## A NOTEBOOK OF CARE FOR THE LARYNGECTOMEE

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# **Health Care Team**

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Surgeon		
6.501	Name	Phone number
Speech Pathologist	Name	Phone number
Social Worker	Name	Phone number
Nurse	Name	Phone number
Dietitian	Name	Phone number
Medical Oncologist	Name	Phone number
Radiation Oncologist_	Name	Phone number

For Dance Center appointments call: 443-849-2087

## Milton J. Dance, Jr. Center Team

Our team will follow you through all stages of care. The team will meet with you before surgery, during your hospitalization and on an ongoing basis.

## Speech-Language Pathologist

The speech-language pathologist will focus on new ways to communicate. Use of an artificial larynx will begin before discharge. Basic care of the heat moisture exchanger (HME) and voice prosthesis (TEP) will be introduced, as appropriate. A swallow assessment may also be performed. Ongoing therapy may be arranged by appointment through the Dance Center by calling 443-849-2087.

#### Social Worker

The social worker is available for patient and family counseling to address concerns and adjustment issues related to the surgery, recovery and rehabilitation. Discharge planning, including referrals for home health care and medical equipment, will also be coordinated.

#### **Head and Neck Nurse Specialist**

The head and neck nurse specialist provides instruction in self-care and airway management. The nurse will review stoma coverings and is available for follow-up as needed.

## **Oncology Dietitian**

The dietitian addresses optimal nutrition and hydration levels to maintain a healthy weight and a healthy body. Maintaining enough nutrition and hydration promotes healing, increases energy levels and allows for overall good feeling.

To speak with a member of the rehabilitation team or to schedule an appointment, please call **443-849-2087**.

**Commented [JMD1]:** Our title is inconsistent throughout the notebook. Sometimes we are Speech-Language Pathologist, Speech Pathologist, Speech therapist.

A Notebook of Care for the Laryngectomee

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#### Introduction

Living with a total laryngectomy (lar-in-jek-tuh-me) involves many changes and adjustments to everyday life. The Milton J. Dance, Jr., Head & Neck Rehabilitation Center staff, with input from laryngectomees, developed this notebook to facilitate the recovery process. This guide contains directions and instructions necessary for life after a total laryngectomy.

There are permanent changes because of a total laryngectomy. These changes may differ slightly for each person. The health care team, including physicians, speech pathologists, nurses, and social workers are always available to answer any questions not addressed in this notebook.

Going home is the first step to life after laryngectomy. Before discharge from the hospital, the patient and family member or caregiver are taught how to safely manage the unique daily care needs of the total laryngectomee. Self-care practice begins in the hospital with nursing supervision to gain skill and comfort before discharge home. A visiting nurse may come to the home after discharge to reinforce self-learning and establish a daily care routine. Initial self-care supplies will be sent home along with discharge instructions.

This notebook is a guide to assist with the challenges of survivorship following a laryngectomy. It includes information about head and neck changes, care routines as learned in the hospital, voicing options and other questions that may arise.

## **Basic Anatomy**

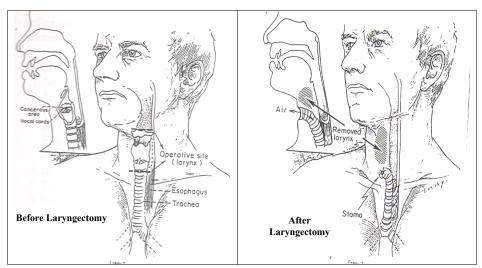
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## **Before Laryngectomy**

The larynx (voice box) connects the pharynx (back of the throat) to the trachea (windpipe). The mucous membranes lining the larynx assist in warming and humidifying inhaled air. The sensitive larynx also triggers a cough reflex when touched by a foreign substance (i.e., food, liquid) to help prevent aspiration (material entering the airway).

A well-known function of the larynx is voice production. Exhaled air passes through the vocal cords causing them to vibrate, producing sound. This sound is then shaped into speech by movements of the tongue, lips, palate, and teeth.



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## **After Laryngectomy**

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Surgery to remove the larynx and vocal cords is called a laryngectomy. The connection between the pharynx (back of the throat) and trachea (airway) no longer exists after a total laryngectomy. The trachea is "bent forward" and sewn to the front of the neck to create a new, permanent opening for breathing. The loss of the vocal cords creates the need for alternative methods of communication. A person who has had his/her larynx removed is referred to as a "laryngectomee".

## **BASIC CARE OF THE STOMA**

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#### What is the Stoma?

The stoma is the permanent opening in your neck through which you breathe. Frequent stoma care is necessary to maintain a clear, clean airway. Use a flashlight to check the stoma. When mucus forms in the stoma, remove it before it dries and forms a crust. The stoma should be cleaned four times daily and as needed.

## Cleaning your airway/stoma

- 1. Instill 1 firm squeeze on the saline "bullet" into the stoma to loosen secretions and cough. \*Only instill sterile saline in the stoma!
- 2. Suction, if necessary, to remove secretions you cannot cough out. Follow the procedure for suctioning on the following page.

## Cleaning the skin around the stoma

Clean the stoma with saline (salt water) using a gauze pad. Mucous plugs or crusts may be removed using LARGE tweezers or forceps. NEVER use a small instrument that may fall into the stoma. Dry the stoma. The skin around the stoma may be washed with mild soap and water, then wiped dry.

### **How to make saline solution:**

- 1. Wash your hands
- 2. Boil 1 quart of water for 5 minutes.
- 3. Add 2 teaspoons of non-iodized (Kosher) salt and let cool.
- 4. Pour the saline into a clean container.
- 5. Cover the container and mark the date and store it in the refrigerator.
- 6. Warm the saline to room temperature before using.

Discard any unused saline after 48 hours.

If a smaller amount of saline is needed, add 1/2 teaspoon of salt to 1 cup of boiled water and follow the same procedure.

\*Saline is also available at the drugstore in squeeze bottles - usually advertised for nasal use. \*Only use saline labeled as "sterile".

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\*Note: If at any time you are having trouble breathing and cannot clear your airway, notify your doctor immediately. If unable to reach the doctor, go to the nearest hospital for help. IF YOU ARE IN DISTRESS, CALL 911 IMMEDIATELY! ©Milton J. Dance, Jr., Head and Neck Center at GBMC 2005, revise2-2017

## **SUCTIONING THE STOMA**

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#### Why suctioning is important,

The amount of mucus in your airway will depend on your general health. Suctioning may be necessary to remove secretions too deep or too thick to be coughed out. Suction when you feel congested or when you cannot clear your airway by instilling saline and coughing. Use a clean catheter each time you suction.

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## **Supplies needed**:

Mirror

Suction machine with connecting tubing

Clear or Red rubber suction catheter - attach the catheter to the connecting tubing

Saline bullets

Container of saline (to rinse catheter after suctioning)

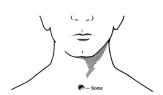
Non-sterile gauze pads

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#### **Follow this procedure:**

- 1. Wash your hands thoroughly then turn on the suction machine.
- 2. Instill 1 firm squeeze on the saline "bullet" to loosen secretions, and cough.
- 3. Take several deep breaths.
- 4. Insert the catheter into your stoma (about 4-6 inches) until you begin to cough or until you meet resistance.
- 5. Place your thumb over the open end of the suction port to create suction and gently rotate the catheter as you pull it out of the stoma. Do not leave the catheter in the trachea for more than 10 seconds.
- 6. Suction saline through the catheter to remove secretions from inside of the catheter.
- 7. If needed, repeat the suctioning process until the airway is clear of mucus.

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## **CARE OF SUCTION EQUIPMENT**

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#### **Care of the Catheters**

Red rubber suction catheters can be cleaned and reused according to the following instructions. Clear plastic catheters cannot be cleaned and should be discarded after using.

- 1. Suction saline through the catheter to clear any secretions.
- 2. Rinse catheters under cool, running water to remove secretions.
- 3. Wash catheters in a mild soap and warm water and rinse thoroughly with tap water.
- 4. Soak catheters for ten minutes in equal amounts of hydrogen peroxide and water. Rinse catheters thoroughly under running water.
- 5. Boil catheters for 3-5 minutes. If possible, place the catheters in a strainer to protect them from the heat of the pan.
- 6. Allow catheters to air-dry thoroughly on a clean towel. Store them in a zip-lock plastic bag. Storing them in the refrigerator may help to preserve the rubber.

\*Red rubber catheters should be thrown away after 30 days or sooner if they are worn. Discard catheters that are cracked, have poor suction, or cannot be cleaned.





### **Care of the suction machine:**

Clean the suction bottle and tubing daily to prevent infection. Empty the suction bottle into the toilet when it becomes full. Wash the bottle and lid with soap and warm water. Rinse and dry thoroughly.

