

# Laryngectomee Visitor Program Manual



Made available through the  
International Association of Laryngectomees  
Revised October, 2015  
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# Laryngectomee Visitor Program Manual

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# Laryngectomy Visitor Program Manual

## Introduction

There are thousands of laryngectomees currently living on all continents, many of whom belong to clubs associated with the International Association of Laryngectomees (IAL). The IAL was founded in the United States in 1952 and originally affiliated with the American Cancer Society (ACS). Since 1997, The IAL became independent and self supporting.

A voluntary, non-sectarian, non-political, tax-exempt association, the IAL coordinates the activities of more than 250 clubs. Known as Lost Chord Clubs, New Voice Clubs, and other appropriate names, the clubs are comprised of laryngectomees and their family members. They provide peer support and social interaction activities and promote public education programs, particularly total rehabilitation and those aimed at smoking cessation, public awareness of the devastating effects of tobacco use are a priority.

The IAL and its member clubs have grown in response to an increasing awareness of the need to better assist individuals who have recently had or who are about to have a laryngectomy. This goal can best be accomplished by training well-rehabilitated laryngectomees to visit these new and prospective patients to provide emotional support and demonstrate that normal everyday activities can be resumed after a laryngectomy.

The primary purpose of this Laryngectomy Resource Manual is to assist laryngectomy clubs in setting up a uniform training program that will qualify visitors to meet the standards agreed upon by the IAL and the local clubs.

Guidelines contained in this manual may need to be adapted to meet the needs and resources of individual clubs. However, they will provide laryngectomy clubs and volunteers with tools to develop and maintain a program that will assist laryngectomees to better understand and adapt to the effects of their surgery.

## 1. Philosophy and Purpose of Visitor Training Program

The goal of the Laryngectomy Visitor Program is to provide individuals who have undergone larynx removal an opportunity to achieve their maximum potential; emotionally, physically, socially and economically. To accomplish the initial step of this goal, recent laryngectomy patients must become aware that former activities can be resumed. Their recent surgery will not necessarily alter their previous lifestyle.

A visit by a concerned, well-rehabilitated laryngectomee who uses at least one type of alaryngeal speech, can make a major contribution to the total rehabilitation of the new or prospective laryngectomee. Specially selected and trained the well-rehabilitated laryngectomee and spouse, when appropriate and possible, visits new laryngectomees in the hospital or at home before and/or soon after they undergo surgery. The presence of this visitor, who is neatly dressed, well-mannered and speaking with ease, can give the patient hope and determination to become rehabilitated. When appropriate the visitor can also answer many of the questions and ease some of the fears that may be troubling the patient and members of the family.

**The laryngectomee visitor is not intended to interfere in any way with the patient's relationship with the physician or other health-care professionals.** The Laryngectomy Visitor Program fosters an open, productive relationship among the volunteers, patients, and members of the medical and allied health professions.

**Whatever alaryngeal speech method is used, only the very best alaryngeal speakers should conduct preoperative visits to prospective laryngectomees.** If this rule is not followed, some patients may become so discouraged that the resulting damage to their morale and motivation may severely affect their potential for rehabilitation. They may even choose not to have surgery with devastating consequences. A poor pre-op visit could also jeopardize the physician's trust in the training program and limit referrals.

## 2. Guidelines and Procedures

### Role of the Coordinator

The responsibility for the successful operation of the Laryngectomy Visitor Program on the local level rests with the club member who serves as the volunteer visitor coordinator. The visitor coordinator must meet the following criteria:

- A trained volunteer with experience in laryngectomy rehabilitation
- Possess good communication skills
- Have good organizational and facilitation skills
- Have sufficient time to devote to the position

The specific responsibilities of the visitor coordinator include:

- Organize and help conduct training sessions for prospective volunteer visitors
- Maintain a working relationship with hospitals to insure cooperation with IAL, local clubs and volunteer visitors
- Ensure that reporting of visits for statistical purposes is carried out through the IAL website

### Role of the Professional SLP Advisor

The role of the professional SLP advisor is to:

- Function as a consultant to the visitor program and visitor coordinator
- Promote the program in the medical community
- Act as a resource person for the Volunteer Visitor Program

### Volunteer Visitor Policy

Since the success of the Laryngectomy Visitor Program depends on how effective the volunteer visitors are, it is therefore important to define what is expected of the volunteers and how they are to provide service to the patients and family members.

