Introduction

Foundation for Voice Restoration

Dedicated to the development of improved communication and enhanced quality of life for those affected by cancer of the larynx

The Recovery Process

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- Total Laryngectomy and Immediate Aftercare
- Breathing through the Neck
- Speaking Again, and a Return to Daily Functioning
Diagnosis and Pre-Operative Care

For many, the diagnosis of larynx cancer occurs only after several months of being treated for a “sore throat” or “hoarse voice”. Knowing that throat cancer is uncommon, the family medical practitioner may not have recognized the need for referral to the otolaryngologist (Ear, Nose and Throat doctor, or ENT), or the tumor may have been difficult to visualize on a cursory exam. Sometimes diagnosis is also delayed because the patient ignores, or, fearing the worst, refuses to acknowledge the need for medical care.

The diagnosis may require several medical tests and procedures, as well as examination by a variety of specialists to determine the best course of action. In some situations, radiation and/or chemotherapy may be recommended in an attempt to avoid surgery, or in addition to it. The ultimate concern, however, must always be for achieving long term survival.
Typically, there is little time once the diagnosis is confirmed to learn all the pertinent information in order to make educated choices. Understanding the complex physiology and medical terminology is time-consuming, and requires tenacity for the person who is faced with immediate and significant bodily and lifestyle changes. The pre-operative period can be a confusing time for patient and family. In addition to medical decisions and treatment planning, the individual may need to address personal finances and employment issues, while planning for post-operative care and living arrangements.
The surgical procedure of total laryngectomy separates the airway from the mouth, nose, and upper digestive tract, and establishes a permanent tracheostoma at the base of the neck for breathing. (See diagrams “Before Laryngectomy” and “After Laryngectomy”, from InHealth Technologies). The surgery may be more extensive in some situations, and involve the use of other compatible tissues from the body, such as the forearm, upper chest, or thigh to replace surgically-removed structures.

Waking up without a voice and having scant means of other communication, weakened from the operation, while having multiple unanswered questions and concerns, is traumatic. Initially the focus is on proper wound healing and physical recovery from the procedure, including a return to swallowing and eating. Typically, the patient and family will be given a brief tutorial in wound care and stoma hygiene before discharge from the
hospital, with little else to begin the recuperative period at home. Pre- or post-operative radiation and/or chemotherapy will complicate and prolong the physical recovery period. This is a most critical time psychologically for the patient and family, as they adjust to the changes in body appearance and functions, and the alterations in communication. Few resources are available to assist in coping during this stressful time, and affect a successful and rapid recovery.
Breathing through the Neck

During the surgical procedure of laryngectomy, the larynx is removed from the upper portion of the trachea (windpipe), and a permanent tracheostoma, or stoma, is established in the neck for breathing. (See diagrams “Before Laryngectomy” and “After Laryngectomy”, from InHealth Technologies.) The change in breathing anatomy and physiology has a number of undesirable effects, primarily owing to the loss of the warming, humidifying, and filtering of inhaled air by the nose and other structures of the upper airway. Consequently, many laryngectomees suffer from various respiratory ailments, including excessive mucus production, coughing, and crusting of the stoma. The sensory functions of taste and smell are also altered secondary to the lack of pulmonary air flowing through the mouth and nose. Caution must be exercised at all times to prevent the inhalation or aspiration of foreign bodies into the lungs via the openstoma, impacting the daily showering routine.
and water activities such as swimming. Additionally, the stoma plays an important role in the success of tracheoesophageal (TE) speech utilizing a voice prosthesis. Routine care and hygiene of the tracheostoma eventually becomes second nature to the laryngectomee, much like brushing the teeth. While nursing professionals typically provide instruction in stoma care to the patient and/or family member prior to hospital discharge, the sterile technique used in the medical setting is impractical and usually not required for self-care at home. The specific stoma care routine varies among laryngectomees, particularly if a heat-and-moisture exchange system (HME), tracheoesophageal voice prosthesis, and hands-free tracheoesophageal valve are used.
Voice is produced by exhaled air passing through the vocal folds ("vocal cords"), setting them into vibration. The sound is further modified by the lips, tongue, teeth, and other structures of the mouth and throat (actions referred to as "articulation" and "resonance") to produce the distinctive consonant and vowel sounds of speech, and to effect the vocal quality. Removal of the vocal cords and larynx during the surgical procedure of laryngectomy results in a loss of the voice producing mechanism. A substitute mechanism is needed to regain understandable speech for daily communication.

Ideally, planning for the restoration of voice begins prior to surgery, by providing information to the patient about the various speaking options, and by careful consideration of the exact surgical technique that will maximize the potential for regaining speech. In the immediate post-operative period, the new laryngectomee will be able to move the
articulators to shape the sounds of speech without emitting a vocal tone (so-called “mouthing the words”), though the listener may find these efforts difficult to decipher. Writing, though slower than speech, may be a good temporary option. If writing ability is limited, an alphabet board for spelling words, or a communication board with pictures of common daily needs, may be helpful. Hand gestures may also be employed for expressing simple ideas quickly. These methods, as well as the more technologically sophisticated computer-based speech output devices, may represent the only options for the small number of individuals who have had extensive surgery and for whom there are structural and physiologic limitations which prohibit recovery of speech.
There are three basic methods of alaryngeal (without a larynx) speech:

- **ESOPHAGEAL SPEECH**, the method by which an individual learns to trap air in the upper esophagus, then release it in a “belch”-like maneuver to produce vibration of the throat tissue for generating a voice. Esophageal speech can be challenging to master depending on the physiologic condition, perserverance of the Laryngectomee, and the availability of a trained instructor. It has an advantage, however, in that no specialized equipment is required, and the method does not require use of the hand.