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## **MAINTAINING HUMIDITY**

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Before your laryngectomy, your nose warmed, filtered and moisturized the air. Now, you breathe dry, unfiltered air directly through the stoma. Therefore, you must humidify the air in other ways to prevent stoma crusting and maintain an open airway. A healthy moisture level also eases breathing and reduces coughing.

Medications such as diuretics, caffeine & anti-depressants can increase dryness.

Suggestions for maintaining humidity

- 1. Wear your HME filter 24/7. See HME section of this notebook.
- 2. Drink plenty of caffeine free fluids to keep secretions thin.
- 3. Place a humidifier by your bed at night while sleeping and in your living area during the day.
- 4. Keep the humidity level in your home at about 50%. Place pans of water on top of radiators and use houseplants to add moisture to the air.
- 5. Try sitting in a steam filled bathroom 2 3 times a day for 20 minutes if you feel very congested.
- 6. If your airway is very dry, instill 1 firm squeeze on the saline "bullet" into the stoma 4-6 times a day.
- 7. Wear a damp stoma bib or gauze square over the stoma to moisturize the air if prescribed

**Mandatory:** Change the water in the humidifier daily and clean your humidifier as directed to prevent the spread of bacteria. Follow the manufacturer's instructions for cleaning.

## **DAILY ROUTINES**

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**Shaving** 

Protect your stoma when shaving. Do not allow shaving cream, lotion, aerosol sprays, or loose hair to enter your stoma. These can irritate your airway and cause violent coughing. If possible, use an electric razor until the neck incision is healed.

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Follow this procedure.

- 1. Wear a stoma cover or towel around the neck when shaving.
- 2. Use of an electric razor may help prevent hair from entering the stoma.
- 3. When using a safety or straight razor, be careful not to cut the skin. Your neck may be numb for several months after surgery.

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Showering, bathing, and shampooing

Do not allow water to enter the stoma while showering or bathing. Use a handheld shower spray or adjust the showerhead so that the stream of water hits your body below the level of your stoma. Protect the stoma with a rubber shower shield (see medical supply section of this notebook) or baby's bib that is plastic on one side and terry cloth on the other, wearing the plastic side out. Do not use talcum powder around the stoma.

When taking a tub bath, keep the water level low in the tub. Use a shower curtain to increase the steam level and humidity.

Shampoo your hair while bending over a sink or while showering. Stand with your back to the shower and tilt your head back to avoid getting soap and water into your stoma. Always wear a shower shield or stoma cover while shampooing.

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## **STOMA COVERING**

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## The stoma covering

A stoma cover or HME filter cassette should always be worn to filter unwanted particles and maintain humidity. A cover will also warm the air as you breathe. It is important to wear a cover in all types of weather. You may notice increased sensitivity to cigarette smoke, dust, fumes, and aerosol sprays (such as hair spray). Avoid wearing materials that contain loose threads or feel uncomfortable in any way. The pattern for making crocheted stoma covers and a list of resources for stoma wear appear in this booklet. Breathable fabrics such as cottons are generally more comfortable than synthetics.

\*Tip for the Men: Do not stop wearing a shirt and tie! Have the second button on a dress shirt sewn over the buttonhole to give the appearance that the button is fastened. This will provide on opening through which you can insert a handkerchief when coughing occurs.

## **DEALING WITH AIRWAY DRYNESS**

#### Humidification

Laryngectomees need to increase humidification to counteract airway dryness. Since your nose can no longer warm or moisten the air that you breathe, it is necessary to humidify the air in other ways to prevent mucous crusting and difficulty breathing. Some patients find that they need to take special precautions during the winter months when gas and forced air tend to create a very dry atmosphere, making breathing difficult. Here are some suggestions that may be helpful.

### Ways to increase humidification:

- Place a warm, steam vaporizer by your bed at night and in your living area during the day. Follow the manufacturer's instructions and clean the vaporizer at least once a week to prevent the spread of bacteria.
- Always wear a stoma cover. For optimal stoma care, see information on the Heat-Moisture Exchanger (HME) in this notebook.
- Instill 1 firm squeeze on the saline "bullet" into the stoma 4-6 times a day to stimulate coughing and add moisture to the airway. Over-the-counter saline nasal sprays can be used to instill and provide a convenient and portable source of humidity. Only use saline sprays labeled as "sterile".
- Sitting in a steam-filled bathroom will help loosen thick secretions. Turn on hot water in the shower, close the door, and allow steam to fill the room.
- Keep the humidity level in your home at about 50% to ease breathing and reduce coughing. Consider purchasing a built-in humidistat to regulate the relative humidity.
- A home nebulizer or humidity collar may be indicated for patients with excessively thick secretions. Discuss this with your doctor, if necessary.
- Check with your doctor before taking over-the-counter medications, such as, diuretics, allergy medications, and anti-depressants. These medications may cause dryness of the mucous membranes.

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• To keep secretions thin, drink plenty of fluids and avoid caffeine products which tend to dehydrate. Water is best! Keep a glass of water by your bed to ease any night cough or dryness.	
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## HEAT-MOISTURE EXCHANGER (HME)

## What is a Heat Moisture Exchanger or HME?

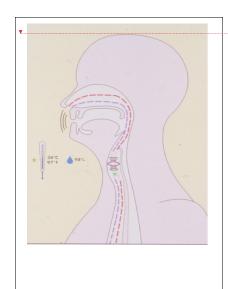
After a laryngectomy, the airway is exposed to the environment through the stoma, lowering the temperature and moisture in the lungs. The HME is a filter that is worn over the stoma and is designed to replace the function of the nose. The HME is sometimes referred to as an 'artificial nose'. The HMEs filter and maintain warmth of the air in the lungs. Routine use of HMEs have been proven to maintain lung function.

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## **BEFORE LARYNGECTOMY**



Temperature: 36°C, 97°F, Humidification: 98%

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## **AFTER LARYNGECTOMY**

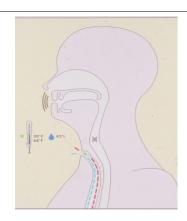


Figure reprinted with permission from ATOS Medical,

Milwaukee, Wisconsin

Without HME:

Temperature: 20°C, 68°F,

**Humdification: 42%** 

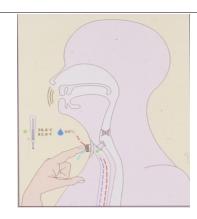


Figure reprinted with permission from ATOS Medical,  $\,$ 

Milwaukee, Wisconsin With HME:

Temperature: 28°C, 83.8°F,

**Humdification: 65%** 

## **Benefits of an HME**

The HME has been shown to improve quality of life by reducing:

- stoma cleaning
- sputum production
- forced expectoration
- shortness of breath
- coughing

- fatigue
- sleep interruption
- anxiety
- depression
- social isolation
- voice problems

### **Using the HME System**

Change the HME cassette at least once every 12 hours and more frequently if it becomes soiled or clogged with secretions.

Remove the HME cassette before coughing.

Continue to instill sterile normal saline into the stoma at least 2-3 times daily. Observe the stoma and report any signs of crusting, bleeding and mucous plugging.

\*Report any problems to your physician, nurse or speech pathologist.

### **HME filters and attachments**

## Stoma foam squares

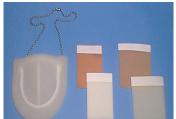
Stoma foam squares cover the stoma and filter incoming air protecting the airway from environmental dust and dirt.

#### Advantages

- Provides better filtration than cloth covers
- Retains limited moisture and heat

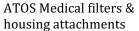
## **Disadvantages**

• Less effective than HME at maintaining heat and moisture retention.



## **Laryngectomy Tubes**







Barton-Mayo Tracheostoma Button

### Purpose of the laryngectomy tube

A laryngectomy tube provides leak-proof retention of the HMEs and tracheostoma valves. It is frequently used for patients who cannot tolerate skin adhesives, or for those who have problems with stomal stenosis (narrowed or small stoma).

## What is a laryngectomy tube?

A laryngectomy tube is a similar in appearance to a tracheostomy tube. It has either one or two parts (cannulas) and may be made of either silicone or metal. Most prescription tubes used at the Dance Center have one cannula and are made of silicone. If you require a metal tube you will receive additional instructions.

### Why do I need one?

After surgery the tube helps to shape and maintain the stoma. If the stoma becomes narrow or small a tube may be prescribed to widen the stoma. Individual needs vary.

## Inserting the laryngectomy tube

A water-based lubricant (e.g. Surgi-lube or KY Jelly) will help you insert your tube. NEVER lubricate your tube with saliva or with oil/petroleum-based

**Commented [JMD3]:** I thought this should go below "Purpose of the laryngectomy tube." Just seems out of order a bit.

products. To insert: Lubricate the inner lip and fold between the thumb and forefinger. Fold the tube in half and insert into the stoma. Release after partial insertion and gently push in to seal. After inserting the tube into the stoma, a simple spiral motion is used to 'lock" the device into place.