#### Qualifications of Volunteer Visitors

A qualified laryngectomy visitor candidate must meet the following qualifications:

- Have had a total laryngectomy
- Have good, understandable alaryngeal speech (electrolarynx, TEP or esophageal speech)
- Demonstrate physical recovery from surgery, as evidenced by resumption of an active lifestyle, positive outlook on life in general, and a mature attitude toward the laryngectomy experience
- Possess a sincere desire to help the new patient adjust to their laryngectomy
- Possess good communications skills, including the ability to listen and to answer questions in an objective manner
- Be a member in good standing of a local laryngectomy club (if available) and be familiar with the goals of the club and the IAL
- Have application (appendix: p. 13) reviewed and approved according to IAL policies
- Have successfully completed training
- Spouse or laryngectomy advocate may also choose to complete Visitor Training.

#### Responsibilities of Visitor

The laryngectomy visitor is expected to be familiar with and abide by the guidelines and policies of the International Association of Laryngectomees.

## Requests for Visits

Requests for visits may originate from a variety of sources. Response to these requests should never violate the patient-physician relationship and local procedures should be developed in a manner that preserves and protects this relationship. (Also see suggestions for developing referrals, in section 5.0)

## Volunteer Visitor/Patient Interaction

### The Visit Protocol

To present a positive image, the Visitor should always be well groomed and appreciate the importance of dressing appropriately.

The Visitor should never visit a patient in the hospital until the patient's physician has approved the visit.

The Visitor should not enter the patient's room without first stopping at the nurse's station to inform them of his/her presence in the hospital. (This also allows the nursing staff an opportunity to provide information about the patient that may facilitate the visit).

Confidentiality pertaining to the visit must be maintained at all times except when a situation arises where the patient appears to be highly agitated, extremely distressed or depressed. If such behavior is observed, it should be reported to the nurse's station.

The Visitor should not make personal comparisons or give medical advice.

The Visitor is only required to report personal observations. The nursing staff will be able to interpret such comments and take whatever action is appropriate to ensure the well-being of the patient.

At times the patient may not be interested in having a visit. **This is the patient's right.** The visitor should then quickly depart and graciously (leaving name and phone number should the patient wish a visit at a later time). The visit refusal should be reported at the nurse's station, with a request that the physician also be notified of the refusal.

Signed permission must be obtained from patient to be included on the local club's mailing list. **Patient confidentiality must be maintained at all times.**

The patient should receive an information kit as described below.

### The Visit

Only currently qualified Visitors should visit patients. Visits should be made at a mutually convenient time. For maximum benefit, the family and other advocates are encouraged to participate in the visit.

As previously stated, the pre-operative visit to the person who has been informed of the necessity of a laryngectomy, or the post-operative visit to the person who has undergone the surgery is the first step toward our ultimate goal of TOTAL rehabilitation for that person. The visit is extremely important. The Visitor must remember the purpose of the visit and focus verbal and non-verbal communication to that end. The Visitor is seeing the patient because the health professional requested that a well-rehabilitated laryngectomee provide emotional support and demonstrate a successful return to a full productive life.

## **Communication**

If the visit is to be effective, the visitor must employ good communication skills. The visitor should be positioned close enough to be heard by the patient and allow the patient a clear view of the lips and facial expressions. In pre-operative visits, patients should be given the opportunity to express their concerns and do most of the talking. In post-operative visits patient should be allowed ample time to write their concerns without interruption by the Visitor. The Visitor may wish to reassure patients that their communication is understood by reading it aloud.

Patients should be encouraged to ask healthcare professionals all questions concerning surgical procedures, medications, tracheostomy tubes and length of hospital stay. It is appropriate to encourage patients to tell the surgeon about personal concerns or things they do not understand. Patients probably have had a thorough explanation of the medical procedures but it is likely that personal anxiety prevented full understanding at the time the information was presented.

The Visitor should mention that there are a variety of methods of communication used by laryngectomees. Let the patient know that after surgery the physician and speech pathologist will help to decide when the patient is ready for speech training and assist the patient in selecting the most appropriate means of communication.

## **Materials for the Patient**

A kit containing information about the local laryngectomee club, The IAL, the American Cancer Society, and other available resources is presented to the patient. Depending upon circumstances at the time of the initial visit, the Visitor should determine whether its contents should be reviewed at that time or at a later date when the patient will have an opportunity to ask questions. See Training Packet Contents and Overview of materials under section Training The Laryngectomee Visitor for a list of resources and other useful items that should be included in the Visitor's Kit or offered to the patient separately.