- **SPEECH utilizing an ARTIFICIAL LARYNX**, the hand-held instrument that produces vibrations to serve as a voicing sound source as the Laryngectomee articulates. Typically easy to operate, the electrolarynx (electronic) is placed against the side of the neck, chin, or cheek, or utilizes a plastic tube
that is placed in the mouth, and generates a somewhat mechanical sounding voice. A Pneumatic Artificial Larynx features a small cup that is held over the stoma and allows exhaled air to pass over a reed for a more natural-sounding voice production, which is then emitted into the mouth via a small tubing.

- **TRACHEOESOPHAGEAL SPEECH** utilizing a voice prosthesis (TEP), is a method developed by Drs. Mark Singer and Eric Blom over twenty years ago, that allows air from the lungs to be shunted from the trachea to the esophagus via a surgically-created opening (puncture) and stimulate vibration of the throat tissue for voicing. A small prosthetic “valve” inserted between the trachea and esophagus prevents food and liquids from entering the windpipe during swallowing, and maintains patency of the puncture tract. The resultant voice quality is usually very natural, and the nearest to normal laryngeal voice of any
method. Consequently, TE speech has gained worldwide acceptance. However, the ongoing need for replacement devices and access to qualified clinicians may be limiting factors.

The preferred method is the one that best meets an individual’s daily communication needs. The ideal situation occurs when more than one method of communication is available to the laryngectomee, because the various devices or the reconstructed voicing mechanism can sometimes fail temporarily.

The successful restoration of speech brings about a return of social interaction, employment opportunities, and a sense of accomplishment. These factors can contribute significantly to the overall feeling of “wellness”, and play an important part in the psychological recovery of the laryngectomee.
Laryngectomees face a number of unique challenges throughout the recovery process. Unlike most surgeries, recovery following a total laryngectomy is not limited to physical healing. There may be concerns regarding the success of the treatments in eradicating all cancerous cells. There are alterations to important body functions and structures, such as the creation of a stoma in the neck for breathing and the loss of voice. The laryngectomee must learn how to care for the stoma and develop a new way of communicating, and he or she must accept and adapt to the changes that have occurred. While these may initially feel like impossible hurdles to overcome, most laryngectomees resume their daily activities, and report a high quality of life.
Total laryngectomy is a relatively uncommon procedure, with estimates of approximately 50,000 laryngectomees in the United States, with little more than 11,000 new cases of larynx cancer in 2007. The National Cancer Institute has designated approximately 60 academic and research facilities in the US as “Cancer Centers” in recognition of their comprehensive, interdisciplinary programs in cancer research. Of these, there are perhaps a dozen programs which provide the full range of coordinated medical, psychological, and rehabilitation services to meet the needs of the laryngectomee.

Two major membership organizations have been established to address the specific informational needs of laryngectomees and provide supportive services. The International Association of Laryngectomees (IAL) is an organization comprised of local member clubs and support groups throughout the US, Canada, and several foreign countries. They
distribute publications and a quarterly newsletter, and hold an annual social and educational meeting.

Additionally, the IAL sponsors an annual Voice Institute, in conjunction with the Annual Meeting, to offer instructional programming to speech-language pathologists in laryngectomy rehabilitation methods, provide clinical speech therapy services to laryngectomees needing assistance with communication skills, and train laryngectomee peer-counselors and volunteers. The Voice Institute faculty is comprised of recognized experts specializing in head/neck cancer treatment and laryngectomy rehabilitation. For those who are able to attend, the Voice Institute provides a unique, comprehensive instructional program.

Some local and regional “New Voice” or “Lost Chord” clubs conduct periodic educational conferences and clinics in addition to their regular support group meetings. Unfortunately, the
number of local groups has been decreasing in recent years, reducing the availability of volunteer mentors and peer-counselors, and restricting an important resource of information for laryngectomees.

WebWhispers is an online support group of nearly 2000 international members who post questions and comments about laryngectomy-related issues from the perspective of patients and caregivers. While not medically-directed, WebWhispers maintains an extensive library of information, in addition to the archives of previous posts on the listserv. Those with internet access will find WebWhispers an extremely helpful resource for information and support.
Other sources of information for laryngectomees include the local and national offices of the American Cancer Society, the National Cancer Institute, Support for People with Oral and Head/Neck Cancers (SPOHNC), and the Yul Brynner Foundation. While not dedicated exclusively to the needs of the larynx cancer patient, these organizations can help to provide important information and assistance about cancer and recovery in general.
The Foundation for Voice Restoration, as part of its goal to assist the Laryngectomee to quickly regain a normal, functional, and productive lifestyle, focuses efforts in three critical areas:

- Educational and Instructional Clinical-Training Manuals, Video/DVD productions, and Classes for patients, caregivers, and professionals.
- Educational and Instructional Counseling Video/DVD productions, and Classes for patients, caregivers, and professionals.
- Online Tutorials and Professional “white papers” by invited medical experts.

Examples of Foundation-sponsored publications include “The Guide for the Laryngectomee,” by Dr. Carla DeLassus Gress, ScD, (in preparation), and the video/DVD presentations, “Managing the Emotions of Laryngectomy Surgery and Recovery,” (for patients and their loved ones), and “Laryngectomy Rehabilitation: Building Healthy Client-Family Relationships for Improved Outcomes,” (for clinicians), both featuring
Caryn Melvin, PhD, as well as the video/DVD presentation “Stoma Care” (in development).

Additionally, the Foundation has established an OUTREACH program to include:
• Sponsorship of Laryngectomee Clinics
• Educational presentations for local clubs
• Tobacco Awareness programs for schools
• Laryngectomee Visitation training

Through these efforts, the Foundation hopes to facilitate a smooth and speedy recovery, by providing critical and accurate medical information specific to the needs of the laryngectomee.