdf>). This treatment can reduce the lymphedema in the neck and face and increase the range of motion in the head. It is a painless method that is done by placing the laser instrument at several locations over the neck for about 10 second intervals.

There are physical therapy experts in most communities who specialize in reducing swelling and edema. Consult one's surgeon to find out if physical therapy is a good therapeutic option for lymphedema.

The National Lymphedema Network has a web site (<http://www.lymphnet.org/resourceGuide/findTreatment.htm>) that contains a list of lymphedema treatment specialists in North America, Europe and Australia.

A facial and neck guide of self administered massage is available at: [http://www.aurorahealthcare.org/FYWB\\_pdfs/x23169.pdf](http://www.aurorahealthcare.org/FYWB_pdfs/x23169.pdf)

## Skin numbness after surgery

The cervical lymph nodes, or glands, are generally surgically removed when the cancer is excised. When the surgeons remove these glands, they also cut some of the sensory nerves that supply the lower facial and neck skin. This creates numbness in the areas supplied by the severed nerves. Some of the numb areas may regain sensation in the months following the surgery, but other areas may remain permanently numb.

Most individuals become accustomed to the numbness and are able to prevent damage to the skin from sharp objects, heat or frost. Men learn not to injure the affected area when shaving by using an electric shaver.

The numb skin should be protected from sun burn by applying sunscreen and/or by shielding it with a garment. Frostbite can be prevented by covering the area with a scarf.

## CHAPTER 6:

### **Methods of speaking after laryngectomy**

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Although total laryngectomy removes the entire larynx (vocal cords/voice box), most laryngectomees can acquire a new way of speaking. About 85-90% of laryngectomees learn to speak using one of the three main methods of speaking described below. About ten percent do not communicate by speaking but can use computer-based or other methods to communicate.

Individuals normally speak by exhaling air from their lungs to vibrate their vocal cords. These vibration sounds are modified in the mouth by the tongue, lips, and teeth to generate the sounds that create speech. Although the vocal cords that are the source of the vibrating sounds are removed during total laryngectomy, other forms of speech can be created by using a new pathway for air and a different airway part to vibrate. Another method is to generate vibration by an artificial source placed on the outside of the throat or mouth and then using the mouth parts to form speech.

The method(s) used to speak again depend on the type of surgery. Some people may be limited to a single method, while others may have several choices.

Each method has unique characteristics, advantages and disadvantages. The goal of attaining a new way to speak is to meet the communication needs of each laryngectomee.

Speech and language pathologists (SLPs) can assist and guide laryngectomees in the proper use of the methods and/or devices they use to obtain the most understandable speech. Speech improves

considerably between six months and one year after total laryngectomy. Active voice rehabilitation is associated with attaining better functional speech.

The three main methods of speaking after laryngectomy are:

## 1. Tracheoesophageal speech

In tracheoesophageal speech pulmonary air is exhaled from the trachea into the esophagus through a small silicone voice prosthesis that connects the two, and the vibrations are generated by the lower pharynx (Figure 2).

The voice prosthesis is inserted into the puncture (called tracheoesophageal puncture or TEP) created by the surgeon in the back of the neck stoma. The puncture is made at the back of the trachea (the windpipe) and goes into the esophagus (food tube). The hole between the trachea and esophagus can be done at the same time as the laryngectomy surgery (a primary puncture), or after healing from the surgery has occurred (a secondary puncture). A small tube, called a voice prosthesis, is inserted in this hole and prevents the puncture from closing. It has a one-way valve at the end on the esophagus side which allows air to go into the esophagus but prevents swallowed liquids from coming through the prosthesis and reaching the trachea and lungs.

Speaking is possible by diverting the exhaled air through the prosthesis into the esophagus by temporarily occluding the stoma. This can be done by sealing it with a finger or by pressing on a special Heat and Moisture Exchanger (HME) filter that is worn over the stoma. (See **HME advantages**, page 65) An HME partially restores the lost nasal functions. Some people use a “hands free” HME (automatic speaking valve) that is activated by speaking (See **Using hands free HME**, page 69).

After occlusion of the stoma exhaled lung air moves through the prosthesis into the esophagus causing the walls and top of the esophagus

to vibrate. These vibrations are used by the mouth (tongue, lips, teeth, etc.) to create the sounds of speech.

There are two different basic types of voice prosthesis: the patient-changed type, designed to be changed by the laryngectomee or by another person, and the indwelling type, designed to be changed by a medical professional (an otolaryngologist or SLP).

The HME or hands free valve can be attached in front of the tracheostoma in different ways: by means of an adhesive housing (or base plate) that is taped or glued to the skin in front of the stoma, or by means of a laryngectomy tube or stoma button that is placed inside the stoma.

Patients who use a voice prosthesis had the best results in speech intelligibility six months and one year after total laryngectomy.

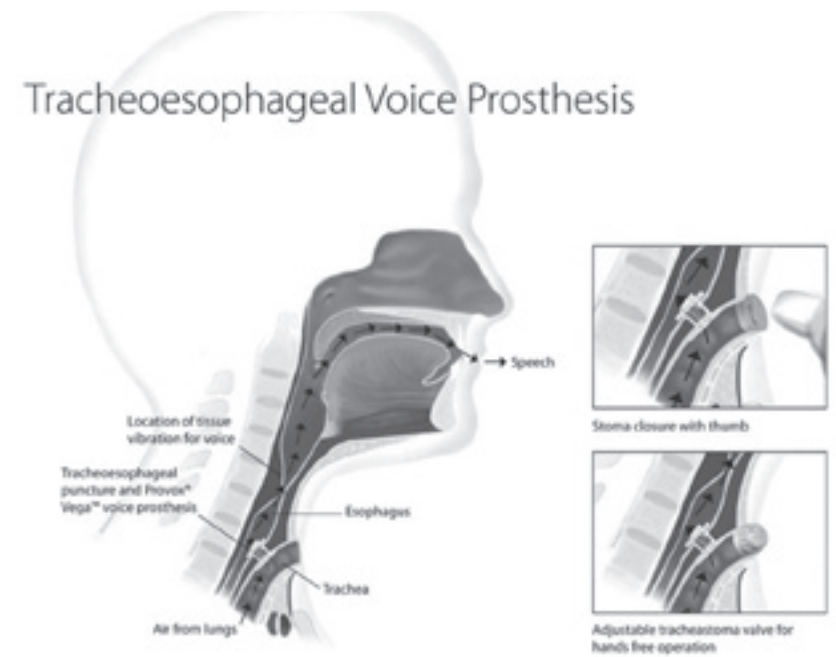


Figure 2: Tracheoesophageal speech

## 2. Esophageal speech

In esophageal speech the vibrations are generated by air that is “belched” out from the esophagus (Figure 3). This method does not require any instrumentation.

Of the three major types of speech following laryngectomy, esophageal speech usually takes the longest to learn. However, it has several advantages, not the least of which includes the freedom from dependency on devices and instrumentation.

Some SLPs are familiar with esophageal speech and can assist laryngectomees in learning this method. Self-help books and tapes can also help in learning this method of speech.

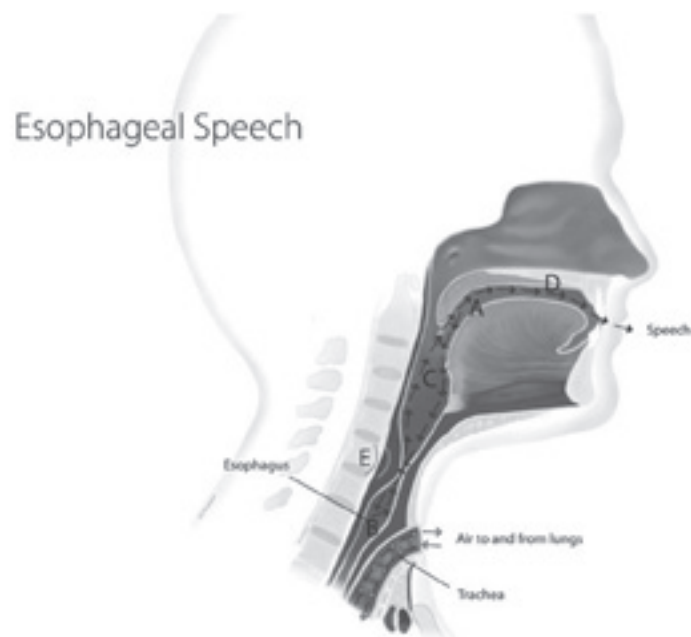


Figure 3: Esophageal speech

## 3. Electrolarynx or artificial larynx speech

The vibrations in this speech method are generated by an external battery operated vibrator (called an electrolarynx or artificial larynx) which is usually placed on the cheek or under the chin (Figure 4).

It makes a buzzing vibration that reaches the throat and mouth of the user. The person then modifies the sound using his/her mouth to generate the speech sounds.

There are two main methods to deliver the vibration sounds created by an artificial larynx into the throat and mouth (intra orally). One is directly into the mouth by a straw-like tube and the other through the skin of the neck or face. In the last method, the electrolarynx (EL) is held against the face or neck.

ELs are often used by laryngectomees shortly after their laryngectomy while they are still hospitalized. Because of the neck swelling and post surgical stitches the intra oral route of delivery of vibration is preferred at that time. Many laryngectomees can learn other methods of speaking later. However, they can still use an EL as a back-up in case they encounter problems with their other speaking methods.

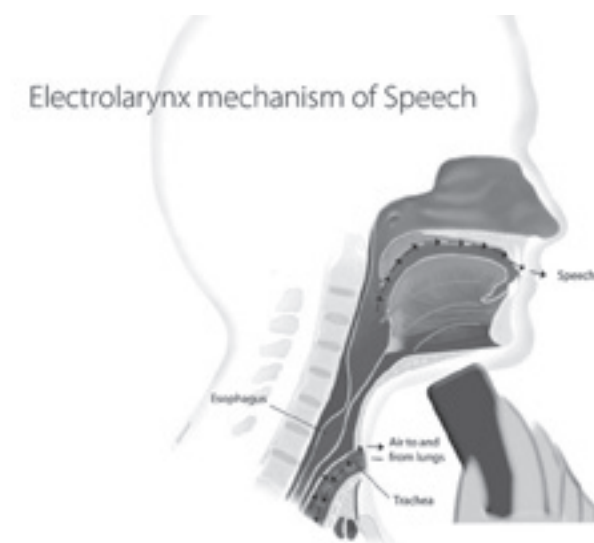


Figure 4: Electrolarynx or artificial larynx speech

## Other methods of speech

A pneumatic artificial larynx (also called Tokyo Larynx) is also available to generate speech. This method uses lung air to vibrate a reed or rubber material that produces a sound (Picture 1). The device's cup is placed over the stoma and its tube is inserted into the mouth. The sound generated is injected into the mouth through the tube. It does not use any batteries and is relatively inexpensive.



Picture 1: Pneumatic artificial larynx

Those who are unable to use any of the above methods can use computer generated speech using either a standard laptop computer or a single purpose speech aid. The user types what he/she wants to say onto a keyboard, and the computer speaks out loud what has been typed. Some cell phones can operate in the same manner.

## Diaphragmatic breathing and speech

Diaphragmatic breathing (also called abdominal breathing) is the act of breathing slowly and deeply into one's lungs by using the diaphragm muscle rather than by using one's rib cage muscles. When breathing using the diaphragm, the abdomen, rather than the chest is expands. This method of breathing allows for greater utilization of the lung capacity to obtain oxygen and dispose of bicarbonate gasses. Neck breathers are often shallow breathers who use a relatively smaller portion of their lung capacity. Becoming accustomed to inhaling by using the diaphragm can increase one's stamina and also improve esophageal and tracheoesophageal speech.

## Increasing the voice volume using a voice amplifier

One of the problems encountered when using tracheoesophageal or esophageal speech is the weakness of the volume. Using a waistband voice amplifier can enable one to speak with less effort and can allow one to be heard even in noisy places. It can also prevent breakage of the stoma's housing seal because the laryngectomee who uses tracheoesophageal speech does not need to create a strong expiratory air pressure to exhale air through the voice prosthesis.

## Speaking over the phone

Speaking over the phone is often difficult for laryngectomees. Their voice is sometimes hard to understand and some individuals may even hang up the phone when they hear them.

It is best to inform the other party about the speaking difficulties of the laryngectomee by first asking them "can you hear me?". This may enable the laryngectomee to inform and explain to their party about their speaking difficulties.

There are phones available that can amplify the outgoing voice, making it easier for the laryngectomee to be heard and understood.

A nationwide phone service allows a person whose speech may be difficult to understand to communicate over the telephone with the help of a specially trained Communications Assistant. No special telephone is needed for this calling option. The three digit number 711 can be used as a shortcut to access Telecommunications Relay Services (TRS) anywhere in the U.S. TRS facilitates telephone conversations by one or more people who have speech and hearing disabilities. All telecommunications carriers in the U.S., including wire-line, wireless and pay phone providers must provide 711 services.

Sending written messages through mobile phones (smart phones, or cell phones) can help laryngectomees communicate in noisy places or when they have other communication difficulties.

## CHAPTER 7:

### **Mucus and respiratory care**

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Mucus production is the body's way of protecting and maintaining the health of the trachea (windpipe) and lungs. It serves to lubricate these airways and keep them moist. After a laryngectomy, the trachea opens at the stoma and laryngectomees are no longer able to cough up mucus into their mouth and then swallow it, or blow their nose. It is still very important to cough and clear one's mucus; however, this must be done through the stoma.

Coughing up mucus through the stoma is the only means by which laryngectomees can keep their trachea and lungs clear of dust, dirt, organisms, and other contaminants that get into the airway. Whenever an urge to cough or sneeze emerges laryngectomee must quickly remove their stoma cover or Heat and Moisture Exchanger (HME) and use a tissue or handkerchief to cover their stoma to catch the mucus.

The best mucus consistency is clear, or almost clear, and watery. Such consistency is, however, not easy to maintain because of changes in the environment and weather. Steps can be routinely taken to maintain a healthy mucus production as shown below.

#### **Mucus production and increasing air humidity**

Prior to becoming a laryngectomee, an individual's inhaled air is warmed to body temperature, humidified and cleansed of organisms

and dust particles by the upper part of the respiratory system. Since these functions do not occur following laryngectomy, it is important to restore the lost functions previously provided by the upper part of the respiratory system.

Following laryngectomy the inhaled air does not get humidified by passing through the nose and mouth; accordingly, tracheal dryness, irritation and overproduction of mucus develop. Fortunately, the trachea becomes more tolerant to dry air over time. However, when the humidity level is too low the trachea can dry out, crack, and produce some bleeding. If the bleeding is significant or does not respond to increase in humidity, a physician should be consulted. And if the amount or color of the mucus is concerning, one should contact a physician.

Restoring the humidification of the inhaled air reduces the overproduction of mucus to an adequate level. This will decrease the chances for coughing unexpectedly and plugging the HME. Increasing the home humidity to 40-50% relative humidity (not higher) can help in decreasing mucus production and keeping the stoma and trachea from drying out, cracking and bleeding. In addition to being painful, these cracks can also become pathways for infections.

Steps to achieve better humidification include:

- Wearing an HME 24/7 which keeps the tracheal moisture higher and preserves the heat inside the lungs
- Wetting the stoma cover to breathe moist air (in those who wear a stoma cover). Although less effective than an HME, dampening the foam filter or stoma cover with clean plain water can also assist in increasing humidification.
- Drinking enough fluid to keep well hydrated
- Inserting 3-5 cc saline into the trachea into stoma at least twice a day

- Taking a steamy shower or breathing in water vapor from a tea kettle (from a safe distance) can also reduce dryness
- Using a humidifier in the house to achieve about 40-50% humidity and getting a hygrometer to monitor the humidity. This is important both in the summer when air conditioning is used, and in the winter when heating is used
- Breathing steam generated by boiling water or a hot shower

There are two types of portable humidifiers - the steam and evaporative ones. A digital humidity gauge (called a hygrometer) can assist in controlling the humidity levels. Over time as the airway adjusts, the need to always use a humidifier may decrease.