These publications provide answers to the most frequently asked questions. The Visitor must be thoroughly familiar with the publications and their contents to be able to assist the patient in understanding the subject matter.

## **Length of Visit**

Common sense and consideration for the patient's well-being should dictate the length of the visit. Careful observation for the patient's non-verbal signals normally will tell the astute visitor when the visit should be terminated. The Visitor should leave before the patient becomes tired or disinterested. The tactful visitor should depart promptly and leave the patient on an optimistic note.

# **3. Recruitment and Screening of Volunteers**

## **Recruitment**

Potential volunteer visitors, both laryngectomees and spouses, should be recruited through the local laryngectomee clubs and hospitals. Efforts should be made to recruit volunteer visitors of both sexes and diverse ethnic and socioeconomic groups.

## **Sequence of Events for Selection**

The applicant receives program information and completes a written application (see appendix: p.13) The application will include the name and contact information of one personal referral. The application is reviewed by the visitor training coordinator and other appropriate personnel. If the application is approved, the candidate is invited to participate in the training program. After successful completion of training the Visitor is presented with an identification card (see appendix: p. 16) indicating he/she is a "Trained Visitor". Such a card can be helpful when introducing oneself at the nurse's station or to those receiving a visit.

## 4. Training the Laryngectomee Visitor

At the completion of the screening, the trainee begins the process of training as outlined below. At the completion of the training, the trainee who has demonstrated competence in the approved methods and techniques of visiting will be awarded certification as a Trained Laryngectomee Visitor (appendix: p. 16).

### Volunteer Training Agenda

(approximately 3.5 hours of training)

30 min **Welcome and group introductions** (program coordinator)

**Purpose:** To acquaint the trainees with each other and with the various organizations related to laryngectomee rehabilitation.

**Objectives:** 1) to explain the role of the IAL and the local laryngectomee clubs  
2) to familiarize the trainees with the materials used in this training

60 min **Medical Overview** (Surgeon and Nurse)

**Purpose:** To acquaint the trainees with the medical aspects of laryngeal cancer

**Objectives:** 1) To explain the medical aspects of Laryngectomy

- Overview of Cancer of the larynx
- Review anatomy and physiology of the larynx
- Treatment options: Surgery, Radiation Therapy, Chemotherapy
- Pre and post operative care of patient
- Patient advocacy; the Visitor is an advocate for the patient and will empower the patient for his own care

30 min **Communication** (Speech Pathologist)

**Purpose:** To acquaint the trainees with options for communication post surgery

**Objectives:** 1) To explain the dynamics of alaryngeal speech  
2) To compare and contrast methods of alaryngeal speech

- Esophageal Speech
- Alaryngeal Speech Devices
- Tracheo-esophageal Puncture (TEP) Speech
- Writing

30 min **Visitor Program Guidelines, Ethics and Responsibilities**

**Purpose:** To acquaint the trainees with the qualifications and responsibilities of a visitor

**Objectives:** 1) to explain the characteristics of an effective visitor  
2) to familiarize the trainees with proper procedure for a visit  
3) to familiarize the trainee with visitor ethics and responsibilities (HIPAA)  
4) to familiarize trainees with components of a quality visit

60 min **Panel Discussion/Evaluation and Summary**

**Purpose:** To share with trainees the experiences of seasoned Visitors  
To determine whether training session has provided necessary information for trainees

**Objectives:** 1) To provide trainees with an opportunity to ask questions and share in the experiences of seasoned Visitors that offer further insight into situations a Visitor may encounter.  
2) To summarize the material used in the training session  
3) To make recommendations for future training

Teaching methods may include videos, PowerPoint, role playing, pictures and personal testimonials.

## Training Packet Contents and Overview of Materials

**Check the Neck (video)**  
**Supplement to First Aid for Laryngectomee**  
**Stoma Cover (at least one)**  
**Stoma Cover pattern book for laryngectomees**  
**Emergency Identification Card**  
**Printed list of resource material**

### Websites for extensive information and links to more:

[www.theial.com](http://www.theial.com)  
[www.webwhispers.org](http://www.webwhispers.org)  
[www.cancer.gov](http://www.cancer.gov)  
[www.cancer.org](http://www.cancer.org)  
[www.spohnc.org](http://www.spohnc.org)  
<http://drbrook.blogspot.com>