Cleaning the laryngectomy tube

Clean the tube daily. Scrub thoroughly with a soft brush in hot soapy water. Rinse well. Soak in peroxide before cleaning if needed to loosen thick/sticky secretions. Rinse well. Insert. The life of a tube varies. If there are difficulties with the tube, please discuss with the medical professional.

I wear a \_\_\_\_\_ tube. Size \_\_\_\_ Length \_\_\_\_ (Date \_\_\_\_)

My Care & Use Notes:



### What information do I need to know about my tube?

A water-based lubricant (e.g. Surgilube or KY Jelly) helps to reinsert the laryngectomy tube. NEVER lubricate your tube with saliva or with oil/petroleum-based products. Clean your tube daily. Scrub thoroughly with a soft brush in hot soapy water. Rinse well. Soak in peroxide before cleaning if needed to loosen thick/sticky secretions. Rinse well. Insert. If you cannot re-insert your tube contact your physician immediately.

**Stoma Tubes** 







**Commented [JMD4]:** Only can be locked if it has a blue ring on it, correct?

**Commented [JMD5]:** Same information is above. Do you want it twice?

Larytube	Tracheostoma Vent	LaryButton
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Medical	permission from	Medical Technologies
Technologies	InHealth Technologies	

### LaryTube (Provox/Atos Medical)

Secured to neck by a tube holder (tie) or an adhesive base plate (Ring model only)

May be punctured or cut by the speech pathologist to permit voicing with a prosthesis.

#### **Barton-Mayo Tracheostoma Button**

A Barton-Mayo Button is a silastic tube that houses either a heat moisture exchanger (HME) cassette or a tracheostoma valve to allow hands-free voicing. The BMB fits inside the stoma and gently grips the tracheal walls, therefore eliminating the needs to use adhesive "peristomal" housing. The Barton-Mayo Button is available in a wide range of sizes to insure optimum fit of individual patients. To order this device you will require a prescription that indicates your specific size (length, depth and angle). To inquire about a Barton-Mayo Button please contact the speech pathologist.





#### **Tracheostoma Vent**

A tracheostoma vent is used for patients who have difficulty with stoma narrowing or shrinking. It may be worn with a Stomafoam square filter and/or stoma cover. The HME filter cassette cannot be used with the tracheostoma vent. The tracheostoma vent may be secured to the neck with a trach tube tie.

The tube may be punctured, or a hole cut by a medical professional to permit voicing for those with a TEP prosthesis.

I wear a _		tube.	
Size	Length	(Date	)

My Care & Use Notes:

## Ordering replacement filters and attachment items

## ATOS MEDICAL <a href="http://www.atosmedical.com/">http://www.atosmedical.com/</a>

2202 North Bartlett Avenue Milwaukee, WI 53201-1009

Toll Free 800-217-0025, P: 414-227-2328, F: 414-278-9033

HME PRODUCTS: Provox Heat and Moisture Exchanger System, Barton-Mayo

**Button** 

## INHEALTH TECHNOLOGIES <a href="http://inhealth.com/voicerestorationindex.htm">http://inhealth.com/voicerestorationindex.htm</a>

1110 Mark Ave., Carpinteria, CA 93013-2918 Phone: (805) 684-9337; Toll Free (800) 477-5969. Fax: (805) 684-8594

HME PRODUCTS: Barton-Mayo Button, Adjustable Tracheostoma Vent and Filter.

## LUMINAUD <a href="http://www.luminaud.com/">http://www.luminaud.com/</a>

8688 Tyler Blvd, Mentor, OH 44060. Phone: (440) 255-9082; Toll Free: 800 255-3408 Canada) & (US; Fax; (440) 255-2250.

HME PRODUCTS: Stoma Filters, Kapitex/Trachinaze stoma studs and filters.

#### LAUDER ENTERPRISES, INC. www.voicestore.com

11115 Whisper Hollow, San Antonio, Texas 78230-3609

Toll free: 800-388-8642 FAX: 201-492-1584

HME PRODUCTS: Stoma Filters, Kapitex/Trachinaze stoma studs and filters.

\*A prescription from your physician or speech pathologist may be needed to order HME supplies. Tell your speech pathologist which company you will be ordering from so the necessary prescription form can be completed. Billing, ordering and reimbursement procedures vary among suppliers and vendors. Check with the supplier/vendor and your insurance provider prior to ordering for specific directions.

## **Communication options for the laryngectomee**

Tracheoesophageal (TE) speech is the one communication option that most closely resembles fluent, natural speech. In many hospitals the tracheoesophageal puncture and prosthesis placement is available as part of the initial surgery or it may be performed several months or years afterwards. Whether one is considering tracheoesophageal speech before or after a laryngectomy, an awareness of what tracheoesophageal speech is and how it works is an essential part of the decision making process.

Two other communication options available after the laryngectomy are the electrolarynx and esophageal speech. These three methods of communication are not exclusive from one another. It is possible to learn and use all three methods of speaking after a laryngectomy.

All three post laryngectomy communication options will be introduced to the patient and family members before surgery at a pre-operative counseling session with our rehabilitation team.

Three communication options available to a laryngectomee

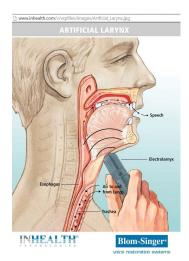
- Electrolarynx or Artificial Larynx
- Tracheoesophageal Speech
- Esophageal speech

## **Electrolarynx or Artificial Larynx**

The electrolarynx, also called an artificial larynx, is an external vibrating device that generates sound for speaking. At a minimum, it is essential to learn to use an electrolarynx as a back-up communication method. Training with an electrolarynx should be implemented by the Speech Pathologist within a day or two after surgery thereby providing an immediate way of communicating. The majority of electric larynges are hand-held and battery powered.

**Purpose of the Electrolarynx:** After your laryngectomy, you will not be able to produce voice with your vocal folds. The eletrolarynx (EL) can be thought of as electric vocal cords, because, like vocal cords, it vibrates. This vibration is transmitted through the soft tissues of the neck, cheek or mouth and then shaped into speech with the lips, jaw and tongue. Many people are surprised to learn that even after their laryngectomy people can recognize them on the telephone. Although there are several ways of producing sounds after a laryngectomy, you will be provided with an electrolarynx within the first few days of your surgery. Your speech pathologist will instruct you in its care and use. He or she will provide materials to help you learn how to communicate with your new device.

**Use of the Electrolarynx:** It is important for individuals to learn more than one method of communication after the laryngectomy. This helps maintain independence. It is also important to have a back-up method of communication. Some people have difficulty with the TEP while others just prefer the convenience of the electrolarynx.



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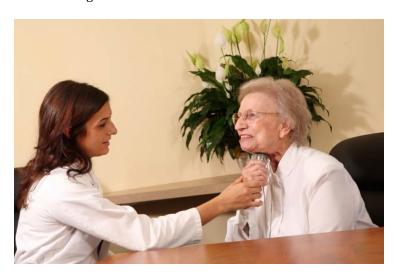
## **Electrolarynx**

## Advantages

- Fairly easy to learn for most patients
- External vibrating source not limited by pharyngoesophageal segment tonicity issues or other internal factors

## Disadvantages

- Mechanical sound
- May be difficult for family, friends or others in daily environment to accept sound and understand patient
- Location of device (Have to wear it or keep it nearby for communication needs)
- Monotone. Difficult to learn how to modify tone
- Patient preference for esophageal or TE voice more natural sounding



## **Tracheoesophageal Speech**

A tract or opening is surgically created from the trachea <u>(windpipe)</u> into the esophagus <u>(food tube)</u> by the surgeon. This opening enables the passage of air from the trachea into the esophagus. The air enters the esophagus creating a vibration. This allows an individual who has had a laryngectomy to make or generate sound in an area of their esophagus known as the pharyngoesophageal segment or PE segment.

## What is a Tracheoesophageal Prosthesis [TEP]?

A TEP is a prosthetic device made of silicone. The prosthesis is a one-way valve that opens under the positive pressure of air traveling up from the lungs through the valve into the esophagus to produce voice.

## What are the primary purposes of the TEP?

One purpose is to maintain a stable opening or passageway from the trachea to the esophagus to allow voicing. Another purpose is to protect against saliva, food or refluxed materials leaking from the esophagus into the trachea. All prostheses have a flap-type valve that stays closed to prevent food, liquid and secretions from entering the airway and opens to allow exhaled air coming up from the lungs through the prosthesis to enter the esophagus for TE voicing.

## **Tracheoesophageal Speech**



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## Indwelling Voice Prostheses: Why choose an indwelling prosthesis?