### **Caring for the airway and neck especially in a cold winter and in high altitude**

Winter and high altitude can be rough for laryngectomees. The air at high altitude is thinner and colder and therefore dryer. Before a laryngectomy, air is inhaled through the nose where it becomes warm and moist before entering the lungs. After a laryngectomy the air is no longer inhaled through the nose and enters the trachea directly through the stoma. Cold air is dryer than warm air and more irritating to the trachea. This is because cold air contains less humidity and therefore can dry the trachea and cause bleeding.

The mucus can also become dry and plug the trachea.

Breathing cold air can also have an irritating effect on the airway causing the smooth muscle that surrounds the airway to contract (bronchospasm). This decreases the size of the airway and makes it hard to get the air in and out of the lungs, thus increasing shortness of breath.

Care for the airway includes all the steps described in the previous section as well as:

- Coughing out or suctioning the mucus using a suction machine to clean the airway
- Avoiding exposure to cold, dry or dusty air
- Avoiding dust, irritants and allergens
- When exposed to cold air, consider covering the stoma with a jacket (by zipping it all the way) or a loose scarf and breathing into the space between the jacket and the body to warm the inhaled air.
- Preventing water from getting into the stoma when showering (see below)

Following a laryngectomy which involves neck dissection most individuals develop areas of numbness in their neck, chin and behind the ears. Consequently, they cannot sense cold air and can develop frostbite at these sites. It is therefore important to cover these areas with a scarf or warm garment.

### Using suction machine for mucus plugs

A suction machine is often ordered for a laryngectomee prior to leaving the hospital for use at home. It can be used to suction out mucus when one is unable to cough it out and/or to remove a mucus plug. A mucus plug can develop when the mucus become thick and sticky, creating a plug that blocks part or, infrequently, even the whole airway.

The plug can cause a sudden and unexplained shortness of breath. A suction machine can be used in these circumstances to remove the

plug. It should therefore be readily available to treat such an emergency. Mucus plugs may also be removed by using a saline “bullet” (0.9% sterile salt water in a plastic tube) or by squirting saline solution into the stoma. The saline can loosen the plug that can be coughed out. This condition may become a medical emergency and, if the plug is not successfully removed after several attempts, dialing 911 may be life saving.

### Coughing blood

Blood in the mucus can originate from several sources. The most common is from a scratch just inside the stoma. The scratch can be caused by trauma while cleaning the stoma. The blood generally appears bright red. Another common cause of coughing blood in a laryngectomee is irritation of the trachea because of dryness which is common during the winter. It is advisable to maintain a home environment with adequate humidity levels (about 40-50%) to help minimize drying the trachea. Squirting sterile saline into the stoma can also help (See **Mucus production**, page 51).

Bloody sputum can also be a symptom of pneumonia, tuberculosis, lung cancer, or other lung problem.

Persistent coughing of blood should be evaluated by medical professionals. This may be urgent if it is associated with difficulties in breathing and/or pain.

### Runny nose

Because laryngectomees and other neck breathers no longer breathe through their nose, their nasal secretions are not being dried by moving air. Consequently, the secretions drip out of the nose whenever large quantities of them are produced. This is especially common when one



is exposed to cold and humid air or irritating smells. Avoiding these conditions can prevent a runny nose.

Wiping the secretion is the best practical solution. Laryngectomees using a voice prosthesis may be able to blow their nose by occluding the tracheostoma and divert air through the nose.

## Respiratory rehabilitation

After a laryngectomy the inhaled air bypasses the upper part of the respiratory system and enters the trachea and lungs directly through the stoma. Laryngectomees therefore lose the part of the respiratory system that used to filter, warm and humidify the air they breathe.

The change in the way breathing is done also affects the efforts needed to breathe and potential lung functions. This requires adjustment and retraining. Breathing is actually easier for laryngectomees because there is less air flow resistance when the air bypasses the nose and mouth. Because it is easier to get air into the lungs, laryngectomees no longer need to inflate and deflate their lungs as completely as they did before. It is therefore not unusual for laryngectomees to develop reduced lung capacity and breathing capabilities.

There are several measures available to laryngectomees that can preserve and increase their lung capacity:

- The use of an HME can create resistance to air exchange. This forces the individual to fully inflate their lungs to get the needed amount of oxygen.
- Regular exercise under medical supervision and guidance. This can get the lungs to fully inflate and improve individuals' heart and breathing rates.

- Using diaphragmatic breathing. This method of breathing allows for greater utilization of the lung capacity. (See **Diaphragmatic breathing and speech**, page 48)

## CHAPTER 8:

### **Stoma care**

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A stoma is an opening that connects a portion of the body cavity to the outside environment. A stoma is created after a laryngectomy to generate a new opening for the trachea in the neck, thus connecting the lungs to the outside. Caring for the stoma to insure its patency and health is crucial.

#### **General care**

It is very important to cover the stoma at all times in order to prevent dirt, dust, smoke, micro-organisms, etc., from getting into the trachea and lungs.

There are various kinds of stoma covers. The most effective ones are called Heat and Moisture Exchangers (HME) because they create a tight seal around the stoma. In addition to filtering dirt, HMEs preserve some of the moisture and heat inside the respiratory tract and prevent the person from losing them. The HME therefore assist in restoring the temperature, moisture and cleanliness of the inhaled air to the condition before the laryngectomy.

The stoma often shrinks during the first weeks or months after it is created. To prevent it from closing completely, a tracheostomy or laryngectomy tube is initially left in the stoma 24 hours a day. Over time this duration is gradually reduced. It is often left overnight until there is no more shrinking.

**Stoma care when using a base plate or adhesive housing:** The skin around the stoma can become irritated because of repeated gluing and removal of the housing. The materials used to remove the old housing and prepare for the new one can irritate the skin. Removal of the old housing can also irritate the skin especially when it is glued.

An adhesive removal wipe containing liquid (e.g., Remove™, Smith & Nephew, Inc. Largo Fl 33773) can assist in removing the base plate or housing. It is placed at the edge of the housing and helps the housing detach from the skin when it is lifted off. Wiping the area with Remove™ cleans the site from remnants of the seal used to glue the housing. It is important to wipe off the leftover Remove™ with an alcohol wipe so that it will not irritate the skin. When a new housing is used wiping off the Remove™ prevents it from interfering with placing glue again.

It is generally not recommended to leave the housing on for more than 48 hours. Some individuals, however, keep the housing much longer, and replace it when it becomes loose or dirty. In some people the removal of the adhesive is more irritating than the adhesives. In the event the skin is irritated, it is better to leave the housing on only for 24 hours. If the skin is irritated, it may be advisable to give the skin a rest for a day or until the area heals and cover the stoma only with a rigid base without any glue or with a foam cover. There are special hydrocolloid adhesives that allow use on sensitive skin.

It is important to use a liquid film-forming skin protecting dressing (i.e., Skin Prep™, Smith & Nephew, Inc. Largo Fl 33773) before placing the glue.

**Stoma care when using tracheostomy tube:** The buildup of mucus and the rubbing of the tracheostomy tube can irritate the skin around the stoma. The skin around the stoma should be cleaned at least twice a day to prevent odor, irritation and infection. If the area appears red, tender or smells bad, stoma cleaning should be performed more frequently. Contacting one's physician is advisable if a rash, unusual odor, and/or yellowish-green drainage appear around the stoma.

## Skin irritation around the stoma

If the skin around the stoma becomes irritated and red, it is best to leave it uncovered and not expose it to any solvents for 1-2 days so that it can heal. Sometimes individuals can develop an irritation to some of the solvents used to prepare and glue an HME base plate (housing). Avoiding these solvents and finding others that do not cause irritation is helpful. Using a hydrocolloid adhesive is often a good solution for patients with sensitive skin.

If signs of infection such as open ulcers and redness are evident topical antibiotics can be useful. Seeking advice from one's physician is helpful especially if the lesion does not heal. The physician can obtain a bacterial culture of the affected area that can guide the choice of antimicrobial therapy.

## Protecting the stoma from water when showering

It is important to prevent water from entering the stoma when taking a shower. A small amount of water in the trachea generally does not cause any harm and can be rapidly coughed out. However, inhalation of a large amount of water can be dangerous.

Methods to prevent water from entering the stoma are:

- Covering the stoma with the palm and not inhaling air when water is directed at the vicinity of the stoma.
- Wearing a bib with the plastic side out.
- Using a commercial device that covers the stoma.
- Wearing one's stoma cover, the base plate, or HME housing while showering may be sufficient especially if water flow

is directed away from the stoma. Pausing air inhalation for a few seconds while washing the area close to the stoma is also helpful. Taking a shower at the end of the day just before removing the HME and its housing is a way to use the housing for water protection. This simple method can make taking a shower easier.

- When washing the hair, lowering the chin below the stoma by bending over.

## Water and pneumonia

Laryngectomees are at risk of inhaling (aspirating) water that may not be free of bacteria. Tap water contains bacteria; the number of bacteria varies depending on the cleaning efficacy of the water treatment facilities and their source (e.g., well, lake, river, etc.). Pool water contains chloride that reduces, but never sterilizes the water. Sea water contains numerous bacteria; their nature and concentrations varies.

When unclean water gets into the lungs it can sometimes cause pneumonia. Developing aspiration pneumonia depends on how much water is inhaled and how much is coughed out, as well as on the individuals' immune system.

## Preventing aspiration into the stoma

One of the major causes of respiratory emergency in a neck breather is the aspiration of thin paper tissue or paper towels into the trachea. This can be very dangerous and can cause asphyxiation. It usually happens after covering the stoma with a paper towel when coughing out sputum. Following the cough there is a very deep inspiration of air that can suck the paper back into the trachea. The way to prevent this is to use a cloth

towel or a strong paper towel that does not break easily, even when moist. Thin tissues should be avoided.

Another way to prevent aspiration of paper tissues is to hold one's breath until one has completely finished wiping off the sputum and removed the paper tissue or paper towel from the stoma area.

Aspiration of other foreign material should also be prevented by covering the stoma at all times by an HME, foam cover, or stoma cover.

Aspiration of water into the stoma while taking a shower can be prevented by wearing a device that covers the stoma (see above). One can keep the HME on while showering and/or avoid breathing in when water is directed at the stoma's site.

Taking a bath in a tub can be done safely as long as the water level does not reach the stoma. The areas above the stoma should be washed with a soapy washcloth. It is important to prevent soapy water from entering the stoma.

## CHAPTER 9:

### **Heat moisture exchanger (HME) care**

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Heat and moisture exchanger (HME) serve as stoma covers and create a tight seal around the stoma. In addition to filtering dust and other large airborne particles, HMEs preserve some of the moisture and heat inside the respiratory tract and prevent their loss, and adds resistance to the airflow. HME assist in restoring the temperature, moisture and cleanliness of the inhaled air to the same condition as before laryngectomy.

#### **HME advantages**

It is very important that laryngectomees wear an HME. In the United States, the HMEs are available through Atos Medical and InHealth Technologies (Picture 2). The HME can be attached by using an intraluminal device inserted into the trachea or stoma, that includes laryngectomy or tracheostomy tubes, Barton Mayo Button™ and/or Lary Button™. The can also be inserted into a housing or a base plate attached to the skin around the stoma.

HME cassettes are designed to be removed and replaced on a daily basis. The foam media in the cassettes are treated with agents that have antimicrobial properties and help to retain moisture in the lungs. They should not be washed and reused because these agents lose their effectiveness over time or when rinsed by water or other cleaning agents.

The HME captures the warm, moistened, and humidified air upon exhalation. It can be impregnated with chlorhexidine (anti-bacterial agent), sodium chloride (NaCl), calcium chloride salts (traps moisture), activated charcoal (absorbs volatile fumes), and is disposable after 24 hours of use.

The HME advantages also include: increasing the moisture within the lungs (subsequently leading to less mucus production), decreasing the viscosity of the airway secretions, decreasing risk of mucus plugs, and re-instating the normal airway resistance to the inhaled air which preserves the lung capacity.

In addition, a special HME-combined with an electrostatic filter also reduces the inhalation (and exhalation/transfer) of bacteria, viruses, dust and pollen. Inhaling less pollen can reduce the airway irritation during high allergens season. Wearing an HME with filter may reduce the risk of getting or transferring viral and bacterial infection, especially in crowded or closed places. A new HME filter designed to filter potential respiratory pathogens is available (Provox Micron™, Atos Medical).

It is important to realize that simple stoma covers, such as a laryngofoam™ filter, ascot, bandana, etc., do not provide the same benefits to a laryngectomee as an HME filter.



**Picture 2: Voice prosthesis (below) and HMEs (above) produced by Atos (Provox) and InHealth**

## The effect of an HME on breathing as a laryngectomee

Laryngectomy compromises the respiratory system by allowing the inhaled air to bypass the nose and upper airways which normally provide humidification, filtration and warmth. It also reduces the resistance and the effort needed for inhalation by removing air resistance and shortening the distance the air travels to the lung. This means that laryngectomees do not have to work as hard to get air past the upper part of the system (nose, nasal passages, and throat), and their lungs do not have to inflate as much as they did before unless the person works to retain their capacity through exercise and other methods. An HME increases the resistance to inhaled air and therefore increases inhalation efforts, thus preserving previous lung capacity.

## Placing an HME base plate (housing)

The key to prolonging the use of an HME's base plate (housing) is not only properly gluing it in place, but also removing the old adhesives and glue from the skin, cleaning the area around the stoma and applying new layers of adhesive and glue. Careful preparation of the skin is very important (Picture 3).

In some individuals the shape of the neck around the stoma makes it difficult to fit a housing or a base plate. There are several types of housing; a speech and language pathologist (SLP) can assist in selecting the best one. Finding the best HME housing may take trial and error. Over time, as the post surgical swelling subsides and the area around the stoma reshapes itself, the type and size of the housing may change.

Below are the suggested instructions on how to place the housing for the HME. Throughout the process it is important to wait patiently and allow the liquid film-forming skin protecting dressing (i.e., Skin Prep™ Smith & Nephew, Inc. Largo, Fl 33773) and silicone skin adhesive to dry before applying the next item or placing the housing. This takes time, but it is important to follow these instructions:

1. Clean the old glue with an adhesive removal wipe (e.g., Remove™, Smith & Nephew, Inc. Largo, Fl 33773).
2. Wipe off the Remove™ with an alcohol wipe. (if you do not do this, the Remove™ will interfere with the new adhesive).
3. Wipe the skin with a wet towel.
4. Wipe the skin with the wet towel with soap.
5. Wash away the soap with a wet towel and thoroughly dry.
6. Apply Skin Prep™ and let it dry for 2-3 minutes.
7. For extra adhesion apply silicone skin adhesive or Skin-Tac™ wipe (Torbot, Cranston, Rhode Island, 20910) and let it dry for 3-4 minutes. (This is especially important for users of automatic speaking valve)
8. Attach the base plate (housing) for the HME at the best location to allow air flow and good attachment.
9. When using hands free HME wait for 5-30 minutes before speaking to allow the adhesive to “set”.

Some SLPs recommend warming the housing prior to placement by rubbing it in the hands, holding it under the armpit for a few minutes, or by blowing warm air on it with a hair drier. Be careful that the adhesive does not become too hot. Warming the adhesive is especially important when you use a hydrocolloid adhesive since the warmth activates the glue.

A video made by Steve Staton demonstrates the placement of the housing at [http://www.youtube.com/watch?v=5Wo1z5\\_n1j8](http://www.youtube.com/watch?v=5Wo1z5_n1j8)



**Picture 3: Placement of HME and its housing on a stoma**

### Using hands free HME

The hands free HME allows speaking without the need to manually press on the HME to close it off, thus blocking exhalation through the stoma and directing air to the voice prosthesis. This device frees one's hand and eases vocational and recreational possibilities. Note that when using a hands free HME more pressure is generated when air is exhaled thus potentially leading to a break in the HME housing's seal. Reducing the exhalation pressure when speaking, speaking slower and softly (almost whispering), and taking a breath after 5-7 words can prevent a break in the seal. Supporting it with a finger before needing to speak loud can also help. It is also important to quickly remove the device before coughing.

The air filter (also called cassette in Provox FreeHands HME) in the hands free device has to be changed on a regular basis (every 24 hours or sooner if it becomes dirty or covered with mucus). However, the HME device can be used for a long period of time (six months to a year) with proper use and cleaning. The hands free device requires initial adjustments to fit the laryngectomee's breathing and speaking abilities. Detailed instructions on how to use and care for the devices are provided by their manufacturers.