### Books and pamphlets:

Gardner, Warren H., Laryngectomy Speech and Rehabilitation. Springfield, IL: Charles C Thomas (1971)

Bralley, R.C. and Omond, T.F., Communication for the Laryngectomized. Danville, IL 61802 The Interstate Printers and Publishers

Emerson, H., and Witterman, B., Progressive Steps to a New Voice. Nashville, TN 37212 Bill Wilderson Hearing and Speech Center

Graham, M.S., The Clinicians Guide to Alaryngeal Speech Therapy. Butterworth-Heinemann, 313 Washington Street, Newton, MA 02158

Keith, R.L., et al., Looking Forward. A Guidebook for the Laryngectomee. Thieme-Stratton Inc., 381 Park Avenue South, New York, NY 10016

Keith, R.L. and Darley, Frederick L., Laryngectomee Rehabilitation. Pro-Ed, 8700 Shoal Creek Blvd, Austin, TX 78757

Kelly, Dan H., and Welborn, Peggy, The Cover Up: Neckwear for the Laryngectomee and Other Neck Breathers. College-Hill Press, Houston TX 77035

Lauder, Edmund, Self Help for the Laryngectomee. San Antonio, TX 78230 Edmund Lauder, 11115 Whisper Hollow, San Antonio, TX 78230

First Steps, available for download from the IAL website, complete information for the new laryngectomee.

Contact ACS via phone or online for a listing of free pamphlets specifically for head and neck cancer patients.

Doyle, P.C. and Keith, R.C. (Editors) (2005). Contemporary Considerations in the Treatment and Rehabilitation of Head and Neck Cancer. Voice, Speech, and Swallowing. Austin, TX: Pro-Ed Publishers.

Doyle, P.C. Foundations of voice and speech rehabilitation following laryngeal cancer. San Diego: Singular Publishing Group. 1994.

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## 5. Suggestions for Developing Referrals

### Physician Referral

The cardinal rule governing hospital visits to patients who will have or have had laryngectomy surgery is that the attending physician must always approve it. Professional ethics demand that this rule be strictly observed by laryngectomee visitors. Some physicians do not request visitors for their patients before and/or after surgery. The reasons below could explain why.

- The physician does not know that trained laryngectomee visitors are available.
- The physician may not recognize the importance of the encouragement and inspiration a well-rehabilitated, trained visitor can provide for a patient
- The physician may simply overlook requesting a visit.
- The physician may not know that the visit can actually strengthen the physician-patient relationship.

A letter or a phone call to otolaryngologists and head and neck surgeons as they enter practice that explains the purpose of the Laryngectomee Patient Visitor Program and the availability of trained visitors is a good idea. A follow up phone call is strongly encouraged.

### Local Laryngectomee Clubs

Many laryngectomized persons learn about the local lost chord club only when they call upon the American Cancer Society for services such as literature and stoma covers. The ACS receiving a call for services should inform the patient about the meetings of the local laryngectomee club and invite the patient to attend. Patients attending meetings and learning about the visitor program are encouraged to tell their physicians about the visitor program.

Laryngectomee clubs should routinely include on their mailing list the names of otolaryngologists and head and neck surgeons in the area. Club members should be urged to talk about the club and its visitor program to local surgeons and to personnel in the surgeon's offices on every possible occasion.

The ambassadors of a laryngectomee club are its visitors and its public speakers who because of their good alaryngeal speech are often the same people. Club members who talk to groups of any kind should always seize the opportunity to tell the public about their club, its visitor program and other activities that contribute to the total rehabilitation of laryngecomees.

The club's speakers should regard every invitation to speak before a professional group as an opportunity to enlist the support of additional professionals. These groups include physician organizations, visiting nurse associations, speech and hearing associations, and students of nursing speech pathology, respiratory therapy and physical therapy. Members of all these groups can be effective in publicizing the visitor program of the IAL clubs.

### Laryngectomee Visitor

The hospital environment provides multiple opportunities to generate referrals. When a trained Visitor sees a patient in the hospital, the Visitor always stops by the nurse's station. These nurses can be extremely helpful by reminding the physician to place a request for a visit on the patient's chart. The club's visitor coordinator should see that such nursing personnel are aware of the procedure for requesting a visit.

Laryngectomee visitors should also get to know the social workers and speech pathologists who are employed by or work with the hospital. These professionals are important members of the rehabilitation team, and when convinced of the value of pre-and post operative visits, they can be helpful in stimulating referrals by the attending physician. Frequently the surgeon will ask the speech pathologist or social worker to make the arrangements for a visit.