The indwelling prosthesis may stay in place on average for 4-6 months or longer. The indwelling prosthesis  $\underline{\text{must not}}$  be removed by the laryngectomee. It  $\underline{\text{must be}}$  removed and replaced by a speech pathologist or physician. It is cleaned by the laryngectomee with a specially designed brush and flushing pipette at least twice daily. As with the traditional, yeast colonization is often the primary reason for valve failure. If yeast colonization occurs and causes valve failure, then an antifungal medications may be prescribed by the physician.

The indwelling prosthesis may provide someone who may otherwise not be a candidate for a TEP the opportunity to have one. Difficulty with either vision or manual dexterity may limit their ability to change their own prosthesis. In these situations, an indwelling prosthesis would be a better option. Another reason to change to an indwelling may be that a person's memory or thinking

ability may begin to falter. This may make it difficult for them to manage their own prosthesis.

Indwelling prostheses have thicker and wider retention collars enabling the strap to be removed after placement. This can be especially important for the laryngectomee interested in hands free speech. A neck strap may interfere with obtaining an airtight seal around the stoma for placement of an adhesive housing. The housing may be required as an attachment for the hands free speech valve. If the neck strap remains it will be difficult to get the airtight seal necessary for functional hands free speech.

After the prosthesis is placed the strap may be removed. There are several different companies who manufacture indwelling prostheses. Use of a specific indwelling prosthesis over another has much to do with patient needs, the experience of the Speech Pathologist, availability of supplies, sizing considerations, success or failure of previously tried prostheses, the condition of the TEP, problems requiring modification of the prosthesis and the personal choice of the laryngectomee.





## **Patient-maintained prostheses**

The laryngectomee may choose to use a patient-maintained prosthesis. The benefit of having a patient-maintained prosthesis is that it can be changed by the laryngectomee, the speech pathologist or the physician. Some patients prefer to be more independent with their prosthesis management while others prefer going to the Speech Pathologist for voice prosthesis (TEP) changes as needed.

**Commented [JMD6]:** I would put this before Indwelling prosthesis since the patient-maintained prostheses are initially mentioned there as it is now.

Individuals who do not live close to a rehabilitation center or a Speech Pathologist may choose the traditional prosthesis.

The laryngectomee must have good vision and be able to manipulate the prosthesis and the insertion tool to remove and replace the prosthesis independently.

Other factors are related to the placement of the prosthesis.

- The size of the stoma should be large enough to allow easy access to the prosthesis for cleaning and changes.
- o If a person has a lot of problems with yeast or candida production and requires frequent changes to the prosthesis, then another prosthesis type that is candida resistant may be recommended to them by the Speech Pathologist. The patient may be prescribed an antifungal medication. The physician may prescribe an anti-fungal medication and/or pharmacological management of gastroesophageal reflux disease using a proton pump inhibitor to reduce candida/yeast growth.

#### When a prosthesis needs to be replaced

### Sizing

The length of the prosthesis is determined by the Speech Pathologist. The wall of the trachea and the wall of the esophagus form a common wall. The depth of the wall between the trachea and the esophagus is similar to a wall between two rooms. It is often referred to as the 'party wall'. The length of the surgically created opening or TEP is measured and the appropriate size prosthesis is selected. The diameter of the prosthesis is the distance around or the width of the prosthesis shaft. The opening or fistula created by the surgeon generally stays the same diameter as the prosthesis. That is, the body naturally heals down to meet the size of the prosthesis occupying that opening. Prosthesis diameters are measured in 'French' measurement.



The size of the tracheoesophageal puncture may change from time to time. Resizing will be done by the Speech Pathologist. A prosthesis that is too short in length will not maintain the opening of the tracheoesophageal puncture causing it to close down on the back end or extrude. Repuncturing by a physician may be necessary if the TEP closes.

A prosthesis that is too long may piston or slide in the tract causing irritation to the tissue. Or, it may be so long as to be pushed up against the wall of the esophagus during speaking attempts. If you notice any of these problems you should call to schedule an appointment with your Speech Pathologist.

Factors that influence successful TE voicing

- □ The extent of the surgical reconstruction.
- Tissue stiffness, fibrosis (hardening), edema (swelling) or spasm from previous cancer treatments.
- Close proximity to a Speech Pathologist with TEP experience.
- □ The ability to care for the stoma and the TEP.

All prostheses must be cleaned daily and changed periodically. You will be instructed on what to look for and what to do when the prosthesis fails and is ready for a change.

Hands Free Option with TEP

The use of a speaking valve attachment over the stoma for a person with a TEP allows hands free TE speech. This brings the laryngectomee closer in appearance to natural speech.

## Care and Management of a Tracheoesophageal Prosthesis

#### **Prosthesis Failure**

A common reason for prosthesis failure is leakage. Leakage is the passage of liquids either through or around the prosthesis into the trachea. Leakage *through* the prosthesis results from failure of the one-way valve to fully close. Leakage *around* the prosthesis is a more complex event and should not occur if the tracheoesophageal tissue is healthy and the prosthesis is sized and seated appropriately.

Sooner or later, most silicone materials in the throat will be exposed to *candida* (yeast) which occurs naturally in the body. If your silicone voice prosthesis develops *candida* growth, it will not seal properly, and fluids may begin to leak through the center of the prosthesis when you are drinking. There is a large variation in the average lifetime of a voice prosthesis. Infection, radiation therapy, antibiotic therapy and even diet may affect durability. Persistent leakage through the TEP despite routine cleaning suggests that the prosthesis may need to be changed.

#### Prosthesis Failure: leakage through or around

- Position yourself in front of a well-lit mirror.
- Take a small sip of dark colored liquid (e.g., coffee or grape juice)
- Observe for any material leaking through or around the prosthesis.
   You may need to have someone else assist you in identifying leakage.
  - Leakage of liquids / failure of TEP:
    - evidence of liquid trickling into your airway either around

or through your prosthesis after you swallow

coughing after drinking and / or eating.

Indwelling Prosthesis – Clinician-Managed (<u>Patient does not change</u>)
Attempt to resolve the leak by cleaning with a brush and saline flush procedure. If you are unable to resolve the leak, contact your Speech Pathologist to arrange an appointment.

#### **Prosthesis Plugs**

Your Speech Pathologist may provide you with a plug that can be inserted into the center of the voice prosthesis if the prosthesis begins to leak. This plug will only be effective if leakage occurs *through* the prosthesis. With this plug in place, you should be able to eat and drink without leakage into your trachea, until you can be seen by your Speech Pathologist. Depending on the type of prosthesis you have, *you may not be able to speak* when the plug is in place.

Contact your Speech Pathologist to arrange an appointment immediately if you suspect your prosthesis has failed.

#### **Prosthesis Extrusion**

It is highly unlikely, that your prosthesis will ever become dislodged from the tract, however if the prosthesis does come out of the tract, it is important that you *respond to the situation immediately*. Your speech pathologist will provide you with a red rubber catheter or white stent on your initial post-operative visit. You will learn how to place the catheter into the tract to maintain the TE fistula.

Procedure for Maintaining the Tract (TE Fistula)

- Insert the catheter or dilator into the TE Fistula.
- Feed the catheter in with your fingers as you swallow.
- Tie off the catheter at the end and tape in place to your neck or chest.
- Contact your Speech Pathologist to arrange an appointment.

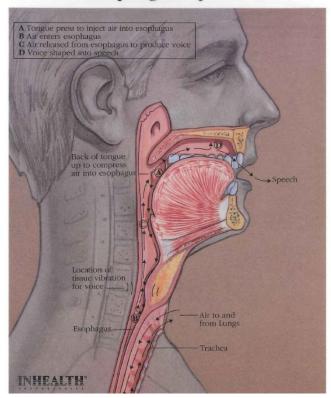
Should your prosthesis come out and you are unable to insert the catheter or dilator, contact your physician immediately.
If you are unable to reach your physician, go to the nearest
emergency room. Request to see the ENT resident on-call, if
possible. *Availability of ENT may vary depending on
location.

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## Esophageal speech

Esophageal speech is a post laryngectomy voicing option that allows hands free speech production. It takes time and dedication to learn this method of speaking. It is highly recommended that consideration of this method and subsequent training of esophageal speech be done with a Speech Pathologist.

## Esophageal Speech



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## How is Esophageal Voice Produced?

Esophageal speech is produced by either inhaled or injected air taken into the mouth and brought down into the esophagus.

The air must be returned quickly from the esophagus. As the air is returned from the esophagus a sound is generated for speaking.

The pharyngoesophageal segment is the vibrating source for sound production. This is true for esophageal voice and tracheoesophageal voice.

Doyle, P.C., Keith, R.L. editors. Contemporary considerations in the treatment and rehabilitation of head and neck cancer: voice, speech, and swallowing, Austin, Tex.: Pro-Ed, c2005. xxi, 794 p.: ill.; 27 cm. RC280.T5 C665 2005. ISBN: 0890799881 Ward, Elizabeth C. and yan As-Brooks. Corina J. Head and neck cancer: treatment, rehabilitation, and outcomes 2nd ed. San Diego, CA United States: Plural Publishing, 2014.