The key to speaking with a hands free HME is to learn how to speak without breaking the seal. Using diaphragmatic breathing allows for more air to be exhaled, thus reducing speaking efforts and increasing the number of words that can be articulated with each breath. This method prevents buildup of air pressure in the trachea which can break the housing's seal. It may take time and patience to learn how to speak in such a way, and guidance by a skilled SLP can be helpful.

It is very important to place the HME housing according to the steps outlined in the section on HME care (See **Placing an HME Housing**, page 67) including cleaning the area around the stoma with Remove™, alcohol, water and soap, placing Skin Prep™ and finally glue (Skin Tag™). Following these instructions can prolong the life of the housing and reduce the likelihood of an air leak through the seal.

Air inhalation is slightly more difficult when using a free hands HME as compared to a regular HME. It is possible to allow for greater amounts of air intake by rotating the valve counter-clockwise in both Atos FreeHands™ and InHealth HandsFree™ devices.

Despite the challenge of keeping the seal, many laryngectomees value the ability to speak in a more natural way and the freedom of using both hands. Some learn that it is possible to keep the seal much longer when they use a voice amplifier thus requiring less effort and generating less air pressure. (See **Increasing the voice using a voice amplifier**, page 49)

## Wearing the HME overnight

Some HMEs are approved for wear 24/7 ( i.e., Atos Medical). If the seal lasts, one can keep it overnight. If it does not last, it is possible to use an improvised base plate for the night period. An Atos Xtra BasePlate™ can be trimmed down by removing the outer soft part and leaving the inner rigid part. The plate is “sticky” and thus can cover the stoma without glue, even enabling one to speak. It is also possible to use the HME inserted in a LaryTube overnight.

## Covering (hiding) the HME

Following laryngectomy, individuals breathe through a tracheostomy site that opens through a stoma on their neck. Most place an HME or a foam filter over the stoma to filter the inhaled air and maintain warmth and humidity in the upper airway. The covered stoma site is prominent and laryngectomees face a choice whether to cover the HME or filter with a garment, an ascot, or jewelry or to leave it uncovered.

The pros and cons of each choice:

Breathing may be easier without an additional cover which can interfere with air flow. Leaving the area exposed allows for easier access to the stoma for purpose of cleaning and maintenance and enables a rapid removal of the HME in case one needs to cough or sneeze. The urge to cough or sneeze is often very sudden and if the HME is not taken out quickly it can become clogged with mucus.

Exposing the site provides an unspoken explanation for the weak and rusty voice of many laryngectomees and encourages others to listen to them more attentively. It also makes it easier for health care providers to recognize the laryngectomee's unique anatomy in case emergency respiratory ventilation is needed. If this condition is not rapidly recognized ventilation may be administered through the mouth or nose rather than through the stoma. (See **Ensuring adequate urgent care of neck breathers including laryngectomees**, page 147)

Openly displaying the covered stoma site also reveals the person's medical history and the fact that he/she are cancer survivors who go on with their lives despite their handicap, cancer being the leading indication for a laryngectomy. Although there are many cancer survivors in the community, their identity is hidden from outward appearances.

Those who cover their stoma site with a stoma cover or cloth often do it because they do not want others to be distracted or offended by the site. They also do not want to expose anything that is disfiguring and want to be inconspicuous and appear as normal as possible. Covering the site is often more common among females who may be



more concerned with their physical appearance. Some individuals feel that being a laryngectomee is only a small part of who they are as a person; they do not want to “advertise” it.

There are advantages and repercussions to each approach and the final selection is up to the individual.

## CHAPTER 10:

# Tracheoesophageal voice prosthesis use and care

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A voice prosthesis is inserted through a previously created tracheoesophageal puncture (TEP) connecting the trachea and esophagus in those wishing to speak through tracheoesophageal speech. It enables the individual to exhale pulmonary air from the trachea into the esophagus through a silicone prosthesis that connects the two; the vibrations are generated by the lower pharynx.

### Types of voice prosthesis

There are two types of voice prosthesis: an indwelling one that is installed and changed by a speech and language pathologist (SLP) or otolaryngologist and a patient-changed one.

The indwelling prosthesis generally lasts a longer time than the patient managed device. However, prosthesis eventually leak mostly because yeast and other microorganisms grow into the silicone leading to incomplete closure of the valve flap. When the valve flap does not close tight anymore, fluids can pass through the voice prosthesis (see below in **Causes of voice prosthesis leak section**, page 75 ).

An indwelling prosthesis can function well for weeks to months. However, some SLPs believe that it should be changed even when it

does not leak after six months because, if left for a longer time, it can lead to dilatation of the puncture.

The patient managed voice prosthesis allows a greater degree of independence. It can be changed by the laryngectomee on a regular basis, (every one to two weeks). Some individuals change the prosthesis only after it starts leaking. The old prosthesis can be cleaned and reused several times.

A number of factors determine an individual's ability to use a patient managed prosthesis:

- The location of the puncture should be easily accessible; the site of the puncture may, however, migrate over time, making it less accessible.
- The laryngectomee should have adequate eyesight and good dexterity, enabling him/her to perform the procedure, and capable of following all the steps involved.

An indwelling voice prosthesis does not need to be replaced as frequently as a patient managed one.

Two videos made by Steve Staton explain how to change a patient-changed prosthesis:

[http://www.youtube.com/watch?v=nF7cs4Q29WA&feature=channel\\_page](http://www.youtube.com/watch?v=nF7cs4Q29WA&feature=channel_page)

[http://www.youtube.com/watch?v=UkeOQf\\_ZpUg&feature=relmfu](http://www.youtube.com/watch?v=UkeOQf_ZpUg&feature=relmfu)

The main difference between the clinician-changed and patient-changed voice prosthesis is the size of the flanges. The larger size flanges on the clinician-changed devices make it harder to accidentally dislodge it. Another difference is that the insertion strap should not be removed from the patient-changeable prosthesis because it helps to anchor the prosthesis. There is generally no difference in voice quality between a clinician-changed and a patient-changed device.

## What to do if the prosthesis leaks or is dislodged

If the prosthesis leaks or has become dislodged or has been removed accidentally, a patient-changed prosthesis can be inserted by those who carry an extra device. Alternatively, a red rubber catheter can be inserted into the TEP which can close within a few hours, to prevent closure. Inserting a catheter or a new prosthesis can prevent the need for a new TEP. Leakage of the prosthesis from the center (lumen) can be temporarily handled by inserting a plug (specific to the type and width of the prosthesis) until it can be changed.

It is advisable that individuals using a voice prosthesis carry a prosthesis plug and a catheter.

## Causes of voice prosthesis leak

There are two patterns of voice prosthesis leak - leak through the prosthesis and leak around it.

Leakage **through the voice prosthesis** is predominantly due to situations in which the valve can no longer close tightly. This may be due the following: colonization of the valve by fungus; the flap valve may get stuck in the open position; a piece of food, mucus or hair (in those with a fee flap) stuck on the valve; or the device coming in contact with the posterior esophageal wall. Inevitably, all prostheses will fail by leaking through, whether from Candida colonization or simple mechanical failure.

If there is continuing leakage through the prosthesis from the time it is inserted, the problem is generally due to the fact that the flap valve remains open because of negative pressure generated by swallowing. This can be corrected by using a prosthesis that has a greater resistance. The trade-off is that having such a voice prosthesis may require more effort when speaking. It is, nevertheless, important to prevent chronic leakage into the lungs.

Leakage **around the voice prosthesis** is less common and is mainly due to trachea-esophageal puncture tract dilation or inability to grip the prosthesis. It has been linked to shorter prosthesis life time. It may occur when the puncture that houses the prosthesis widens. During insertion of the voice prosthesis, some dilation of the puncture takes place, but if the tissue is healthy and elastic, it should shrink back after a short time. The inability to contract may be associated with gastroesophageal reflux, poor nutrition, alcoholism, hypothyroidism, improper puncture placement, local granulation tissue, incorrectly fitted prosthesis, TEP tract trauma, recurrent or persistent local or distant cancer and radiation necrosis.

Leakage around the prosthesis can also occur if the prosthesis is too long for the user's tract. Whenever this occurs, the voice prosthesis moves back and forth in the tract (pistoning), thereby dilating the tract. The tract should be measured and a prosthesis of more appropriate length should be inserted. In this circumstance, leakage should resolve within 48 hours. If the tissue around the prosthesis does not heal around the shaft within this time period, comprehensive medical evaluation is warranted to determine the cause of the problem.

Another cause of leakage around the prosthesis is the presence of narrowing (stricture) of the esophagus. The narrowing of the esophagus forces the laryngectomee to swallow harder using greater force, so that the food/liquid goes through the stricture. The excess swallowing pressure pushes the food/liquid around the prosthesis.

Several procedures have been used to treat persistent leakage around the prosthesis. These include temporary removal of the prosthesis and replacement with a smaller-diameter catheter to encourage spontaneous shrinkage; a purse-string suture around the puncture; injection of gel, collagen or micronized AlloDerm® (LifeCell, Branchburg, N.J. 08876); cautery with silver nitrate or electrocautery; autologous fat transplantation; and inserting a larger prosthesis to stop the leak. Treatment of reflux (the most common cause of leakage) can allow the esophageal tissue to heal.

Increasing the diameter of the prosthesis is generally not recommended.

Generally a larger diameter voice prosthesis is heavier than a smaller one, and the weakened tissue is often not able to support a bigger device, making the problem even worse. However, some believe that using a larger diameter prosthesis reduces the speaking pressure (larger diameter allows better airflow) which allows greater tissue healing to occur while the underlying cause (most often reflux) is treated.

The use of prosthesis with a larger esophageal and/or tracheal flange may be helpful, as the flange acts as a washer to seal the prosthesis against the walls of the esophagus and/or trachea, thus preventing leakage.

Both types of leakage can cause excessive, strenuous, coughing which may lead to the development of abdominal wall and inguinal hernias. The leaked fluid can enter the lungs and causing aspiration pneumonia. Any leakage can be confirmed by direct visualization of the prosthesis while drinking colored liquid. If leakage occurs and cannot be corrected after brushing and flushing the voice prosthesis, it should be changed as soon as possible.

With the passage of time, a voice prosthesis generally tends to last longer before it begins to leak. This is because the swelling and increased mucus production are reduced as the airway adapts to the new condition. Improvement is also due to better prosthesis management by laryngectomees as they familiarize themselves with their device.

Patients with a TEP need to be followed by a SLP because of normal changes in the tracheo-esophageal tract. Re-sizing of the tract may be needed as it can change in length and diameter with time. The length and diameter of the prosthesis puncture generally change over time as the swelling generated by creation of the fistula, surgery, and radiation gradually decreases. This requires repeated measurements of the length and diameter of the puncture tract by the SLP who can select a properly sized prosthesis.

One of the advantages of having a voice prosthesis is that it can assist in dislodging food stuck in a narrow throat. When food get stuck

above the prosthesis, trying to speak or blowing air through the voice prosthesis can sometimes force the stuck food upward and relieve the obstruction. (See **How to remove or swallow food that is stuck in the throat or esophagus**, page 87)

The prosthesis may have to be changed if there is an alteration in the quality of the voice, especially when the voice becomes weaker or one needs more respiratory effort to speak. This may be due to yeast growth which interferes with the opening of the valve.

## Preventing the voice prosthesis from leaking

It is advisable to clean the voice prosthesis' inner lumen at least twice a day and after each meal.

Proper cleaning may prevent and/or stop leakage through the voice prosthesis:

1. Before using the brush provided by the manufacturer, dip it in a cup of hot water and leave it there for a few seconds.
2. Insert the brush into the prosthesis (not too deep) and twist it around a few times to clean the inside of the device.
3. Take the brush out and rinse it with hot water and repeat the process 2-3 times until no material is brought out by the brush. Because the brush is dipped in hot water one should be careful not to insert it beyond the voice prosthesis inner valve to avoid traumatizing the esophagus with excessive heat.
4. Flush the voice prosthesis twice using the bulb provided by the manufacturer using warm (not hot!) potable water. To avoid damage to the esophagus sip the water first to make sure that the water temperature is not too high.

Warm water works better than room temperature water in cleansing the prosthesis probably because it dissolves the dry secretions and mucus and perhaps even flushes away (or even kills) some of the yeast colonies that had formed on the prosthesis.

## What to do if the indwelling voice prosthesis leaks

A leak can take place when a piece of dry mucus, a food particle, or hair (in those with a free flap) prevents a complete closure of the prosthesis's valve. Cleaning the prosthesis by brushing and flushing it with warm water (see the previous section) can remove these obstructions and stop the leakage.

If the leakage through the voice prosthesis happens within three days after its insertion it may be due to a defective prosthesis or one that was not placed correctly. It takes some time for the yeast to grow. If the prosthesis leaks when new, it is due to another cause. In addition to brushing and flushing with warm water, cautiously rotating the prosthesis a couple of times to dislodge any debris may help. If the leak persists the voice prosthesis should be replaced.

The easiest way of temporarily stopping the leak until the voice prosthesis can be changed is to use a plug. A plug is specific for the type and width of each voice prosthesis. It is a good idea to obtain a plug from the prosthesis' manufacturer and have it handy. Sealing the prosthesis will prevent speaking, but it allows eating and drinking without leakage. The plug can be removed after eating and drinking and reinserted as needed. This is a temporary solution until the voice prosthesis is replaced.

It is important to stay well hydrated despite the leakage. Avoiding fluid losses in hot weather through perspiration by staying in an air-conditioned environment and ingesting liquids in a way that is less likely to leak are helpful. Drinks that contain caffeine increase urination and should be avoided. Viscous fluids tend not to leak and consuming them can provide essential liquids despite the leak. Many

food items that contain large amount of liquids are more viscous (e.g., jelly, soup, oat meal, toast dipped in milk, yogurt ) and are therefore less likely to leak through the prosthesis. On the other hand coffee and carbonated drinks are more likely to leak. Fruits and vegetables contain large amount of water (e.g., watermelon, apples, etc). The way to find out what works is to cautiously try any of these.

Another method to reduce the leak until the prosthesis can be changed that may work for some individuals is to try and swallow the liquid as if it is a food item. Such maneuver is less likely to lead to fluid leakage through the voice prosthesis.

These measures can be used to keep well-hydrated and nourished until the voice prosthesis can be changed.

## Cleaning the voice prosthesis

It is recommended that the voice prosthesis be cleaned at least twice a day, (morning and evening), and preferably after eating (see: **Preventing the: Voice prosthesis from leaking**, page 78) because this is the time when food and mucus can become trapped there. Cleaning is especially helpful after eating sticky food or whenever one's voice is weak.

Initially, the mucus around the prosthesis should be cleaned using tweezers, preferably with rounded tips. Following that the manufacturer-provided brush should be inserted into the prosthesis and twisted back and forth. The brush should be thoroughly washed with warm water after each cleaning. The prosthesis is then flushed twice with warm (not hot) water using the manufacturer's provided bulb.

The flushing bulb should be introduced into the prosthesis opening while applying slight pressure to completely seal off the opening. The angle that one should place the tip of the bulb varies between individuals. (The SLP can provide instructions how to choose the best angle.) Flushing the prosthesis should be done gently because using

too much pressure can lead to splashing of water into the trachea. If flushing with water is problematic, the flush can also be used with air.

The manufacturers of each voice prosthesis brush and flushing bulb provide directions on how to clean them and when they should be discarded. The brush should be replaced when its threads become bent or worn out.

The prosthesis brush and flushing bulb should be cleaned with hot water, when possible and soap and dried with a towel after every use. One way to keep them clean is to place them on a clean towel and expose them to sunlight for a few hours, on a daily basis. This takes advantage of the antibacterial power of the sun's ultraviolet light to reduce the number of bacteria and fungi.

Placing 2-3 cc of sterile saline in the trachea at least twice a day (and more if the air is dry), wearing an HME 24/7 and using a humidifier can keep the mucus moist and reduce the clogging of the voice prosthesis.

## Preventing yeast growth in the voice prosthesis

Overgrowth of yeast is one cause of a voice prosthesis leaking and thus failing. Nevertheless, it takes some time for yeast to grow in a newly installed voice prosthesis and form colonies that prevent its valve's from closing completely. Accordingly, failures immediately after voice prosthesis installation are unlikely due to yeast growth.