Finally, a quality visit is its own best "advertisement". The positive attitude of a patient after a visit can clearly demonstrate the value of visits and convince the physician to request

laryngectomee visitors for other patients. When a patient (or a patient's family) reacts favorably to a visit, as is almost always the case, it also reflects favorably on the physician because the patient and family appreciate the fact the physician cared enough to request the visit. This point should be emphasized whenever members of the club have any contact with physicians.

## 6. Evaluation of Program

In an ongoing effort to maintain a visitor program of the highest quality, it will be necessary to know how it is evaluated by those involved. This information can be used to update and improve training programs.

## 7. Support Activities

The **IAL** has conducted **Annual Meetings** since its beginnings in 1952. These meetings are usually conducted for three or four days in the summer in the larger cities around North America. The purpose of the meetings is to present various workshops, discussions, lectures and panels regarding alaryngeal speech and rehabilitation of laryngectomees, to conduct the business of the IAL and to engage in the usual social activities which are an important part of total rehabilitation. Attendance averages between 200-300 people.

The **Voice Institute** runs concurrently with the annual meeting, to train teachers of alaryngeal speech. The course presents an intensive program in teaching alaryngeal speech and promoting the overall rehabilitation of laryngectomees. The faculty includes outstanding authorities on the subject. Some faculty and lecturers are laryngectomees. The Voice Institute is recognized internationally as an outstanding course on alaryngeal speech and laryngectomee rehabilitation.

# Appendix

# Laryngectomy Visit Report Form

Date \_\_\_\_\_ Visit is Pre or Post Op (circle one)

Patient initials: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: M F How many attended Visit \_\_\_\_\_

Date of Surgery \_\_\_\_\_ Total laryngectomy \_\_\_\_\_ Partial laryngectomy \_\_\_\_\_ Primary TEP: Y N

Method of patient communication: \_\_\_\_\_

Visit Information covered	Y	N
Speech options	_____	_____
Speech Pathology visit	_____	_____
Information Kit Issued	_____	_____
Information re Lost Chord Club Meeting	_____	_____

Questions /additional information requested by patient/family

Visited by \_\_\_\_\_, trained Visitor \_\_\_\_\_  
Print name Date

\_\_\_\_\_  
Signature

## Application for Laryngectomy Visitor Training

Name: \_\_\_\_\_  
Last First Middle

Address: \_\_\_\_\_

Telephone: Home \_\_\_\_\_ Work \_\_\_\_\_ Cell \_\_\_\_\_  
Circle preferred contact number

Name and address of personal physician/surgeon \_\_\_\_\_

Name and address of Speech Pathologist \_\_\_\_\_

Educational background \_\_\_\_\_

Occupation \_\_\_\_\_

Name and address of employer \_\_\_\_\_

Other training and experience, including volunteer training \_\_\_\_\_

\_\_\_\_\_

Most convenient times for volunteer service \_\_\_\_\_

Days of week \_\_\_\_\_ Hours \_\_\_\_\_

Name and Contact information on one personal reference:

\_\_\_\_\_

\_\_\_\_\_  
Signature and date

---

### For Sponsoring Group Use Only:

Approved: \_\_\_\_\_

\_\_\_\_\_  
Visitor Program Coordinator

\_\_\_\_\_  
Club President

Club Name \_\_\_\_\_

Dates of Training \_\_\_\_\_

## Laryngectomy Visitor Screening Interview

Applicants name: \_\_\_\_\_  
Interview Date: \_\_\_\_\_  
Interviewed by: \_\_\_\_\_

How did you hear about the Laryngectomy Visitor Program?

What do you know about the program:

Why do you wish to work as a laryngectomy visitor?

What other volunteer experience have you had?

Would you feel comfortable working with patients of all ages?

How do you suppose you might relate to those with different life-styles?  
Members of different ethnic groups?

Please tell us about your surgery, reaction to cancer, and subsequent adjustment.  
(note whether there is complete denial or any other apparent problem)

How do you suppose you would react to:

A patient who seems very depressed?

A patient who cries?

A patient who is hostile to his/her doctor or to you?

A patient who is angry or resentful about his/her surgery?

What would you say to a patient who asked about specific treatment...his/hers or yours?