### Esophageal Speech

The advantages of esophageal speech are:

- Advantages
  - Does not require any supplies. Lowest cost option. All one needs is their own body and practice-practice
  - More natural sound compared to electrolarynx
  - Can vary pitch, loudness to a certain degree
- Disadvantages
  - It can be difficult to learn and certainly does requires a lot of practice
  - Need to find a speech pathologist who can teach esophageal speech.
  - Barriers such as stoma blasts, inability to produce due to pharyngoesophageal segment issues.
  - If TEP in place it may be difficult to transition between the 2
  - Shorter # of words produced compared to TE voice and electrolarynx

It is highly recommended that consideration of this method and subsequent training of esophageal speech be done with a Speech Pathologist.

#### **HEALTH AND SAFETY**

DO NOT SWIM due to the danger of getting water into the lungs. Laryngectomees cannot tread water because of the low-lying stoma. Boating, water activities, or even being near the water should be done with extreme caution. Falling in deep water may be fatal!

Frequent mouth care is needed to prevent infection and avoid bad breath. Use a saline solution or alcohol-free mouthwashes to prevent mouth dryness.

Your sense of smell and taste may be decreased since you no longer breathe through your nose and mouth. For safety reasons, have smoke and carbon monoxide detectors installed. Check the batteries frequently. Ask friends and family members not to smoke around you.

Avoid bending over after meals, particularly soon after surgery.

Some laryngectomees are unable to gargle, whistle, blow their nose and strain (as in moving your bowels), lift heavy objects, or perform strenuous activity. Eat a high fiber diet to avoid constipation and ask your doctor to recommend a stool softener.

Report the following signs and symptoms to your doctor: bleeding from or around the stoma, shortness of breath, narrowing of the stoma, foreign bodies in the stoma which cannot be removed, redness around the stoma, change in the color, amount or consistency of secretions, fever, difficulty swallowing and pain.

#### **EMERGENCY PREPAREDNESS**

**Prior to discharge or as soon as you arrive home** have a friend or family member contact the local police and fire department to notify those agencies that you have had a laryngectomy and are a permanent neck breather. Some patients have a family member record a message to be played to "911" in case of an emergency. Family members should learn "mouth to stoma" resuscitation.

Contact your local utility company for priority assistance in case of a power failure or other emergencies.

Always carry identification and wear a Medic Alert Bracelet. These can be ordered through a local pharmacy.

Consider keeping a "tracheostomy mask" in your emergency kit. It allows for oxygen delivery via stoma and may not be readily available on EMS vehicles.

Available online for ~\$2-3. One resource listed on WebWhispers: https://www.walgreens.com/store/c/sunset-healthcare-solutions-adult-trach-or-tracheostomy-mask/ID=prod6253005-product

Applications are available on "smart phones" to manage your personal medical history.

Consider purchasing a combustible gas detector. A person with a laryngectomy is less able to detect a gas leak due to the decreased sensitivity to odors. Information can be obtained through the local utility company or at <a href="https://www.safehomeproducts.com">www.safehomeproducts.com</a>.

The IAL has a booklet, "Rescue Breathing for Layngectomees and Other Neck Breathers" that is available online. It reviews the principles of rescue breathing for total and partial neck breathers.

 $\underline{http://webwhispers.org/library/documents/BWRescueBreathing 2-05.pdf}$ 

#### **NOTIFY YOUR HEALTHCARE TEAM...**

The following may be early warning signs of infection or other problems, notify your physician or another member of your healthcare team if you experience:

#### Possible signs of infection:

• Changes in sputum color, volume, odor and consistency

#### **Breathing Problems:**

- Shortness of breath
- Wheezing
- Increased coughing
- Increased respiratory rate
- Increased use of accessory muscle use when breathing

## **Sputum Changes:**

- Change in the typical color of your sputum (yellow, green, tan or brown)
- Increased quantity of sputum
- Change in the consistency of your sputum
- Bloody sputum

## **Stoma Symptoms:**

- Pulsating tube
- Bleeding from the stoma or around the stoma site
- Malodorous drainage from the stoma site
- Swelling or redness at the stoma site

\*Note: If at any time you are having trouble breathing and cannot clear your airway, notify your doctor immediately. If unable to reach the doctor, go to the nearest hospital for help. IF YOU ARE IN DISTRESS, CALL 911
IMMEDIATELY!

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#### **DEALING WITH THE EMOTIONAL ISSUES**

The patient who has to deal with voice loss following a total laryngectomy can be faced with emotional issues. The patient is dealing with many changes, including voice and body image. Feelings of anxiety, distress and depression may follow. Some of these reactions are considered normal adjustment responses. Sometimes emotional distress may interfere daily activity and the rehabilitation process.

Families and significant others are also affected by the illness, the surgery and its aftermath. They are dealing with the patient's emotions while having their own adjustment issues. New stresses often include role reversal, financial concerns and care giving responsibilities. Family members may try too hard to do everything just right. It is easy to feel overwhelmed and guilty. They must be patient while providing encouragement, support, but also independence.

Counseling is available through the Dance Center Social Worker at no cost. This can help with the emotional and practical issues that are faced during the rehabilitation process. Call the Dance Center at 443-849-2087 to schedule an appointment.

Support groups can also be helpful. A resource list is provided in this booklet. When necessary, a referral for a psychiatric evaluation can be made, especially if antidepressant or other medication may be indicated.

### Sexuality and the Laryngectomee

It is common for the laryngectomee to have concerns about sexuality and body image. The surgery definitely alters appearance and changes communication patterns. This can create fears of being unattractive and unlovable. However, meaningful physical intimacy is possible. Adjustments will be necessary but can be made. Emotions, the feelings of love and caring between partners, will not change. It is important to be open and communicate feelings and expectations freely. Being aware of specific ways to deal with the changes that come after surgery can also enhance the sexual experience.

The stoma itself, due to odors and the noises from breathing, can be a distraction and concern during physical intimacy. The unexpected feeling of breathing from the stoma rather than the mouth may startle a partner. Wearing a stoma cover or a stoma filter during this time reduces the noise and feeling of air that comes from the stoma. A cover is also more attractive than keeping the area open. Odors may also reduce desire. Again, the stoma cover or filter can help with this. Also, keep the area around the stoma clean and avoid spicy foods and garlic. Try using a small amount of cologne or other fragrances in order to minimize unpleasant odors. Positioning during intimacy is another way of alleviating some of the concerns related to the stoma. Simple changes in positions can improve the direction of air-flow from the stoma making it more comfortable for both partners.

The fact that there will be a change in speaking after surgery may interfere with communication during sex. Being aware of these changes and making necessary adjustments is the key to overcoming this obstacle. If one has a prosthesis (TEP) or uses esophageal speech, communication may be easier. The electro-larynx can be more distracting and awkward. Non-verbal communication becomes very important and is in fact often used by people without communication problems.

Adjusting to the new body and the new speaking methods takes time and patience. As one adjusts to every aspect of these changes, sexual activity should feel more natural as well. The important lesson to remember is that open communication between partners is essential. Partners should discuss the anticipated changes a head of time and consider together new techniques

and body adjustments. If there is ever a feeling that you need additional help with this matter, couples counseling can be helpful.

#### **SUPPORT GROUPS**

The Milton J. Dance Head and Neck Rehabilitation Center offers two support groups for patients and family members. All of the groups meet at the Greater Baltimore Medical Center. If you wish, your name will be placed on our mailing list to notify you of the date, time, and location of each support group meeting.

#### **Patient and Family Support Group**

The Patient and Family Support Group meets on the third Tuesday of each month from 7-8:30 PM. This group is open to patients, family members and significant others of patients who have been diagnosed with cancer of the head and neck. The focus of this group is on sharing the experience and feelings associated with the head and neck cancer diagnosis in a supportive environment. The group is co-led by the Social Worker and Head and Neck Rehabilitation Nurse.

## **HopeWell Cancer Support**

Street address: 10628 Falls Road, Lutherville, MD 21093, Phone: 410-832-2719

Formerly known as the Wellness Community, HopeWell Cancer Support offers a free program of support, education, and hope for adults with cancer and their families in the greater Baltimore community. Programs include support groups, networking groups, educational workshops, stress reduction classes, exercise classes, support for children and www.hopewellcancersupport.org

#### **DISCHARGE PLANNING**

Before you are discharged, the hospital case manager will assess your discharge needs and review available resources with you. Medical equipment, such as the suction machine, will be ordered and a visiting nurse may be consulted to follow you at home, according to your doctor's orders. The visiting nurse will help with your care until you and your family are comfortable with your routine. Referrals to other community resources can be made as needed.