The presence of yeast should be established by the person who changes the failing voice prosthesis. This can be done by observing the typical yeast (*Candida*) colonies that prevent the valve from closing and, if possible, by sending a specimen from the voice prosthesis for fungal culture.

Mycostatin (an antifungal agent) is often used to prevent voice prosthesis failure due to yeast. It is available with a prescription in the form of a suspension or tablets. The tablets can be crushed and dissolved in water.

Automatically administering anti-fungal therapy just because one assumes that yeast is the cause of voice prosthesis failure may be inappropriate. It is expensive, may lead to the yeast developing resistance to the agent, and may cause unnecessary side effects.

There are, however, exceptions to this rule. These include the administration of preventive anti-fungal agents to diabetics; those receiving antibiotics; chemotherapy or steroids; and those where colonization with yeast is evident (coated tongue etc.).

There are several methods that help prevent yeast from growing on the voice prosthesis:

- Reduce the consumption of sugars in food and drinks. If you consume them, brush your teeth well after consuming sugary foods and/or drinks.
- Brush your teeth well after every meal and especially before going to sleep.
- Diabetics should maintain adequate blood sugar levels.
- Take antibiotics only if they are needed.
- After using an oral suspension of an antifungal agent, wait for 30 minutes to let it work and then brush your teeth. This is because some of these suspensions contain sugar.
- Dip the voice prosthesis brush in a small amount of mycostatin suspension and brush the inner voice prosthesis before going to sleep. (A homemade suspension can be made by dissolving a quarter of a mycostatin tablet in 3-5 cc water). This would leave some of the suspension inside the voice prosthesis. The unused suspension should be discarded. Do not to place too much mycostatin in the prosthesis to prevent dripping into the

trachea. Speaking a few words after placing the suspension will push it towards the inner part of the voice prosthesis.

- Consume probiotics by eating active-culture yogurt and/or a probiotic preparation
- Gently brush the tongue if it is coated with yeast (white plaques)
- Replace the toothbrush after overcoming a yeast problem to prevent re colonizing with yeasts
- Keep the prosthesis brush clean

### **The use of *Lactobacillus acidophilus* to prevent yeast overgrowth**

A probiotic that is often used to prevent yeast overgrowth is a preparation containing the viable bacteria *Lactobacillus acidophilus*. There is no FDA approved indication to use *L. acidophilus* to prevent yeast growth. This means that there were no controlled studies to ensure its safety and efficacy. *L. acidophilus* preparations are sold as a nutritional supplement and not as a medication. The recommended dosage of *L. acidophilus* is between 1 and 10 billion bacteria. Typically, *L. acidophilus* tablets contain somewhere within this recommended amount of bacteria. Dosage suggestions vary by tablet, but generally it is advised to take between one and three *L. acidophilus* tablets daily.

Although generally believed to be safe with few side effects, oral preparations of *L. acidophilus* should be avoided in people with intestinal damage, a weakened immune system, or with overgrowth of intestinal bacteria. In these individuals this bacterium can cause serious and sometimes life threatening complications. This is why individuals should consult their physician whenever this live bacteria is ingested. It is especially important in those with the above conditions.

## CHAPTER 11:

### **Eating, swallowing, and smelling**

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Eating, swallowing, and smelling are not the same after laryngectomy. This is because radiation and surgery create permanent lifelong changes. Radiation therapy can cause fibrosis of the muscles of mastication which can lead to the inability to open one's mouth (trismus or lockjaw) making eating more difficult. Eating and swallowing difficulties can also be generated by a decrease in saliva production and a narrowing of the esophagus, plus a lack of peristalsis in those with flap reconstruction. Smelling is also affected because inhaled air bypasses the nose.

This chapter describes the manifestations and treatment of the eating and smelling challenges faced by laryngectomees. These include swallowing problem, food reflux, esophageal strictures, and smelling difficulties.

#### **Maintaining adequate nutrition as a laryngectomee**

Eating may be a lifelong challenge for laryngectomees. This is because of swallowing difficulties, decreased production of saliva (which lubricates food and eases mastication), and an alteration in one's ability to smell.

The need to consume large quantities of fluid while eating can make it difficult to ingest large meals. This is because when liquids fill the stomach there is less room left for food. Because liquids are absorbed within a relatively short period of time, laryngectomees

end up having multiple small meals rather than fewer large ones. The consumption of large quantities of liquid makes them urinate very frequently throughout the day and night. This can interfere with one's sleep pattern and can cause tiredness and irritability. Those who suffer from heart problems (e.g., congestive heart failure) may experience problems due to overloading their bodies with excess fluid.

Consuming food that stays longer in the stomach (e.g., proteins such as white cheese, meat, nuts) can reduce the number of daily meals, thus reducing the need to drink liquids.

It is important to learn how to eat without ingesting excessive amounts of liquids. For example, relieving swallowing difficulties can reduce the need to consume fluids, while consuming fewer liquids prior to bedtime can improve sleeping pattern.

Nutrition can be improved by:

- Ingesting adequate, but not too much liquid
- Drinking less liquid in the evening
- Consuming “healthy” food
- Consuming a low carbohydrate and high protein diet (high sugar enhances yeast colonization)
- Requesting dietitian assistance

It is essential to make sure a laryngectomee follows an adequate and balanced nutrition plan that contains the correct ingredients, despite difficulties with their eating. A low carbohydrate and high protein diet that includes vitamins and minerals supplements is important. The assistance of nutritionists, speech and language pathologists (SLPs), and physicians in ensuring that one maintains adequate weight is very helpful.

## How to remove (or swallow) food that is stuck in the throat or esophagus

Some laryngectomees experience recurrent episodes of food becoming stuck in the back of their throat or esophagus and prevents them from swallowing.

Clearing the stuck food can be accomplished using these methods:

1. First do not panic. Remember that you cannot suffocate because, as a laryngectomee, your esophagus is completely separate from your trachea.
2. Try to drink some liquid (preferably warm) and attempt to force the food down by increasing the pressure in your mouth. If this does not work -
3. If you speak through a tracheoesophageal puncture (TEP), try to speak. This way the air you blow through the voice prosthesis may push the food above the TEP into the back of your throat, relieving the obstruction. Try this first standing up and if it does not work bend over a sink and try to speak. If this does not work -
4. Bend forward (over a sink or hold a tissue or cup over the mouth), lowering your mouth below the chest and applying pressure over your abdomen with your hand. This forces the contents of the stomach upward and may clear the obstruction.

These methods work for most people. However, everyone is different and one needs to experiment and find the methods that best work for them. Swallowing does, however, get better in many laryngectomees over time.

Some laryngectomees report success in removing the obstruction by gently massaging their throat, walking for a few minutes, jumping



up on their feet, sitting and standing several times, hitting their chest or the back, using a suction machine with the catheter paced in the back of their throat, or just waiting for a while until the food is able to descend into the stomach by itself.

If nothing works and the food is still stuck in the back of the throat it may be necessary to be seen by an otolaryngologist or go to an emergency room to have the obstruction removed.

## Food and stomach acid reflux

Most laryngectomees are prone or develop gastroesophageal reflux disease, or GERD.

There are two muscular bands or sphincters in the esophagus that prevent reflux. One band is located where the esophagus enters the stomach and the other is behind the larynx at the beginning of the esophagus in the neck. The lower esophageal sphincter often becomes compromised when there is a hiatus hernia which in more than three quarters people over seventy. During a laryngectomy, the sphincter in the upper esophageal sphincter (the cricopharyngeus) which normally prevents food from returning to the mouth is removed. This leaves the upper part of the esophagus flaccid and always open which may result in the reflux of stomach contents up into the throat and mouth. Therefore, regurgitation of stomach acid and food, especially in the first hour or so after eating, can occur when bending forward or lying down. This can also occur after forceful exhalation of air when those who use a TEP try to speak.

Taking medications that reduce stomach acidity such as antacids and proton pump inhibitors (PPI), can alleviate some of the side effects of reflux, such as throat irritation, damage to the gums and bad taste. Not lying down after eating or drinking also helps prevent reflux. Eating small amounts of food multiple times causes less food reflux than eating large meals.

**Symptoms and treatment of stomach acid reflux.** Acid reflux occurs when the acid that is normally in the stomach backs up into the esophagus. This condition is also called “gastroesophageal reflux disease,” or GERD.

The symptoms of acid reflux include:

- Burning in the chest (heartburn)
- Burning or acid taste in the throat
- Stomach or chest pain
- Difficulty in swallowing
- Raspy voice or a sore throat
- Unexplained cough (not in laryngectomees unless their voice prosthesis leaks)
- In laryngectomees: granulation tissue forms around the voice prosthesis, short voice prosthesis device life, voice problems

Measures to reduce and prevent acid reflux include:

- Losing weight (in those who are overweight)
- Reducing stress and practicing relaxation techniques
- Avoiding foods that worsen symptoms (e.g., coffee, chocolate, alcohol, peppermint, and fatty foods)
- Stopping smoking and passive exposure to smoke

- Eating small amounts of food several times a day, rather than large meals
- Sitting upright when eating and staying upright thirty to sixty minutes later
- Avoiding lying down for three hours after a meal
- Elevating the head of the bed by 6-8 inches (by putting blocks of wood under two legs of the bed or a wedge under the mattress) or by using pillows to elevate the upper portion of the body by at least about 45 degrees
- Taking a medication that reduces the production of stomach acids, as prescribed by one's physician
- When bending down, bend the knees rather than bend the upper body

**Medications for the treatment of acid reflux.** There are three major types of medication that can help reduce acid reflux symptoms: antacids, histamine H2-receptor antagonists (also known as H2 blockers), and proton pump inhibitors. These drug classes work in different ways by reducing or blocking stomach acid.

Liquid antacids are generally more active than tablets, and more active if taken after a meal or before going to bed, but they work only for a short time. H2 blockers ( e.g., Pepcid, Tagamet, Zantac ) work by reducing the amount of acid produced by the stomach. They last longer than antacids and can relieve mild symptoms. Most H2 blockers can be bought without a prescription.

Proton pump inhibitors (e.g., Prilosec, Nexium, Prevacid, Aciphex) are the most effective medicines in treating GERD and stopping the production of stomach acid. Some of these medicines are sold without

a prescription. They may reduce the absorption of calcium. Monitoring the serum calcium levels is important; individuals with low calcium levels may need to take calcium supplements.

It is advisable to see a physician if the GERD symptoms are severe or last a long time and are difficult to control.

## Speaking when eating and after laryngectomy

Laryngectomees who speak through a tracheoesophageal voice prosthesis have difficulties in speaking when they swallow. This is especially challenging during the time it takes the food or liquids to pass by the esophageal TEP site. Speaking during that time is either impossible or sounds “bubbly.” This is because the air introduced into the esophagus through the voice prosthesis has to travel through the food or liquids. Unfortunately it takes the food much longer to go through the esophagus, in someone who has had a flap to replace the pharynx. This is because the flap has no peristalsis (contraction and relaxation), the food goes down mainly due to gravity.

It is therefore important to eat slowly, mix the food with liquids while chewing and allow the food to pass through the TEP area before trying to speak. Over time, laryngectomees can learn how much time is needed for food to pass through the esophagus to allow speech. It is helpful to drink before attempting to speak after eating.

There are eating and swallowing exercises that a speech and language pathologist (SLP) can teach a laryngectomee that may assist them in relearning how to swallow without difficulties.

## Swallowing difficulties

Most laryngectomees experience problems with swallowing (dysphagia) immediately after their surgery. Because swallowing involves the coordination between more than twenty muscles and several nerves,

damage to any part of the system by surgery or radiation can produce swallowing difficulties. The majority of laryngectomees relearn how to swallow with minimal problems. Some may only need to make minor adjustments in eating such as taking smaller bites, chewing more thoroughly, and drinking more liquids while eating. Some experience significant swallowing difficulties and require assistance in learning how to improve their ability to swallow by working with a SLP who specializes in swallowing disorders.

Swallowing functions change after a laryngectomy and can be further complicated by radiation and chemotherapy. The incidence of swallowing difficulty and food obstruction can be as high as fifty percent of patients, and if not addressed, can lead to malnutrition. Most difficulties with swallowing are noticed after discharge from the hospital. They can occur when attempting to eat too fast and not chewing well. They can also happen after trauma to the upper esophagus by ingesting a sharp piece of food or drinking very hot liquid. These can cause swelling which may last a day or two. (I describe my personal experiences with eating in my book “My Voice” in Chapter 20 entitled Eating.)

Swallowing problems (or dysphagia) are common after total laryngectomy. The problems may be temporary or long term. Risks of swallowing problems include poor nutritional status, limitations in social situations and diminished quality of life.

Patients experience difficulties in swallowing as a result of:

- Abnormal function of the pharyngeal muscles (dysmotility)
- Cricopharyngeal dysfunction of the the cricoid cartilage and the pharynx
- Reduced strength of the movements of the base of the tongue

- Development of a fold of mucous membrane or scar tissue at the tongue base called “pseudoepiglottis”. Food can collect between the pseudoepiglottis and the tongue base
- Difficulty with tongue movements, chewing, and food propulsion in the pharynx because of removal of the hyoid bone and other structural changes
- A stricture within the pharynx or esophagus may decrease food passage leading to its collection
- Development of a pouch (diverticulum) in the pharyngoesophageal wall that can collect fluid and food resulting in the complaint of food “sticking” in the upper esophagus

Laryngectomees are usually not allowed to swallow food immediately after surgery and must be fed through a feeding tube for two to three weeks. The tube is inserted into the stomach through the nose, mouth or the tracheo-esophageal puncture and liquid nourishment is supplied through the tube. This practice, however, is slowly changing; there is increasing evidence that in standard surgeries, oral intake can start with clear liquids as soon as 24 hours after surgery. This may also help with swallowing as the muscles involved will continue to be used.

Following an episode of food obstruction in the upper esophagus swallowing may be difficult for a day or two. This is probably because of the local swelling in the back of the throat; normally, this will disappear with time.

Ways to avoid such episodes:

- Eating slowly and patiently
- Taking small bites of food and chewing very well

- Swallowing a small amount of food at a time and always mixing it with liquid in the mouth before swallowing. Warm liquid makes it easier to swallow.
- Flushing the food with more liquids as needed (warm liquids may work better for some individuals in flushing down the food).
- Avoiding food that is sticky or hard to chew. One needs to find out for him/her self what food is easier to ingest. Some foods are easy to swallow (e.g., toasted or dry bread, yogurt, and bananas) and others tend to be sticky (e.g., unpeeled apples, lettuce and other leafy vegetables, and steak).

Swallowing problems may improve over time. However, dilatation of the esophagus may be needed if the narrowing is permanent. The extent of the narrowing can be evaluated by a swallow test. Dilatation is usually done by an otolaryngologist or a gastroenterologist (see **Dilation of the esophagus**, page 96.)

### Tests used for the evaluation of swallowing difficulty

There are five major tests that can be used for the evaluation of swallowing difficulties:

- Barium swallow radiography
- Videofluoroscopy (motion X-ray study)
- Upper endoscopic evaluation of swallowing
- Fiberoptic nasopharyngeal laryngoscopy

- Esophageal manometry (measures esophagus muscle contractions)

The specific test is chosen according to the clinical condition.

**Videofluoroscopy** which is usually the first test done to most patients, records swallowing during fluoroscopy. It allows accurate visualization and study of the sequence of events which make up a swallow; it is limited to the cervical esophagus. The video, taken from both the front and the side, can be viewed at much slower speeds to enable accurate study. This helps identify abnormal movement of food, such as aspiration, pooling, movement of anatomic structures, muscle activities, and exact oral and pharyngeal transit times. The effects of various barium consistencies and positions can be tested. Thick or solid food boluses can be used for patients who complain of solid food dysphagia.

### Narrowing of the esophagus and swallowing problems

A stricture of the esophagus is a narrowing along the pharyngo-esophagus that blocks or inhibits the ease of food passage, resulting in the esophagus having an hour-glass configuration.

Strictures after laryngectomy can be due to the effects of radiation and the tightness of the surgical closure and can also develop gradually as scarring forms.