## Laryngectomy Visitor Training Program Evaluation by Trainee

1. On what subject discussed today do you feel you need to know more?

Check all that apply

- Medical surgical procedure
- Dos and don'ts of visiting
- Difficult questions asked of a visitor
- How to develop better communication skills
- Understanding hospital procedures
- Understanding affiliation with IAL/ Lost Chord Clubs/ ACS
- Understanding literature in your kit
- How to report your visit
- Understanding your role as a Visitor

2. Would you feel confident in making an independent visit to a new laryngectomy?

Yes \_\_\_\_\_ No \_\_\_\_\_ If not, why not? \_\_\_\_\_

3. Do you feel that the panel discussion and summary were helpful in reinforcing what you learned during the training session?

Yes \_\_\_\_\_ No \_\_\_\_\_ If not, why not? \_\_\_\_\_

4. What questions do you have that were not discussed/answered in the training session? \_\_\_\_\_

5. Did the audiovisuals used in your training enhance the learning process?

6. What is your opinion of the entire training course?

Excellent \_\_\_\_\_ Fair \_\_\_\_\_ Good \_\_\_\_\_ Poor \_\_\_\_\_

How can it be improved? \_\_\_\_\_

Name \_\_\_\_\_ optional

Date \_\_\_\_\_

<p><b>OFFICIAL LARYNGECTOMEE VISITOR</b> this certifies that</p> <hr/> <p>successfully completed Visitor Training for the rehabilitation of laryngectomee patients in accordance with guidelines of the International Association of Laryngectomees (IAL).</p> <hr/> <p>Issue Date                      Visitor Signature</p> <hr/> <p>(Coordinator)</p>	<p><b>OFFICIAL LARYNGECTOMEE VISITOR</b> this certifies that</p> <hr/> <p>successfully completed Visitor Training for the rehabilitation of laryngectomee patients in accordance with guidelines of the International Association of Laryngectomees (IAL).</p> <hr/> <p>Issue Date                      Visitor Signature</p> <hr/> <p>(Coordinator)</p>
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# Information For Trained Visitors

Originally compiled and created by  
Jessie Mae Hart 1931-2012  
Trained Visitor  
Visitor trainer  
ACS esophageal speech teacher  
Past member of the IAL Board of Directors  
Revised 2013 in conjunction with  
The IAL and the Texas Laryngectomee Association

# Laryngectomy Visitation Training

## Purpose of this training

- To produce qualified laryngectomy Visitors

## Qualifications of Visitors

- Person who has mastered alaryngeal speech
- Well rehabilitated
- Completed Visitor Training
- Total Laryngectomy
- Approval of healthcare provider as a suitable Visitor

## Goal of Visit

- To inspire total rehabilitation

## Visitor Protocol

- Present a positive image
- Stop at Nurse's station
- Knock on patient's door
- Introduce yourself
- Do not give medical advice
- Answer questions truthfully
- Introduce information kit
- Get permission to place patient's name on mailing list

## The Visit

- Pre and post op visits
- Length of visit
- Do's and Don'ts
- Follow up

## Recruitment of Visitors

- Local Lost Chord Club
- Recommendation from Physician or health care provider

## The Visit

1. Always knock on the patient's door before entering
2. Be very certain that your appearance is favorable
3. Make sure your stoma is properly covered
4. Identify yourself to the patient as a Visitor from (name your club or ACS)
5. Sit or stand close to the patient so that you can be heard, but do not sit on bed
6. Position yourself so the patient can see your lips and face
7. Observe the noise level in the hospital. Ask if you can turn off the TV/radio
8. Take a Visitation Kit that includes the following items:
  - Self Help for the Laryngectomee by Edmund Lauder
  - Emergency cards, one for pocket and one for auto
  - Laryngectomee Care at Home
  - Neck Breather information
  - Medic-Alert bracelet information
  - Sample of crocheted stoma cover and pattern
  - Sample of foam stoma covers
  - A brochure from the local Lost Chord Club with meeting time and place
  - Information about the loan closet, visitation program, availability of speech classes
  - The Web Whisper's Website
  - International Association of Laryngectomees website and information
  - State Association information and website if available
9. Be sure to get the patient's name and address and permission for the Club Newsletter
10. Keep the visit brief. The patient tires easily
11. Always leave on an optimistic note

## **The Visit** (continued)

### **Do's**

1. Be a good listener
2. Be honest
3. Be sympathetic but not overly sentimental
4. Accept the patient's emotional responses
5. Remember that a touch or smile may show you care more than spoken words
6. If the patient seems suicidal, immediately refer back to hospital staff
7. Assume responsibility for continued contact either with phone call or note
8. Pre and post operative visits are ideal, but this may be the surgeon's prerogative to decide the timing of visits, pre-, post-, or both.