Basic supplies to get you started will be sent home with you. These include:

- 1. Saline solution
- 2. Suction catheters
- 3. 4x4 Gauze squares to use when coughing
- 4. Saline "bullets"
- 5. Large, plastic tweezers for stoma care

Laryngectomy supplies will be ordered through a medical supply company and delivered to your home. The hospital case manager will provide you with contact information for both the medical supply company and visiting nurse agency. You can refer to our resource list in this booklet for ongoing options to purchase laryngectomy-specific supplies. If you have any problems obtaining any supplies, please contact the Dance Center and someone will be able to assist you.

Make an appointment with your physician and speech-language pathologist for the week following your discharge or as instructed by your physician.

#### **CHECKLIST OF NECESSARY SUPPLIES**

The following supplies should always be kept accessible:

## **Laryngectomy Supplies**

- o Spare laryngectomy tube (if applicable)
- Spare Velcro strap (if applicable)
- Spare optiderm housing (if applicable)
- Spare HME filters
- o Dressing supplies, gauze sponges
- o Hydrogen peroxide, sterile water, normal saline
- o Water soluble lubricant such as Surgilube or KY Jelly
- o Blunt-end bandage scissors
- Large Tweezers or hemostats
- o Sterile Q-tips
- o Small flashlight and mirror

## **Suction Equipment**

- o Portable battery-powered suction machine
- Suction connecting tubing
- Suction catheters
- o Normal saline solution
- Sterile or clean paper cups
- Saline ampules ("bullets")

#### **Contact Information**

Prior to discharge to home, the hospital case manager/social worker will provide contact numbers for the following:

- Visiting nurse agency
- Medical supply/equipment agency
- o Tube feeding formula/equipment agency

## Local and Regional Support Groups for The Laryngectomee

## **Baltimore County**

Greater Baltimore Medical Center Patient and Family Support Group for Head and Neck Cancer Patients 6701 N. Charles Street, Physicians Pavilion East Conference Center Baltimore, MD

Contact: Dorothy Gold, LCSW-C, OSW-C

Phone: (443) 849-2980

#### **Baltimore City**

The Lost Chord Club of Maryland Messiah Eng. Lutheran Church 1025 South O'Donnell Street Baltimore, MD

Contact: Ray Reprogel Phone (410) 644-9490

#### **Charles County**

Randall W. King New Voice Club of La Plata Harry White Wilber American Legion Post #82 Route 301 La Plata, MD

Contact: Wanda Miller-Kochanek

Phone: (410) 674-6138

#### **Montgomery County**

Laryngectomee Club of Montgomery County American Cancer Society 11331 Amherst Avenue Silver Spring, MD

Contact: Herbert Simon Phone: (301) 588-2352

## FREQUENTLY ASKED QUESTIONS

#### Airway and Stoma Management

## How long should I keep my suction machine?

Patient's requiring radiation therapy should keep the suction machine until the completion of therapy. Ideally, you should always keep the suction machine in your home just in case of an emergency. It is always wise to check with your physician prior to returning the suction machine.

## How often should I instill saline into my stoma?

3-4 times daily to stimulate a cough reflex.

### When should I stop instilling saline?

Laryngectomees should continue to instill to maintain a healthy airway.

#### How do I use my inhaler?

Inhalers must be used over your stoma. Please consult your physician to obtain the proper dispensing method and device.

# I feel constricted when my stoma is covered. Why is it so important to wear a stoma cover?

Stoma covers help protect your clothing and keep foreign matter from entering your airway. Some stoma covers also help to maintain humidity in your airway. Stoma covers can also provide a more presentable social appearance.

#### Gauze 4x4 squares are too expensive. Why can't I use tissues?

Tissues tend to fall apart when wet. Tissue particles may enter your airway. This is not healthy for your lungs and can irritate your airway.

## General Health and Personal Care

#### How will I know if I have a cold?

You may notice a change in the thickness, color and odor of your secretions. These symptoms may or may not be accompanied by a fever. You may also have a runny nose. Consult your physician.

## Will I be able to sneeze, cough and blow my nose?

Sneezing and coughing now occur through the stoma. Be sure to cover your stoma. Blowing your nose in the traditional fashion is no longer possible because your upper and lower airways have been separated. Laryngectomees who have a TEP may be able to blow their nose by covering the stoma, allowing lung air to travel up through the prosthesis into the throat and nose.

## Will I be able to taste and smell after my laryngectomy?

This is very individualized. In general, your sense of taste and smell will be reduced. There are techniques that your SLP can share with you to help regain these senses.

# Are there any special concerns for personal hygiene after a laryngectomy?

See section entitled Health and Safety

Will laryngectomy surgery affect physical intimacy? It is common to worry about sexual adjustment after a laryngectomy. You will certainly be able to continue to have physical intimacy with your partner after the surgery. However, some adjustments will be necessary, such as dealing with the stoma, the odors, and ways to communicate. Specific suggestions for enhancing the experience may include changing positions, using a stoma cover, avoiding foods that could bring on strong smells, and working on non-verbal communication. The social worker is available for counseling or referrals on specific issues.

**Before my surgery, I smoked cigarettes and drank alcohol, why should I quit now?** Smoking interferes with circulation and wound healing. Tobacco use will decrease the body's ability to heal after surgery. Continued cigarette use also increases the risk of another smoking-related cancer. Alcohol will dry and irritate the lining of the mouth and throat. Heavy alcohol use will affect

nutrition and slow healing. And may increase the risk of smoking-related cancer.

Why is it difficult for me to swallow solid foods? Sometimes, after a laryngectomy, there can be a narrowing of the esophagus (food tube), making it difficult to swallow solid foods. Reflux (indigestion) is common after laryngectomy. Treatment for swallowing problems is available. Discuss this further with your physician and speech-pathologist.

## **Prostheses and Heat-Moisture Exchangers**

#### How long does a voice prosthesis last?

The lifespan of the voice prosthesis varies patient to patient and model to model. Generally, the prosthesis will need to be replaced every 2-6 months. If voice quality decreases, or liquids leak through the prosthesis, contact your speech-pathologist for an appointment.

## How often should I change my traditional TEP?

Generally, traditional TEPs need to be changed every 2 days. However, individual usage may vary. Please check with your speech-language pathologist for individualized care instructions.

# What lubricants should be used to insert a stoma vent, laryngectomy tube, stoma stud or Barton Button.

Water-based lubricants such as Surgilube or K-Y jelly are the safest form of lubrication for all stoma tubes. Avoid petroleum-based products (Vaseline), antibacterial ointments, such as Neosporin or Bacitracin, saliva or tap water.

#### How often does a prosthesis need to be cleaned?

The frequency and method of cleaning varies with everyone. Generally, a prosthesis should be cleaned in the morning and in the evening. Additional cleaning may be required. Please follow the cleaning protocol provided by your speech pathologist.

### Can HME filters or Stomafoam squares be reused?

No, these products are designed for single use. Reusing these products places the laryngectomee at increased risk of respiratory problems.

#### What can be done to make a prosthesis last longer?

The lifespan of a TEP is affected by many factors. To minimize damage to the prosthesis, clean the device as instructed in both the morning and the evening. Many laryngectomees require daily use of anti-fungal medications such as Nystatin to control candida (yeast) growth. Please follow the directions given to you.

#### Where are HME and TEP supplies sold?

Supplies for the HME and TEP are available from several sources. Supplies may be obtained during your therapy appointment at the Milton J. Dance, Jr. Head & Neck Rehabilitation Center. Supplies may be purchased from companies, such as InHealth, ATOS, Lauder or Luminaud. Please refer to the resources list of this booklet for contact information. Your speech pathologist will provide you with prescriptions for the supplies that you are currently using. Please keep copies of this documentation in your binder for easy reference.

### **Leisure Activities**

#### Can a Laryngectomee whistle?

Whistling requires a steady stream of air to pass over the lips. Laryngectomy, separates the airway from the lips, making whistling difficult. Laryngectomees that can whistle have learned to draw air into the esophagus and release it on command.

# Is it possible for a laryngectomee to play the trumpet (or other brass/woodwind instrument) after surgery?

Brass and wind instruments require a steady stream of air from the mouth and would be difficult to play. Esophageal air can theoretically allow some sound to be made with wind instruments, however the sound cannot be adequately sustained and controlled. Currently, these instruments cannot be played at the stoma.

#### Is it possible to lift weights or other heavy objects?

Physical limitations after a laryngectomy vary from patient to patient. Heavy lifting and straining may be more difficult from before surgery.

If a neck dissection and/or post-surgical radiation was performed, there may be shoulder restrictions that affect lifting. Physical therapy is often helpful to safely improve range of motion and strength.

A light weight lifting program may be resumed after receiving clearance from your physician. However, heavy weight lifting would not be recommended. A person may become tired and short of breath more easily after a laryngectomy. Plan your workout based on your own comfort, energy and strength level. A personal trainer is recommended to set up an appropriate program.