Interventions that can help the patient include:

- Dietary and postural changes
- Myotomy (cutting the muscle)
- Dilatation (see below)

The free flap that is sometimes used to replace the larynx has no peristalsis, making swallowing even more difficult. After surgery in such cases the food descends to the stomach mostly by gravity. The time for the food to reach the stomach varies between individuals and ranges from 5 to 10 seconds.

Chewing the food well and mixing it with liquid in the mouth prior to swallowing is helpful, as is swallowing only small amounts of food each time, and waiting for it to go down. Drinking liquids between solid foods is helpful in flushing down the food. Eating takes longer; one must learn to be patient and take all the time needed to finish the meal.

The swelling immediately after surgery tends to decrease over time which reduces the narrowing of the esophagus and ultimately makes swallowing easier. This is good to remember because there is always hope that swallowing will improve within the first few months after surgery. However, if this does not occur dilatation of the esophagus is one therapeutic option.

## Dilatation of the esophagus

Narrowing of the esophagus is a very common consequence of laryngectomy; dilatation of the narrow esophagus is often needed to reopen it. The procedure usually needs to be repeated and the frequency of this procedure varies among individuals. In some people this is a lifelong requirement and in others the esophagus may stay open after a few dilatations. The procedure requires sedation or anesthesia because it is painful. A series of dilators with greater diameter are introduced into the esophagus to dilate it slowly. While the process breaks down the fibrosis, the condition may return after a while.

Sometimes a balloon rather than a long dilator is used to dilate a local stricture. Another method that may help is the use of topical and injectable steroids in the esophagus. Although dilation is done by an otolaryngologist or a gastroenterologist, in some cases it can be

accomplished by the patient at home. In difficult cases, surgery may be needed to remove the stricture or replace the narrow section with a graft.

Because dilation breaks down fibrosis, the pain generated by the procedure may last for a while. Taking pain medication can ease the discomfort. (See **Pain management**, page 101)

## Use of Botox®

Botox® is a pharmaceutical preparation of toxin A which is produced by *Clostridium botulinum*, an anaerobic bacteria that causes botulism, a muscle paralysis illness. The botulinum toxin causes partial paralysis of muscles by acting on their presynaptic cholinergic nerve fibers through the prevention of the release of acetylcholine at the neuromuscular junction. In small quantities it can be used to temporarily paralyze muscles for three to four months. It is used to control muscle spasms, excessive blinking, and for cosmetic treatment of wrinkles. Infrequent side effects are generalized muscle weakness and rarely even death. Botox® injection has become the treatment of choice for selected individuals to improve swallowing and tracheo-esophageal speech after laryngectomy.

For laryngectomees, injections of Botox® has been used to reduce the hypertonicity and spasm of the vibrating segment, resulting in an esophageal or trachea-esophageal voice that requires less effort to produce. However, it is only effective for overactive muscles and may require the injection of relatively large doses into the spastic muscles. It can also be used to relax muscle tightness in the lower jaw when one experiences difficulties in swallowing. It cannot help conditions that are not due to muscle spasms such as esophageal diverticula, strictures due to fibrosis after radiation, and scars and narrowing after surgery.

A constrictor muscle hypertonicity or pharyngoesophageal spasm (PES) is a common cause for tracheo-esophageal speech failure following laryngectomy. Constrictor muscle hypertonicity can increase

peak intra-esophageal pressure during speaking, thus interfering with fluent speech. It may also disturb swallowing by interfering with the pharyngeal transit of food and liquids.

Botox® injection can be carried out by otolaryngologists in the clinic. The injection can be done percutaneously or through an esophago-gastro-duodenoscope. The percutaneous injection into the pharyngeal constrictor muscles along one side of the newly formed pharynx (neopharynx) is done just above and to the side of the stoma.

An injection through an esophago-gastro-duodenoscope can be performed whenever a percutaneous injection is not feasible. This method is used in patients with severe post-radiation fibrosis, disruption of the cervical anatomy, and anxiety or inability to withstand a percutaneous injection. This method allows direct visualization and greater precision. The injection into the PES segment is often done by a gastroenterologist and is followed by gentle expansion by balloon massage to facilitate uniform distribution of the Botox®.

## Pharyngo-cutaneous fistula

A pharyngo-cutaneous fistula is an abnormal connection between the pharyngeal mucosa to the skin. Typically a salivary leak develops from the pharyngeal area to the skin, indicating a breakdown of the pharyngeal surgical suture line. It is the most common complication after laryngectomy and usually occurs seven to ten days after the operation. Previous radiation is a risk factor. Oral feeding is withheld until the fistula heals by itself or is surgically repaired.

The closure of the fistula can be evaluated by a “dye test” (such as ingestion of methylene blue which appears in the skin if the fistula is unobstructed) and/or by radiographic contrast studies.

## Smelling after laryngectomy

Laryngectomees may experience difficulties with their sense of smell. This is despite the fact that regular laryngectomy surgery does not involve nerves related to the sense of smell and the sense of smell, or olfaction, remains intact. What has changed, however, is the pathway of airflow during respiration. Before a laryngectomy, air flows into the lungs through the nose and mouth. This movement of air through the nose allows for scents and aromas to be detected as they come in contact with the nerve endings in the nose responsible for the sense of smell.

After a laryngectomy, however, there is no longer an active air flow through the nose. This can be perceived as a loss of smell. The “polite yawn technique” can help laryngectomees regain their capacity to smell. This method is known as the “polite yawn technique” because the movements involved are similar to those used when one attempts to yawn with a closed mouth. Swift, downward movement of the lower jaw and tongue, while keeping the lips closed, will create a subtle vacuum, drawing air into the nasal passages and enabling the detection of any scent through the new airflow. With practice, it is possible to achieve the same vacuum using more subtle (but effective) tongue movements.

## CHAPTER 12:

# Medical issues after radiation and surgery: pain management, cancer spread, hypothyroidism, and prevention of medical errors

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This section describes a variety of medical issues affecting laryngectomees.

**Hypertension** is discussed in page 28 and **Lymphedema** in page 37.

### Pain management

Many cancer patients and survivors complain of pain. Pain can be one of the important signs of cancer and may even lead to its diagnosis. Thus, it should not be ignored and should be a sign to seek medical care. The pain associated with cancer can vary in intensity and quality. It can be constant, intermittent, mild, moderate or severe. It can also be aching, dull, or sharp.

The pain can be caused by a tumor pressing or growing into and destroying nearby tissues. As the tumor increases in size, it may cause pain by putting pressure on nerves, bones or other structures. Cancer of the head and neck can also erode the mucosa and expose it to saliva

and mouth bacteria. Cancer that has spread or recurred is even more likely to cause pain.

Pain can result also from treatments for cancer. Chemotherapy, radiation and surgery are all potential sources of pain. Chemotherapy can cause diarrhea, mouth sores, and nerve damage. Radiation of the head and neck may cause painful and burning sensations to the skin and mouth, muscle stiffness and nerve damage. Surgery also can be painful, may leave deformities and/or scars that take time to improve.

Cancer pain can be treated by various methods. Eliminating the source of the pain through radiation, chemotherapy, or surgery is best, if possible. However, if not possible, other treatments include oral medication, nerve blocks, acupuncture, acupressure, massage, physical therapy, meditation, relaxation, and even humor. Specialists in pain management can offer these treatments.

Pain medication can be administered as a tablet, dissolvable tablet, intravenously, intramuscularly, rectally or through a skin patch. Medication includes: analgesics (e.g., aspirin, acetaminophen), nonsteroidal anti-inflammatory drugs (e.g., ibuprofen), weak (e.g., codeine) and strong (e.g., morphine, oxycodone, hydromorphone, fentanyl, methadone) opioids.

Sometimes patients do not receive adequate treatment for cancer pain. The reasons for this include doctors' reluctance to inquire about pain or offer treatments, patients' reluctance to speak about their pain, fear of addiction to medication, and fear of side effects.

Treating pain can both increase patients' well-being, as well as ease the hardship imposed on their caregivers. Patients should be encouraged to talk to their health care providers about their pain and seek treatment. Evaluation by a pain management specialist can be very helpful; all major cancer centers have pain management programs.

## Symptoms and signs of recurrent or new head and neck cancer

Most individuals with head and neck cancer receive medical and surgical treatment that removes and eradicates the cancer. However, there is always the possibility that the cancer may recur; vigilance is needed to detect recurrence or possibly new primary tumors. It is therefore very important to be aware of the signs of laryngeal and other types of head and neck cancer so that they can be detected at an early stage.

Signs and symptoms of head and neck cancer include:

- Bloody sputum
- Bleeding from the nose, throat, mouth
- Lumps on or outside the neck
- Lumps or white, red or dark patches inside the mouth
- Abnormal-sounding or difficult breathing
- Chronic cough
- Changes in voice (including hoarseness)
- Neck pain or swelling
- Difficulty in chewing, swallowing or moving the tongue
- Thickening of the cheek(s)



- Pain around the teeth, or loosening of the teeth
- A sore in the mouth that doesn't heal or increases in size
- Numbness of the tongue or elsewhere in the mouth
- Persistent mouth, throat or ear pain
- Bad breath
- Weight loss

Individuals with these symptoms should be examined by their otolaryngologists as soon as possible.

## Head and neck cancer spread

Laryngeal cancer like other head and neck cancers, can spread to the lungs and the liver. The risk of spread is higher in larger tumors and in tumors that had been recognized late. The greater risk of spread is in the first five years and especially in the first two years after the cancer appears. If the local lymph glands do not reveal cancer the risk is lower.

Individuals who had cancer at one time may be more likely to develop another type of malignancy not related to their head and neck cancer. As people age, they often develop other medical problems that require care, for example, hypertension and diabetes. It is therefore imperative to receive adequate nutrition, take care of one's dental (See **Dental issues**, page 117), physical and mental health, be under good medical care and be examined on a regular basis (See **Follow-up by family physician, internist and medical specialists**, Page 112). Of course, head and neck cancer survivors, like everyone else, need to watch for all types of cancers. These are relatively easy to diagnose by

regular examination and include breast, cervix, prostate, colon, and skin cancer.

## Low thyroid hormone (hypothyroidism) and its treatment

Most laryngectomees develop low levels of the thyroid hormone (hypothyroidism). This is due to the effects of radiation and the removal of part or all of the thyroid gland during laryngectomy surgery.

The symptoms of hypothyroidism vary; some individuals have no symptoms while others have dramatic or, rarely, life-threatening symptoms. The symptoms of hypothyroidism are nonspecific and mimic many normal changes of aging.

**General symptoms** — The thyroid hormone stimulates the body's metabolism. Most symptoms of hypothyroidism are due to the slowing of metabolic processes. Systemic symptoms include fatigue, sluggishness, weight gain, and intolerance to cold temperatures.

**Skin** — Decreased sweating, dry and thick skin, coarse or thin hair, disappearance of eyebrows, and brittle nails.

**Eyes** — Mild swelling around the eyes

**Cardiovascular system** — Slowing of the heart rate and weakening of the contractions, decreasing its overall function. These can cause fatigue and shortness of breath with exercise. Hypothyroidism can also cause mild hypertension and raise cholesterol levels.

**Respiratory system** — Respiratory muscles can weaken, and lung function can decrease. Symptoms include fatigue, shortness

of breath with exercise, and decreased ability to exercise. Hypothyroidism may lead to swelling of the tongue, hoarse voice, and sleep apnea (not in laryngectomees).

**Gastrointestinal system** — Slowing of the digestive tract actions, causing constipation

**Reproductive system** — Menstrual cycle irregularities, ranging from absent or infrequent periods to very frequent and heavy periods

Thyroid deficiency can be corrected by taking synthetic thyroid hormone (Thyroxine). This medicine should be taken on an empty stomach with a full glass of water thirty minutes before eating, preferably before breakfast or at a similar time of day. This is because food containing high fat (e.g., eggs, bacon, toast, hash brown potatoes, and milk) can decrease thyroxine absorption by forty percent.

Several formulations of synthetic thyroxine are available, but there has been considerable controversy if they are similar in efficacy. In 2004 the FDA approved a generic substitute for branded levothyroxine products. The American Thyroid Association, Endocrine Society, and the American Association of Clinical Endocrinologists objected to this decision, recommending that patients remain on the same brand. If patients must switch brands or use a generic substitute, serum thyroid stimulating hormone (TSH) should be checked six weeks later.

Because there may be subtle differences between synthetic thyroxine formulations, it is better to stay with one formulation when possible. If the preparation must be changed, follow-up monitoring of TSH and sometimes free thyroxine (T4) serum levels should be done to determine if dose adjustments are necessary.

After starting therapy, the patient should be reevaluated and serum TSH should be measured in three to six weeks, and the dose adjusted if needed. Symptoms of hypothyroidism generally begin to resolve after two to three weeks of replacement therapy and may take at least six weeks to dissipate.

A thyroxine dose can be increased in three weeks in those who continue to have symptoms and who have a high serum TSH concentration. It takes about six weeks before a steady hormone state is achieved after therapy is initiated or the dose is changed.

This process of increasing the dose of hormone every three to six weeks is continued, based upon periodic measurements of TSH until it returns to normal (from approximately 0.5 to 5.0 mU/L). Once this is achieved, periodic monitoring is needed.

After identification of the proper maintenance dose, the patient should be examined and serum TSH measured once a year (or more often if there is an abnormal result or a change in the patient's condition). Dose adjustment may be needed as patients age or have a weight change.

## Preventing medical and surgical errors

Medical and surgical mistakes are very common. They increase malpractice lawsuits, the cost of medical care, patients' hospital stays, and morbidity and mortality.

A manuscript describing my personal experiences facing medical and surgical errors in my care was published in Disabled-World.com at <http://www.disabled-world.com/disability/publications/neck-cancer-patient.php>

The best way of preventing errors is for the patient to be his or her own advocate or have a family member or friend serve as one's advocate.

Medical errors can be reduced by:

- Being informed and not hesitating to challenge and ask for explanations
- Becoming an "expert" in one's medical issues

- Having a family or friends remain in the hospital
- Getting a second opinion
- Educating medical providers about one's condition and needs (prior to and after surgery)

The occurrence of errors weakens patients trust in their health care providers. Admission and acceptance of responsibility by medical providers can bridge the gap between them and the patient and can reestablish lost confidence. When such a dialogue is established, more details about the circumstances leading to the mistake can be learned thus helping to prevent similar errors. Open discussion can assure patients that their providers are taking the matter seriously and that steps will be taken to make their hospital stays safer.

Not discussing mistakes with the patient and family increases their anxiety, frustration and anger, thus interfering with their recovery. And of course, such anger may also lead to malpractice suits.

Greater vigilance by the medical community can reduce errors. Obviously medical errors should be prevented as much as humanly possible; ignoring them can only lead to their repetition. Institutional policies should support and encourage healthcare professionals to disclose adverse events. Increased openness and honesty following adverse events can improve provider-patient relationships. There are important preventive steps that can be implemented by every institution and medical office. Educating the patient and their caregivers about the patient's condition and treatment plan is of utmost importance. Medical professionals can safeguard and prevent mistakes when they see deviations from the planned therapy.

These steps by the medical establishment can prevent medical errors:

- Implement better and uniform medical training

- Adhere to well established standards of care
- Perform regular records review to detect and correct medical errors
- Employ only well educated and trained medical staff
- Counsel, reprimand, and educate staff members who make errors and dismiss those who continue to err
- Develop and meticulously follow algorithms (specific sets of instructions for procedures), establish protocols and bedside checklists for all interventions
- Increase supervision and communication among health care providers
- Investigate all errors and take action to prevent them
- Educate and inform the patient and his/her caregivers about the patient's condition and treatment plans
- Have a family member and or friend serve as a patient advocate to ensure the appropriateness of the management
- Respond to patients' and family complaints, admit responsibility when appropriate, discuss these with the family and staff and take action to prevent the error(s)

## CHAPTER 13:

### **Preventive care: follow-up, avoiding smoking, and vaccination**

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Preventive medical and dental care is essential for patients with cancer. Many individuals with cancer neglect to attend to other important medical problems and focus exclusively on their cancer. Neglecting other medical issues can lead to serious consequences that may influence well-being and longevity.

The most important preventive measures for laryngectomees and head and neck cancer patients include:

- Proper dental care
- Routine examinations by family physician
- Routine follow-up by an otolaryngologist
- Appropriate vaccinations
- Stop smoking
- Using proper techniques (e.g., using sterile water for stoma irrigation)
- Maintaining adequate nutrition

Routine dental follow-up and dental preventive care are discussed in Chapter 14 (page 117).