### **Don'ts**

1. Don't show your stoma unless the patient specifically asks to see it and only if you feel comfortable doing it
2. Do not give a speech lesson. This may harm the patient's throat at this point.
3. Don't offer medical advice. Every patient is different and the doctor should answer questions regarding treatment.
4. Don't criticize the patient's doctor
5. Don't undermine the patient's trust in the doctor
6. Do not be late or not show up for the visit
7. Don't repeat confidential information to family or friends
8. Be sure you attend the monthly support group meetings so you will be there to greet your new patient

## Daily Problems

The sooner we learn to communicate the sooner we begin to feel human again. Being able to speak gives one back their independence. The person can take charge of their life again. Writing notes is no fun. Conversations pass you by. You can't write fast enough to keep up and people get tired of waiting on you to write. Most people start out with an artificial larynx. Some may be reluctant to try the speech aid since it feels or sounds funny to them. However, with a little practice, it works well for speech and allows the new laryngectomee to take charge of their life again.

### Daily problems new laryngectomees encounter

- Washing hair
- Taking a shower without drowning
- Wearing a stoma cover
- Good dental hygiene, laryngectomees are famous for bad breath
- Be very careful about personal hygiene; wear deodorant and be careful of aftershave or perfume, since the sense of smell is often gone
- Going back to work or getting disability
- Changing of lifestyle, due to change in income
- Depression can creep up and must be acknowledged (depression is not unusual after this surgery. Seek help from your doctor as there are many medications that can help you cope)
- Uncertain of the future

### Encourage Coping Behaviors

- Seek information
- Attend Lost Chord Club Support Group
- Keep a sense of humor
- Adjust to your new situation
- Count your blessings

## Stoma Care and Humidification

Stoma care is very important. What is a stoma and what does it do? A stoma is the opening in the neck formed during the surgical reconstruction of the airway bringing your windpipe (trachea) out through the neck so you can breathe. The air no longer travels through the mouth and nose to eventually enter the lungs. The air now enters through the stoma in your neck and goes directly into the lungs without the benefit of the nose filtering, humidifying or warming the air. The metal, plastic, or silicone tube called a 'stoma keeper' may be placed in the stoma to keep it open for easier breathing, easier cleaning out secretions produced by the lungs, or to limit the shrinking of the stoma. The doctor will determine how long to wear the 'stoma keeper'. Some laryngectomees don't need to wear a stoma keeper. Each laryngectomee is different. There is no longer a connection between the lungs and the mouth and nose. The airway is now completely separated from the esophagus that takes food to the stomach. Breathing now requires the air to enter the lungs through the stoma in the neck and it is a permanent change. If the stoma were to close, Breathing would not be possible.

Your doctor may direct you to use some antibiotic ointment around your stoma.

The inside of the stoma may require saline to hydrate the tender mucosal tissues found there. Saline may be in the form of saline bullets, a spray, or an eyedropper. Some people find that a humidifier used in the room where they sleep to be helpful. Humidified air facilitates easier breathing and less crusting around the stoma. It also can prevent mucous plugs from developing that inhibit the flow of air into the lungs. Adequate humidity in the air is equally important to the laryngectomee in the summer and the winter months.

The following suggestions will help provide adequate humidity and hydration:

- Drink at least eight (8) glasses of water a day. Limit coffee consumption.
- Have a room humidifier where you spend the most time (den or bedroom)
- Always wear a stoma cover!!! All the time!!
- The stoma cover may be dampened with water to add moisture to the air breathed through it.
- Never go out without a cover over the stoma.
- The speech pathologist or doctor may help with a Heat Moisture Exchange System that will facilitate humidification, filtration, and warming of the air, all the things the nose provided naturally.