#### Can a laryngectomee enjoy swimming and boating?

Common sense should be used when considering water activities. After a laryngectomy your airway/lungs are exposed to the outside environment through the opening in your neck (stoma). This places the laryngectomee at high risk for drowning because water can very easily enter the lungs.

Certainly, enjoyment of the water can still occur. Large boats or ships are appropriate choices. It is unadvisable to consider smaller boats, sailing or water sports because of the high risk of falling into the water and drowning.

#### What support groups are available to laryngectomees?

There are support groups for laryngectomees across the country. The Laryngectomee Interest/Support Group at GBMC meets the first Tuesday of each month at 12:00. Attending the group provides the opportunity to meet other laryngectomees, discuss concerns and practice speaking. The patient and family support group is the third Tuesday of each month at 7:00 pm. This group is open to all patients with head and neck cancer and their family members.

There are web-based support groups which provide patient education through articles, newsletters and email. Two very active websites are Web Whispers and Larynx Link through the International Association of Laryngectomees. These sites can be accessed by going to: <a href="http://www.webwhispers.org/">http://www.webwhispers.org/</a> and <a href="http://www.larynxlink.com/Main/ial.htm">http://www.larynxlink.com/Main/ial.htm</a>.

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#### LARYNGECTOMEE RESOURCES

#### **ORGANIZATIONS**

#### INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES (IAL)-

http://www.larynxlink.com/Main/ial.htm

c/o The American Cancer Society, 1599 Clifton Road, NE, Atlanta, Georgia 30329

The purposes of the IAL are to promote and support the total rehabilitation of the laryngectomee by the exchange of ideas and dissemination of information to member clubs and to the public, to facilitate the formation of new clubs, to foster improvement in laryngectomee programs, and to improve the minimum standards for teachers of post-laryngectomy speech. The IAL publishes a newsletter, sponsors an annual meeting for laryngectomees and speech-language pathologists and provides a wealth of information on its website.

#### WEBWHISPERS.ORG

#### http://www.webwhispers.org/index.html

An informational sharing website for individuals dealing with laryngeal cancer. Read the monthly newsletter, *Whispers on the Web*. Sign on to their email lists and the WebWhispers Forum message boards. Ask questions about treatments, surgical procedures, recovery, and life after your laryngectomy. There are also sections containing administrative information, other links, and activities.

# **HOPEWELL CANCER SUPPORT** – Finding Strength in Community www.hopewellcancersupport.org

For support and information call: 410-832-2719, Fax: 410-337-0937 901 Dulaney Valley Road, Suite 710, Towson, Maryland 21204 Support groups, networking groups, educational workshops, stress reduction classes, exercise classes, support for children & teen, expressive arts experiences, social activities. A free program of hope, learning, and friendship for adults with cancer and their families.

#### **REFERENCE MATERIALS**

#### **AIRWAY EMERGENCIES**

#### INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES

Publication entitled:

"Rescue Breathing for Laryngectomees and Other Neckbreathers" You can access this publication from:

http://www.webwhispers.org/Library/documents/BWRescueBreathing2-05.pdf

"Check the Neck" from the American Cancer Society is available through the International Association of Laryngectomees. Send request to: Ron Langseth, 1593 Corsica Place, Costa Mesa, CA 92626. Cost \$10.00 made payable to the IAL.

#### NUTRITIONAL INFORMATION

AMERICAN CANCER SOCIETY ACS – NUTRITIONAL COUNSELING FOR PATIENTS

"Dietitian on Call Program" through the Mid-Atlantic Patient Resource Center at 888-ACS-NEED. After the call, a registered dietitian contacts each patient to develop plans that meet their unique needs. You can also contact your ACS local chapter or the National number 800-227-2345. For more information visit <a href="http://www.cancer.org/">http://www.cancer.org/</a> and search for nutrition. Or, for reading material relating to cancer and nutrition, link to <a href="http://www.cancer.org/docroot/MBC/MBC">http://www.cancer.org/docroot/MBC/MBC</a> 6.asp?sitearea=ETO.

#### TYPE AND TALK

#### NATURAL READER

NaturalReader is text-to-speech software with natural sounding voices. This easy to use software can convert any written text such as MS Word, Webpage, PDF files, and Emails into spoken words.

For more information, link to: <a href="http://www.naturalreaders.com/index.htm">http://www.naturalreaders.com/index.htm</a>

#### TEXT TO SPEECH

Free online text-to-speech computer program. Speech available in English, as well as 9 other languages.

Accessible at: <a href="http://text-to-speech.imtranslator.net/">http://text-to-speech.imtranslator.net/</a>

#### **MEDICAL SUPPLIES**

## ATOS MEDICAL <a href="http://www.atosmedical.com/">http://www.atosmedical.com/</a>

2202 North Bartlett Avenue Milwaukee, WI 53201-1009

Toll Free 800-217-0025, P: 414-227-2328, F: 414-278-9033

Provox® Prostheses and accessories, Provox Free Hands, Provox Heat and Moisture Exchanger System, Barton-Mayo trachestoma and the  $TruTone^{TM}$  artificial larynx.

#### BRUCE MEDICAL SUPPLIES <a href="http://www.BruceMedical.com/">http://www.BruceMedical.com/</a>

411 Waverly Oaks Road, Suite 154, Waltham, MA 02452 Phone Toll Free: 800-225-8446, Fax: 781-894-9519

Distributors for: Servox Digital, SolaTone, Nu-Vois III, OptiVox Plus, TruTone,

ChatterVox.

#### **COMMUNICATIVE MEDICAL CLINIC** www.communicativemedical.com/

PO Box 8241, Spokane, WA 99203-0241 Phone: 800-944-6801, Fax: 509-838-3948

Offers a wide range of laryngectomee supplies, stoma covers, etc.

## CYBERBIOMET-INTERNATIONAL LTD. <a href="http://www.cyberbiomed.com/">http://www.cyberbiomed.com/</a>

3605 S. Ocean Blvd. A-335, Palm Beach, FL 33480-6312 USA; Phone: 561-582-1125, Fax: 561-892-0567. Distributors of the MicroVox, HiVox, and GoldVox electrolarynx devices and various other laryngectomee-related devices and accessories. Email: cbm@cyberbiomed.com. \*website is in Polish

#### E. BENSON HOOD LABORATORIES http://www.hoodlabs.com/

575 Washington Street, Pembroke, MA 02359: Toll Free: 800-942-5227, Phone: 781-826-7573. Email: <a href="mailto:customerservice@hoodlabs.com">customerservice@hoodlabs.com</a>; Stoma and speech products: silicone stents to the Panje Voice Button, the Groningen Voice Button and the innovative VoiceMaster.

## **EAGLE MEDICAL SUPPLY** www.eaglemedicalsupply.com

11080 Executive Dr, Boise, Idaho 83713 Phone: 877-944-4446 Fax: 208-322-0931

We offer an expanding variety of high quality laryngectomy and tracheostomy supplies at affordable, competitive prices.

#### **INHEALTH TECHNOLOGIES**

## http://www.inhealth.com/voicerestoration.htm

1110 Mark Ave., Carpinteria, CA 93013-2918 Phone: 805-684-9337, Toll Free 800-477-5969, Fax: 805-684-8594

Distributor of the Blom-Singer Voice Prostheses and accessories, The Blom-Singer Adjustable Tracheostoma Valve II, Heat Moisture exchanger system, Servox®, Batteries and Accessories.

## KAPITEX HEALTHCARE, LTD. <a href="http://www.kapitex.com/">http://www.kapitex.com/</a>

1 Sandbeck Way, Wetherby, West Yorkshire, LS22 7GH, England – Tel +44(0)1937

580211; Fax +44(0)1937 580796

Focuses on Head and Neck cancer and airway management for laryngectomy and tracheostomy patients. Traci-Naze, Buchanan, Laryngofoam, and Hydrolox stoma filters, tracheostomy tubes and associated equipment, and DeltaNex cravats and Romet stoma covers. Email at: <a href="mailto:info@kapitex.com">info@kapitex.com</a> Kapitex products are distributed in the USA by Lauder Enterprises and Luminaud, Inc.

#### LAUDER ENTERPRISES, INC. www.voicestore.com

11115 Whisper Hollow, San Antonio, Texas 78230-3609

Toll Free: 800-388-8642 Fax: 201-492-1584 <a href="mailto:info@voicestore.com">info@voicestore.com</a> Electrolarynx (Servox, TruTone, SolaTones, Optibox, NuVois, Cooper-Rand, Romet), Accessories, Stoma Filters, Voice Amplifiers, Books, Insurance Information, Emergency Labels/Stickers and more.