Using proper techniques for stoma care is presented in Chapter 8 (page 59).

Adequate nutrition is discussed in Chapter 11 (page 85).

## **Follow-up by family physician, internist and medical specialists**

Continual medical follow-up by specialists, including the otolaryngologist, radiation oncologist (for those who got radiation treatment), and oncologist (for those who received chemotherapy), is crucial. As time passes from the initial diagnosis, treatment and surgery, follow-up occurs with less frequency. Most otolaryngologists recommend monthly follow-up examination in the first year after diagnosis and or surgery and less often afterwards, depending on the patient's condition. Patients should be encouraged to contact their physician whenever new symptoms arise.

Regular checkups ensure that any changes in health are noted and that whenever a new problem emerges it is addressed and treated. The clinician will perform a careful examination to detect cancer recurrence. Checkups include a general examination of the entire body and specific examination of the neck, throat and stoma. Examination of the upper airway is performed using an endoscope or indirect visualization with a small, long-handled mirror to check for abnormal areas. Radiological and other studies may also be performed as needed.

It is also very important to be followed by an internist or family physician, as well as dentist, to address other medical and dental issues.

## **Influenza vaccination**

It is important for laryngectomees to be vaccinated for influenza regardless of age. Influenza can be more difficult to manage and vaccination is an important preventive tool.

There are two types of influenza vaccine: an injection one that is adequate for all ages and an inhalation one (live virus) only given to individuals younger than fifty years who are not immune-compromised.

Available vaccines include:

1. The "flu shot" - an inactivated vaccine (containing killed virus) given by a needle, usually in the arm. The flu shot is approved for persons older than six months, including healthy individuals and those with chronic medical conditions.
2. The nasal-spray flu vaccine - a vaccine made with live, weakened flu viruses that do not cause the flu (sometimes called LAIV for "live attenuated influenza vaccine" or FluMist®). LAIV is approved for use in healthy individuals ages 2-49 years (with the exception of pregnant women).

A new vaccine for influenza is prepared for every new season. While the exact strains that cause influenza are unpredictable, it is likely that strains that caused the illness at other parts of the world will also cause illness in the U.S. It is best to consult one's physician prior to vaccination to ensure that there is no reason why one should not be vaccinated (such as egg allergy).

The best way to diagnose Influenza is a rapid test of nasal secretions by one of the diagnostic kits. Because laryngectomees have no connection between the nose and the lungs, it is advisable to test nasal secretions in addition to tracheal sputum (using a kit that was approved for sputum testing).

Information about these tests can be found in the Center of Disease Control website (<http://www.cdc.gov/flu/professionals/diagnosis/rapidlab.htm>).

One “advantage” of being a laryngecomee is that one generally gets fewer infections caused by respiratory tract viruses. This is because “cold” viruses generally first infect the nose and throat; from there they travel to the rest of the body, including the lungs. Because laryngectomees do not breathe through their noses, cold viruses are less likely to infect them.

It is still important for laryngectomees to receive yearly immunization for influenza viruses, to wear a Heat and Moisture Exchanger (HME) device to filter the air that gets into the lungs, and to wash their hands well before touching the stoma or the HME or before eating. The Atos (Provox) Micron HME with electrostatic filter is designed to filtrate potential pathogens and to reduce susceptibility to respiratory infections.

The influenza virus is capable of spreading by touching objects. Laryngectomees who use a voice prosthesis and need to press their HME to speak may be at increased risk of introducing the virus directly to their lungs. Washing hands or using a skin cleanser can prevent the spread of the virus.

## Vaccination against the pneumococcal bacteria

It is advisable that laryngectomees and other neck breathers get vaccinated against the pneumococcus bacteria which is one of the major causes of pneumonia. In the United States there are two types of vaccines against the pneumococcal bacteria: the pneumococcal conjugate vaccine (Prevnar 13 or PCV13) and the pneumococcal polysaccharide vaccine - a 23-valent pneumococcal polysaccharide vaccine (Pneumovax or PPV23).

One should consult their physician about receiving the pneumococcal vaccination.

The Center for Disease Control publishes the current guidelines at: <http://www.cdc.gov/vaccines/>

## Avoiding smoking and alcohol

Individuals with head and neck cancer should receive counseling about the importance of smoking cessation. In addition to smoking being a major risk factor for head and neck cancer, the risk of cancer is further enhanced by alcohol consumption. Smoking can also influence cancer prognosis. Patients with laryngeal cancer who continue to smoke and drink are less likely to be cured and are more likely to develop a second tumor. When smoking is continued both during and after radiation therapy, it can increase the severity and duration of mucosal reactions, worsen the dry mouth (xerostomia), and compromise the patient outcome.

Smoking tobacco and drinking alcohol also decrease the effectiveness of treatment for laryngeal cancer. Patients who continue to smoke while receiving radiation therapy have a lower long-term survival rate than those who do not smoke.

## CHAPTER 14:

# Dental Issues and hyperbaric oxygen therapy

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Dental issues can be challenging for laryngectomees, mainly because of the long term effects of radiation therapy. Maintenance of good dental hygiene can prevent many problems.

## Dental Issues

Dental problems are common after exposure of the head and neck to radiation therapy.

Radiation affects include:

- Reduced blood supply to the maxillary and mandibular bones
- Reduced production and changes in the chemical composition of saliva
- Changes in the bacteria that colonize the mouth

Because of these changes dental caries, soreness, and gingival and periodontal inflammation can be particularly problematic. These can be lessened by good mouth and teeth care, i.e., by cleaning, flushing,

and using fluorinated toothpaste after each meal when possible. Using a special fluorinated preparation with which to gargle or apply on the gum helps in preventing dental carries. Keeping well hydrated and using saliva substitute when needed are also important.

It is advisable that patients receiving radiation therapy to the head and neck visit their dentist for a thorough oral examination several weeks prior to initiation of the treatment and be examined on a regular annual or semiannual basis throughout life. Getting regular dental cleaning is also important.

Because radiation treatment alters the blood supply to the maxillary and mandibular bones patients may be at risk of developing bone necrosis (**osteoradionecrosis**) at those sites. Tooth extraction and dental disease in irradiated areas can lead to the development of osteoradionecrosis. Patients should inform their dentist about their radiation treatment prior to these procedures. Osteoradionecrosis may be prevented by administration of a series of hyperbaric oxygen therapy (see below) before and after extraction or dental surgery. This is recommended if the involved tooth is in an area that had been exposed to a high dose of radiation. Consulting the radiation oncologist who delivered the radiation treatment can be helpful in determining if this is necessary.

**Dental prophylaxis** can reduce the risk of dental problems leading to bone necrosis. Special fluoride treatments may help to prevent dental problems, along with brushing, flossing, and having one's teeth cleaned regularly.

A home care dental lifelong routine is recommended:

- Flossing each tooth and brushing with toothpaste after each meal
- Brushing the tongue with a tongue brush or a soft bristled toothbrush once a day

- Rinsing with a baking soda rinse daily. Baking soda helps neutralize the mouth. The rinse is made of one teaspoon of baking soda added to 12 oz. of water. The baking soda rinse can be used throughout the day.
- Using fluoride in fluoride carriers once a day. These are commercially available and are also custom made by dentists. They are applied over the teeth for ten minutes. One should not rinse, drink, or eat for thirty minutes after fluoride application.

**Stomach acid reflux** is also very common after head and neck surgery, especially in individuals who have had partial or complete laryngectomy (see **Symptoms and treatment of stomach acid reflux**, page 89). This can also cause dental erosion (especially of the lower jaw) and, ultimately teeth loss.

These ill effects can be reduced by:

- Taking acid reducing medication
- Eating small amounts of food and liquid each time
- Not lying down right after eating
- When lying down, elevate the upper part of body with a pillow to 45 degrees

## Hyperbaric oxygen therapy

Hyperbaric oxygen (HBO) therapy involves breathing pure oxygen in a pressurized room. HBO therapy is a well-established treatment for decompression sickness (a hazard of scuba diving) and can be used to prevent osteoradionecrosis.



HBO is used to treat a wide range of medical conditions including bubbles of air in the blood vessels (arterial gas embolism), decompression sickness, carbon monoxide poisoning, a wound that won't heal, a crush injury, gangrene, skin or bone infection causing tissue death (such as osteoradionecrosis), radiation injuries, burns, skin grafts or skin flaps at risk of tissue death, and severe anemia.

In an HBO therapy chamber, the air pressure is raised up to three times higher than normal air pressure. Under these conditions, the lungs can gather much more oxygen than is possible when breathing pure oxygen at normal air pressure.

The blood carries this oxygen throughout the body, stimulating the release of chemicals called “growth factors” and stem cells that promote healing. When tissue is injured, it requires even more oxygen to survive. HBO therapy increases the amount of oxygen in the blood and can temporarily restore normal levels of blood gases and tissue function. These promote healing and the ability of the tissues to fight infection.

HBO therapy is generally safe and complications are rare. These can include: temporary nearsightedness (myopia), middle ear and inner ear injuries (including leaking fluid and eardrum rupture due to increased air pressure), organ damage caused by air pressure changes (barotrauma), and seizures as a result of oxygen toxicity.

Pure oxygen can cause a fire if there is a source of ignition, such as a spark or flame. It is therefore forbidden to take items that could ignite a fire (e.g., lighters or battery powered devices) into the HBO therapy room.

HBO therapy can be performed as an outpatient procedure and does not require hospitalization. Hospitalized patients may need to be transported to and from the HBO therapy site if it is an outside facility.

Treatment can be performed in one of two settings:

- **A unit designed for one person** in an individual (monoplace) unit, while the patient lies down on a padded table that slides into a clear plastic tube.

- **A chamber designed to accommodate several people** in a multiperson HBO room where the patient may sit or lie down. A hood or mask delivers the oxygen.

During HBO therapy the increased air pressure creates a temporary feeling of fullness in the ears - similar to being in an airplane or at high altitude - that can be relieved by yawning.

A therapy session may last from one to two hours. Members of the health care team monitor the patient throughout the session. Following therapy, the patient may feel lightheaded for a few minutes.

To be effective, HBO therapy requires more than one session. The number of sessions required depends on the medical condition. Some conditions, such as carbon monoxide poisoning, can be treated in as few as three visits. Others, such as osteoradionecrosis or non-healing wounds, and may require 25 to 30 treatments.

HBO therapy alone can often effectively treat decompression sickness, arterial gas embolism and severe carbon monoxide poisoning. To effectively treat other conditions, HBO is used as part of a comprehensive treatment plan and is administered in conjunction with additional therapies and medications that fit one's individual needs.

## CHAPTER 15:

### **Psychological issues: depression, suicide, uncertainty, sharing the diagnosis, the care giver, and source of support**

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Head and neck cancer survivors, including laryngectomees face many psychological, social and personal challenges. This is mainly because head and neck cancer and its treatment affect some of the most basic human functions --breathing, eating, communication, and social interaction. Understanding and treating these issues are no less important than dealing with medical concerns.

Individuals diagnosed with cancer experience numerous feelings and emotions which can change from day to day, hour to hour, or even minute to minute and can generate a heavy psychological burden.

Some of these feelings include:

- Denial
- Anger
- Fear
- Stress

- Anxiety
- Depression
- Sadness
- Guilt
- Loneliness

Some of the psychological and social challenges faced by laryngectomees include:

- Depression
- Anxiety and fear of recurrence
- Social isolation
- Substance abuse
- Body image
- Sexuality
- Return to work
- Interaction with spouse, family, friends, co-workers
- Economic impact

## Coping with depression

Many people with cancer feel sad or depressed. This is a normal response to any serious illness. Depression is one of the most difficult issues faced by a patient diagnosed with cancer. Yet, the social stigma associated with admitting depression makes it difficult to reach out and seek therapy.

Some of the signs of depression include:

- A feeling of helplessness and hopelessness, or that life has no meaning
- No interest in being with family or friends
- No interest in hobbies and activities one used to enjoy
- A loss of appetite, or no interest in food
- Crying for long periods of time, or many times each day
- Sleep problems, either sleeping too much or too little
- Changes in energy level
- Thoughts of suicide, including making plans or taking action to kill oneself, as well as frequently thinking about death and dying

The challenges of life as a laryngectomee in the shadow of cancer mean that it is even more difficult to deal with depression. Being unable to speak, or even having difficulty with speaking, make it harder to express emotions and can lead to isolation. Surgical and medical care

is often not sufficient to address such issues; more emphasis should be given to mental well-being after laryngectomy.

Coping with and overcoming depression are very important, not only for the well-being of the patient, but also may facilitate recovery, increase one's chance for longer survival and ultimate cure. There is growing scientific evidence of a connection between mind and body. Although many of these connections are not yet understood, it is well recognized that individuals who are motivated to get better and exhibit a positive attitude recover faster from serious illnesses, live longer, and sometimes survive immense odds. Indeed, it has been shown that this effect may be mediated by alterations in the cellular immune responses and a decrease in natural killer cell activity.

There are, of course, many reasons to feel depressed after learning one's cancer diagnosis and living with it. It is a devastating illness for patients and their families, even more so because medicine has not yet found a cure for most types of cancer. By the time the disease has been discovered, it is too late for prevention and, if the cancer has been discovered at an advanced stage, the risk of dissemination is high and the chance of ultimate cure significantly decreased.

Many emotions run through the patient's mind after learning the bad news. "Why me?" and "Can it be true?" Depression is part of the normal mechanism of coping with adversity. Most people go through several stages in coping with a difficult new situation such as becoming a laryngectomee. At first one undergoes denial and isolation, then anger, followed by depression, and finally, there is acceptance.

Some people get "stuck" at a certain stage such as depression or anger. It is important to move on and get to the final stage of acceptance and hope. This is why professional help as well as understanding and assistance by family and friends are very important.

Patients have to face their ultimate mortality, sometimes for the first time in their life. They are forced to deal with the illness and its immediate and long term consequences. Paradoxically, feeling depressed after learning about the diagnosis allows the patient to accept the new reality. Not caring any more makes it easier to live with

an uncertain future. Yet, while thinking that "I do not care anymore" may make it temporary easier, such a coping mechanism may interfere with seeking appropriate care and can lead to a rapid decline in one's quality of life.

## Overcoming depression

Hopefully a patient can find the strength to fight depression. Immediately after a laryngectomy individuals may be overwhelmed by new daily tasks and realities. They often experience a mourning period for their many losses, which include their voice and their prime state of health. They also have to accept many permanent deficits including not being able to speak "normally". Some may feel that they have a choice between succumbing to a creeping depression or becoming proactive and returning to life. A desire to get better and overcome a handicap can be the driving force to reversing the downhill trend. Depression may recur; requiring a continuous struggle to overcome it.

Some of the ways laryngectomees and head and neck cancer patients can cope with depression include:

- Avoid substance abuse
- Seek help
- Exclude medical causes (e.g., hypothyroidism, side effects of medication)
- Determine to become proactive
- Minimize stress
- Set an example for others

- Return to previous activities
- Consider antidepressant medication
- Seek support from family, friends, professional, colleagues, fellow laryngectomees, and support groups

These are some of the ways of renewing one's spirit:

- Develop leisure activities
- Build personal relationships
- Keep physically fit and active
- Social reintegration with family and friends
- Volunteer
- Find purposeful projects
- Rest

Support by family members and friends is very important. The continuous involvement and contribution to others' lives can be invigorating. One can draw strength from enjoying, interacting and impacting the lives of their children and grandchildren. Setting an example to one's children and grandchildren not to give up in the face of adversity can be the driving force to be proactive and resist depression.

Getting involved in activities one liked before the surgery can provide a continuous purpose for life. Participating in the activities of a local laryngectomee club can be a new source of support, advice and friendship.

Seeking the help of a mental health professional such as a social worker, psychologist or psychiatrist can also be helpful. Having a caring and competent physician and a speech and language pathologist who can provide continuous follow-up is very important. Their involvement can help patients deal with emerging medical and speech problems and can contribute to their sense of well being.

## Suicide among head and neck cancer patients

The suicide rate in cancer patients is twice of that of the general population according to recent studies. These studies clearly point to the urgent need to recognize and treat psychiatric problems like depression and suicidal ideation in patients.