## Changes in Body Functions after a Total Laryngectomy

- 1. Larynx:** When the larynx is removed, a person cannot make any sound for speech. Not even a whisper. There's no sound in laughter or crying. Crying is soothing and laughter is fun. It changes the ability to lift heavy loads that requires holding one's breath. It changes the ability to push for elimination.
- 2. Ability to swallow:** Many laryngectomees have a smaller esophagus after the surgery depending on the extent of the surgery and reconstruction. It will require slower eating and drinking more liquids during meals to allow the food to pass. Bending over to drink from a fountain or bending over too soon after eating will allow food or drink to come out through the nose. Dilatorion of the esophagus sometimes helps to make the swallow easier. A modified barium swallow test may be ordered to determine the extent of the swallowing problem.
- 3. Digestion:** Reflux is not uncommon. The upper esophageal sphincter was sacrificed and there is nothing to stop the backflow of liquids through the nose. Sitting up at 90 degrees during and for about 30 minutes after eating will allow all the food to enter the stomach. Sleeping with the head elevated may also help prevent reflux.
- 4. Permanent stoma:** The stoma is the opening in the neck just below the Adam's apple that was created by bringing the trachea forward through the neck during reconstruction. Normal size is between a nickel and a quarter. Breathing is compromised if the stoma is smaller than a dime. Some laryngectomees must have their stoma revised and made larger when there is stenosis (shrinking).
- 5. Showering can be a challenge.** Some laryngectomees choose to wear a shower collar. Some simply aim the shower lower on their chest and allow the water to sprinkle around the stoma for added moisture. Shampooing hair is easier if one bends over to shampoo and rinse so the water runs off the head and not down the neck into the stoma. One could simply cover the stoma with a washcloth for protection when rinsing hair or face.
- 6. Increase in mucous:** This is a common problem experienced by new laryngectomees. The lungs are learning a new way to breathe with less resistance and without the nose to filter the air. While in the hospital, the patient will be breathing misted air and taking breathing treatments with use of saline bullets to moisturize the trachea and stoma, facilitate coughing, and prevent the formation of mucous plugs. In the hospital, a suction machine is used to help remove the excess secretions from the stoma. Some laryngectomees are discharged from the hospital with a suction machine to use at home. It is important to prevent mucous plugs that compromise breathing. Finding the right

## Changes (continued)

balance of drinking plenty of water, using saline bullets to help clear out secretions two or three times per day and using a humidifier will all help. Coughing is from the neck now and laryngectomees must learn how to cover their stoma instead of their mouth and nose when they cough.

7. **Coughing:** This has changed and can catch a laryngectomee unaware. Sometimes it seems as if the coughing will never stop. This slowly subsides and usually normalizes along with the excess mucous production typically within six months of the surgery. Wearing a stoma cover or a Heat Moisture Exchange system will help reduce the amount of mucous and coughing. Blowing nose: some people can and others can't. If there is a trachea-esophageal puncture, it increases the likelihood of blowing the nose. Sneezing: Although there is the sensation in the nose, the sneeze will only come out of the stoma. It is most unusual.
8. **Snoring:** Laryngectomees cannot snore. This can be a blessing to your family.
9. **Smelling and tasting:** Most laryngectomees find that smell is diminished since the air no longer enters through the nose. Usually after awhile, some sense of smell and taste return. Radiation therapy affects the taste buds by reducing or preventing the sense of taste. There is nothing wrong with the nose except that the air is not brought through the nose for breathing. By fanning or wafting the air into the nose, a sniff of what is cooking or the smell of coffee is appreciated. This works pretty well.  
The sense of taste is also diminished. This is partly because of the inability to smell. Some laryngectomees say taste for food has changed, but usually after some time following the surgery and radiation therapy, the sense of taste can return.
10. **Thyroid:** A large number of laryngectomees lose their thyroid during the surgery or as a result of the radiation therapy. Since the thyroid regulates the body's metabolism, this can be a serious problem. Fatigue and lack of ambition are symptoms that the thyroid is not working properly. The doctor sometimes overlooks the thyroid function. If a new laryngectomee is feeling unusually tired or lackluster, they should ask for blood work to check the thyroid function.
11. **Physical activities:** There is nothing that a laryngectomee could do before the surgery that he cannot do after the surgery with a little determination. Some swim, fish, lift, and find that their pulmonary status is better than before the surgery.



- 12. Sexuality:** There may be feelings of inadequacy for both males and females. With no ability to make sound, some males feel castrated. Even an animal can make sound. This is not made up and it is even addressed in the literature. Females can be rather vain and having a hole in one's neck does not contribute to feeling feminine.

## In Conclusion

Every day is a challenge for newly laryngectomized persons, especially when they did not have pre-operative counseling. Many say that it is a whole new life. Everything is different. There are so many changes and adjustments, so many frustrations. Often, they feel as if they don't know anything about anything, because no one told them what to expect. That is why trained Visitors are so important.