#### **LUMINAUD** http://www.luminaud.com/

8688 Tyler Blvd., Mentor, OH 44060 Phone: 440-255-9082 Toll Free: 800-255-3408 (US and Canada) Fax: 440-255-2250.

Electrolarynges: Cooper-Rand, Denrick 3, Nu-Vois, OptiVox, Servox Inton, TruTone, SolaTone. Hands-free versions of the cooper-Rand. Also service for the Romet, NeoVox, AT&T 5C&5E. Rand Voice Amplifier, Chatter-Vox, Voicette, Mini-Vox, Ameriphone Dialoguer XL-25S for outgoing voice,

"Executive 2" and headset for outgoing/incoming voice on the telephone. Mics for any need, including hands-free and Hi-Gain mics. A terminal for Voicette/home phone connection.

## **NORTHERN PHARMACY & MEDICAL EQUIPMENT**

http://www.northernpharmacy.com/

6701 Harford Road, Baltimore, MD 21234 Toll free: 800-486-0714 or 410-832-2719

Medical equipment including Tracheostomy supplies, dressing materials, trach tubes, suction supplies, 4x4 gauze. Will order supplies upon request.

#### SIEMENS HEARING INSTRUMENTS, INC.

http://www.siemens-hearing.com/

16 East Piper Ln., Ste 126, Prospect Heights, IL 60070 Toll Free: 800-333-9093

Servox Electrolarynx, Rechargeable Batteries, Oral Connectors, Charging Console and Accessories.

#### STERLING MEDICAL

http://www.sterlingmedical.com/ext/sms/sterlingmedical.nsf

To order, call 1-800-229-0900 or order online by sending an e-mail to place your order: <a href="mailto:Order@sterlingmedical.com">Order@sterlingmedical.com</a>

Provides a source for medical disposable products ranging from wound care dressings, gauzes, and tapes to laryngectomy supplies. Specialized service programs provide products to your home. Sterling Medical serves to bill your insurance company directly for all covered and medically necessary items. Sterling is a PARTICIPATING Medicare provider and can help with all your benefit needs and questions. Sterling Medical accepts assignment for items and services furnished to Medicare beneficiaries. Accepting assignment means accepting Medicare's approved amount as payment in full except for any deductibles or co-pay.

#### THE MEDICAL SUPPLY COMPANY, INC. www.medsupplyco.com

1-888-MED-8282

Provides a source for quality medical supplies (including tracheostomy/laryngectomy, enteral, wound care, etc.) at a reasonable cost.

#### ULTRAVOICE, LTD. <a href="http://www.ultravoice.com/">http://www.ultravoice.com/</a>

3612 Chapel Road, Newtown Square, PA 19073 Toll Free: 800-721-4848

UltraVoice is a speech simulator built into an upper denture or a retainer activated by a control unit with hands free features.

## JEWELRY AND HANDMADE NECKWARE

#### **ACCESSORIES II**

3106 Coral Avenue, Apt. D, Costa Mesa, CA 92626. Phone 714-427-0070 520 Washington Blvd., Suite 258, Marina del Rey, CA 90292. Phone 310-335-2925.

Adaptable, affordable jewelry and accessories from the Jewelry Lady.

#### **BEADS N' STITCHES**

Custom designed necklaces for laryngectomees. Contact Maryann Phone: 516-396-9893 or <a href="https://www.beadsnstitches.com">www.beadsnstitches.com</a>

#### **BOW'S ART GALLERY**

Stoma covers, crocheted necklaces, hats, copper enameled jewelry, prints by artist Bow Porter. www.bowsgallery.com/

#### **BRILLIANT BEADS**

Lampwork, beads, and custom jewelry by Gillian Soskin; jewelry designer and dentist whose primary focus is Head & Neck Cancer patients <a href="https://www.brilliantbeads.net">www.brilliantbeads.net</a>

#### DJ'S SEW UNIQUE

4742-10<sup>TH</sup> Street - Byron Center, Michigan 49315 Phone: 616-878-9124 Stoma style t-shirts, ascots to country collars. Write or call for brochure.

#### **FASHONS FOR YOUR NECK**

Stoma covers and trach bands for men, women, and children. Custom made and in-stock designs available. <a href="www.stomacoversandtrachbands.com/">www.stomacoversandtrachbands.com/</a>

#### **HEAR ME ROAR BEADS**

Wide variety of beaded necklaces (and earrings and bracelets to match) www.hearmeroarbeads.com or email at: hearmeroarbeads@aol.com

## LA BLANCA JEWELRY www.mockingbirdsquare.com

3828 Oak Farms Blvd., Lancaster, TX 75134 Phone: 972-224-1093 bonton408@aol.com

#### **NANCY HORVATH**

283 Greene Road, Warminster, PA Write to Nancy for hand-made stoma covers free of charge.

## **Miscellaneous Resources**

## Inflatable Vest PFD with L.I.F.T. www.mustangsurvival.com/lift/

Personal Flotation Device: Mustang Survival developed the revolutionary Lifesaving Inflatable Flotation Technology - LIFT - inflatable cell, which can provide up to 9 inches of distance between the mouth and the surface of the water. This distance elevates the head <u>and chest</u> up and out of the way of waves.

**DISCLAIMER:** THE INFORMATION CONTAINED ON THIS LIST DOES NOT NECESSARILY CONSTITUTE ENDORSEMENT OF THESE PRODUCTS.

## **Glossary Terms**

**Artificial Larynx**: A device that replaces the vibration of the vocal cords, which is the power source of the voice. Communication is achieved by forming words with the mouth, teeth and tongue, as the artificial larynx vibrates.

**Catheter**: A red rubber tube used to suction the airway. The catheter may also be used, as directed by the speech-language pathologist, to keep the TE fistula open should the voice prosthesis ever become dislodged from the tract.

**Drain**: A tube placed into an incision to withdraw fluid from the tissues to promote healing.

**Dysphagia**: Difficulty swallowing.

**Esophageal Speech**: Air is caught or injected into the mouth and directed quickly into the esophagus. The injected air is then projected rapidly to produce a "burp" vibration or sound. Words are formed with the mouth teeth and tongue.

**Esophagus**: The food passage connecting the throat to the stomach.

**Flap**: Tissue transferred from one part of the body to another to repair surgical defect area after removal of the cancer. The flap fills the surgical defect area.

**Heat Moisture Exchanger (HME):** A stoma covering system that acts like an artificial nose to filter, moisturize, and warm the air inhaled through the stoma.

**Inner Cannula**: A part of the metal laryngectomy/tracheostomy tube. It fits into the outer cannula, and locks into place.

**Instill**: The process of placing 3-4 eyedroppers of saline into the stoma to loosen mucus and to elicit a cough.

**Laryngectomee**: A person who has had a total laryngectomy.

Laryngectomy: Removal of the larynx.

**Laryngectomy Tube**: A metal or plastic tube that is worn temporarily while the stoma is healing following surgery.

**Larynx: (Pronounced: `lae**rinks) The area of the body that houses the vocal cords (voice box).

**Maxillo-Facial Prosthodontist**: A dental specialist who deals with dentures, partial or complete, or similar prostheses.

**Modified Barium Swallow (MBS):** An x-ray that evaluates the swallowing process.

**Nasogastric Tube (NGT):** A tube placed through the nose into the stomach to decompress the stomach or to provide nourishment.

**Neck Dissection:** Surgical procedure for removal of lymph nodes in the neck.

**Obturator:** This is the guidewire that fits inside the outer cannula of the metal laryngectomy/tracheostomy tube to guide the tube easily into the stoma.

**Outer Cannula:** A part of the metal laryngectomy/tracheostomy tube. It holds the stoma open and houses the inner cannula.

**Prosthesis:** This is a plastic shunt that allows air to pass from the trachea into the esophagus for voicing and prevents aspiration of esophageal contents.

**Skin Grafts:** Skin transferred from one part of the body to another to repair defects in the lining of the mouth and/or throat.

**Stoma:** A permanent opening in the neck for breathing.

**Stoma Cover:** A bib, covering or filter that is always worn to filter unwanted particles, maintain humidity, retain heat and maintain an attractive appearance.

**Stoma Vent:** A plastic tube that is worn in the stoma to maintain the size of the stoma.

**Suctioning:** The process of clearing the mucous and secretions from the airway with a clean catheter and suction machine.

**TEP:** (tracheo-esophageal puncture) A surgically created opening between the trachea and the esophagus through which a voice prosthesis is placed.

**Trachea:** The windpipe or airway below the voice box.

**Vocal Cord:** A band of tissue that passes across the opening of the voice box and functions to produce sound.

**Voice Prosthesis:** A one-way valve, generally made of silicone, that directs air from the trachea into the esophagus for speech and prevents aspiration of secretions from the esophagus.

**Xerostomia:** Dry mouth caused by a decrease in saliva.

www.gbmc.org/mjdancehome