Most studies have found high incidence of depressive mood disorders associated with suicide among cancer patients. In addition to major and minor depressive disorders, there is also a high rate of less severe depression in elderly cancer patients which is sometimes not recognized and often undertreated. Many studies have shown that in about half of all suicides among people with cancer, major depression was present. Other important contributory factors include anxiety, affective disorder, pain, lack of social support systems, and demoralization.

The relative increase in suicide risk is highest in the first five years after cancer diagnosis and declines gradually after that. However, the risk remains elevated for fifteen years after a cancer diagnosis. Higher suicide rates among patients with cancer are associated with being male, white, or unmarried. Among men, higher suicide rates are noted with increasing age at diagnosis. Suicide rates are also higher among patients with advanced disease at diagnosis.

Suicide rates varied by type of cancer: The highest rates are among patients with cancers of the lung and bronchus, stomach, and head and neck, including the oral cavity, pharynx, and larynx. A high prevalence of depression or distress is found among patients with these types of

cancers. The high rate of depression in head and neck cancer may be explained by the devastating influence of the illness on one's quality of life. This is because it affects appearance and essential functions such as speaking, swallowing, and breathing.

Screening cancer patients for depression, hopelessness, distress, severe pain, coping problems, and suicidal ideation is a useful way to identify those at risk. Counseling and referral to mental health specialists when appropriate may prevent suicide in at-risk cancer patients. This approach also involves speaking with patients at heightened risk for suicide (and their families) about reducing their access to the most common methods used to commit suicide.

### **Coping with uncertain future**

Once one has been diagnosed with cancer and even after successful treatment, it is difficult and close to impossible to completely free oneself from the fear that it may return. Some people are better than others in living with this uncertainty; those who adjust well end up being happier and are more able to go on with their lives than those who do not.

What makes predicting the future difficult is that the scans used to detect cancer (positron emission tomography or PET, computed tomography or CT, and magnetic resonance imaging or MRI) generally only detect cancer that is larger than one inch; physicians may miss a small lesion located at a site that is difficult to visualize.

Patients have therefore to accept the reality that the cancer may return and that physical examination and vigilance are the best ways of monitoring their condition.

What often helps with coping with a new symptom (unless it is urgent) is to wait a few days before seeking medical assistance. In general the majority of new symptoms will go away within a short period. Over time, most people learn not to panic and to use past

experience, common sense and their knowledge to rationalize and understand their symptoms.

Hopefully, over time, one gets better in coping with an uncertain future and learns to accept it and live with it, striking a balance between fear and acceptance.

Some suggestions of ways one can cope with the uncertain future include:

- Separating oneself from the illness
- Focusing on interests other than cancer
- Developing a life style that avoids stress and promotes inner peace
- Continuing with regular medical check-ups

### **Sharing the diagnosis with others**

After being diagnosed with cancer one has to decide whether to share the information with others or keep it private. Individuals may choose to keep the information private out of fear of stigmatization, rejection or discrimination. Some do not want to show vulnerability and weakness or feel that they are pitied by others. Acknowledged or not, sick people – especially those with a potentially terminal illness – are less able to be competitive in society and are often intentionally or unintentionally discriminated against. Some may fear that otherwise compassionate friends and acquaintances may distance themselves in order to be protected from a perceived inevitable loss - - or simply because they do not know what to say or how to behave.

Keeping the diagnosis private can create emotional isolation and burdens as one faces the new reality without support. Some may share

the diagnosis only with a limited number of people to spare others from the emotional trauma. Of course asking people to keep this often devastating information private deprives them from receiving their own emotional support and assistance.

Sharing the information with family and friends may be difficult and is best presented in a way that suits the individual's coping abilities. It is best to communicate one on one and to allow each person to ask questions and express their feeling, fears and concerns. Delivering the news in an optimistic fashion, highlighting the potential for recovery, can make it easier. Telling young children can be challenging and is best done according to their abilities to digest the information.

Following surgery and especially after a laryngectomy, it is no longer possible to hide the diagnosis. Most people do not regret sharing their diagnosis with others. They generally discover that their friends do not abandon them and they receive support and encouragement which helps them through difficult times. By "getting out of the closet" and sharing their diagnosis, survivors are making a statement that they do not feel ashamed or weak because of their illness.

Laryngectomees are a small group among cancer survivors. Yet they are in a unique position because they bear their diagnoses on their neck and through their voice. They cannot hide the fact that they breathe through their stomas and speak with weak and sometimes mechanical voices. Yet their survivorship is a testament that a productive and meaningful life is possible even after being diagnosed with cancer.

## Caring for a loved one with cancer

Being a caregiver for a loved one with a serious illness such as head and neck cancer is very difficult and can be physically and emotionally taxing. It can be extremely hard to watch the person suffer, especially if there is little that they can do to reverse the illness. Caregivers should, however, realize the importance of what they are doing even when they get no or little appreciation.

Caregivers often fear the potential death of their loved one and life without them. This can be very anxiety provoking and depressing. Some cope by refusing to accept the diagnosis of cancer and believe that their loved ones illness is less serious in nature.

Caregivers often sacrifice their own well being and needs to accommodate those of the person they care for. They often have to calm their loved one's fears and support them despite often being the target of vented anger, frustration and anxieties. These frustrations may be exaggerated in those with head and neck cancer who often have difficulty expressing themselves verbally. Caregivers frequently suppress their own feelings and hide their own emotions to prevent upsetting the sick person. This is very taxing and difficult.

It is useful for the patient and their caregivers to openly and honestly talk to each other share their feelings, worries, and aspirations. This may be more challenging to those with difficulty speaking. Jointly meeting health care providers allows for better communication and facilitates shared decision making.

Unfortunately, the well-being of caregivers is frequently ignored, as all the attention is focused on the sick individual. It is essential, however, that the needs of the caregiver are not ignored. Receiving physical and emotional support through friends, family, support groups, and mental health professionals can be very helpful to the caregiver. Professional counseling can be on an individual or support group basis, or joint with other family members and/or the patient. Caregivers should find time for themselves to "recharge" their own batteries. Having time dedicated to their own needs can help caregivers continue to be a source of support and strength to their loved ones. There are organizations available to aid with respite care.

## Sources of social and emotional support

Learning that one has laryngeal or any head and neck cancer can change the individual's life and the lives of those close to them. These

changes can be difficult to handle. Seeking help to better cope with the psychological and social impact of the diagnosis is very important.

The emotional burden includes concerns about treatment and its side effects, hospital stays, and the economical impact of the illness including how to deal with medical bills. Additional worries are directed to caring for one's family, keeping one's work, and continuing one's daily activities.

Reaching out to other laryngectomees and head and neck cancer support groups can be helpful. Hospital and home visits by fellow survivors can provide support and advice and can facilitate recovery. Fellow laryngectomees and head and neck cancer survivors frequently can provide guidance and set an example for successful recovery and the ability to return to a full and rewarding life.

Sources for support include:

- Members of the health care team (physicians, nurses, and speech and language pathologists) can answer and clarify questions about treatment, work, or other activities.
- Social workers, counselors, or members of the clergy can be helpful if one wishes to share one's feelings or concerns. Social workers can suggest resources for financial aid, transportation, home care, and emotional support.
- Support groups for laryngectomees and other individuals with head and neck cancer, can share with patients and their family members what they have learned about coping with cancer. Groups may offer support in person, over the telephone, or on the Internet. Members of the health care team may be able to help in finding support groups.

The International Association of Laryngectomees website provides a list of the local laryngectomee clubs in the US and internationally at <http://www.theial.com/ial/>

A complete list of potential resources and support groups can be found at the Addendum (page 159).

### **Some “benefits” being a laryngectomee**

There are also few “benefits” being a laryngectomee, including:

- No more snoring
- Excuse for not wearing a tie
- Not smelling offensive or irritating odors
- Experiencing fewer colds
- Low risk of aspiration into the lungs
- Easier to intubate through the stoma in an emergency



## CHAPTER 16:

### **Use of CT, MRI and PET scans in the diagnosis and follow-up of cancer**

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Computed Tomography (CT), Magnetic resonance imaging (MRI), and Positron Emission Tomography (PET) scans are non-invasive medical imaging procedures that enable the visualization of internal body structures. They are also used to detect cancer and follow up its progression and response to therapy.

MRI can be used for cancer diagnosis, staging, and treatment planning. The main component of most MRI systems is a large tube-shaped or cylindrical magnet. Using non-ionizing radiofrequency waves, powerful magnets, and a computer, this technology produces detailed, cross-sectional pictures of the inside of the body. In some cases, contrast dyes are used to illuminate certain structures in the body. These dyes may be injected directly into the bloodstream with a needle and syringe or they may be swallowed, depending on the area of the body being studied. With MRI, it is possible to distinguish between normal and diseased tissue and precisely pinpoint tumors within the body. It is also useful in detecting metastases.

Additionally, the MRI provides greater contrast between the different soft tissues of the body than a CT scan. Thus, it is especially useful for imaging the brain, spine, connective tissue, muscles, and the inside of bones. To perform the scan the patient lies within a large device that creates magnetic field that aligns the magnetization of atomic nuclei in the body.

MRI tests are painless. Some patients report feelings of mild to severe anxiety and/or restlessness during the test. A mild sedative can be given before the test to those who are claustrophobic or find it difficult to lie still for long periods of time. MRI machines produce loud banging, thumping, and humming sounds. Wearing earplugs can reduce the effect of noise.

CT is a medical imaging procedure that utilizes computer-processed X-rays to generate tomographic images or 'cuts' of specific areas of the patient's body. These cross-sectional images are used for diagnostic and therapeutic purposes in many medical disciplines. Digital geometry computerized processing is utilized to generate a three-dimensional image of the inside of a body site or organ from a large number of two-dimensional X-ray images taken around a single axis of rotation. Contrast dyes can be used to illuminate certain structures in the body.

PET scan is a nuclear medicine imaging test that creates a three-dimensional image or picture of the functional metabolic processes in the body. It uses a radioactive substance called a "tracer" that is administered through a vein to look for disease in the body. The tracer travels through the blood and collects in organs and tissues with high metabolic activity. A single PET scan can accurately image the cellular function of the entire human body.

Since a PET scan detects increased metabolic activity of any cause, such as cancer, infection, or inflammation, it is not specific enough and therefore cannot differentiate between them. This can lead to equivocal interpretation of the results and may create uncertainty that can lead to further tests which may not be needed. In addition to the financial burden this can cause, it may generate anxiety and frustration.

It is also important to realize that these tests are not perfect and can miss a small tumor (less than one inch). A thorough physical examination should also accompany any scanning.

PET and CT scans are often done in the same session and are performed by the same machine. While the PET scan demonstrates the biological function of the body, the CT scan provides information

with respect to the location of any increased metabolic activity. By combining these two scanning technologies, a physician can more accurately diagnose and identify existing cancer.

The general recommendation is to perform fewer PET/CT scans the longer the elapsed time from the surgery that removed the cancer. Generally, PET/CT is performed every three to six months during the first year, then every six months during the second and then yearly throughout life. These recommendation, however, are not based on studies and are merely the opinion or consensus among the specialists. More scans are performed if there are concerns or suspicious findings. However, when scheduling a PET and/or CT scan, any potential benefit gained by the information should be weighed against any potential deleterious effects of exposure to ionizing radiation and or X-rays.

Sometimes physicians do not need a PET scan and only request a CT dedicated to the area in question. Such a CT is more precise compared to a combined PET/CT, the former can also include the injection of contrast material to assist in the diagnosis of the problem.

On occasion CT is not helpful, especially in those who had extensive dental work, including fillings, crowns or implants, that can interfere with the interpretation of data. Not performing a CT spares the patient from receiving a substantial amount of radiation. Instead, an MRI of the area can be done.

When viewing the scans, the radiologists compare the new scan(s) with the old one(s) to determine if there have been any changes. This can be useful in determining if there is new pathology.

## CHAPTER 17:

# **Urgent care, cardiopulmonary resuscitation (CPR), and care of laryngectomees during anesthesia**

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## **Rescue breathing for laryngectomees and other neck breathers**

Laryngectomees and other neck breathers are at great risk of receiving inadequate acute care when they experience breathing difficulties or when they need cardiopulmonary resuscitation (CPR). Emergency departments (EDs) and emergency medical response services (EMS) personnel often do not recognize a patient who is a neck breather, do not know how to administer oxygen in the proper way, and may erroneously give mouth-to-mouth ventilation when mouth-to-stoma ventilation is indicated. This can lead to devastating consequences, depriving sick people from the oxygen needed to survive.

Many medical personnel are not familiar with the care of laryngectomees because a laryngectomy is a relatively rare procedure. Currently laryngeal cancers are detected and treated early. A total laryngectomy is generally indicated only for large tumors or for tumors that recur after previous treatment. There are currently only about 60,000 individuals who have undergone this procedure in the United States. As a result, acute care health providers have less contact than ever with laryngectomees.

This section describes the special needs of laryngectomees and other neck breathers, explains the anatomical changes after laryngectomy, outlines how laryngectomees speak and how to recognize them, explains how to distinguish between total and partial neck breathers, and describes the procedures and equipment used in rescue breathing for total and partial neck breathers.

**Causes of sudden respiratory distress in laryngectomees.** The most common indication for a laryngectomy is cancer of the head and neck. Many laryngectomees also suffer from other medical problems resulting from their malignancy and its treatment which often includes radiation, surgery and chemotherapy. Laryngectomees also have difficulties in speaking and must therefore use various methods to communicate.

The most common cause of sudden breathing difficulty in laryngectomees is airway blockage due to aspiration of a foreign body or a mucus plug. Laryngectomees may also suffer from other medical conditions including heart, lung and vascular problems that are often age related.

**Total laryngectomy.** The anatomy of laryngectomees is different from the anatomy of those who have not undergone this procedure. After a total laryngectomy, the patient breathes through a stoma (an opening in the neck for the trachea). There is no longer a connection between the trachea and the mouth and nose. (Figure 1) Laryngectomees may be difficult to recognize because many cover their stomas, with foam covers, ascots, or other garments. Many also apply a heat and moisture exchanger (HME) or a hands free device (See **Chapter 9**, page 65 and page 69) over their stoma.

**Communication methods used by laryngectomees.** Laryngectomees use a variety of methods of communication (See **Chapter 6**, page 43), including writing, silent articulation, sign language and three speech

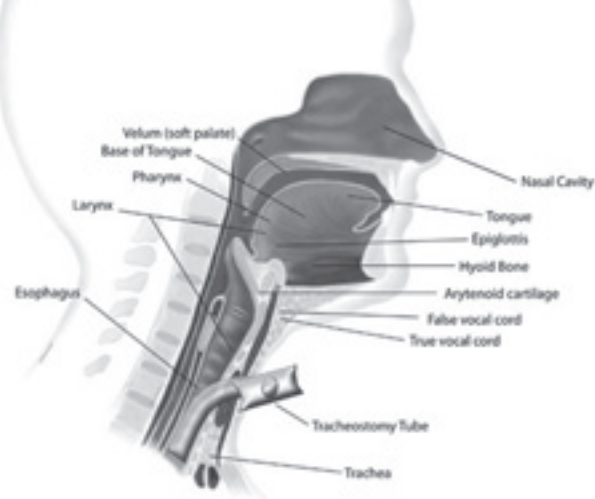
methods. These methods are esophageal speech, voice prosthesis via a tracheo-esophageal puncture (TEP), and electronic larynx (artificial larynx device) speech. Each of these methods substitutes the vibration generated by the vocal cords with another source while the actual formation of words is performed by the tongue and lips.

**Differentiation between partial neck breathers and total neck breathers.** It is important for medical personnel to differentiate partial neck breathers from total neck breathers (laryngectomees) because the management of each group is different. The trachea is not connected to the upper airway in neck breathers and all breathing is done through the tracheostomy site. In contrast, although a tracheostomy site is present in partial neck breathers, there is still a connection between the trachea and the upper airway (Figure 5). Although partial neck breathers breathe mainly through their stomas, they are also able to breathe through their mouth and nose. The extent of breathing through the upper airway in these individuals varies.

Many partial neck breathers breathe through a tracheostomy tube, which may be protruding from the stoma and is often strapped to the neck. Failure to recognize a partial neck breather may lead to inappropriate treatment.

**Partial Neck Breather**

(Ventilate through stoma and occlude nose and mouth)

**Figure 5: Anatomy of partial neck breather**

**Preparing for rescue breathing.** The steps to rescue a neck breather are:

1. Determine the patient's unresponsiveness
2. Activate the emergency medical services
3. Position the person by raising their shoulders
4. Expose the neck and remove anything covering the stoma such as filter or cloth, that may prevent access to the airway
5. Secure the airway in the stoma and remove anything blocking the airway such as the filter or HME
6. Clear any mucus from the stoma

It is not necessary to remove the stoma's housing unless it blocks the airway. Laryngectomy tubes or stoma buttons may be carefully removed. The voice prosthesis should not be removed, unless it is blocking the airway, since it generally does not interfere with breathing or suctioning. If the prosthesis is dislodged it should be removed and replaced with a catheter to prevent aspiration and fistula closure. If present, the tracheal tube may need to be suctioned after insertion of 2-5 cc of sterile saline or be entirely removed (both outer and inner parts) to clear any mucus plugs. The stoma should be wiped and suctioned. The next step is to listen for breathing sounds over the stoma. If the tracheostomy tube is blocked the chest may fail to rise.

If a tracheostomy tube is used for resuscitation it should be shorter than the regular one so that it can fit the length of the trachea. Care should be used in inserting the tube so that it does not dislodge the voice prosthesis. This may require the use of a tube with a smaller diameter.

If the patient is breathing normally he/she should be treated like any unconscious patient. If prolonged administration of oxygen is required, it should be humidified.

It may be difficult to detect a carotid artery pulse in the neck of some laryngectomees because of post radiation fibrosis. Some patients may not have a radial artery pulse in one of their arms if tissue from that arm was used for a free flap to reconstruct the upper airway.

**Ventilation of total neck breathers.** CPR for neck breathers is generally similar to the one performed on normal individuals with one major exception. Neck breathers are administered ventilation and oxygen through their stoma. This can be done by a mouth-to-stoma ventilation or by using an oxygen mask (infant/toddler mask or an adult mask turned 90°) (Pictures 4 and 5). It is useless to try to perform mouth-to-mouth ventilation.



Picture 4: Oxygen mask



Picture 5: Infant bag valve mask used in rescue breathing

**Ventilation of partial neck breathers.** Although partial neck breathers inhale and exhale mainly through their stomas, they still have a connection between their lungs and their noses and mouths. Therefore, air can escape from their mouths and/or noses, thus reducing the efficacy of ventilation. Even though partial neck breathers also receive ventilation through their stomas, their mouths should be kept closed and their noses sealed to prevent air from escaping. This can be done by holding the patient's mouth and nose tightly closed.

**In conclusion:** Emergency department and EMS personnel should be vigilant in recognizing those who do not breathe through the mouth and nose. The knowledge of health care providers in communities may vary. Many health care providers are not familiar with the care of neck breathers although this is taught at CPR courses. It is essential that medical personnel learn to identify neck breathers and differentiate partial neck breathers from total neck breathers. Proper administration of oxygen and ventilation through the stoma and specific details of CPR to neck breathers should be practiced periodically. The medical and EMS community should maintain their knowledge about the proper treatment of neck breathers so that effective care of these individuals is provided in urgent circumstances.

Respiratory problems unique to neck breathers include mucus plugs, and foreign body aspiration. Although partial neck breathers inhale and exhale mainly through their stomas they still have a connection between their lungs, their noses, and their mouths. In contrast, there is no such connection in total neck breathers. Both partial and total neck breathers should be ventilated through their tracheostomy sites. However, the mouth needs to be closed and the nose sealed in partial neck breathers to prevent the escape of air. An infant or toddler bag valve mask should be used in ventilating through the stoma.

### Ensuring adequate urgent care of neck breathers including laryngectomees

Neck breathers are at a high risk of receiving inadequate therapy when seeking urgent medical care because of shortness of breath.

Neck breathers can prevent a mishap by:

1. Wearing a bracelet that identifies them as neck breathers

2. Carrying a list describing their medical conditions, their medication, the names of their doctors, and their contact information
3. Placing a sticker on the inside of their car windows identifying them as laryngectomees. The card contains information about caring for them in an emergency
4. Placing a note on their front door identifying them as neck breathers
5. Using an electrolarynx can be helpful and allow communication even in an emergency. Those who use a TEP for speech may not be able to speak because their HME may need to be removed.
6. Informing the local 911 emergency services, EMSs and police department that they are neck breathers and may not be able to speak during an emergency
7. Ensuring that the medical personnel of their local ED can recognize and treat neck breathers

It is up to laryngectomees to be vigilant and increase the awareness of the medical personnel and EMSs in their area. This can be an ongoing task, since knowledge by health providers may vary and change over time.

A video that explains the methods needed to administer urgent respiratory care to neck breathers can be viewed at:

<http://www.youtube.com/watch?v=YE-n8cgl77Q>

Neck breathers can share this presentation with their emergency care givers (Closest ED and EMT).

## Undergoing a procedure or surgery as a laryngectomee

Undergoing a procedure, (e.g., a colonoscopy) by sedation or surgery by either local or general anesthesia is challenging for laryngectomees.

Unfortunately, most medical personnel who care for laryngectomees before, during, and after surgery are not familiar with their unique anatomy, how they speak, and how to manage their airways during and after the procedure or operation. These include nurses, medical technicians, surgeons and even anesthesiologists.

It is therefore advisable that laryngectomees explain their unique needs and anatomy beforehand to those who will be treating them. Using explanatory illustrations or pictures is helpful. Those with voice prostheses should allow the anesthesiologist to view their stoma in order to understand its function and be warned not to remove it. It is helpful to provide the anesthesiologist the video that illustrates how to ventilate neck breather (freely available by contacting Atos Medical Inc.) or provide them with the link to it on YouTube at:

<http://www.youtube.com/watch?v=YE-n8cgl77Q>

Medical personnel should understand that an individual with a total laryngectomy has no connection between the oropharynx and the trachea and therefore ventilation and airway suctioning must be done through the stoma, and not through the nose or mouth.

Undergoing a procedure with sedation or surgery under local anesthesia is challenging for a laryngectomee because speaking with an electrolarynx or voice prosthesis is generally not possible. This is because the stoma is covered by an oxygen mask and the patient's hands are typically bound. However, individuals who use esophageal speech can communicate throughout the procedure or surgery done under local anesthesia.

It is important to discuss one's special requirements with the medical team prior to surgery. This may require repeating it several times, first to surgeons, then to the anesthesiologist in the pre surgical evaluation, and lastly on the day of surgery to the anesthesia team that

is actually going to be in the operating room. Whenever undergoing a medical procedure or surgery under local anesthesia one could coordinate with the anesthetist how to notify him/her of pain, or the need to be suctioned. Hand signals, head nodding, lip reading or sounds produced by rudimentary esophageal speech can be helpful.

Using these suggestions may help laryngectomees get adequate care.

### **Cardio-pulmonary resuscitation (CPR) new guidelines**

The new American Heart Association CPR 2010 guidelines require only cardiac compressions; mouth to mouth breathing is no longer necessary. The main purpose of the new guidelines is to encourage more people to deliver CPR. Many individuals avoid mouth to mouth resuscitation because they feel inhibited to breathing into someone's mouth or nose. The impetus for the new guidelines is that it is better to use the chest compressions method only, rather than doing nothing.

An official video that demonstrates the Hands-Only CPR is available at:

<http://www.youtube.com/watch?v=zSgmledxFe8>

Because laryngectomees cannot administer mouth to mouth ventilation, the old CPR guidelines excluded them from providing the respiratory part of CPR. Since the new guidelines do not require mouth to mouth ventilation, laryngectomees can also deliver CPR. However, when possible the old CPR method using both airway ventilation and cardiac compressions should be utilized. This is because the "chest compressions only" method cannot sustain someone for a long period of time since there is no aeration of the lungs.

Laryngectomees who require CPR may also need respiratory ventilation. One of the common causes of breathing problems in laryngectomees is airway obstruction due to a mucus plug or foreign body. Removing these may be essential. Mouth to stoma resuscitation

is important and is relatively easier to deliver than mouth to mouth breathing.

Laryngectomees who breathe through a HME and perform CPR on a person in need of resuscitation may need to temporarily take their HME off. This allows laryngectomees to inhale more air when they deliver up to one hundred heart compressions per minute.



## CHAPTER 18:

### **Travelling as a laryngectomee**

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Traveling as a laryngectomee can be challenging. The trip may expose the traveler to unfamiliar places away from their routine and comfortable settings. Laryngectomees may need to care for their airways at unfamiliar locations. Travelling usually requires planning ahead so that essential supplies are available during the trip. It is important to continue to care for one's airway and other medical issues while travelling.

#### **Caring for the airway while flying on a commercial airline**

Taking a flight (especially a long one) on a commercial airline presents many challenges. Several factors can lead to deep vein thrombosis or DVT. These include dehydration (due to the low moisture in the cabin air at high altitude), lower oxygen pressure inside the plane, and the passenger's immobility. These factors, when combined, can cause a blood clot in the legs that, when dislodged, can circulate through the blood stream and reach the lungs, where it can cause pulmonary embolism. This is a serious complication and a medical emergency.

In addition, the low air humidity can dry out the trachea and lead to mucus plugs. Airline attendants are typically unfamiliar with the means of providing air to a laryngectomee i.e., directing air to the stoma and not the mouth or nose.

These steps can be taken to prevent potential problems:

- Drinking at least eight ounces of water for every two hours on a plane, including ground time
- Avoiding alcohol and caffeine drinks as they are dehydrating
- Wearing loose-fitting clothes
- Avoiding crossing the legs while seating, as this can reduce blood flow in the legs
- Wearing compression socks
- If in a higher risk category, asking one's doctor whether to take aspirin before flying to inhibit blood clotting
- Performing legs exercises and standing up or walking whenever possible during the flight
- Booking an exit row, bulkhead, or aisle seat that allows greater leg room
- Communicating with flight attendants through writing if the noise during the flight make it difficult to speak
- Inserting saline into the stoma periodically during the flight to keep the trachea moist
- Placing medical supplies, including stoma care equipment and an electrolarynx (if used) in an accessible place in carry-on luggage (durable medical equipment and supplies are permitted to bring on board, as an extra carry-on bag)

- Covering the stoma with a heat and moisture exchanger (HME) or a moist cloth to provide humidity

- Informing the flight attendants that one is a laryngectomee

These measures make airline travel easier and safer for laryngectomees and other neck breathers.

### **What supplies should be carrying when travelling?**

When travelling it is useful to carry all one's airway management supplies and medications in a dedicated bag. The bag should not be checked in and access to it should be easy.

Suggested items to be included in the bag include:

- A summary of one's medication taken on a regular basis, one's medical diagnoses, the names and contact information of one's medical providers, a referral to a speech and language pathologist (SLP) and prescriptions for one's medication
- Proof of medical and dental insurance
- A supply of the medications taken
- Paper tissues
- Tweezers, mirror, flash light (with extra batteries)
- Blood pressure monitor ( for those who are hypertensive)
- Saline bullets

- Supplies for placing HME housing (alcohol, Remove, Skin Tag, glue)
- A supply of HMEs and HME housings
- Carrying an electrolarynx (with an extra battery) even by those using a voice prosthesis may be helpful in case one is unable to speak
- A voice amplifier (if needed, with extra batteries or a battery charger)

Individuals who use a voice prosthesis should also bring these items:

- A brush and flushing bulb to clean one's tracheoesophageal voice prosthesis
- An extra hands free HME and an extra voice prosthesis
- A red Foley catheter (to place in the voice prosthesis' puncture in case the voice prosthesis is dislodged)

The quantity of items depends on the length of the trip. It can be useful to carry contact information for SLPs and physicians in the area of travel.

### **Preparing a kit with essential information and material**

Laryngectomees may need to receive emergency and non-emergency medical care at a hospital or other medical facility. Because of their difficulty in communicating with medical personal and providing

information, especially when in distress, it is helpful to prepare a folder with this information. Additionally, it is useful to carry a kit containing items and supplies needed to maintain their ability to communicate and care for their stoma. The kit should be kept at a place that is easily accessible in an emergency.

The kit should contain the following:

- An updated and current summary of the medical and surgical history, allergies and diagnoses
- An updated list of the medications taken and the results of all procedures, radiological examinations, scans, and laboratory tests. These may be placed on a disc or USB flash drive
- Information and proof of medical insurance
- Information (phone, email, address) of the laryngectomee's physician(s), SLP, and family members and friend(s)
- A figure or drawing of a side view of the neck that explains the anatomy of the laryngectomee's upper airway and if relevant where the voice prosthesis located
- A paper pad and pen
- An electrolarynx with extra batteries (even for those using voice prosthesis)
- A box of paper tissues
- A small supply of saline bullets, HME filters, HME housing, and supplies needed to apply and remove them ( e.g., alcohol,

Remove™, Skin-Tcg™, glue) and clean the voice prosthesis (brush, flushing bulb)

- Tweezers, mirror, flash light (with extra batteries)

Having these items available when seeking emergency or regular care can be critically important.

## Addendum

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### Useful resources:

American cancer society information on head and neck cancer at: <http://www.cancer.gov/cancertopics/types/head-and-neck/>

United Kingdom cancer support site on head and neck cancer at: <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Larynx/Laryngealcancer.aspx#.UJGZu8V9Ilg>

International Association of Laryngectomees at: <http://www.theial.com/ial/>

Oral Cancer Foundation at: <http://oralcancerfoundation.org/>

Mouth Cancer Foundation at: <http://www.mouthcancerfoundation.org/>

Support for People with Oral and Head and Neck Cancer at: <http://www.spohnc.org/>

A site that contains useful links for laryngectomees and other head and neck cancer patients at: <http://www.bestcancersites.com/laryngeal/>

Head and Neck Cancer Alliance at: <http://www.headandneck.org/>

Head and Neck Cancer Alliance Support Community at: <http://www.inspire.com/groups/head-and-neck-cancer-alliance/>

WebWhispers at: <http://www.webwhispers.org/>

My Voice - Itzhak Brook MD information Website at: <http://dribrook.blogspot.com/>

Brook I. My Voice: A Physician's Personal Experience with Throat Cancer. Createspace, Charleston SC, 2009. ISBN:1-4392-6386-8  
<http://www.createspace.com/900004368>

### **Laryngectomees groups in Facebook:**

Throat and Oral Cancer Survivors  
Laryngectomy Support  
Survivors of Head and Neck Cancer  
Larynx laryngeal Cancer Information and Support  
Support for People with Oral and Head and Neck Cancer (SPOHNC)

### **List of the major medical suppliers for laryngectomee:**

Atos Medical: <http://www.atosmedical.us/>  
Bruce Medical Supplies: <http://www.brucemedical.com/>  
Fahl Medizintechnik: <http://www.fahl-medizintechnik.de/>  
Griffin Laboratories: <http://www.griffinlab.com/>  
InHealth Technologies: <http://store.inhealth.com/>  
Lauder The Electrolarynx Company: <http://www.electrolarynx.com/>  
Luminaud Inc.: <http://www.luminaud.com/>  
Romet Electronic larynx: <http://www.romet.us/>  
Ultravoice: <http://www.ultravoice.com/>

## **About the author**

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Dr. Itzhak Brook is a physician who specializes in pediatrics and infectious diseases. He is a Professor of Pediatrics at Georgetown University Washington D.C. and his areas of expertise are anaerobic and head and neck infections including sinusitis. He has done extensive research on respiratory tract infections and infections following exposure to ionizing radiation. Dr. Brook served in the US Navy for 27 years. He is the author of six medical textbooks, 135 medical book chapters and over 750 scientific publications. He is an editor of three and associate editor of four medical journals. Dr. Brook is the author of "My Voice - a Physician's Personal Experience with Throat Cancer" and "In the Sands of Sinai - a Physician's Account of the Yom-Kippur War". He is a board member of the Head and Neck Cancer Alliance. Dr. Brook is the recipient of the 2012 J. Conley Medical Ethics Lectureship Award by the American Academy of Otolaryngology-Head and Neck Surgery. Dr. Brook was diagnosed with throat cancer in 2006.

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